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Citation for final published version:

Gleeson, Aoife, Noble, Simon and Mann, Mala 2021. Advance care planning for home health staff: a systematic review. *BMJ Supportive and Palliative Care* 11 (1) , pp. 209-216. 10.1136/bmjspcare-2018-001680

Publishers page: <https://spcare.bmj.com/content/early/2019/02/26/bm...>

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Advance care planning for home health staff: a systematic review

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Abstract

Background

Advance care planning (ACP) is a process where patients express their wishes regarding their future healthcare. Its importance has been increasingly recognised in the past decade. As increasing numbers of elderly people are living in care homes, the aim of this review was to identify the most effective ACP interventions to train/educate all levels of healthcare professionals working in care homes.

Design

A systematic review. Two independent reviewers undertook screening, data extraction and quality assessment. Data sources Searched from inception to June 2018: Ovid Medline, Ovid Medline in process, Ovid Embase, Cochrane Central Register of Controlled Trials, EBSCO Cinahl and Ovid PsycINFO. results Six studies were included: three before and after studies, one cluster randomised controlled trial (RCT), one non-blinded RCT and one qualitative study. Five studies reported on ACP documentation, three on impact on ACP practice and three studies on healthcare-related outcomes. All quantitative studies reported an improvement in outcomes. In the three studies reporting on health-related outcomes, one showed significant reductions in hospitalisation rate, days and healthcare costs; one reported significant reductions in hospital deaths; and the third showed reductions in hospital days and deaths. A meta-analysis could not be performed due to the heterogeneity of the outcome measures. The included qualitative study highlighted perceived challenges to implementing an educational programme in the care home setting.

Conclusion

There is limited evidence for the effectiveness of ACP training for care home workers. More well-designed studies are needed.

Trial registration number CRD42016042385.

Introduction

Advance care planning (ACP) is a voluntary process where a person is enabled to discuss and communicate their preferences with regard to their future healthcare.

While there has been a significant increase in interest in ACP since the 1990s¹ and there is evidence to show that patients appreciate engagement in medical care and decision-making,² there remains a large mismatch between the desire of the general public to be involved in care planning and its actual uptake.

The UN reports that the number of people aged over 60 years is estimated to more than double by 2050 and more than triple by 2100.³ In England and Wales, the proportion of the population aged 65 or over increased by 11% from 2001 to 2011, of whom 3.2% lived in care homes in 2011.⁴ The proportion of people dying in care homes in England and Wales has also increased, with an increase from 16.7% to 21.2% between 2004 and 2014.⁵ Deaths in care homes in the USA have also gradually increased,⁶ and it is predicted that this figure may reach 40% by 2020.⁷ In parallel with this, delivery of hospice care in US care homes more than doubled between 1999 and 2006.⁸ Given these changing demographics, it is understandable that there is increasing focus in recent years on ensuring everyone is aware of their right to discuss and document their future healthcare wishes. However, while two-thirds of the British public say they would be comfortable discussing end-of-life care with their general practitioner, only 7% had written down any wishes or preferences about their future healthcare.⁹ The reasons for this are unclear but may include uncertainty about ACP, healthcare professionals' communication style when introducing the topic of ACP and the timing of introducing the concept of ACP. Given that ACP can help to improve compliance with patients' advance wishes for their future care,¹⁰ and may help to improve satisfaction of family members with the care their loved one received while also reducing their stress and anxiety,¹¹ it is important to ensure healthcare professionals are skilled in broaching and discussing these issues.

Older age and greater functional impairment are two factors recognised to be associated with greater uptake of ACPs.¹² As these factors are common in care home residents¹³ and as the proportion of people dying in care homes increases, it is of increasing importance to offer care home residents an opportunity to make their future care wishes known. This is especially important as undertaking ACP with care home residents has been shown to have beneficial effects for care home residents which include an increased likelihood of dying in their current place of care, and reduced risk of hospitalisation.¹⁴ As cognitive impairment is also prevalent in care homes, hence it is recommended that this process is commenced as early as possible.^{15 16}

The overall aim of this systematic review was to identify the most effective ACP interventions to train/educate all levels of healthcare professionals working in care homes (nursing and residential). The individual objectives of the study were to identify ACP interventions that are available to train all levels of healthcare professionals (nurses, healthcare assistants, doctors etc) working in care home settings (nursing homes or residential care homes) and to identify the most effective of these ACP interventions.

Methods

The review was conducted in accordance with the Preferred Reporting Items for Systematic Review and Meta-Analysis statement for systematic reviews.¹⁷

Literature search

A comprehensive search was conducted across a range of databases to identify relevant studies in the English language. The search strategy was developed using both keywords and medical subject headings in OVID Medline (online supplementary file).

The search strings consisted of keywords pertaining to ACP combined with healthcare professionals and nursing homes and education.

Both published and unpublished literature was considered where publicly available, as were studies in press. The following databases were searched from inception through June 2018: Ovid Medline, Ovid Medline in process, Ovid Embase, Cochrane Central Register of Controlled Trials, EBSCO Cinahl and Ovid PsycINFO. In addition, we searched websites of eight relevant organisations and electronic tables of contents of seven key journals for relevant studies published within the last 2 years, which are listed in figure 1. We carried out citation tracking in Google Scholar of the included studies checked for further significant studies. Furthermore, reference lists of systematic reviews were screened for relevant studies. Figure 2 presents the process.

Inclusion and exclusion criteria

With reference to the PICOS search strategy tool, the inclusion criteria were as follows: The target population (P) were healthcare professionals working in care home settings. This included doctors, nurses and allied healthcare professionals. Interventions (I) targeted were any form of training or education provided to the target population regardless of length of the training provided. In relation to quantitative studies, as all study designs were considered, comparators (C) included no intervention, usual care, and comparison within groups in the case of before and after studies. Outcomes of interest (O) included both qualitative and quantitative measures of effectiveness focused on healthcare professional-related outcomes and patient-related outcomes. These included ACP documentation and level of compliance with best practice, clinical outcomes for patients, patient healthcare use, patient healthcare costs, perceptions of patients and carers regarding quality of care, and attitudes and confidence of staff relating to ACP. Only studies written in English were included in this review. Original research studies with quantitative (randomised controlled trials [RCTs], case-controlled studies, cohort studies and cross-sectional), qualitative and mixed-methods study designs (S) were considered for inclusion in this review. Hence, articles were included if they focused on (1) ACP interventions for healthcare professionals and (2) ACP interventions for use in care homes (nursing homes/residential homes). Articles were excluded if the focus was on ACP interventions for patients/family members or ACP interventions for use in hospital/hospice/home settings. As this review focused on effectiveness of educational interventions, that is, on measurable outcomes, only original research was considered for inclusion. Hence, editorials, abstracts and commentaries were excluded.

Figure 1 Supplementary searches.

Figure 2 Preferred Reporting Items for Systematic Review and Meta-Analysis flow diagram

Study selection

Two reviewers (AG and SN) independently assessed the search results by title and abstract to identify potentially relevant studies. This was followed by checking full-text papers against the inclusion criteria. Disagreement between the authors over the risk of bias in particular studies was resolved through discussion and the involvement of a third review author where agreement could not be reached.

Data extraction

Data were extracted by one reviewer (AG) and checked by a second (MM). Data were extracted from eligible studies using a standardised form which was developed with the review question in mind to provide a consistent approach, reduce bias, and to improve the validity and the reliability of the process. Data extracted included the characteristics of the study and training content. Data extraction was undertaken for a total of 28 studies, hence incorporating a pilot phase where the two reviewers developed a shared understanding of the requirements of the process, thus ensuring a consistent approach. Any discrepancies were resolved through discussion.

Quality assessment

All studies were individually assessed for their methodological quality using a standard methodological appraisal tool. Risk of bias was assessed using the Specialist Unit for Review Evidence checklist (2013).¹⁸ The checklist is adapted and updated from the former Health Evidence Bulletins Wales checklist with reference to the National Institute for Health and Care Excellence Public Health Methods Manual (2012) and previous versions of the Critical Appraisal Skills Programme checklists. Two reviewers carried out the risk of bias and discrepancies were resolved through discussion or with a third reviewer where agreement could not be reached.

Analysis

A narrative synthesis of the findings from the included studies was developed which outlines the type of intervention being trialled and the characteristics of the training provided (content, mode of delivery, fidelity and adequacy). The preliminary synthesis was developed by extracting descriptive data from each included study into an Excel sheet which was then checked by a second reviewer (SN).¹⁹ Data captured included content of the training, mode of delivery of the training provided, level of detail in the description of the training provided and outcome measures used to assess training provided. The final two fields were used as proxy measures of fidelity and adequacy of the studies. The Excel sheet data were then used to explore relationships between the included studies and this relationship summarised in tabular format. Meta-analysis was not possible due to the diverse nature of the included studies.

Types of interventions

Training objectives were directed towards increasing ACP discussions and documentation, improving compliance with ACP policies and improving healthcare outcomes. The interventions used included use of specific ACP documentation, education sessions/workshops and regular facilitation/support.

Results

Our systematic search identified 1118 studies as potentially eligible for this review. After removing duplicates, 853 studies remained, which were screened based on title and abstract. A total of 571 studies were excluded mostly because ACP training was not an overarching intervention. Seventy-nine studies were assessed in full text and 73 studies excluded for various reasons (see online

supplementary appendix). The main characteristics of the included studies are summarised in online supplementary table 1.

Study characteristics

A total of six studies involving 179 care homes met the criteria for inclusion (see online supplementary table 1), which includes five studies with quantitative design and one qualitative study. The characteristics of the quantitative studies will be outlined first. Three of these studies used a before and after study design, while the remaining two quantitative studies were RCTs (one cluster randomised RCT, one non-blinded RCT). The educational interventions in the five studies varied in length, number and complexity. Two studies provided training alone, while the remaining three studies included more complex interventions. The shortest intervention was two 4-hour workshops with an additional home assignment, that is, three modules. The training was based on a three-step model for shared decision-making (choice talk, option talk and decision talk). A second study provided 2 days of training based on the 'Let Me Decide' model to facilitators who then delivered the training sessions locally. In this study, three nurses per care home attended the 2-day workshop and then acted as local facilitators. Details of length/frequency of delivery of local education sessions or in-service training were not provided.

In the remaining three quantitative studies, the intervention included both education delivery and facilitation, in which the core training was delivered over 4 days. In one of these studies where the training was based on the Gold Standards Framework (GSF) for Care Homes, a starter pack and access to the GSF website was provided, and care homes were supported by a local facilitator. In the other two studies, participants were additionally required to attend four workshops. In the first of these studies, champions attended four workshops over 1 year and then co-ordinated and led changes in practice in their respective care homes, with support from facilitators who attended the homes every 10 to 14 days. In the final quantitative study, two co-ordinators per care home attended four workshops after attending an initial 4-day training. Facilitators visited the care homes two to three times per month and provided support at induction days. In the Action Learning arm, co-ordinators also completed 9 monthly action learning sets. In all of the included studies, information is provided about the length, format and timings of the interventions. However, details of the training plan/curriculum used, the level of experience of the trainers or the reliability of the training methods used in each study were not provided.

Regarding outcome measures, outcome measures used broadly fall into three categories: ACP recording, impact on practice and healthcare outcomes. All studies included ACP recording as an outcome measure. In four of the studies, ACP documentation included numbers of documented ACP-related conversations, written advance care plans, use of end-of-life care plans and numbers of DNAR (do not attempt resuscitation) orders. In the remaining study, impact on ACP recording was measured through a self-report survey. Three of the studies also focused on impact on ACP practice—two used self-report to measure perceived change in practice while the third study used an audit tool to assess practice before and after the intervention. Healthcare outcomes were used in three of the studies and included numbers of hospital admissions, number of hospital bed days used, healthcare cost and actual place of death. In one of these studies, only the last five deaths per home were examined.

All quantitative studies reported an improvement in ACP outcomes. In the three studies which included healthcare outcomes, there was a decrease in hospital admissions and hospital deaths. In the non-blinded RCT which focused on six nursing homes with 527 residents in the intervention arm and 606 residents in the control arm, there was a significant reduction in hospitalisation rate (0.27 vs 0.48), hospital days (2.61 vs 5.86) and healthcare costs. Clifford et al, in their before and after study,

also reported a significant reduction in hospital deaths,²⁰ while Hockley et al showed a both a reduction in hospital deaths (15% vs 8% after the intervention) and a 38% reduction in hospital bed days.²¹

Hence, there is some evidence to suggest that ACP training could improve documentation and communication of ACP decisions and has the potential to reduce inappropriate hospitalisation of care home residents.^{20–22} While the cluster RCT failed to show meaningful clinical impact,²³ there was a suggestion of an overall benefit from the implementation of the Let Me Decide programme (reduction in hospitalisation, hospital deaths, hospital days and healthcare costs).²² Two of the three before and after studies also showed improvements in practice and clinical impact, but sample sizes were small. In relation to the suggested benefit from the implementation of the Let Me Decide programme, the potential benefit of this programme may need to be rationalised against the cost of implementation which has not been provided. The reported baseline investment was 36 days of nursing time (18 nurses at a 2-day workshop), but the training sessions provided locally would also need to be included.

The included qualitative study reports on the implementation of a modular training programme to staff champions in 30 care homes by 18 trained facilitators.²⁴ The modular training included communication skills training and training on ACP. The champions then disseminated this training within their respective care homes. The study explores both the experience of the facilitators (n=9) and the care homes (n=6), and reports on the perceived challenges of implementing training in the care homes. Findings from the interviews with the facilitators include increased confidence on completing the programme, the importance of having consistency with champions, the importance of providing a clear outline to potential champions of the commitment needed, the negative impact of staff sickness and turnover. Other perceived challenges to implementing the programme included time and portfolio development. The case studies with 6 of the 30 included care homes found that the programme had been an overall positive experience which was perceived to have raised the profile of end-of-life care and led to improved practice. It was perceived that ACP become routine and there was a sense that end-of-life care records had improved. However, cascading of learning was not consistently done and the interviewees found that interviewees who were not champions had a poorer understanding of the programme.

Methodological quality

Quantitative studies

The five studies included a total of 149 care homes (range, 6–95). All of the included studies were focused on educational interventions for staff in care homes and hence applicable. Three of the studies included small sample sizes and while the second largest study included 38 care homes, 14 of the care homes included were not randomised. Only two of the included studies were RCTs,^{22 23} and one of these did not randomise the control arm.²³ In one non-randomised study, the pre-audit scores were lower for the intervention group.²⁵ Another study included no control group, while the remaining study which used a before and after design showed significant improvements in ACP documentation but only included seven care homes. Given the small size of the majority of the included studies, it is difficult to generalise from the results of the included studies. In the three before and after studies,^{20 21 25} two had small sample sizes (n=7 and 19). In one of these,²⁵ pre-test audit scores of the intervention group were lower, making the results unreliable. While the third of these studies included 95 care homes, this only represented 54.7% of the overall cohort, again making it difficult to generalise from these results. It is not possible to generalise from the results of one of the RCTs as the sample size was small (n=6) and there was potential selection bias (pool of 150 care homes with 78 meeting a specific inclusion criterion, but inclusion criteria were not specifically stated). In the

cluster randomised study, the 14 care homes included in the observational arm were not randomised, hence making it difficult to draw concrete conclusions.

In relation to consistency, all of the included quantitative studies reported on impact ACP documentation and impact on practice and concluded that educational interventions for staff in care homes lead to improvement in practice with regard to ACP documentation and practice. The three studies which included healthcare outcomes also conclude that the intervention led to reduction in hospital use and costs.

With regard to clinical impact, the unblinded RCT, which included 1292 residents from 6 care homes, showed a significant reduction in hospitalisation and hospital bed days used for residents in the intervention arm. However, retrospective data were collected for all residents, but prospective data were only collected for consenting residents, hence introducing potential bias.²² The cluster RCT failed to show a significant clinical impact. One of the before and after studies reported on compliance with ACP policy and practice but did not report on clinical impact.²⁵ In a second before and after study, the before-death and after-death analysis was only undertaken on the last five deaths, and after-death analysis was performed in only 44 of the 79 included care homes.²⁰ The final before and after study showed a non-significant reduction in hospital bed days and death in hospital in a sample of 228 (95 pre-intervention, 133 post-intervention).²¹ We have used the Scottish Intercollegiate Guidelines Network considered judgement checklist for summarising the findings from each study.²⁶ Online supplementary table 2 shows a summary of the quality of each of the included quantitative studies.

Qualitative study

The included paper reports on the findings from a questionnaire and interview study with half of the facilitators (n=9) who completed delivery of the programme to at least one care home, and also reports on case studies with a cohort (20%) of the included care homes. The interview guide used includes a list of questions rather than topics, one of which may be considered a leading question "Have you seen improvements in the EOL care at your home since completing the programme?" The form of data analysis used was thematic analysis, but no details are provided of the steps taken. As interviews were held with facilitators who volunteered to be interviewed, this may have introduced bias. The care homes included for the case studies were selected by the research team based on geographical location and social economic status. As selection was not randomised, it is possible that results may be biased.

Discussion

ACP is a fundamental component of providing highquality end-of-life care to patients who are anticipated to die within 12 months. The increasing number of care home residents, by virtue of age, performance status and comorbidities, makes a proactive approach to ACP highly sensible. The standard and consequently the success of ACP in this environment are dependent on the knowledge skills and attitudes of care home staff. This requires effective education strategies within a time and finance constrained clinical service. This review sought to identify the most effective ACP interventions to train/educate all levels of healthcare professionals working in care homes. Based on the size, heterogeneity and quality of the included studies in this review, it is not possible to recommend a specific educational intervention as optimally effective to train healthcare professionals in care homes. The perceived challenges to implementing an educational intervention for healthcare professionals in care homes highlighted in the one included qualitative study are of interest, especially in relation to planning an educational intervention to improve ACP uptake in the care home setting.²⁴

In keeping with the results of this review, in their review of how healthcare systems evaluate ACP, Biondo et al found that ACP document completion and recording of ACP conversations were the most frequent outcome measures used.²⁷ They grouped the outcome measures identified into 14 categories, and in keeping with our findings, the next most common outcome measure used was healthcare resource use. They found that patient-reported, family-reported or healthcare professional-reported outcomes were less commonly used. As documentation is the most frequent outcome measure identified, it is important to consider the impact of increasing documentation of future care wishes. In their systematic review, Lewis et al considered the effectiveness of ACP documentation in encouraging healthcare professionals to engage in end-of-life care discussions.²⁸ They concluded that while there was a high perception that existing ACP documentation encouraged end-of-life care discussions, that this was derived predominantly from qualitative and cross-sectional opinion surveys and hence fell short of proving effectiveness. Factors influencing engagement with ACP recognised to be complex and it is recognised that these include are multiple healthcare professional factors. Lovell et al identify healthcare professional factors as including uncertainty regarding timing and responsibility for initiating the ACP discussion, discomfort with the process of ACP, healthcare professional attitude to ACP, and practical issues including time and setting.¹² It is interesting that only time and resource issues were identified as challenges in O'Brien et al's study.²⁴ This may reflect that ACP training led to a greater level of confidence and comfort in staff in supporting residents with planning for their future healthcare.

The main limitation of the study was the variable quality and heterogeneity of the included papers, which precluded conducting a meta-analysis. In accordance with the review protocol, the types of studies included in the review were RCTs, observational studies (case-controlled studies, cohort studies, cross-sectional). However, due to the heterogeneity of identified quantitative studies, a wider search was conducted to identify relevant qualitative studies that fit the inclusion criteria, to ensure that relevant and potentially valuable data were not excluded. While the one included qualitative study provides food for thought, it was not possible to identify the most effective educational intervention for healthcare professionals in care homes to improve ACP outcomes based on the results of this review. A further limitation of the study is that only papers written in English were included. Again, this may have led to the exclusion of valuable data. Despite the limitations, this review still contributes to useful insights into ACP educational interventions.

The training interventions employed in the studies included in this review varied in length and complexity, but were not fully described. In order to compare interventions, future studies should include detailed descriptions of training used, level of experience of the trainers, reliability of the training (ie, whether the training curriculum has been validated) and perceived benefit/burden of the training to healthcare professionals. While the results of this review suggest that further studies are needed to identify effective ACP educational interventions for healthcare professionals in care homes, it is important that the most relevant outcome measures to evidence the effectiveness of ACP are employed. Acknowledging that ACP is a complex intervention which involves the interaction of multiple agencies and which is influenced by a diverse range of factors, further studies may need to focus on determining the most important indicators to determine successful implementation of ACP interventions. As is reflected in this review, the majority of existing studies focus on completion of ACP documentation.²⁷ As there remains a lack of evidence to substantiate the assertion that having prior written preferences for future healthcare encourages timely ACP conversations, future studies should focus on patient-derived and family-derived outcome measures in order to ensure meeting the ultimate goal of improving and optimising patient and family experience. Combining quantitative and qualitative methods would also enable a richer insight to be gained, hence allowing a detailed understanding of a complex intervention.

Conclusion

Despite the clear need for the effective implementation of ACP strategies in care homes, there are limited data to support the most effective educational intervention to facilitate this. Whether this implies a need for a new education package or is merely a reflection of the varying quality of studies and lack of consistent outcome measures is likely to remain a matter of debate.

In the very least, this review has highlighted the need for well-designed studies focused on the impact of ACP educational interventions in the care home setting. However, such studies should first consider the need for developing a set of core outcome measures in order to standardise further work in this area.

Collaborators Annmarie Nelson.

Conception or design of the work: AG. Collection: MM. Analysis/interpretation: AG, SN. Drafting the article: AG. Critical revision of the article: SN, MM. Final approval of the version to be published: AG, SN, MM.

Funding

The study was funded by the research team.

Competing interests

None declared.

Patient consent for publication

Not required.

Provenance and peer review

Not commissioned; externally peer reviewed.

Data sharing statement

All additional data, including records of database searches, can be made available for review through the principal author (AG).

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