



**QUEEN'S  
UNIVERSITY  
BELFAST**

## **Effectiveness of advance care planning with family carers in dementia nursing homes: A paired cluster randomized controlled trial**

Brazil, K., Carter, G., Cardwell, C., Clarke, M., Hudson, P., Froggatt, K., McLaughlin, D., Passmore, A., & Kernohan, G. (2017). Effectiveness of advance care planning with family carers in dementia nursing homes: A paired cluster randomized controlled trial. *Palliative Medicine*, 32(3), 603.  
<https://doi.org/10.1177/0269216317722413>

**Published in:**  
Palliative Medicine

**Document Version:**  
Peer reviewed version

**Queen's University Belfast - Research Portal:**  
[Link to publication record in Queen's University Belfast Research Portal](#)

### **Publisher rights**

© The Author(s) 2017

Reprints and permissions:

[sagepub.co.uk/journalsPermissions.nav](http://sagepub.co.uk/journalsPermissions.nav) This work is made available online in accordance with the publisher's policies. Please refer to any applicable terms of use of the publisher.

### **General rights**

Copyright for the publications made accessible via the Queen's University Belfast Research Portal is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

### **Take down policy**

The Research Portal is Queen's institutional repository that provides access to Queen's research output. Every effort has been made to ensure that content in the Research Portal does not infringe any person's rights, or applicable UK laws. If you discover content in the Research Portal that you believe breaches copyright or violates any law, please contact [openaccess@qub.ac.uk](mailto:openaccess@qub.ac.uk).

**Effectiveness of Advance Care Planning with Family Carers in Dementia Nursing**

**Homes: A Paired Cluster Randomized Controlled Trial**

Kevin Brazil, Gillian Carter, Chris Cardwell, Mike Clarke, Peter Hudson, Katherine Froggatt, Dorry McLaughlin, Peter Passmore and W George Kernohan

Corresponding author: Kevin Brazil, School of Nursing & Midwifery, Queen's University Belfast, Medical Biology Centre, 97 Lisburn Road, BT9 7BL, UK

E-mail: [k.brazil@qub.ac.uk](mailto:k.brazil@qub.ac.uk);

Telephone: +44 (0)28 90975782

Suggested Running title: ACP with Family Carers in Dementia Nursing Homes

## **Abstract**

**Background:** In dementia care a large number of treatment decisions are made by family carers on behalf of their family member who lacks decisional capacity, Advance Care Planning (ACP) can support such carers in the decision-making of care goals. However, given the relative importance of ACP in dementia care, the prevalence of ACP in dementia care is poor.

**Aim:** To evaluate the effectiveness of ACP with family carers in dementia care homes.

**Design:** Paired cluster randomized controlled trial. The intervention comprised: a trained facilitator; family education; family meetings; documentation of ACP decisions; and intervention orientation for GPs and nursing home staff.

**Setting/participants:** Twenty-four nursing homes with a dementia nursing category located in Northern Ireland, UK. Family carers of nursing home residents classified as having dementia and judged as not having decisional capacity to participate in ACP discussions.

**Results:** The primary outcome was family carer uncertainty in decision-making about the care of the resident (DCS scale). There was evidence of a reduction in total DCS score in the intervention group compared with the usual care group (-10.5, 95% confidence interval -16.4 to -4.7;  $p < 0.001$ ).

**Conclusions:** ACP was effective in reducing family carer uncertainty in decision-making concerning the care of their family member and improving perceptions of quality of care in nursing homes. Given the global significance of dementia, the implications for clinicians and policy makers include them recognising the importance of family carer education and improving communication between family carers and formal care providers.

**Key words**

Advance care planning, randomized controlled trial, dementia, family caregivers

**What is already known on this topic?**

In dementia care a large number of treatment decisions are made by family carers on behalf of their family member who lacks decisional capacity, ACP can support such carers in the decision-making of goals of care.

There is limited evidence that ACP has the potential to reduce inappropriate hospital admissions and health-care costs for individuals living with dementia.

Studies have tested different interventions which target nursing home staff for education and a few have focused on the provision of information and education to family carers regarding the terminal nature of dementia.

**What this paper adds?**

There are five key elements to a successful ACP intervention: 1) a trained facilitator; 2) family education; 3) family meetings; 4) documentation of ACP decisions; and 5) orientation of GPs and nursing home staff to the intervention.

An ACP intervention with the five key elements is effective in reducing family carer uncertainty in decision-making concerning the care of their family member and increasing family carer satisfaction in nursing home care.

Family carer education is essential to enable family carers to weigh the burden or benefit of treatment options for advanced stages of dementia.

## **Introduction**

Advance care planning (ACP) has been defined as a process of discussion between a patient, their health care providers, and those close to them, about future care in the event that the patient may lose capacity to make decisions for themselves, as their illness progresses.<sup>1</sup> As such, it has become viewed as a means of navigating the uncertainties at the end of life by identifying and supporting patients' needs and preferences for care.

While ACP is viewed as communication between a patient, their family and healthcare providers and designed to identify patient values and goals of care at the end of life, ACP has several documented outcomes. These outcomes include clarification of patient's preferences, values and aims for future medical treatments and care; the identification of the refusal of specific future treatments should the patient later become unable to communicate; and the appointment of a person to take decisions on the patient's behalf if they subsequently lose decisional capacity.<sup>1-3</sup>

From both an ethical and clinical standpoint, understanding when a treatment becomes futile for a person with dementia is contested, especially as they enter the later stages of the disease and they lose decisional capacity. It is made more challenging if their

wishes have not been stated in advance. Family carers may then be required to make difficult and emotional choices about whether or not to proceed with a life sustaining treatment.<sup>4-6</sup> It is viewed that ACP is a mechanism to support family carers in the difficult decision-making of such goals of care.<sup>2-3, 7</sup> Nonetheless, given the relative importance of ACP in dementia care, the prevalence of ACP in dementia care is poor.<sup>8-</sup>

9

Although guidelines for dementia care suggest that ACP should commence as early as possible<sup>10-12</sup> most residents in nursing homes with advanced dementia do not have an advance care plan<sup>13-14</sup> This has generated calls for a systematic approach to ACP in nursing homes.<sup>15-16</sup> However, the ACP intervention studies to date have used different approaches, making comparisons and data synthesis difficult. A systematic review of ACP in nursing homes<sup>17</sup> reported that ACP definitions vary across studies. The absence of detail on interventions makes it difficult to integrate evidence to determine best practice for ACP in nursing homes. Hence, the purpose of this study was to articulate a family focused ACP intervention and evaluate its impact in dementia care nursing homes. To help family carers participate in decision-making on goals of care at the end of life they need to understand the course of dementia, possible complications and therapeutic options.<sup>18</sup> Recognizing the uncertainty experienced by family carers in this

process the primary hypothesis was that the ACP intervention would reduce family carer uncertainty in decision-making concerning the care of the family member. We also wanted to test whether the ACP intervention would yield higher family carer satisfaction with nursing home care; reduce family carer psychological distress; reduce nursing home resident hospitalisations; reduce hospital deaths; and, increase the number of completed Do Not Resuscitate (DNR) orders.

## **Methods**

As ACP is introduced into practice at the unit level (rather than at individual level), a paired cluster randomized trial was used. Nursing homes for the study were drawn from the largest independent private provider of health and social care services, and at commencement (September 2014) this provider had 74 nursing homes in Northern Ireland (NI). The expression 'nursing homes' describes facilities in the UK that provide care to residents who require continual nursing care. Homes eligible to participate in the study were those given a dementia nursing category by NI's Regulation and Quality Improvement Authority (RQIA). In total, 24 nursing homes were identified and matched into pairs by the number of dementia beds in the facility. Randomisation occurred at the paired facility level where the 24 nursing homes were randomly assigned (12 nursing homes per treatment) to ACP with usual care (intervention group) versus usual care



alone (control group). The random number generator in Excel was used when a pair of nursing homes was ready to be enrolled, such that one was allocated to intervention and one to usual care at the same time. This was done by a member of the research team with no knowledge of the nursing home, and the allocation was concealed until after both homes in the pair had confirmed their willingness to join the study. Recruitment of the 24 homes took place in a staggered manner over nine months.

#### *Participants and recruitment procedure*

In the participating nursing homes, resident records were reviewed by the nursing home manager to identify those individuals classified as having dementia and judged as not having decisional capacity to complete an ACP. For each eligible resident, the nursing home manager also completed a Functional Assessment Staging Tool (FAST) score.<sup>19</sup> This tool was designed to assess the stage of dementia by outlining key symptoms. Following identification of eligible residents, the family members most responsible for care of each resident were identified as potential study participants. These individuals were mailed a pre-notification letter by the nursing home manager endorsing the study and extending an invitation to an information event held at the nursing home. In parallel, the nursing home manager identified resident General Practitioners (GPs) and other health and social care providers who they felt should receive a letter to inform

them about the study. Following the information event, and randomization a recruitment baseline questionnaire package was mailed to the potential participant's home address by the nursing home administrator. Non-respondents were sent a reminder postcard and then, if necessary, a replacement questionnaire. Respondents in the intervention group were invited to participate in up to two family meetings with the ACP facilitator. A follow-up questionnaire was mailed to them six weeks after baseline. Participants in the usual care group completed a follow-up questionnaire only. The research team mailed the follow-up questionnaire package to participants, and, as in baseline data collection, with two further points of contact if necessary. As a gesture of appreciation for participating in the project participants who completed both survey rounds were entered into a raffle for a small prize.

### *Ethics*

Ethical approval was obtained from the regional Office of Research Ethics Committees Northern Ireland (ORECNI) (Ref. 14/NI/0082) and the Queen's University Belfast Research Governance Office. Participants gave informed consent before taking part and signed a consent form.

### *ACP intervention*

The combination of components for this intervention represents elements identified as important to ACP: a trained ACP facilitator; family education; family meetings; documentation of advance care plan decisions; and orientation of GPs and nursing home staff to the intervention.<sup>1-3, 15, 20-22</sup> Prior to the launch of the trial two nursing homes participated in a pilot of the study protocol resulting in no change to the intervention.

The ACP facilitator selected for this role was a Registered Nurse with minimum of three years post registration experience and a minimum of two years working in a field related to palliative care. In preparation for their role in this project the selected candidate completed the Respecting Choices 'Online ACP Facilitator Curriculum'<sup>23</sup> and 'The End of Life Care for All' (e-ELCA)<sup>24</sup> online training programmes, augmented with face-to-face orientation on ACP and dementia by local expertise.

Family meetings were typically scheduled in the nursing home by the ACP facilitator. Prior to the meeting, participants were mailed the booklet "Comfort care at the end of life for persons with Dementia – a guide for caregivers (Northern Ireland version)". Originally developed in Canada, this booklet provided information on the trajectory of the disease, clinical issues, decision-making processes, and symptom management.<sup>25</sup> It

has shown a high level of acceptability,<sup>18, 26-27</sup> and has been identified as a best practice instrument.<sup>28</sup> Prior to use in this study the original booklet was reviewed by an expert panel including a service user, before being pilot tested to assure that the contents resonated with culture and practice in NI.

The structure (preparing, conducting and documentation) of the family meeting was based on clinical practice guidelines developed for conducting family meetings.<sup>29</sup> In the initial family meeting the contents of the booklet were reviewed and the family carers were assisted by the ACP facilitator to reflect on the resident's goals, values, beliefs, and end of life care options in order to facilitate best interest decision-making. In the second meeting, family carers had the opportunity to review a draft advance care plan developed by the facilitator based on their previous discussion, to address any outstanding issues, and sign the standardized advance care plan document, retaining a personal copy. As a follow-up to the family meetings, the advance care plan was placed in the resident's medical records following orientation on the contents with the nurse-in-charge, and a copy was sent to the resident's GP.

### *Outcome measures*

The primary outcome was family carer uncertainty in decision-making about the care of the resident. This was measured using the 16-item Decisional Conflict Scale (DCS) in which items were scored, averaged and transformed to provide an overall score<sup>30</sup> The instrument also provides five subscales: 1) 'Informed', which measures awareness of options, benefits, and risks; 2) 'Values Clarity', which measures feelings of support, advice, and pressure from others; 3) 'Support', which measures the perceived level of support in decision making; 4) 'Uncertainty', which measures the respondent's degree of confidence about the decision; and, 5) 'Effective Decision' measures the likelihood of adhering to the decision and satisfaction with the decision.

Secondary outcomes included family carer satisfaction with nursing home care, measured by the Family Perceptions of Care Scale (FPCS).<sup>31</sup> This 25-item scale was designed to assess family carer perceptions of the care given to a family member in the last four weeks of life. On the basis of pilot testing, the tense was adjusted to recognise that the resident was not deceased. The FPCS provides an overall score as well as four subscales scores: 1) 'Resident Care', which measures family members opinions of care provided to the resident; 2) 'Family Support', reports on perceptions of nursing home care directed towards family members to assist family members to assist them with

decision-making; 3) 'Communication', concerning the timeliness, comprehensiveness, and clarity of the communication between staff and the family member; and 4) 'Rooming' assessing perception of appropriate placement of the resident in the facility. Additionally, family carer psychological distress was measured using the General Health Questionnaire (GHQ).<sup>32</sup> The GHQ is a 12-item self-report instrument which measures psychological morbidity. If a resident died during the data collection period family carers received the Quality of Dying in Long-Term Care instrument (QOD-LTC)<sup>33</sup> four weeks after the death. Staff involved in the care of the resident received the QOD-LTC one week after the death. The 11-item instrument assessed the quality of dying experience.

Nursing home administrative records of residents whose family member participated in the study were reviewed for six months after the completion of the follow-up questionnaire. The review examined hospitalisation rates; completion rates for Do Not Resuscitate (DNR) orders; and, place of death.

### *Analysis*

Frequencies were determined for categorical variables and summary statistics (using mean and standard deviation for approximately symmetrical variables) were calculated for quantitative variables. The primary analysis for the continuous outcomes was

conducted using a two-stage method, using meta-analysis models, recommended for the analysis of paired cluster randomized trials.<sup>34</sup> First, for each outcome, analysis of covariance was used to calculate the difference in mean (and accompanying standard error) between the intervention and control group adjusting for baseline<sup>35</sup> within the 11 pairs of homes. This difference in mean (and standard error) was then pooled using a random effects meta-analysis model to calculate the pooled difference in mean and 95% CI.<sup>34</sup> Chi-squared tests were conducted and  $I^2$  statistics (measuring the proportion of the variation in the treatment estimate due to heterogeneity) were calculated to determine the consistency of the treatment effect across the paired clusters.<sup>36</sup> Secondary outcomes based upon proportions which had small cell counts (e.g. hospitalisations, DNRs and place of death) were analysed by calculating the proportion at the home level and then using a Wilcoxon-signed rank test to compared these proportions between the intervention and control groups.<sup>37</sup> A separate sensitivity analysis, recommended for missing outcome data when a baseline is available<sup>38</sup>, was conducted for the primary outcome. Specifically, within the pairs of homes a covariate adjusted complete-case analysis was conducted with variables included in the model (specifically age, gender and FAST score) which could be associated with outcome or probability of missingness and the random effects meta-analysis model was used to pool

these estimates as previously (not shown as estimates were similar to the main analysis).

All analyses were conducted in STATA 14.<sup>39</sup>

## **Results**

Subsequent to pilot testing, 24 homes were randomized before baseline data collection.

One nursing home in the usual care group withdrew from the study prior to family carers being contacted because of competing workload priorities and the inability to accommodate the project. Participants were recruited from January 2015 until September 2015.

Insert Figure 1 about here

Figure 1 reveals that 695 family carers were eligible to participate in the trial: 38 were removed from the study as their mailing address was incorrect or their family member had either recently died or were discharged prior to the mailing of baseline questionnaires. This resulted in an adjusted sample of 657 family carers who were mailed the baseline questionnaire. The overall response rate in the initial baseline mail-out was 197 (30%), 36% response rate in the usual care group and 24% for the intervention group.



In the intervention group 67 (84%) of the 80 individuals who completed the baseline questionnaire also completed the intervention with 61 family carers completing the follow-up questionnaire (Figure 1). In the usual care group 117 family carers completed the baseline questionnaire and 98 (84%) family carers completing the follow-up questionnaire.

Table 1 shows characteristics for family carers and their relative residing in the nursing home. Most family carers were identified as daughters of the resident and most residents were identified as having moderately severe to, severe dementia.

Insert Table 1 around here

ACP family meetings were delivered to 67 out of 80 participants who completed the baseline questionnaire in the intervention group (Figure 1). On average the meetings lasted 60 minutes. Most family carers attended the family meetings on their own 69% (n= 46) but typically reported that they consulted with family members between the meetings. ACP facilitator time for each family encounter was on average 130 minutes,

including administration, conducting the meetings, drafting an ACP and liaising with nursing home staff.

Family carers identified preferences for future care that typically included their relative be pain free and in comfort; non-essential medication to be discontinued; their relative to be able to die in the nursing home; availability of religious support; nursing home staff to provide the resident emotional support in the family's absence, and to notify the family when the resident's condition deteriorated. Family carers specified that they wanted to be consulted on decisions concerning transfer to a hospital to avoid unnecessary hospitalizations; to avoid life prolonging measures if there was little or no significant hope of improving quality of life; and for those family residents with a DNR in place that resuscitation was avoided.

Insert Table 2 around here

An examination of the total mean score and sub-scores of the DCS at baseline (T1) and follow-up (T2) in the intervention and control groups suggests evidence of effectiveness (Table 2). There was evidence of a difference between the intervention and usual care group on the total DCS score at 7 weeks after adjusting for baseline (-10.5, 95%

confidence interval (CI) -16.4 to -4.7;  $p < 0.001$ ). There was marked heterogeneity in the association across the 11 pairs of homes ( $I^2=58%$ , heterogeneity  $p = 0.01$ ). On closer inspection (see Figure 2), this was largely due to a larger effect in Pair 2. After omitting Pair 2 from the overall analysis, the effect remained (-8.4, 95% CI -13.1 to -3.7;  $p = 0.001$ ) and the heterogeneity was reduced ( $I^2=32%$ , heterogeneity  $p = 0.15$ ). Evidence of differences between the intervention and usual care group on all subscales of the DCS (Table 2) were also revealed.

Insert Figure 2 about here

Insert Table 3 around here

Table 3 reports the findings for the secondary outcomes GHQ and the FPCS at T1 and T2. There was little evidence of a difference between the intervention and usual care group on the total GHQ score at 7 weeks after adjusting for baseline. This result was fairly consistent across pairs ( $I^2=26%$ , heterogeneity  $p= 0.19$ ). There was evidence of a difference in the total FPCS total score between the intervention and usual care group after adjusting for baseline (8.6, 95% CI 2.3 to 14.8;  $p = 0.01$ ), which was also fairly consistent across pairs ( $I^2=14%$ , heterogeneity  $p= 0.31$ ). This difference was driven by the two subscales; 'Family Support' and 'Communication'. Six residents died during the

data collection period. A low response rate did not allow for analysis of the QOD-LTC between the two groups.

Insert Table 4 around here

Table 4 shows the increase in DNRs, and reductions in hospital admissions and deaths in the intervention group compared with the usual care group but none of these differences were statistically significant. While there was a reduction in admissions in the ACP group of around 11% (7% versus 18%) we cannot rule out the possibility of a type 2 error i.e. that there are reductions in hospital admissions but we did not detect them as statistical significant.

## **Discussion**

In this paired cluster randomized trial, the ACP intervention significantly reduced family carer uncertainty in decision-making concerning the care of the family member; and, improved family carer satisfaction in nursing home care. However the intervention did not have a detectable impact on family carer psychological distress; the number of completed DNRs; reduced hospitalisations; or, number of deaths in a hospital.

Flo et al<sup>17</sup> conducted a review of ACP in nursing homes and reported that most studies had tested different interventions, with staff education being the most common (learning courses and practical training). While most studies targeted nursing home staff for education, some interventions similar to ours, focused on providing information and education to family carers regarding the terminal nature of dementia. As was the case in our study, most previous studies did not use nursing home residents as study informants. Those studies that did include residents excluded those with advanced dementia.

The challenge of recruiting family carers in this type of research is noteworthy. In our case, the cross-sectional approach to recruitment generated low initial response from family carers. This observation highlights what is recognized in the literature, that successful ACP engagement, is predicated on the initiation of a health care provider who is engaged in a trusting relationship and who recognizes the importance of timing when to initiate ACP discussions.<sup>40</sup>

The booklet that we used for family carer education 'Comfort care at the end of life for persons with Alzheimer's Disease or other Degenerative Diseases of the Brain' has been shown through multi-country studies to have high levels of acceptability among family

carers, nurses and physicians<sup>18, 26-27</sup> and the WHO has identified the booklet as a best practice instrument<sup>28</sup>. The tools used in previous ACP intervention studies have been diverse. However, it was commonly viewed across studies, as in our work, that ACP is a decision-making process. Flo et al<sup>17</sup> further noted variation across studies on the level of formalization of the ACP conversation and its documentation. In our study family meetings were implemented using a standardized approach based on clinical practice guidelines<sup>29</sup>. Furthermore, advance care plan documentation was also standardized.

Despite the widespread acceptance of relying on family carers in best interest decision making, the presence of family carer stress and conflict around the 'right' decision makes the decision-making process challenging. The concern for a 'right decision' shifts the importance of ACP as a means to support best-interest decision-making, where consideration is whether a decision is the least restrictive of a person's right or freedom.<sup>41</sup>

Our study has both strength and limitations. We showed that the intervention was successful for the target population. An important feature of our study was that participants were offered a standardized ACP approach allowing for generation of a detailed description of the intervention and its implementation. Explicit details on the

model and its operation facilitates the opportunity to disseminate the model to other nursing home settings. Another important strength of our study is the use of cluster randomization of nursing homes to avoid contamination between participants in the intervention and control groups. The paired nature of our design also allowed the balancing of potential confounding variables to ensure similarity between groups. We also utilised internationally recognized and widely used outcome instruments.

Our study has some limitations. One limitation was the inability to blind the allocation between randomization and data collection. Nursing homes had to be randomized before we collected baseline data, which reduced the internal validity of the study, as did the lack of blinding for follow-up data. The accuracy of nursing home reports of DNR, hospitalisations and location of death was dependent on nursing home manager access to records and also record keeping. While the study did not include an economic analysis it did record time spent by the ACP facilitator on a family case basis. This information can be used to estimate manpower costs and inform commissioning business cases.

### **Acknowledgements**

The research team would like to thank the carers and the lay individuals for their contribution and participation in the study.

## **Funding**

Funding to undertake this study was received from the Health and Social Care Public Health Agency, and The Atlantic Philanthropies. All members of the research team were independent from the funders. The funders played no role in the design and conduct of the study; in the collection, management, analysis, and interpretation of the data; or in the preparation, review, or approval of the manuscript.

## **Declaration of conflicting interests**

All authors declare: no support from any organization for the submitted work; no financial relationships with any organizations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

## **Implications for Practice and Policy**

This paired cluster randomized trial indicates that it is feasible to implement an ACP intervention in dementia care nursing homes with effective outcomes. Implications for clinicians and policy makers include recognizing the importance of improving communication between family carers and formal care providers who are involved in



resident nursing home care. Secondly, family carer education is essential to enable family carers to weigh the burden or benefit of treatment options when the family member enters the late stages of dementia. Furthermore, ACP needs to become part of the usual nursing home care involving various formal care providers such as the resident's GP and nursing home staff. In conclusion, it should be recognized that the approach pursued in cultivating and supporting sustainable ACP expertise will be shaped by broader nursing home conditions and should be accounted for in practice and policy deliberations.

## References

1. Royal College of Physicians. Concise Guidance to Good Practice: A series of evidence-based guidelines for clinical management: Number 12 Advance care planning National Guidelines. 2009.
2. NHS End of Life Care. Advance Care Planning: A Guide for Health and Social Care Staff. 2008.
3. NHS Improving Quality. Capacity, care planning and advance care planning in life limiting illness: A Guide for Health and Social Care Staff. 2014.
4. Caron CD, Griffith J and Arcand M. End-of-life decision making in dementia: The perspective of family caregivers. *Dementia*. 2005; 4: 113-36.
5. Sachs GA, Shega JW and Cox-Hayley D. Barriers to excellent end-of-life care for patients with dementia. *Journal of General Internal Medicine*. 2004; 19: 1057-63.
6. Livingston G, Leavey G, Manela M, et al. Making decisions for people with dementia who lack capacity: qualitative study of family carers in UK. *British Medical Journal*. 2010; 341.
7. Seymour J, Almack K and Kennedy S. Implementing advance care planning: a qualitative study of community nurses' views and experiences. *BMC Palliative Care*. 2010; 9: 4-.
8. Laakkonen M-L, Raivio MM, Eloniemi-Sulkava U, Tilvis RS and Pitkälä KH. Disclosure of Dementia Diagnosis and the Need for Advance Care Planning in Individuals with Alzheimer's Disease. *Journal of the American Geriatrics Society*. 2008; 56: 2156-7.
9. Godwin B and Waters H. 'In solitary confinement': Planning end-of-life well-being with people with advanced dementia, their family and professional carers. *Mortality*. 2009; 14: 265-85.
10. World Health Organisation. Dementia a Public Health Priority. Geneva: World Health Organisation, 2012.
11. Hertogh CPM. Advance care planning and the relevance of a palliative care approach in dementia. *Age and Ageing*. 2006; 35: 553-5.
12. Brown M, Grbich C, Maddocks I, Parker D, Connellan PR and Willis E. Documenting end of life decisions in residential aged care facilities in South Australia. *Australian and New Zealand Journal of Public Health*. 2005; 29: 85-90.
13. Mitchell SJ, Kiely DK and Hamel M. Dying with advanced dementia in the nursing home. *Arch Intern Med*. 2004; 164: 321-6.
14. Caplan GA, Meller A, Squires B, Chan S and Willett W. Advance care planning and hospital in the nursing home. *Age and Ageing*. 2006; 35: 581-5.
15. Detering KM, Hancock AD, Reade MC and Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *British Medical Journal*. 2010; 340.
16. Molloy D, Guyatt GH, Russo R and et al. Systematic implementation of an advance directive program in nursing homes: A randomized controlled trial. *Journal of the American Medical Association* 2000; 283: 1437-44.

17. Flo E, Husebo BS, Bruusgaard P, et al. A review of the implementation and research strategies of advance care planning in nursing homes. *BMC Geriatr.* 2016; 16: 24.
18. Arcand M, Brazil K, Nakanishi M, et al. Educating families about end-of-life care in advanced dementia: acceptability of a Canadian family booklet to nurses from Canada, France, and Japan. *Int J Palliat Nurs.* 2013; 19: 67-74.
19. Sclan SG and Reisberg B. Functional Assessment Staging (FAST) in Alzheimer's Disease: Reliability, Validity, and Ordinality. *International Psychogeriatrics.* 1992; 4: 55-69.
20. Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life.* Washington DC: The National Academies Press, 2015.
21. General Medical Council. *Guidance for Doctors: Treatment and care towards the end of life: good practice in decision making.* 2010.
22. Robinson L, Dickinson C, Rousseau N, et al. A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. *Age and Ageing.* 2012; 41: 263-9.
23. Gundersen Health System. *Respecting Choices Facilitator Curriculum.* La Crosse: Gundersen Health System, 2013.
24. NHS - Health Education England. *End of Life Care for All (e-ELCA).* 2014.
25. Arcand M and Caron C. *Comfort Care at the End of Life for Persons with Alzheimer's Disease or Other Degenerative Diseases of the Brain - A Guide for Caregivers.* Centre de santé et de services sociaux - institut universitaire de gériatrie de Sherbrooke, 2005.
26. van der Steen JT, De Graas T, Hertogh CMPM, et al. Physicians' and Nurses' Perceived Usefulness and Acceptability of a Family Information Booklet about Comfort Care in Advanced Dementia. *Journal of Palliative Medicine.* 2011; 14: 614-22.
27. van der Steen JT, Arcand M, Toscani F, et al. A Family Booklet About Comfort Care in Advanced Dementia: Three-Country Evaluation. *Journal of the American Medical Directors Association.* 2012; 13: 368-75.
28. World Health Organisation Regional Office for Europe. *Palliative care for older people: better practices.* Copenhagen: World Health Organisation 2011.
29. Hudson P, Quinn K, O'Hanlon B and Aranda S. Family meetings in palliative care: Multidisciplinary clinical practice guidelines. *BMC Palliative Care* 7: (2008, accessed 16 01 14).
30. O'Connor AM. Validation of a decisional conflict scale. *Medical decision making : an international journal of the Society for Medical Decision Making.* 1995; 15: 25-30.
31. Vohra JU, Brazil K, Hanna S and Abelson J. Family perceptions of end-of-life care in long-term care facilities. *Journal of Palliative Care.* 2004; 20: 297-302.
32. Goldberg DP and Williams P. *A user's guide to the General Health Questionnaire.* Basingstoke: NFER-Nelson, 1988.
33. Munn, J. C., S. Zimmerman, L. C. Hanson, C. S. Williams, P. D. Sloane, E. C. Clipp, J. A. Tulsky and K. E. Steinhauser (2007). "Measuring the Quality of Dying in Long-Term Care." *Journal of the American Geriatrics Society* 55(9): 1371-1379.

34. Thompson SG, Pyke SD and Hardy RJ. The design and analysis of paired cluster randomized trials: an application of meta-analysis techniques. *Stat Med*. 1997; 16: 2063-79.
35. Vickers AJ and Altman DG. Statistics notes: Analysing controlled trials with baseline and follow up measurements. *Bmj*. 2001; 323: 1123-4.
36. Higgins JP, Thompson SG, Deeks JJ and Altman DG. Measuring inconsistency in meta-analyses. *Bmj*. 2003; 327: 557-60.
37. Donner A and Klar N. *Design and Analysis of Cluster Randomization Trials in Health Research*. London: Arnold, 2000.
38. Groenwold RH, Donders AR, Roes KC, Harrell FE, Jr. and Moons KG. Dealing with missing outcome data in randomized trials and observational studies. *American journal of epidemiology*. 2012; 175: 210-7.
39. StataCorp. *Stata Statistical Software: Release 14*. College Station, TX: StataCorp LP., 2015.
40. Mullick A, Martin J and Sallnow L. An introduction to advance care planning in practice. *BMJ*. 2013; 347.
41. Vig EK, Starks H, Taylor JS, Hopley EK and Fryer-Edwards K. Surviving surrogate decision-making: what helps and hampers the experience of making medical decisions for others. *J GEN INTERN MED*. 2007; 22: 1274-9.

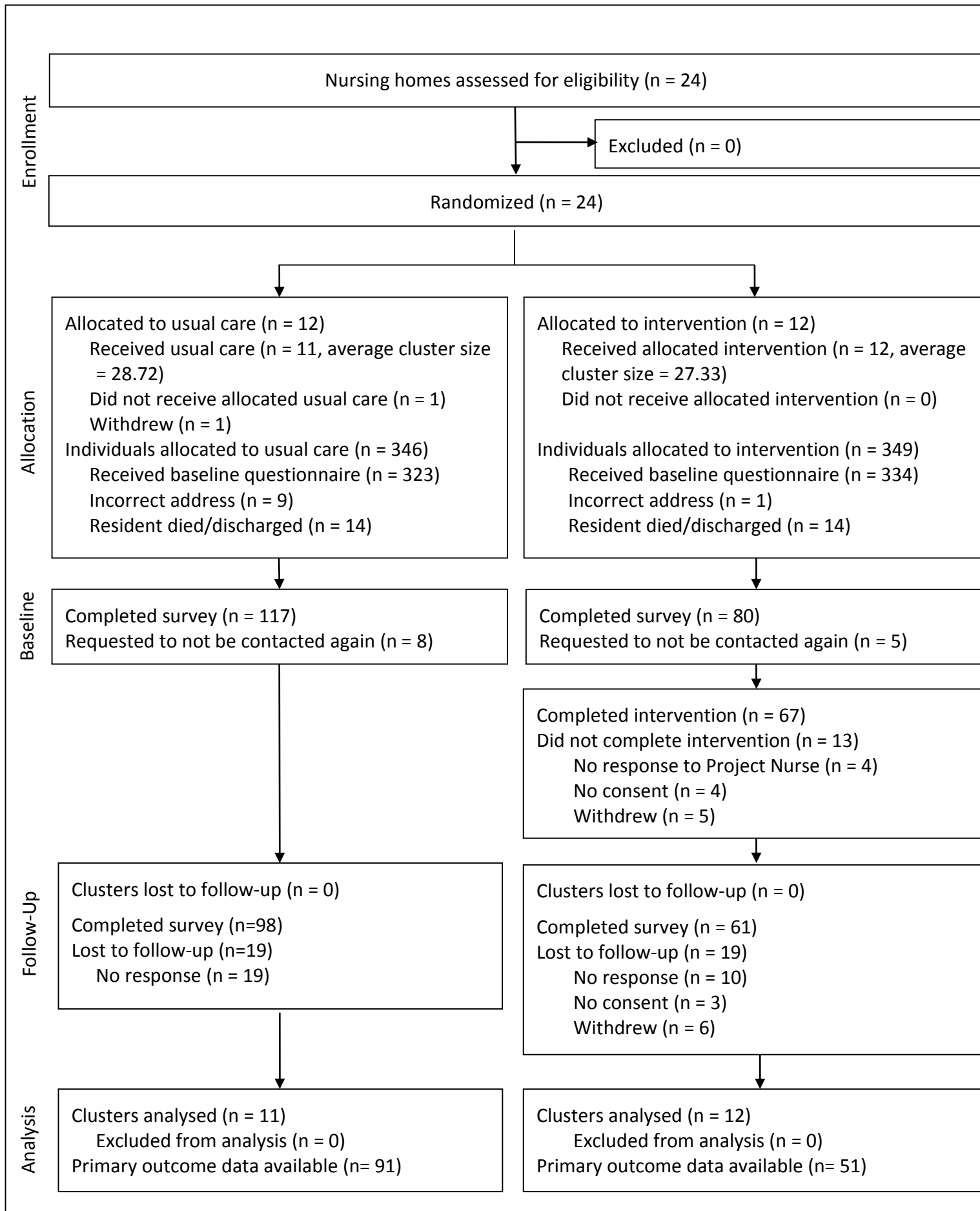
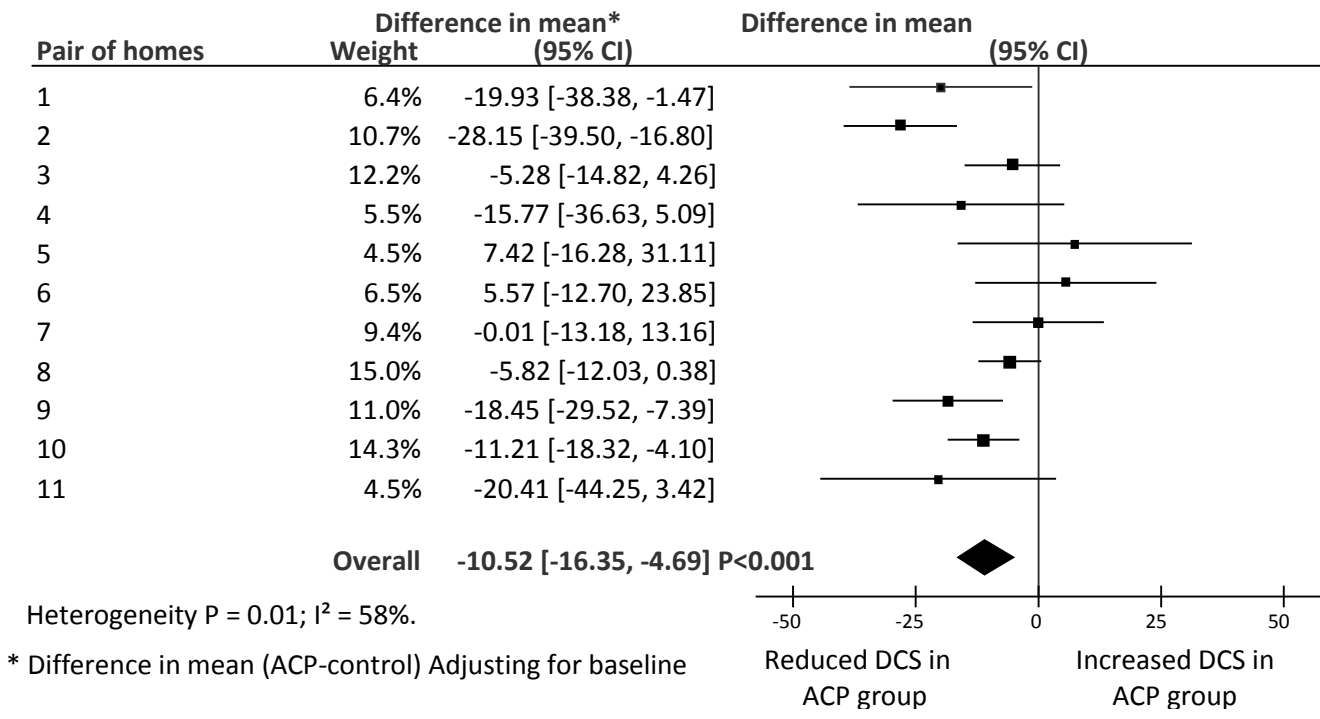


Figure 2



**Table 1.** Respondents' characteristics at baseline. Values are numbers (percentages).

Characteristics	As randomised		Included in main analysis	
	Intervention (n = 79)	Usual Care (n = 117)	Intervention (n = 51)	Usual Care (n = 91)
<b>Gender</b>				
Male	15 (19.0)	45 (38.5)	8(15.7)	34(37.4)
Female	64 (81.0)	72 (61.5)	43(84.3)	57(62.6)
<b>Age</b>				
Mean (SD)	61.6 (11.8)	59.9 (10.6)	61.6(11.6)	60.3(11.0)
Range n(%)				
18-30	1 (1.3)	0 (0.0)	1(2.0)	0(0.0)
31-40	2 (2.5)	3 (2.6)	1(2.0)	3(3.3)
41-50	9 (11.4)	17(14.5)	5(9.8)	12(13.2)
51-60	21 (26.6)	39 (33.3)	15(29.4)	33(36.3)
61-70	26 (32.9)	24 (20.5)	17(33.3)	17(18.7)
71-80	8 (10.1)	18 (15.4)	3(5.9)	17(18.7)
81-90	5 (6.3)	2 (1.7)	4(7.8)	2(2.2)
<b>Relationship of care home resident</b>				
Parent	44 (55.7)	70 (59.8)	28(54.9)	53(58.2)
Spouse	12 (15.2)	20 (17.1)	7(13.7)	16(17.6)
Sibling	5 (6.3)	6 (5.1)	4(7.8)	6(6.6)
Extended family	18 (22.8)	20 (17.1)	12(23.5)	15(16.5)
<b>FAST Score</b>				
Mild dementia	2(2.5)	2(1.7)	1(2.0)	2(2.2)

Moderate dementia	2(2.5)	4(3.4)	1(2.0)	3(3.3)
Moderately severe dementia	49 (62.0)	54 (46.2)	34(66.7)	45(49.5)
Severe dementia	26 (32.9)	57 (48.7)	15(28.4)	41(45.1)

---

FAST: Functional Assessment Staging Tool.



**Table 2.** Comparison of primary outcome decisional conflict scale (DCS) between the control and intervention group.

Primary Outcomes	Time	Control		Intervention		Difference in mean <sup>b</sup> (95% CI)	P	I <sup>2</sup> (hetero P)
		n <sup>a</sup>	mean (SD)	n <sup>a</sup>	mean (SD)			
Total DCS Score	T1 <sup>c</sup>	91	34.7(21.0)	51	28.3(22.3)			
	T2 <sup>d</sup>	91	30.7(20.5)	51	18.3(19.7)	-10.5(-16.4, -4.7)	<0.001	58% (0.01)
DCS Subscore: Informed	T1	94	39.5(26.2)	56	33.8(26.0)			
	T2	94	37.4(25.7)	56	20.2(22.7)	-15.0(-22.0, -8.0)	<0.001	58% (0.01)
DCS Subscore: Values clarity	T1	94	36.2(24.8)	55	33.2(28.3)			
	T2	94	32.5(24.0)	55	21.2(25.2)	-12.8(-24.1, -1.6)	0.03	75% (<0.01)
DCS Subscore: Support	T1	95	31.6(21.5)	55	26.8(24.2)			
	T2	95	27.4(20.9)	55	17.1(19.5)	-7.7(-12.9, -2.5)	<0.001	16% (0.29)
DCS Subscore: Uncertainty	T1	94	38.2(22.2)	54	34.4(27.5)			
	T2	94	31.8(21.2)	54	21.6(21.6)	-8.3(-14.5, -2.2)	0.01	34% (0.13)
DCS Subscore: Effective decision	T1	94	29.6(21.7)	54	24.4(22.1)			
	T2	94	25.8(19.7)	54	16.8(21.0)	-7.3(-11.5, -3.0)	<0.001	1% (0.44)

<sup>a</sup>Numbers only include those who contribute at both time points.

<sup>b</sup>Pooled difference in mean adjusting for baseline, summarized at pair home level and pooled across homes using meta-analysis.

<sup>c</sup>Time 1 baseline.

<sup>d</sup>Time 2 follow-up.

**Table 3.** Comparison of secondary outcomes General Health Questionnaire (GHQ) and Family Perception of Care Scale (FPCS) between intervention and control group.

Secondary outcomes	Time	Control		Intervention		Difference in mean <sup>b</sup> (95% CI)	P	I <sup>2</sup> (hetero P)
		n <sup>a</sup>	mean (SD)	n <sup>a</sup>	mean (SD)			
Total GHQ Score	T1 <sup>c</sup>	88	12.6(6.1)	55	11.4(5.3)			
	T2 <sup>d</sup>	88	11.6(5.4)	55	9.9(6.1)	-0.5(-1.9, 0.8)	0.44	26% (0.19)
Total FPCS Score	T1	88	131.0(22.9)	42	138.0(21.4)			
	T2	88	133.6(23.8)	42	144.6(25.6)	8.6(2.3, 14.8)	0.01	14% (0.31)
FPCS Subscale: Resident Care	T1	91	59.1(11.3)	46	61.6(10.6)			
	T2	91	60.1(11.4)	46	63.6(12.3)	2.1(-0.5, 4.7)	0.11	9% (0.36)
FPCS Subscale: Family Support	T1	91	26.8(7.1)	45	28.7(7.1)			
	T2	91	28.2(7.3)	45	32.7(7.2)	3.9(1.7, 6.1)	<0.001	16% (0.29)
FPCS Subscale: Communication	T1	96	33.1(5.2)	52	34.3(6.9)			
	T2	96	33.2(5.4)	52	35.6(6.9)	2.2(0.8, 3.6)	<0.001	27% (0.19)
FPCS Subscale: Rooming	T1	95	12.2(1.8)	56	12.9(1.2)			
	T2	95	12.2(1.9)	56	12.7(1.9)	0.3(-0.2, 0.9)	0.21	31% (0.15)

<sup>a</sup> Numbers only include those who contribute at both time points.

<sup>b</sup> Pooled difference in mean adjusting for baseline, summarized at pair home level and pooled across homes using meta-analysis.

<sup>c</sup> Time 1 baseline.

<sup>d</sup> Time 2 follow-up.

**Table 4.** Do Not Resuscitate orders (DNRs), hospitalizations and location of death.

	Usual Care	Intervention	P <sup>a</sup>
No. of completed DNRs <sup>b</sup>	23 (42%) <sup>c</sup>	21 (51%)	0.18
Hospital admissions <sup>b</sup>	17 (18%)	5 (7%)	0.12
Location of death <sup>b</sup> :			
Nursing home	24 (80%)	12 (86%)	
Hospital	6 (20%)	2 (14%)	0.94

DNR: Do Not Resuscitate.

<sup>a</sup>P-value based upon a Wilcoxon sign rank comparison of paired home proportions.

<sup>b</sup>During 6 months after last point of contact with study.

<sup>c</sup>Out of people on whom DNR information was available and were know not to have a DNR at the start of the study.