Advanced care planning in care homes for older people: a qualitative study of the views of care staff and families

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Abstract

Objective: to explore views on advance care planning in care homes for older people.
Design: qualitative exploration of views from care home staff and the family of residents in care homes for older people.
Setting: all care homes for the elderly in two London Boroughs.
Participants: staff (care managers, nurses and care assistants), community nurses and families.
Methods: individual semi-structured interviews.

Results: themes of the analysis: (i) Benefits: staff and family revealed positive opinions towards advance care planning. Staff felt it provided choice for residents and encouraged better planning. (ii) Barriers: staff and families perceived residents as reluctant to discuss advance care planning. Some care assistants were reluctant to be involved. Furthermore, families and staff reported prevalence of dementia among residents as another barrier. Nurses and care managers identified both family involvement and unforeseen medical circumstances as problematic. (iii) Facilitators: (a) early initiation of discussions (b) family involvement to establish preferences (c) residents and staff being well-known to each other and (d) staff training, were perceived to facilitate ACP.

Conclusions: overall, staff and families support the concept of ACP. Methods to overcome the identified barriers are required to embed ACP within end of life care in care homes.

Keywords: advanced care planning, nursing homes, end of life, aged, elderly

Introduction

Advance care planning (ACP) is a process in which anticipatory decisions are derived to assist the provision of person centred care. It is increasingly recognised that ACP should be promoted as part of end of life care and because care homes are increasingly becoming the last residence for many older adults, ACP needs to be facilitated in these settings.

Patient choice is becoming an increasingly important part of policy in health care [1] and is especially important for individuals at the end of their life as deterioration of mental and physical functions may lead to a situation where a person can no longer express their preferences. ACP establishes important information such as areas of concern for an individual, their beliefs and their preferences. ACP has its origins in the principles of autonomy and self-determination, establishing a person’s views about their care and wishes and enabling their point of view to be considered even in the event of diminished capacity [2]. ACP is different to traditional care planning as it makes plans in anticipation of future deterioration in a person’s condition [3]. Few advance refusals of treatment are legally valid but they can be used to decide a person’s best interests should they lose mental capacity [4].

Studies from North America, where ACP is more established, show moderate evidence for its benefits in improving end of life care [4] and there is evidence to suggest that knowledge of preferences facilitates ACP in a range of healthcare disciplines [5, 6].
In the UK, 20% of deaths in people over the age of 65 occur in care homes for older people [7], making them a significant place in which ACP could be used. Previous research conducted in Australia has shown that providing training on ACP to residents’ families and staff in nursing homes reduces the number of admissions of dying residents to hospital by 22.7% [8]. A recent UK postal survey of 500 care home managers reported that 89% of the managers already recommended or required that residents in their care home completed advance care plans [9]. Therefore, it is important to explore how ACP is viewed by health and social staff, residents and families in these settings. The aim of the present study was to explore the views of care home staff and families regarding ACP in homes providing nursing care or personal care only.

**Methods**

**Participants**

Care homes for older people in two London boroughs were identified through the Commission for Social Care website [10] and the local Care Home Support Team. Care homes were excluded if they were specifically for residents with learning disabilities, mental health problems (not including dementia), alcohol dependency or not registered for old age.

In each home, the manager and a randomly selected nurse and care assistant were invited to participate. In care homes providing personal care only and who did not employ nurses, a community nurse who visited the home was invited to participate. If a nurse or care assistant declined to participate, another was randomly selected from staff lists.

Participating homes were grouped into four mutually exclusive subsets; (i) nursing or dual-registered without the Gold Standard Framework for Care Homes (GSFCH) [11], (ii) nursing or dual-registered in early stages of the GSFCH, (iii) nursing or dual-registered in later stages of the GSFCH and (iv) residential. A care home was randomly selected from each subset in order to achieve a purposeful sample; within these selected homes the managers provided the names of residents and their family members (or friends if no close family were available) who they felt would be capable of being interviewed. The aim was to recruit four residents and their family members (if available) from each type of home and an additional four family members to represent residents with cognitive impairment.

**Ethical consideration**

The study was approved by King’s College Research Ethics Committee (REF: 07/H0808/136 & 07/Q0703/89). Written informed consent was obtained from all participants who took part.

**Interviews**

ACP was one of several areas covered during a semi-structured interview about end of life care in care homes. The interviews were guided by a topic guide designed to be flexible to the participant’s ability and willingness to answer the questions. As the National Health Service End of Life Care Programme recommended using the Preferred Place of Care Plan [11] (now the modified Preferred Priorities for Care Plan) it was introduced to participants as an example of ACP and was used to elicit their knowledge and perspectives on the subject. The topic guide was piloted on a participant from each group and was simplified and shortened as appropriate. Participants received a £20 gift voucher to compensate them for their time. Interviews were recorded and transcribed verbatim.

**Data analysis**

The interviews were analysed using the framework analysis approach [12], which allowed the exploration of new themes whilst content coding categorical questions and allowing comparison of themes between participants. It comprises five stages: (i) familiarisation; (ii) identifying a thematic framework; (iii) indexing; (iv) charting and (v) mapping and interpretation.

**Results**

Staff from 34 of the 38 eligible care homes took part. Sixteen care homes were residential care homes (2 employing nurses), 10 were nursing and 8 were dual-registered. Thirty-three care home managers took part (one managed two homes). The response rate for care assistants was 29 of 50 (58%), for nurses employed by the home 18 of 28 (64%), for community nurses 10 of 20 (50%) and for residents’ family and friends, 8 of whom were family and friends of residents with dementia, 15 of 46 (33%).

We interviewed 14 of 41(34%) residents, but only one resident shared their views about ACP during the interview the other 13 residents did not discuss ACP. Therefore, we were unable to include residents’ views in this study.

Staff in each care home reported having some kind of ACP in place. Ten of the 33 care home managers interviewed had heard of the Preferred Place of Care Plan but none had used it. Despite this all care homes were using some form of ACP within their home.

The themes of the qualitative analysis were organised around (i) benefits, (ii) barriers and (iii) facilitators. Quotes are shown in Table 1, and comparisons of sub-themes between different groups of participants are shown in Table 2.

**Benefits**

Staff and families spoke positively about ACP. However, family and friends failed to qualify why they perceived ACP...
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Table 1. Comparison of the sub-themes of analysis by group (frequency by group)

<table>
<thead>
<tr>
<th></th>
<th>Managers</th>
<th>Nurses</th>
<th>Care assistants</th>
<th>Family and friends</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benefits of ACP</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Promotes choice</td>
<td>13</td>
<td>8</td>
<td>8</td>
<td>0</td>
</tr>
<tr>
<td>Aids treatment decisions</td>
<td>7</td>
<td>1</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Barriers to ACP</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unplanned medical scenarios</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Staff and family conflict</td>
<td>5</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>over care</td>
<td></td>
<td></td>
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<tr>
<td>Residents reluctant to discuss ACP</td>
<td>10</td>
<td>8</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Families reluctant to discuss ACP</td>
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<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Other staff reluctant to discuss ACP</td>
<td>9</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Personal reluctance to discuss ACP</td>
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<td>5</td>
<td>5</td>
<td>2</td>
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<tr>
<td>Facilitators of ACP discussions</td>
<td></td>
<td></td>
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<tr>
<td>Early initiation</td>
<td>4</td>
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<td>0</td>
<td>1</td>
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<tr>
<td>Family involvement</td>
<td>4</td>
<td>4</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Residents familiarity with staff</td>
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<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Planning over time</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
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<tr>
<td>Training for staff</td>
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<td>0</td>
<td>0</td>
<td>0</td>
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<tr>
<td>Sensitive approach</td>
<td>2</td>
<td>0</td>
<td>3</td>
<td>1</td>
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<tr>
<td>Direct approach</td>
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<td>1</td>
<td>0</td>
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</table>

Table 2. Quotations of participants

Quote 1: I think, so much of this stuff can be just tokenism… my father, when I filled in something for him… about his life… but then I didn’t hear anything about it after that… [Son of a recently deceased resident of a nursing home]

Quote 2: …they have a choice, they have choices… and they… participate in the care, they are the last word… [Nurse working in a residential home]

Quote 3: …well, it helps the care or the care provider… what to do and what to expect and what next step to follow… [Care assistant in nursing home]

Quote 4: Yeah if you ask mum where she would want to be she’d say with me… she doesn’t know she’s in a residential home, she thinks… she’s in a waiting room from the hospital, waiting to go home… [Family member of a resident]

Quote 5: Somebody may tell you, ‘yes I’d be happy to die here… but if, during an end of life phase they have some terrible bleed… there’s no choice other than sending to hospital… [Care manager of a nursing home]

Quote 6: Some of them, some of them as I say reluctant to respond… I think, maybe they’re afraid… of dying… [Nurse in a residential home]

Quote 7: Don’t think that’s the job of the care home staff… “Now you’re in the home we want to know where to send you when you die?” I mean, that would be a very creepy thing to do… [Wife of a resident with dementia living in a residential home]

Quote 8: That one I think has got nothing to do with the care – I think the family are supposed to be doing that. [Care Assistant working in a nursing home]

Quote 9: I know there’s other people (staff), some of them they have trouble discussing it… [Nurse working in a nursing home]

Quote 10: Sometimes some of the relatives who who are looking after things they haven’t accepted… sometimes they do not want to broach the subject of death just now [Care Assistant working in a nursing home]

Quote 11: …Relatives… they’ve discussed with you and they’ve understood what’s… the relative [wants]… but at the last minute they’ve changed their minds, and they think that the hospital will be the best place for their relative… [Care Manager of nursing home]

Quote 12: Yeah I think, especially it can help, you have to try and involve the family as well. [District Nurse who visited care homes in the borough of Lambeth]

Quote 13: It’s the relationship you build… its not fair that I hardly know them and I go in and say ‘where would you prefer to die?’ [District Nurse who visited care homes in the Borough of Lambeth]

Quote 14: I mean, assuming that some people will have had bad that comparison with their relatives when they’re- before they were in the home and when they were still reasonably fit… [Wife of a resident in a residential home]

Quote 15: We need to tell some people (staff) that there are certain things you can and can’t say and other people that there are things that you should be saying that possibly you’re not. [Manager of a nursing home]

Quote 16: You have to put it in a very diplomatic way… [Care assistant in Dual-Registered care home]

Quote 17: If you go around and try and dilly-dally around it, it just gets worse. You’ve just got to basically go for the jugular and just—just say, “This is what we need to talk to you about, I know it’s not a pleasant thing to ask, but we do need to know this and it is important to us and it’s also going to be important to you, so what would you like to do?” [Care manager of a residential home]

as a good idea. In contrast, the son of a resident whose father had died a few weeks prior to the interview felt that participating in such a discussion had provided no real benefit for his father (quote 1). Staff felt ACP promoted respect for residents’ wishes (quote 2) and aided their treatment decisions (quote 3).

Barriers

Staff and families identified residents who lacked cognitive capacity as a common barrier to ACP (quote 4).

Nurses and managers (the majority of whom were qualified nurses) identified unforeseen medical scenarios as barriers to fulfilling certain advance recommendations (quote 5).

Staff and family alike felt that the reluctance of some residents to discuss end of life issues was a further barrier to ACP. Some staff felt this may be because of residents’ fear of thinking about death (quote 6), whereas family members also attributed it to them not feeling comfortable discussing these issues with care home staff (quote 7). Furthermore, some care assistants (quote 8) revealed reluctance to discuss end of life issues with residents, identifying that they felt it should be the role of the resident’s family to engage in ACP discussions and not the role of the staff. Managers and nurses believed that some care home staff had difficulty with ACP because of their cultural beliefs (quote 9). Care assistants who reported reluctance were
from a similar range of ethnic backgrounds to the nurses and managers, who themselves indicated no reluctance to engage in ACP discussions. Staff also perceived that at times family members are reluctant to discuss their relatives’ preferences. This was attributed by staff to their reluctance to accept that their relative was towards the end of life (quote 10).

Conflict between family and staff over ACP was identified by care managers and nurses but not by care assistants or family members. A common conflict concerned the nurses’ and managers’ awareness of the resident’s wish to die in the care home, but family insisting on a transfer to hospital. Staff felt that families believed that their relative would receive better care in hospital. In contrast, staff believed the care home could provide a more comfortable setting (quote 11) for end of life care.

Facilitators
Perceived facilitators of ACP were: to involve family members to help establish the resident’s preferences (quote 12). In addition, staff who approach discussions with residents should have a prior familiarity with them (quote 13) and should start discussions early and in gradual stages before the onset of serious health problems (quote 14). ACP was also seen to be facilitated by providing guidance to staff on how to approach such discussions (quote 15). However, some nurses and care managers considered a direct approach facilitated discussion (quote 16), whereas others felt it was better to approach the subject cautiously and indirectly, and to measure the resident’s reactions to peripheral topics first. Family members and care assistants stated it was important to approach the subject sensitively (quote 17).

Discussion
This study compared the views of residents’ families and friends and health and social care professionals and compared the views between staff in different roles. The care home staff and community nurses interviewed saw benefits to ACP through promoting choice and aiding treatment decisions. Managers and nurses saw unforeseen medical scenarios as a barrier to ACP, whereas some care assistants were reluctant to engage in ACP and felt the family should be involved. Conversely, nurses and managers were comfortable engaging in such discussions but considered that family involvement could sometimes prevent a resident’s preferred choices being fulfilled. Other barriers to ACP concerned residents either lacking the cognitive capacity to have such discussions or having a reluctance to discuss ACP. However, early initiation of ACP, family involvement to establish preferences, and staff building rapport and familiarity with the residents and their family were all seen to facilitate ACP.

A limitation of this study was the failure to elicit the views of residents. This may have been for several reasons including some residents lacking education beyond 16 years of age, the questions regarding ACP being towards the end of a relatively extensive interview schedule, the researchers being unknown to the participants and also the sensitivity of the topic.

In a previous study [13], medical inpatients expressed a desire to write a living will; the most commonly stated reason for doing so was so their views would be known. The results of our study also showed that staff perceived one of the main benefits of ACP was to promote choice for residents.

In an American study [14] in 25% of occasions where an advance care directive was in place, the care was inconsistent either due to inattention to written documentation or because other considerations were prioritised above the patient’s wishes. Our study highlights an enthusiasm towards ACP, but nevertheless it is important that residents and families do not reach a false sense of expectation that such discussions will automatically lead to established wishes being fulfilled.

Dementia was seen as a major barrier to residents engaging in ACP discussions. This is in keeping with current statistics that show there is a high prevalence of dementia in care homes [15]. The recent Mental Capacity Act (2005) [4] means that anybody making decisions about the care or treatment of an individual who lacks capacity must take into account the individual’s wishes and preferences when assessing their best interests and highlights the importance of early discussion and family involvement. The prevalence of cognitive impairment in care homes is high and means that residents cannot always express their wishes. Instead their family, friends and health professionals must use their knowledge of the resident to decide the individual’s best interests. However, this study highlights that under these circumstances, the family and health professionals might have different views about what is in the resident’s best interests. There is evidence that advance care wishes, because they are not legally binding, are sometimes ignored [14] and that surrogates are poor decision makers [16]. In regards to this study, nurses and managers suggested that families can sometime overrule residents’ wishes. Therefore, when using families to establish a resident’s best interests, every effort must be taken to accurately reflect their own likely preferences.

Consistent with this study, previous research in this area has shown that managers also stated resident’s ability to engage in ACP was shaped by their willingness, physical, emotional and cognitive abilities [9]. Care staff and family perceived some residents to be unwilling to engage in discussions about ACP. In a study [17] which used focus groups with older adults to establish views about ACP, it was highlighted that in order for people to engage in ACP with their physicians, they needed to feel they trusted them and be in a relationship built up over time. This is similar to the views expressed in this study, where staff building a relationship with the residents was perceived to facilitate resident’s having such a discussion with them.
Nurses and managers identified unforeseen medical scenarios as a barrier to ACP. This is consistent with other studies that have shown prognosis cannot always be predicted [18], especially in dementia illnesses [19]. Many care home residents arrive after discharge from hospital [20]. Several London Hospitals are currently piloting a Peace Document [21] which is sent to the care home with the resident and provides information on probable medical complications that could arise for that particular person and options to treat them, in order to reduce the uncertainty around ACP.

A limitation with interviewing family members and friends of existing care home residents and also comparing their views to those of staff is that, unlike staff, they may have not yet experienced the outcome of ACP practices. As such it may have been more useful to interview relatives of deceased residents who have a more complete perspective on the process. Another limitation of the study concerns the fact that the study did not represent the views of general practitioners: including their views may have provided a deeper understanding since they are significant members of the multi-disciplinary team. However, interviewing community nurses who were linked to the community surgeries, to a degree, represented the views of primary care practitioners.

Current guidelines [22] recommend that ACP discussions should be initiated in primary care settings, by an appropriately trained professional. The guidelines also highlight the importance of having a rapport with the individual and, where necessary, being supported by a professional with the relevant specialist knowledge. Eliciting views on ACP from care home residents is difficult and in many cases frailty or reduced cognitive capacity results in them being incapable or unwilling to discuss their views. This raises the question of whether ACP discussions in care homes are initiated too late. Current guidelines [22] suggest general practices should annually review the number of deceased patients in their practice who were offered ACP. Furthermore, future research needs to consider whether general practitioners might be better placed to engage in such discussions with patients reaching a particular age or with those patients whose health appears to be deteriorating. Future research needs to be directed at finding the optimal time and environment for eliciting such views from residents.

Key points

- Little is known about the views of residents, families and staff on ACP in care homes.
- This study investigates some of the perceived benefits by family and staff.
- Common barriers across care homes for older people, and ways to facilitate ACP discussions.

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Conflict of interest

There are no conflicts of interest.

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References

Older people’s use of NHS Direct

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Abstract

Introduction: the 24 h telephone health information and advice service in England and Wales, NHS Direct, aims to help callers manage health problems and relieve pressure on primary healthcare services. Although older people may use NHS Direct less than other age groups, no research has specifically investigated older people’s use of the service.

Aims: the aim of this study was to describe the older people’s use of NHS Direct and to explore differences in the use of NHS Direct among subgroups of older people.

Methods: a cross-sectional exploratory descriptive design utilising quantitative methods was adopted. Data on all calls made to NHS Direct by, or on behalf of, people aged 65 and over between 1 December 2007 and 30 November 2008 were analysed.

Results: a total of 402,959 telephone calls were made to NHS-Direct regarding older people during the 12-month study period. The call rate was higher among women and in older age groups. Most calls were regarding actual symptoms, e.g. pain, digestive problems.

Conclusions: this research identifies the characteristics of calls made to NHS Direct relating to older people and how they use the service. This will help with the planning and development of services to meet the needs of the older population.

Keywords: older people, NHS Direct, health services, telephone triage, elderly