Living and dying: Responsibility for End of Life care in care homes without on-site nursing provision, a prospective study

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Abstract

The aim of the study was to describe the expectations and experiences of end of life care of older people resident in care homes, and how care home staff and the health care practitioners that visited the care home interpreted their role. A mixed method design was used. The everyday experience of 121 residents from six care homes in the East of England were tracked, 63 residents, 30 care home staff with assorted roles and 19 NHS staff from different disciplines were interviewed.

The review of care home notes demonstrated that residents had a wide range of health care problems and that length of time in the care homes, functional ability or episodes of ill health were not necessarily meaningful indicators that a resident was about to die. GP and district nursing services provided a frequent but episodic service to individual residents. There were two recurring themes that affected how staff engaged with the process of advance care planning with residents; "talking about dying" and "integrating living and dying" . All participants were committed to providing end of life care supporting residents to die in the care home if wanted. However, an on-going lack of clarity about role and responsibilities in providing end of life care, doubts from care home and primary health care staff about the capacity of the health care service or care home staff to provide support and uncertainty in how to work together when residents' pathways to death were unclear, complicated the process. The findings suggest that to support this population there is a need for a pattern of

working between health and care staff that can encourage review and discussion between multiple participants over sustained periods of time.

What is known about this topic?

- Older people resident in care homes have a limited life expectancy.
- Care homes that do not have on site nursing provision rely on primary care services for access to medical, nursing and specialist services..

What this paper adds

- It makes explicit the competing demands and expectations of primary care and care home staff when providing end of life care to residents in care homes.
- In care homes where end of life resources are used it can help to coordinate services for residents needing end of life care, but only if a person is recognised as dying.

Introduction

Care homes are the major providers of long-term health care for older people in the UK (Netten et al 2001, Mathie et al 2012). In England the majority of care homes for older people do not have on-site nursing provision and rely on primary health care services for medical and nursing care and access to

specialist services for their residents (Care Quality Commission 2012, Davies et al 2011). As many as 27 different health care services can visit to provide care and treatment for residents (Gage et al 2012). It is a pattern of service provision that is often uncoordinated, with working relationships individually negotiated and context specific (British Geriatrics Society 2011, Goodman et al 2012). This means that providing health care and particularly end of life care is a negotiated process. This paper presents findings from a prospective study of older people's experiences of living and dying in care homes. It describes the characteristics of residents from six residential care homes (care homes with no on-site nursing), and how care home and primary health care staff saw their respective responsibilities, when planning for end of life care.

Background

Care home residents, because of their age and frailty, have a limited life expectancy. Investment in training and facilitation for care home staff in end of life care has demonstrated the potential and value of structured approaches that encourage advance care planning, reduce unplanned admissions to hospital and increase staff confidence in their ability to provide end of life care (NEoLCP 2010, Badger et al 2011, Gandy et al 2011, Shaw et al 2010, Hall et al 2011). Less well understood is how gradual changes in the health of older people and key events over time affect how end of life care is discussed and interpreted by residents, family, care home staff and visiting health care professionals (Shaw et al 2010).

Findings reported here consider the characteristics and events in the lead up to death of older people resident in care homes where there was no nursing provision and how care home staff, District Nurses and GPs interpreted their respective responsibilities for discussions and decisions about end of life care.

Method

The aim of the study was to describe the expectations and experiences of end of life care of older people resident in care homes, and how care home staff and the health care practitioners that visited the care home interpreted their role.

A prospective mixed method study tracked older people living in six care homes in the East of England over one year. A list of potential care homes to recruit to the study was drawn up by searching the Commission for Social Care Inspection (now the Care Quality Commission) Directory of Care Homes and Care Services for care homes with no on-site nursing that had been assessed as providing good or satisfactory care. Details of the size of each home was also collected since the study sought participation from homes of average or above size (27-60 residents). Recommendations were then sought from local NHS services to indicate care homes from the resultant list they perceived as providing good care. Nine care homes were invited to participate in the study and, following meetings and discussions, six agreed. All potential participants (residents, care home staff and primary care health professionals) were provided with letters and information sheets about the study. Informal coffee

mornings were held at each of the care homes to introduce the study and answer any questions from those interested in participating. Following a period of at least 48 hours after information had been handed out, researchers returned to the care homes to discuss the study further and obtain full written consent. Where the older person was assessed as not having the capacity to consent, consultees were identified and invited to provide an opinion on if the older person had capacity to consent whether they thought they would have agreed to have their care home notes reviewed.

The study ran from January 2008 to September 2010 and data collection in each care home lasted just over 12 months. Residents' care notes and medical records held within the care homes were reviewed at four time points over this 12 month period. Additionally, for residents who died during the study, data were collected regarding care, use of primary care resources and hospital admissions during their last four weeks of life to explore responsibilities in decisions and provision of care in the different models of end of life care. A more detailed account of the method and the resident interviews and experiences of end of life care are discussed elsewhere (Mathie et al 2012).

This paper reports findings from the care notes review and interviews with district nurses, GPs and care home staff. Interviews were semi-structured, digitally recorded and focused on staff experience of providing end of life care. Interviews were transcribed and entered onto NVivo8 for organisation prior to analysis. Analysis involved three stages; i) familiarisation, decontextualisation and segmenting the data into categories, ii) comparing categories (both within

and between) for common and divergent themes, iii) looking at relationships in the themes identified and the practices observed. Ethics review was provided by the Southampton and South West Hampshire Research Ethics Committee (REC ref: 08/H0502/38) and local government and NHS organizations.

Findings

The participating care homes reflected the mix of provision and variable access to health care support that is common across the care home sector. Half the care homes participating in the study were in private ownership and half were not-for-profit organisations (Table one). One care home had sought accreditation as a Gold Standard Framework (GSF) provider, signifying they had completed the GSF Care Homes Training programme for end of life care and integrated the practices into the day-to-day work of the care home.

INSERT TABLE 1 about here

In total, 30 care home workers (9 care assistants, 8 senior care workers, 2 activity co-ordinators, 4 deputy managers, 1 assistant manager and 6 care home managers) and 19 NHS professionals (3 GPs who were attached to 3 of the 6 care homes, 11 district nurses: including 1 team leader and 1 clinical manager), and 5 palliative care specialist staff working in community homecare teams/hospices) linked to the participating care homes, gave consent and were interviewed.

How the health care services were organised to work with care homes was variable. For example, four of the care homes were visited as necessary by district nurses attached to GP surgeries local to the care homes. The other two care homes were visited by district nurse teams with designated responsibilities for care homes.

A total of 121 residents took part in the study in interviews and by agreeing to the review of their notes from a total population of 257 residents. Ninety residents (74.4%) remained in the study for the full 12 months. Of those who left the study, 23 died, two moved to different accommodation, and six did not return to the home. The most common health problem recorded in residents' notes was dementia (38%) although this was probably under recorded (Prince et al 2011). Just under half of the sample's care home record made mention of them having three or more co-morbidities (e.g. diabetes, heart failure, arthritis) separate to a dementia diagnosis. Resident characteristics are summarised in table 2.

Insert table 2 about here

Services received by residents were recorded at each time point for the previous three months. The three months prior to baseline showed GPs were the most widely accessed service by residents, with 87.6% of residents having at least one recorded contact. District nurses had at least one recorded contact with 30.6% of residents during the three months prior to baseline. However,

their frequency of visits per resident was higher than GPs (mean number of visits per resident for district nurses 3.12 compared with GPs of 1.86), this was due to daily visits from district nurses to particular residents who required insulin injections or wound dressing across all the care homes.

Data for residents who were living at the end of the year's data collection were compared with that of residents who had died. Analysis showed no significant difference in age or time they had spent living in a care home (see table 3). Unless a particular terminal health condition (e.g. a cancer diagnosis or end stage renal disease) was present and the illness's pathway to death understood, it would appear there was little to distinguish residents' health and function on reaching death and those who had longer left to live. In the care home that was GSF accredited to provide end of life care, there was evidence of primary health care staff being more involved in on-going reviews than in other homes and relatives were more likely to be contacted. Similarly, in another care home, once residents were recognised as dying, their care notes contained records of when discussions around end of life care had taken place and their contents. Of the 23 deaths that occurred during the study period, in depth analysis showed 9 deaths were anticipated, 3 unexpected, 7 uncertain and 4 unpredictable. For the seven residents who's deaths were uncertain, there were prolonged periods of diagnostic uncertainty, with multiple GP visits, for residents with diverse, non-specific (but cumulative symptoms). It was only 'clear' with hindsight, to care home or primary health care staff that the residents had been close to the end of life.

Using Kaplan Meir methods to analyse the data, the relationship between the frequency of deaths and a need for assistance with eating at baseline (log range test p=0.017) and a lower Barthel score indicating increased dependency for activities of daily living (mean Barthel score for survivors 12.8 (SD=4.8) compared with those who died 10.1 (SD=4.8). However, the sample was small and this should be interpreted with caution.

INSERT Table 3 about here

The review of care home notes had demonstrated that residents had a wide range of health care problems; length of time in care homes, functional ability or episodes of ill health were not necessarily meaningful prognostic indicators that a resident was about to die. GP and district nursing services provided a frequent but episodic service to individual residents and this became more regular with supporting documentation when it was recognised someone was dying. The interviews with care home staff and primary health care professionals (GPs and district nurses) explored how the different participants interpreted their roles and responsibilities in providing end of life care and focused on conversations about how end of life care discussions were initiated and how decision making about treatments and referrals were negotiated.

All staff interviewed recognised the importance of initiating discussions about preferred priorities for care or preferences about end of life. They highlighted that understanding a resident's wishes could mean avoiding unnecessary

admissions to hospital or stop invasive, distressing interventions. What emerged from the interviews were two recurring themes that affected how staff engaged with the process of advance care planning with residents, decision making about end of life care and how a resident was identified as dying. The two themes are summarised as "talking about dying" and "integrating living and dying".

Talking about dying

Interviews with care home managers revealed that four out of the six care homes operated 'as and when' policies for end of life discussions. Of the others, one had become GSF accredited and the other had a manager with a strong personal commitment to fulfilling residents' end of life wishes. Despite this, care home staff in these two homes expressed similar hesitancy to other participants; voicing uncertainty around how to talk about death with residents, when was the right time, or how to involve relatives. There were multiple possibilities depending on presence of family and the hierarchy and organisation of the care home. Two care assistants illustrate the range of views on whether it was considered appropriate for care staff to be involved in end of life discussions and their expectations that more than one relative or professional would lead on these discussions:

"If the person is 'compos mentis' their family discuss that with them because I think that's more appropriate than me doing it because it's a very, very difficult subject." (Care assistant 1, care home 3)

"I would say the seniors and the management are involved as well, so is the family and any other professionals who would be involved so it's very difficult to say who is responsible, we are all involved." (Care assistant 2, care home 2).

Care home staff, through daily contact and close relationships, recognised that there were opportunities to enter discussions about end of life wishes with residents, but either felt unable to do this or did not think it was possible to say who had responsibility to raise the subject. Many care home staff hoped GPs and district nurses would take the lead, at the right moment, even though health care professionals were described as only visiting to address specific health events or to undertake interventions, such as wound care.

The GPs and District Nurses acknowledged that their relationships with residents were mediated through the care home staff. Time restrictions, limited intermittent contact with residents, and apparent wellness of residents during initial consultations were all factors that complicated and inhibited discussions about end of life care. GPs spoke of respecting and trusting care home staff's knowledge of residents. At the same time some believed that placing responsibility for discussions with residents about their preferences and priorities for care at the end of life on care home staff might not be appropriate

"…they know the residents so well and if I can't actually talk to the residents directly which I usually can at some point, you know they know what the resident's wishes would be and I, I respect them and I trust them and I would

obviously always talk to the relatives as well... I don't think it [initiating conversations about end of life and preferred priorities for care] would be fair on the home, although in an ideal world they're the ones with the relationship. But I think, they're not medically trained and it's not fair to ask them to do that." (GP 1)

Participants described the complexity of coordinating and having discussions when so many people could be involved over relatively long periods of time, as so few residents had a discrete period when they were formally diagnosed as approaching the end of life. Conversations could be relayed between residents, care home staff, GPs, district nurses and relatives and how this process was documented was not discussed or reviewed. The role and contribution of relatives were seen as key and, if discussions had not taken place before a time of crisis, then even those with advance care plans in place and consensus between the older person, care home and health care staff about end of life care, clinicians could still feel pressured to act differently to what they thought might be in the best interests of the older person:

"relatives are far more difficult to deal with than patients, far more because some of them have got some totally inappropriate ideas and they're all, laden with guilt... you just have to steer it so that they eventually see that actually it would be kinder [to let the person die]" (GP 3)

Participants working inside and outside the care homes, including those in the GSF accredited care home, were unclear about when and who was responsible for initiating discussions about end of life care and who should be involved.

Integrating living and dying

The care home notes review had demonstrated recognising that a resident was dying and in need of end of life care was not a straightforward process. GPs and district nurses described key indicators and a sense residents were 'giving up', bedbound ("off their legs"). They were confident that these kinds of changes would be communicated by care home staff to family and primary health care staff. However, as their emphasis was on visiting in response to specific health needs, it was unclear how residents who had vague or non-specific signs of deterioration over a prolonged period of time would be identified or drawn to their attention. This care worker talked about looking out for signs but saw it as difficult and one that was based on shared discussion between the staff within the care home over a sustained period of time when the manager might (or might not) speak to the family but not necessarily the visiting GP or district nurse.

"Yes, I mean, when they're here, you can see perhaps a steady decline, and then we talk about it in our staff meetings and handovers and things. Then perhaps [Manager] would speak to the family, things like that. It's just a matter of looking out for signs. It's difficult really" (Senior Care Worker 1, care home 1)

Only staff in the GSF home spoke of identifying three levels of care; Tender Loving Care (TLC) then palliative care and then the Liverpool Care Pathway (the last 48 hours when residents are checked every 15-30 minutes).

The manager in the GSF home commented that sometimes their estimates were wrong and that residents died quicker or slower than expected

 "we've got no crystal ball with it, you can't say exactly oh yeah they're going to be 48 hours' (Care Home Manager, care home 4).

When the need for end of life care was recognised role demarcations emerged in how end of life care was delivered. In the GSF care home the use of End of Life care tools ensured there was shared documentation and regular review of notes and symptoms. However, District Nurses' and GPs' input were concentrated in the last days of life. The pattern of primary health care involvement in end of life care mirrored how contact was maintained for everyday care and was linked to specific tasks. GPs for example, visited for medication reviews and changes, while district nurses were more involved in arranging equipment and monitoring. They were less than explicit about how they supported unqualified staff or liaised with relatives.

There were some suggestions on how primary care staff could be involved in training initiatives for care home staff, but the inference was that this could

relieve the district nursing service of having to provide on-going technical support, as this next quote suggests;

"I think if we could have more education so that the (care home) staff, I think the staff give ... a wonderful level of care, but it's all maybe having the Macmillan nurse come out and do some teaching sessions or somebody do teaching sessions because it's things like the syringe driver, if we put the syringe driver up it's almost teaching them every single time what the driver is, when to call us, etc, etc, ... so it's education about that, it's reinforcing mouth care and pressure area care" (District Nurse 3)

These approaches to care did not create opportunities for pro-active, advance care planning, or discussion and review of residents' needs. None of the participants working inside and outside the care homes, including those in the GSF accredited care home, were clear about when and who was responsible for initiating discussions and how on-going review and end of life care could be incorporated into activities that were either focused on day to day needs or were episodic and task or issue specific.

Discussion

There have been repeated initiatives in end of life care to improve the support provided by generally unqualified and poorly paid staff to older people living in care homes (NEoLCP 2010, Badger et al 2011). Our study found that at the frontline of care primary health care and care home staff recognise the

importance and value of each other's work, could articulate what good end of life care looked like and often have good working relationships. However, this study underlines some underlying issues around how difficult it is to provide proactive care that affect how primary health care professionals work with care home staff (Jacobs et al 2001, Goodman et al 2003, Goodman et al 2012) and how care home staff can work with the NHS.

Talking about dying is difficult, and care home staff did not necessarily recognise that it was their role to have these kind of conversations. Similarly, recognising deterioration was not easy and a more nuanced process than was openly discussed between primary health care and care home staff. The challenge for care home staff and the ethos of the care home was how to care for the dying with the living (Froggatt 2001). GPs and district nurses were frequent visitors to the care homes but we found little evidence in the residents' notes or interviews, of review or conversations about residents' general health and wellbeing that could have included discussions about, signs of deterioration, and advance care planning.

Prognostication for people who are frail and may die with or from dementia is very difficult (Goodman et al 2010, Van Der Steen 2011) and there is an increasing understanding of different pathways or trajectories to death when cancer is not the main disease. Relatively little is known about how to enable clinicians and care home staff to plan their care and conversations to reflect the older person's experience of dying (Dy and Lynn 2007). The findings presented

here demonstrate the value of greater collaboration between care homes and primary health care staff and the need to discuss how residents and family members can be involved over time. The one care home in this study that used a structured approach to end of life care (GSF) had more planned support from primary health care professionals, its staff had more opportunities for reflection, and they received more specialist palliative care input. However, this was only true once a resident was recognised as dying. Advance care planning that involved residents and family members or conversations about the overall wellbeing of residents or signs of deterioration did not occur any more often in this care home than the others in the study.

Primary health care staff expected to lead on discussions about end of life care and decision making. Studies consistently suggest that care home staff feel that their expertise and knowledge are undervalued and that there is a lack of clarity with health care professionals about their roles and responsibilities in care homes, particularly in end of life care (Davies et al 2011, Goddard et al 2011). The findings presented here indicated that health care professionals did value care home staff knowledge but this did not translate into shared decision making or where there were concerns about the capacity of the health care services to provide on-going support how the two groups could work together.

 The value of structured approaches for the last few weeks of life in these settings need to be strengthened and expanded to encourage on-going review between all participants (Boockvar et al 2000).

This study is limited in studying six care homes and associated primary care services in areas that may not be representative. To be able to address such a sensitive topic our sample of homes was selected from care homes regarded as providing good care with good working relationships with primary health care professionals. It did not engage with practice in homes where there were recognised problems with quality of care.

Conclusion

End of life care for older people living and dying in care homes, with no on-site nursing provision, is characterised by considerable ambiguity around when and how to talk about end of life, how to recognise if people are dying and how decision making about care and treatments is negotiated. When someone is recognised as dying structured assessment and end of life resources supported better communication and integrated working. However this was limited to the last days of life and did not appear as able to engage with older people whose pathway to death was incremental or characterised by illness and recovery. To understand how the possibility of dying is interwoven with every day care in care homes there is a need to address more closely the everyday processes and patterns of how primary care services, and district nurses in particular, work with care home staff from the time of a person's move to a care home to their death.

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Table 1: Residential Care Home Characteristics

	Care Home					
	1	2	3	4	5	6
Occupancy	58	60	30	58	27	55
Ownership	Private	Private	Not-for-profit	Private	Not-for-profit	Not-for-profit
Religious affiliations	No	No	Yes	No	No	Yes
End of Life Documentation	Procedures l for caring for dying, Bereavement information (completed by relatives prior to admission)	Procedures for caring for dying, Preferred funeral arrangements	Procedures for caring for dying resident, Procedure for death of resident, Funeral arrangements	Preferred Priorities of Care (PPC),* Liverpool Care Pathway (LCP),** Gold standards framework (GSF)***	End of life care policy	Do Not Attempt Resuscitation Cardiopulmonary (NACPR) leaflet and form, Final wishes form, End of Life leaflet for residents

*PPC, a document for a person to record their preferences and priorities for end of life care. This does not a legal document for refusing treatment.

LCP, a detailed care pathway for a patients last days of life. It records treatments and observations. * GSF, a systematic evidence based approach for improving care for patients reaching end of life. Accreditation is awarded following a training programme and evidence of implementing the method into care home working practices.

Table 2: Resident characteristics at baseline (n=121)

Mean age	87.5 (range 61 – 102, std dev 7.08)
Percentage aged 85 or over	66.9%
Female residents	94 (77.7%)
Male residents	27 (22.3%)
Number of Medications	Median 6, Range 0 - 15
Percentage of residents with 3 or more co-morbidities	46.2%
Median Barthel Score	13 (range 1 – 20, std dev 4.9)

Table 3: Age and residence at time 1 of residents who remained in the study for the duration and those who died

	Still in Study n=90	Died n=23
Median Age (mean age)	88 (87.3)	89 (89.2)
Median length of residency in months (mean number of months)	17.5 (28.1, std dev 36.4)	18 (22.2, std dev 19.1)