RESEARCH PAPER

Advance care plans in UK care home residents: a service evaluation using a stepped wedge design

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Abstract

Introduction: advance care planning (ACP) in care homes has high acceptance, increases the proportion of residents dying in place and reduces hospital admissions in research. We investigated whether ACP had similar outcomes when introduced during real-world service implementation.
Methods: a service undertaking ACP in Lincoln, UK care homes was evaluated using routine data. Outcomes were proportion of care homes and residents participating in ACP; characteristics of residents choosing/declining ACP and place of death for those with/without ACP. Hospital admissions were analysed using mixed-effects Poisson regression for number of admissions, and a mixed-effects negative binomial model for number of occupied hospital bed days.
Results: About 15/24 (63%) eligible homes supported the service, in which 404/508 (79.5%) participants chose ACP. Residents choosing ACP were older, frailer, more cognitively impaired and malnourished; 384/404 (95%) residents choosing ACP recorded their care home as their preferred place of death: 380/404 (94%) declined cardiopulmonary resuscitation. Among deceased residents, 219/248 (88%) and 33/49 (67%) with and without advance care plan respectively died in their care home (relative risk 1.35, 95% confidence interval [CI] 1.1–1.6, *P* < 0.001). Hospital admission rates and bed occupancy did not differ after implementation.
Discussion: About 79.5% participants chose ACP. Those doing so were more likely to die at home. Many homes were unwilling or unable to support the service. Hospital admissions were not reduced. Further research should consider how to enlist the support of all homes and to explore why hospital admissions were not reduced.

Keywords: Advance care planning, hospital admissions, care home residents, older people

Key Points

- The majority of care home residents offered advance care plans (ACPs) took them up, with most preferring care in the care home.
- Residents undertaking ACP were more likely to die in their care home. No effect was seen on hospital admissions.
- Barriers to implementing ACP included organisational policies, care home staff beliefs about ACP and care home staff shortages.

Introduction

Care home residents are typically disabled, have multiple long-term conditions and live with frailty [1]. The overall prognosis of care home residents is poor: in England and Wales the 1-year mortality rate was 26% for care home residents compared with 3.3% for community residents in a study published in 2013 [2]. Interventions for medical crises may be less effective and more burdensome for people with severe frailty [3–5]. In these circumstances, given choice, some residents would opt for care emphasising palliation over increased life expectancy [6].

Advance care planning (ACP) is a process in which people can record preferences for future care including degree of preference for life-sustaining treatments, level of treatment burden they are prepared to accept and end-of-life care preferences including preferred place of death. The intention is that they will be taken into account by care home staff and health care practitioners in the event of a decline in health or medical crisis, and as a result could alter the nature or setting of the health care response. These processes can be adapted to support residents with cognitive impairment, taking account of relevant legal and ethical frameworks, and with involvement of family members or others to act as proxies.

Systematic review has shown that ACPs in care homes decrease hospitalisation rates by 9–26% and increase number of residents dying in their care home as their preferred place of death by 29–40% [7]. In the UK, ACP is recommended as good practice for care home residents [8–10].

There are many reasons why findings from research studies undertaken in specific settings at specific time points may not generalise to other care settings or contexts. Real-world implementation is affected by organisational and human factors that are much more difficult to control than in clinical trials. These include working with a wider range of residents, families, staff and organisations than those volunteering to participate in research.

We had previously established a service to provide advanced care planning in a town in rural Lincolnshire UK and found some evidence that we could reduce hospitals admissions and increase number of residents able to die in a place of their choice, but this work was undertaken in a cohort of enthusiastic homes [11]. When asked to implement a service more widely in the more diverse City of Lincoln, we recognised an opportunity to further understand the impact of ACP in real-world care home settings.

In this paper, we report the findings of our implementation study in which we evaluated the implementation of this ACP service for care home residents in Lincoln. Our objectives were to describe: the number of care homes prepared to support ACP; the proportion of residents who choose ACP; the proportion of residents choosing to die in place in their care homes and the extent to which these wishes could be respected; and the impact of the service on hospital admissions and bed occupancy rates.

Method

Methodology

As this was a service evaluation, data available for analysis were restricted to that acquired during routine practice under terms approved by the Caldicott Guardians (officers with a responsibility for access to and use of clinical data) of the acute and community trusts and for each general practice. Residents or care homes could not be randomised to a no treatment condition. However, as implementation was necessarily undertaken in one home at a time, the order in which the service was implemented could be done on a randomised basis and observation of hospital admissions could be compared between those occurring in the pre- and post-intervention phases. This enabled us to use statistical models as used in stepped wedge RCTs to compare pre- and post-implementation phases and adjust for time effects.

Setting

The service was implemented in Lincoln, UK (population 95,000). All care homes for older people (with and without nursing) registered by the Care Quality Commission (CQC, the regulator of English care homes) in Lincoln were eligible for the service; one was used as a pilot site and is not included in this report. Care home managers were invited to participate. Residents admitted to the care home for respite care or rehabilitation rather than long-term care were excluded from the study. All other residents of participating homes were eligible to be offered the ACP process.

Intervention

One of the authors (GG) was asked by West Lincolnshire Clinical Commissioning Group to set up a service delivering ACP, based upon one previously established in Boston, Lincolnshire [11]. The Bromhead Medical Charity, which had funded the Boston service, agreed to fund the new service and United Lincolnshire Hospitals NHS Trust (ULHT), which had hosted the Boston service, agreed to host it. One of the authors met all care home and general practice managers before the service started to discuss the rationale and evidence for ACP, implementation, referral and provided written referral guidance and information. Two weeks before the start of the initial assessments, a team member visited the care home, to establish which General Practitioners (GPs) covered the home, and GP practice managers to initiate the referral and information sharing processes. In conjunction with the referral process, training sessions about ACP, the service and referral criteria were offered to all care homes. We found that training was important, but because of staff turnover needed regular repetition. The team comprised two registered general nurses, a physiotherapist, an occupational therapist and an old-age psychiatrist (GG) all of whom had extensive experience in healthcare of older people. Residents referred by their GPs, their families and their care staff were invited to participate in the ACP process. However, residents who were not referred by their GP could not be included.

The ACP process involved a comprehensive multidisciplinary assessment of medical conditions, mobility, falls risk, continence and mental health, as well as potential for rehabilitation, diagnostic assessment and medication review. This assessment led to formulation of a management plan discussed at the weekly multidisciplinary team and documented in electronic primary care record, following which residents were offered opportunity to complete an ACP. The assessment used the Edmonton Frail Scale [12], the Barthel Index to assess performance of activities of daily living [13], the Montreal Cognitive Assessment [14] to assess cognitive status, the Malnutrition Universal Screening Tool [15] and the Mini-Nutritional Assessment [16] to assess nutritional status.

The ACP process involved discussion of the resident's present condition, their prognosis, health crises which might arise (including cardiopulmonary resuscitation, artificial feeding and hydration, treatment of sepsis, myocardial infarction, stroke and falls with suspected fracture), possible interventions and locations of care which might be available. Discussions were held with family members in residents who lacked mental capacity to make decisions for themselves using the principles of Best Interests [17], but discussions with family members were encouraged even in those with mental capacity to make their own decisions. The outcome was recorded in a document held at the care home and communicated to GPs and community staff on the resident's electronic care records.

A team member was designated key worker for each care home, and responsible for follow-up of existing residents, initial assessment and ACP for new residents. Weekly multidisciplinary team meetings enabled discussion of new referrals and existing residents.

All residents, during both control and intervention phases, had the same access to NHS primary care services as other community-dwelling people. Every resident was registered with a local GP, responsible for organisation of primary and community health care services. No formal ACP service or specific ACP promotion process was in place in the locality at the time of the study.

Outcomes

The outcomes of interest were:

- The proportion of care homes that agreed to allow residents to participate in the service.
- The proportion of residents who put an ACP in place, and their characteristics.
- The preference for place of death and for a do-not-resuscitate order in those with an ACP.
- The place of death during follow-up of those who chose to have an ACP and those who chose not to, ascertained by the ACP service team.
- The number of hospital admissions per month of residents in participating homes was identified by a member of the informatics department of the sole local hospital trust (UHLT) who searched its hospital administration system,

using care home post codes and addresses. Hospital admission data were retrieved for a total of 49 months: from December 2014 to November 2015 (12 months) before implementation of the service, for the 24-month implementation phase (December 2015–November 2017) and for a further 13 months thereafter (December 2017–December 2018).

- A post hoc analysis of occupied hospital bed days per month per home was conducted after analysis of the hospital admission rates had showed no reduction in admission rates. Due to evaluation resource issues, the data gathered for this analysis were limited to a total of 30 months (3 months before implementation, during the 24 months of implementation and a further 3 months after implementation).

Sample size

No sample size calculation was conducted. Post hoc, the 95% confidence intervals of the mean difference in admissions between the pre- and post-intervention phases were used to examine the precision of our findings.

Randomisation sequence

Randomisation of the order in which the ACP service was implemented was carried out by an experienced member of the Department of Research and Development at UHLT. The name of the next randomised care home was released 2 weeks before the service would be implemented, so that meetings could be held with the care home manager to establish with which general practices residents were registered, and to ask general practitioners to refer the residents for assessment.

Statistical methods

Simple descriptive statistics were used to summarise the implementation of the ACP service, t-tests to compare those who put ACPs in place with those who did not and contingency table analyses to compare the place of death for those who died with or without an ACP in place.

For the analysis comparing the number of hospital admissions per home per month, we censored the data from months where the team was putting the first wave of ACPs in place, which varied from 2 to 3 months depending upon the home. This gave a total of 360 care home months for the control period, and 341 care home months for the intervention period (34 months in total were censored). The corresponding number of care home month data for occupied bed days was 225 for the control period and 191 for the intervention period (the same 34 months were censored).

A mixed effects Poisson regression model was used to compare the number of admissions between the control and intervention periods. A mixed effects negative binomial model was used to compare the number of occupied hospital bed days between the intervention period and control. Both

Table 1. Characteristics of care homes participating in the project

Care Home	Registration	Places	Corporate status	Residents offered assessment
1	Residential	23	Large corporate	27
2	Residential	50	Single home	48
3	Dual	22	Large corporate	20
4	Residential	50	Large corporate	62
5	Dual	48	Large corporate	49
6	Residential	44	Large charitable	63
7	Residential	33	Medium corporate	33
8	Dual	46	Large corporate	41
9	Residential	18	Small corporate	17
10	Dual	54	Large corporate	55
11	Nursing	24	Small corporate	27
12	Nursing	50	Small corporate	44
13	Nursing	40	Small corporate	32
14	Residential	30	Single home	33
15	Dual	47	Medium corporate	11

models were fitted with a random effect for clustering and adjusted for time effects.

Results

Care home recruitment

The service was implemented between 1 December 2015 and 31 December 2017. Twenty-five care homes were identified in the city. One was used as pilot site; the order of implementation for the remaining 24 homes was randomised.

Following randomisation, seven care homes declined to participate. The reasons given were staffing challenges (2 homes); concern about distressing residents and relatives by discussions of death (4 homes); a policy to admit residents to hospital when they became unwell (1 home). The service had to withdraw from one home after the intervention had commenced because of an unannounced intensive CQC inspection, and there were insufficient resources for care home staff to work with the ACP team in one home. Therefore, the project was successfully implemented in 15/24 (63%) of care homes. The characteristics of the participating care homes are detailed in Table 1.

Resident recruitment

Five hundred and forty-eight residents in 15 care homes were referred, of whom 17 died before assessment and 14 left the care homes leaving 517 eligible residents. Eight declined to participate and data from one case were missing. ACPs were drawn up for 404/508 (79.5%): 104 declined to develop an ACP. A consort diagram of recruitment is illustrated in Figure 1.

Baseline resident characteristics

Baseline data were available for 508 participants. Residents for whom ACPs were in place were older, frailer, more dependent, cognitively impaired and malnourished than those for whom ACPs were declined (Table 2).

ACP preferences

The care home was preferred place of death for 396/404 (98%): two preferred hospital, and one hospice and five residents did not specify. Three hundred and eighty of 404 (95%) declined cardiopulmonary resuscitation.

Place of death

After 12 months of follow-up, 300/508 (59%) participants who had been assessed for ACP had died: 253/404 (63%) with an ACP and 47/104 (45%) without (relative risk 1.39, 95% confidence interval [CI] 1.1–1.7, $P = 0.0013$).

A significantly higher proportion of participants with ACPs who died did so in their care home (223/253, 88%) compared with those without ACPs (30/47, 64%) (relative risk 1.39, 95%CI 1.1–1.7, $P < 0.0001$).

Hospital admissions and occupied hospital bed days

In the 15 participating homes, there were 717 hospital admissions over 360 control care home months: median (Inter Quartile Range; IQR) 2 (0.5–3) admissions per care home month. In the intervention period, there were 789 admissions over 341 care home months: median 2 (IQR, 1–3) admissions per care home month. There was no statistically significant difference in the rate of admission between control and intervention phases (Incidence Rate Ratio; IRR: 1; 95% CI, 0.89–1.4).

In post hoc analysis of occupied hospital bed days, there were 6,795 occupied bed days recorded over 225 care home months of control period: median 22 (IQR, 4–41) occupied bed days per care home per month. In the intervention period, for the same 15 homes, there were 5,251 occupied bed days over 191 care home months: median 17 (IQR, 3–42) occupied bed days per care home per month. Similar
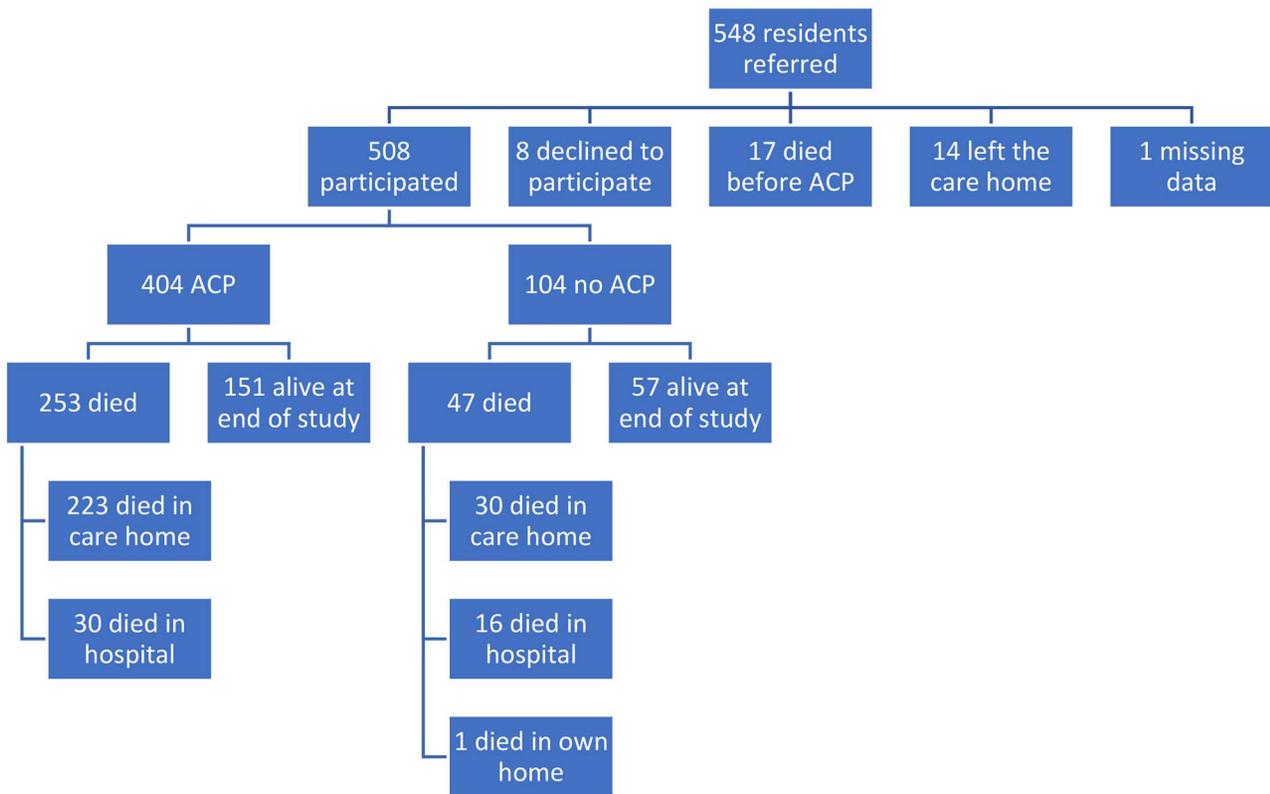
Figure 1. Recruitment of care home residents.

to hospital admissions, there was no statistically significant difference in rate of occupied bed days per month between intervention and control periods (IRR, 1.1; 95% CI, 0.69–1.7).

Discussion

Only two-thirds of eligible care homes participated in the service, indicating a sizeable proportion of residents were denied its benefits. About 404 (79.5%) advance care plans were prepared on behalf of 508 participants, indicating that the service was generally acceptable. As would be anticipated and appropriate, those who chose to put an ACP in place were older, frailer, more disabled, cognitively impaired and malnourished than those who did not, and more likely to die over the subsequent year. For most residents who put an advance care plan in place, the care home was their preferred place of death, and a similarly high proportion chose a do-not-resuscitate order. The preferences residents made in their ACPs may have influenced their care: a higher proportion of residents with ACPs who died did so in their care home than those without ACPs. There was, however, no reduction in hospital admissions.

The willingness and capability of care homes to participate in ACP services have not previously been described, but inability of some homes to participate in this study limited the number of residents who were able to express their health care preferences, and hence ability for those

preferences to be accommodated. Reasons were that some care homes were understaffed, some staff believed that ACP distressed residents and some organisational policies were held as underlining the importance of admitting residents with acute illness. Given that most residents in this evaluation were willing to put an ACP in place (in line with similar proportions in research studies), we believe that the latter two reasons do not represent a good rationale for denying residents opportunity to participate in ACP. Staffing, meanwhile, is even more critical in social care following the COVID-19 pandemic than before [18], and endeavours to improve ACP in the sector are unlikely to succeed until recruitment improves.

Given that we found a nonsignificant increase in hospital admissions following introduction of this ACP service (IRR, 1.1; 95%CI 0.89–1.4), we conclude that we did not observe a reduction in admission rates of 0.19 and 0.2 admissions per resident per year found in the Australian [19] and Canadian [20] studies, respectively. Our findings may be partly methodological given the relatively small sample size, resulting in a low number of admissions over the observation period. However, our best estimate is that admissions were unlikely to be avoided despite what was otherwise a successful implementation as evidenced by high uptake of ACPs by residents.

Several reasons could explain this. Care home staff may not have had sufficient confidence in ACPs to change their admission practices. Furthermore, although ACPs usually

Table 2. Comparison of baseline resident characteristics between those with and without ACPs

	All *N* = 508	ACP *N* = 404	No ACP *N* = 104	Mean difference
Age (years ±SD)	85.5 ± 7.7	86.0 ± 7.5	83.9 ± 8.29	2.138 95%CI 0.529–3.77 (*P* = 0.01)
Female	*N* 358 (70.5%)	*N* 285 (71.6%)	*N* 73 (66.4%)	−0.043 95% CI −0.12 to 0.04 (*P* = 0.286)
Edmonton Frail Scale (0–17) ± SD 0–7: not frail 8–9: mild frailty 10–11: moderate frailty ≥12: severe frailty	12.4 ± 2.9	12.6 ± 2.5	11.5 ± 2.2	1.08 95%CI 0.56–1.6 (*P* < 0.001)
Barthel ADL Index (range 0–20: 20 = functional independence; 12–17 = mild dependency; 0–11 = high dependency; <3 = total dependency)	8.1 ± 6.3	7.6 ± 6.3	10.2 ± 5.8	−2.177 95%CI −3.51 to 0.84 (*P* = 0.001)
Montreal Cognitive Assessment (range 0–30: ≥26 = no cognitive impairment; 18–25 = mild cognitive impairment; 10–17 = moderate cognitive impairment; <10 severe cognitive impairment)	7.2 ± 7.9	6.7 ± 7.8	9.6 ± 8.1	−2.270 95%CI −3.96 to 0.58 *P* value (*P* = 0.008)
Malnutrition universal screening tool (range: 0 = low risk; 1 = medium risk; ≥2 = high risk)	1.0 ± 1.4	1 ± 1.5	0.8 ± 1.5	0.20 95%CI −0.12 to 0.53 (*P* = 0.224)
MNA-SF (range > 11 = no malnutrition; 8–11 = risk of malnutrition; <8 = malnutrition)	7.9 ± 3.4	7.6 ± 3.5	8.7 ± 3	−1.08 95%CI −1.82−−0.35 (*P* = 0.004)
Body mass index (range < 18.5 underweight; 18.5–24.9 = normal BMI; ≥25–29 = overweight; >30 = obese)	23.3 ± 12.2	23.2± 13.5	23.6 ± 5.4	−0.35 95%CI −3.01 to 2.32 (*P* = 0.8)

Table 3. Hospital admissions and occupied hospital bed days by study group

Outcome	Control homes		Intervention homes		Incident rate ratio[a] (95% CI)	*P*-value
	Events	Median (IQR)	Events	Median (IQR)		
Hospital[b] admissions	717	2 (0.5–3)	789	2 (1–3)	1.1 (0.89–1.4)	0.36
Occupied [c] hospital bed days	6,795	22 (4–41)	5,251	17 (3–42)	1.1 (0.69–1.7)	0.73

CI: confidence interval [a]Adjusted for time effects [b]The number of observations in the control period = 360 and in the intervention period = 341 [c]The number of observations in the control period = 225 and in the intervention period = 191

specified a preference for place of death, this does not mean that hospital admissions for potentially nonfatal episodes were unwanted. Even for those prioritising palliation over life expectancy, hospital admission may provide the best means to achieve prompt and effective palliation if primary care provision is limited, especially in the context of the sudden medical crises typical in care residents. It may be that reductions in admissions will only be as a result of ACPs if care home staff are experienced in their application, and if there is adequate provision of prompt and effective community medical and palliative care to support them. It is also important to note that decisions to admit to hospital are not fully in control of care home staff, so emergency and out-of-hours healthcare services, which care homes often call for advice rather than for admission [21], need to be fully on board for the impact of the intervention to be realised. The effect of ACPs could be underestimated because admissions rates in this analysis were recorded at the level of the home and therefore included admission from residents with and without ACPs. However, our best estimate is that admissions were unlikely to be avoided despite what was otherwise a successful implementation as evidenced by the high uptake

of ACPs by residents. Due to unavailability of data, we are unable to comment on whether the ACP programme made any impact upon rates of attendance at the local emergency department.

Given our observations, we propose that although it is possible that ACPs can reduce hospital admissions, as evidenced by trial findings, it is possible that this may not be seen in non-research or other settings. For this reason, we advise that further evaluations are conducted across a wider range of settings, outwith the artificial constraints of a research context [22]. Process evaluations are also required to establish the conditions under which admissions are and are not avoided.

A final consideration is whether a reduction in hospital admissions is a necessary condition to justify the implementation of an ACP programme. The primary purpose of an ACP is to support and respect the rights of individuals for their healthcare preferences to be followed, particularly in circumstances where they are not able to exercise their autonomy directly. In our study, a common preference was for their final illness to take place in the care home rather than hospital, and our findings demonstrated evidence that this was achieved. It is a matter for society to debate whether the provision of this intervention should depend upon whether hospital admission rates are also reduced. A more nuanced analysis, taking account of 'inappropriate admissions' [23] or admissions for ambulatory care sensitive conditions [24] might be more sensitive to the impact of ACP. It could, though, be asserted that focus on admissions skews analysis towards the priorities of healthcare systems and what we can measure, and away from the priorities of individuals approaching end of life. Our analyses here suggested that individual experience improved, even as the impact on system level metrics was uncertain. We advise that ACP services should be put in place on the ethical grounds of enabling vulnerable people, residents of care homes, to exercise choice over their life and death, irrespective of whether doing so affects the number of hospital admissions.

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