A video-supported nurse-led advance care planning on end-of-life decision making among frail geriatric patients: Protocol for a randomized controlled trial

Abstract

Aim

To examine the effect of a video-supported nurse-led advance care planning to frail geriatric patients on end-of-life decision making outcomes in patients and their carers.

Design

This is a double-blinded randomized controlled trial with parallel arms.

Methods

The protocol was approved by the Institutional Review Board of the participating hospital on 1 August 2018. Frail elders and their carer if any are enrolled during hospitalization, and undergo randomization after discharged. The intervention group receives a 2-week video-supported nurse-led advance care planning programme (n=149) while the control group receives a 2-week health education program at home (n=149). Follow-up surveys via telephone at 1 month and 6 months measure outcomes regarding end-of-life decision making from both the patients and the carers.

Discussion

The results will help identify effective elements of advance care planning and inform the development of an evidence-based structured advance care planning intervention in response to the need for quality end-of-life care.

What problem will the study address?

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Advance care planning discussion is to understand patient's values, preferences and treatment for care on their anticipation of future deterioration. Treatment options for end-of-life care may not be well received especially elders because in the discussion process, technical medical terms are presented in an abstract, hypothetical way that are hard to understand. The present study aims to evaluate the effect of a nurse-led advance care planning supplementing with a video showing end-of-life treatment options to promote end-of-life care decision making among frail geriatric patients.

Trial registration:

Chinese Clinical Trial Registry ChiCTR-IOR-17012341

Keywords: nurse; advance care planning; advance directives; decision aids; end-of-life; frailty; geriatrics

INTRODUCTION

Respecting patients' wishes about end-of-life (EOL) care is considered as an essential part of high quality medical care (Allison, 2013; Cook, Rocker, & Heyland, 2013; Institute of Medicine, 2014). Patients' preferred goal of care and preferences for treatment options in the context of anticipated health deterioration have to be known to their loved ones, carers and healthcare providers before they become incapacity for decision making. Thus, there are calls for advance care planning (ACP) which facilitates better communications among the three parties: the patient, their family/carers, and healthcare providers and enables a shared understanding on patient's end-of-life care preferences. Advance directive (AD) extends individual rights in health care decision-making that an individual can indicate the kinds of care they would prefer if their decision-making capacity is compromised.

Yet, the development of ACP in clinical practice has emerged only very slowly worldwide even though it has been noted that the concept of planning ahead for future care was well accepted by patients. Without knowing preference for treatment options of the patient, physicians tend to opt for the use of life-sustaining treatments which may not be in concordance with patient's preferences for EOL care. This does not only increase healthcare costs, but also compromises both the quality of EOL care and patient-centred care. Since the majority geriatric patients do not have an opportunity to indicate their preferences for future care, the burdens of making treatment decisions for EOL care will rest on their family members/carers, and inevitably increase their distress, anxiety and depression, and may also create disputes due to the inadequate communications between family members and healthcare providers over treatment decisions for the patients. Hence, it is necessary to empower frail older adults to plan ahead for their future care, increases their carer' understanding of their wishes, and facilitates quality clinical communication with their healthcare providers, and finally with their decision about EOL care preferences to be known.

BACKGROUND

There is a consensus that informing and respecting patients' preference for care and treatment at their end-of-life is an essential component of high-quality medical care (Allison, 2013; Cook, Rocker, & Heyland, 2013; Institute of Medicine, 2014). EOL care is usually treated as a tenet to promote comfort and avoid unwanted life-support measures in the final stage of life. However, under the cure-oriented practice, physicians usually opt for the use of life-sustaining treatments such even when the patient or family prefers comfort care (the SUPPORT principal investigators, 1995). Advance care planning is a voluntary discussion process allowing individuals to clarify their values and preferences and treatment for care on their anticipation of future deterioration and to ensure their wishes and preferences are known to loved ones, surrogate decision makers and health care providers (World Health Organization, 2011; National Health Service, 2014). Two of the most desirable outcomes of ACP including the completion of an advance directive (AD) which states individual's preferences of EOL treatment and assignment of a surrogate for decision making in the event of loss of decision making capacity (Sinuff et al., 2015). Communication of patient's anticipating preferences before end stage of life may result in many desirable outcomes including the prevention of unnecessary and unwanted care, an increase in patient autonomy and satisfaction, a reduction in family distress and burden for decision making as well as a reduction in the use of aggressive medical treatment at EOL and healthcare expenditures (Baker, Leak, Ritchie, Lee, & Fielding, 2012; Detering, Handcock, Reade, & Silvester, 2010; Thompson, 2013;

Tierney, Dexter, Gramelspacher, Perkins, Zhou, & Wolinsky, 2001; Wright et al., 2008). Given the anticipated benefits of ACP to the patients, their family and the healthcare system, there has been growing interest in promoting ACP in many countries and leading medical organizations, (Cook et al., 2013; IOM, 2014; Giovanni, 2012; National Health Service, 2014) but communication regarding EOL care with healthcare providers and documentation of patient preferences still remains inadequate (Heyland et al., 2013).

In reality, however finding the right time to discuss ones' wills and make decisions about their EOL care may not be easy – either too early or too late will be undesirable. As argued by Billing and Bernacki (2014), it will be too early for people to make decision about their EOL care when they are still healthy and presented with abstract, hypothetical choices about a distant future while it may be too late for patients who are approaching the end stage of life to make the decision, especially when unexpected deterioration occurs. In such a situation, communication with patients will become difficult, or even impossible if they become incapable of making these decisions for themselves. In this sense, geriatric patients who are frail seemed to be an appropriate target population for EOL care discussion because this group of patients may not have terminal illnesses but are old, frail and at a high risk of sudden deterioration and becoming mentally incompetent that death is in the foreseeable future (Clegg, Young, Illiffe, Rikkert, & Rockwood, 2013). Frailty is an age-associated condition that is characterised by reduced functional reserve and increased risk of adverse health outcomes including increased risk of mortality, healthcare service utilization, disability, and reduced quality of life (Clegg et al., 2013; Lee, Heckman, & Molnar, 2015; Kwong, Lai, & Chan, 2014). With the rapid growth in the aging population worldwide, the size of geriatric patients who are frail should be increasing rapidly as well, and the related hospital cost for this special group are also expected to be increased tremendously. All these highlight the importance of ACP in preparing frail elders for treatment options at their end stage in the life, although ACP is recommended as an integral part of care for patients with life-limiting disease (IOM, 2014).

In the last two decades, many interventions have been developed to promote quality ACP: interventions developed before 2000 tended focusing on AD completion while interventions developed latter tended focusing on communication in addition to AD. A recent systematic review (SR) of 55 RCTs in 2014 reported that, regardless the types of interventions, ACP programmes increase AD completion, occurrence of discussions about ACP and concordance between preferences for care and delivered care (Houben, Spruit, Groenen, Wouters, & Janssen, 2014). While the SR has shown some benefits of ACP interventions, the rates in AD completion reported in 18 studies (intervention: 0-37.9%, control: 0.4-23.9%) and occurrence of discussion about ACP reported in 11 studies (intervention: 10.0-72.6%, control: 4.3-56.6%) were still undesirably low. While it has been advocated the importance of ACP in preparing patients and carers for treatment decision making at the end of life (Sinuff et al., 2015), only a few of the ten included studies targeting elders in the SR had included completion of AD or occurrence of discussion as their study outcomes and none have examined the impact of ACP on carer outcomes nor compared the impacts between ACP components (i.e. AD only versus communication and AD).

In addition, when discussion of EOL treatment options, it is unavoidable to use technical medical terms such as CPR, antibiotics and intravenous infusion in an abstract, hypothetical way but these medical terms may not be understandable for laymen, especially those with limited health literacy. Elders usually have a lower level of health literacy may find it difficult to understand the content, and as a result, the treatment options for EOL care discussed in the ACP may not be well received. Without a clear understanding of treatment options in the context of anticipated health deterioration, it will be hard for individuals to consider or even imagine what their preferred goal for care when they are approaching the end of their life are.

Decision aids in various formats including booklets, video, interactive CD-ROM and self-directed computer program have been developed to improve the quality of ACP by providing support to informing patients about care options, assisting them to make better decisions and prompting communication of their preferences for future care (Austin, Mohottige, Sudore, Smith, & Hanson, 2015; Bulter, Ratner, McCready, Shippers, & Kane, 2014). Among the decision tools, video-based intervention presents a unique advantage to enhance the quality of ACP by providing realistic visual images of treatment options and outcomes instead of presenting treatment choices in an abstract, hypothetical way (Elwyn et al., 2009). Video-based decision aids were shown in a SR of ten RCTs to be a promising way to promote patient preferences for CPR and knowledge related to ACP but not in completion of AD (Jain, Corriveau, Quinn, Gardhouse, Vegas, & You, 2015). However, all the reviewed RCTs did not have a discussion component in the intervention with an exception. In Yamada et al's study (1999), discussion with healthcare providers after watching the video was optional but only 12% of the participants reported had such a discussion. Without clinical communication in the process, it is quite sure that the core aim of ACP in promoting a shared decision making among different related parties cannot be achieved. In response to the above findings, it is reasonable to expect that a video-support ACP programme which led by healthcare providers should be a promising way to further improve the quality of ACP discussion, and hence could lead to more favorable outcomes, especially in frail elders.

THE STUDY

Aims

This study attempts to address the first question regarding the effective elements in ACP directly by comparing two structured ACP programmes, one focuses on communication and AD with a video decision aids and the other focuses on AD only on their impacts on outcomes of frail elders and their carers.

Objectives:

1. Compare the relative effectiveness of two structured ACP programmes among frail elders on completion of AD and occurrence of discussion regarding EOL care
2. Compare the relative effectiveness of two structured ACP programmes on carers on decision making confidence, anxiety and depression
3. Compare the relative effectiveness of two structured ACP in promoting quality of communication regarding EOL, decisional conflict and knowledge of ACP among frail elders
4. Compare the relative effectiveness of two structured ACP programmes on healthcare utilization
5. Assess the congruence in response to elder’s EOL preferences between patients and carers

6. Explore communication patterns in ACP among elders, carers and healthcare professionals and its influence with shared decision making

Design/Methodology

Study design: A parallel group 1:1 randomized controlled trial embedded with a qualitative study will be employed to examine the effectiveness of the video-supported nurse-led ACP programme on frail geriatric patients. Figure 1 shows the flowchart of the study.

Subjects: The study will recruit pairs of patient and their carers by referrals from the medical ward of a hospital which is a major tertiary referral centre specialising in comprehensive medical treatment for adult heart and lung diseases, as well as providing geriatric medicine and palliative medicine services in Hong Kong. Patients will be eligible if they are (1) at age ≥60, (2) frail as measured by a score of FRAIL scale ≥ 1 (Morkey, Malmstrom, & Miller, 2012), (3) able to communicate, and (4) cognitively intact as measured by MMSE score >17 (Fan, 1992) at the time of recruitment. Patients will be excluded if they have already signed an AD or have been referred to palliative care service before the study. Patients will be asked to nominate an informal carer who will likely be a substitute decision maker for them in future healthcare to participate in the study. Carers will be eligible if they are: (1) at age ≥18; (2) identified as the primary informal carer to a participating patient; and (3) communicable in Chinese. Patient-carer dyads will be recruited with patients can join without a carer but carers cannot join without a corresponding patient in the study.

Sample size determination

Sample size calculation is based on the main outcome variable according to the main hypotheses, the completion of AD at 6-month follow-up. Based on a previous study regarding the AD completion rates of 16.5% in the ACP arm compared to 1.7% in the attention control arm (Chan et al., 2018), a sample size of 119 per group is needed to achieve a statistical power of 80% at 5% significance level of a 2-sided chi-square test. Assuming a 20% attrition rate at 6 months, n=149 will be required in each group to achieve a significant outcome. Hence, the total sample size of the study will be 298.

Treatment Materials

Intervention group: Video-supported ACP programme (Table 1)

The video-supported ACP programme has been developed based on our previous study and currently tested for its feasibility. For the video decision tool, taking reference to the local guideline, we are developing a 3-min video covering treatment options of EOL care in Hong Kong including (1) cardiopulmonary resuscitation (CPR), (2) mechanical ventilation, (3) tube feeding and (4) intravenous fluids, and antibiotics. The video will include (1) images of simulated chest compressions and intubation on a mannequin, (2) images of a mannequin on ventilator receiving intravenous medicines, (3) images of a mannequin on tube feeding and (4) images of a mannequin receiving intravenous fluids and antibiotics. No special effects will be used in the film. The images will be supplemented with a verbal description describing CPR. Previous studies have shown videos with 3 minutes supplemented with verbal description are reasonable to demonstrate the message (Volabdes et al., 2013).

Using the patient-centerd approach, the structured ACP programme consists of four main elements: (1) patients' understanding of their illness, (2) patients' values and beliefs underpinning care preference, (3) possible health conditions in the future, and (4) introducing the idea of AD and its arrangement (Table 1). However, there is no restriction regarding the order of the four topics to be discussed during the intervention. The ACP programme was designed to have two 1-hour sessions. The video will be shown when discussing the life-sustaining treatment options in topic (3). Both the patient and the carer, if any, will be involved in the intervention, and the patient will be given a personal ACP workbook to summarize the ACP process for record. Discussion during the ACP programme will be summarized and documented in the patient's medical record, and also be signified in the patient's electronic hospital record, to ensure the patient's care preference will be clear to the healthcare team.

Control group: Health education programme

Patient-carer dyads in the control group will receive two weekly home visits with person-centered health education about specific symptoms or diseases provided by another trained facilitator. A leaflet about ADs with contact information for signing AD will be distributed at the end of the second session.

Procedure

Before the implementation of the study, a nurse who has at least five years of clinical experience will be trained to be the ACP facilitator (RN1) and to implement the intervention. A two-day training workshop, including tutorial, video-showing, case scenario discussion and role play, adapted from a series of our previous studies, will be provided by the research team to equip the nurse with the knowledge and skills necessary for conducting ACP.

Nurses of the participating hospital will identify and refer potential eligible patients who will be discharged from the hospitals. A research assistant of the study (RA1) will then approach these referral patients individually and screen for eligibility.

For those who are eligible for the study, RA1 will explain the nature and the purpose of the study and a written information sheet will be provided. Consented patients will be asked to nominate an informal carer, and RA1 will then approach the nominated carer and explain the study to him/her. After providing written informed consents, the patient and the carer (if applicable) will self-complete the baseline assessment questionnaire independently with the assistance from RA1 if necessary, and a home visit within one week will be scheduled. A sequence of group identifies based on computer-generated random codes using 1:1 allocation will be prepared and put in serially numbered opaque sealed envelops by one team member who will have no contact with study subjects prior to the start of subject recruitment. RA1 will then randomly assign the dyad to either the intervention or the control group by opening a serially numbered opaque sealed envelop at the study site. For those dyads assigned to the intervention group, their information will be sent to the trained ACP facilitator (RN1) to receive the video-supported ACP programme. For those assigned to the control group, their information will be sent to another research nurse (RN2) to receive the health education programme. Patients who want to sign an AD will be referred to a designated physician with ACP experience and complete an AD which is adapted from the modified directive model form by Hospital Authority of Hong Kong (2014). Another RA (RA2) will conduct follow-ups with patient-carer dyads at 1 and 6 months respectively. This procedure can ensure both the interventionists (RN1 & RN2) and the outcome assessor (RA2) are blinded to the group allocation. Since both treatment groups will cover ACP elements (in a different extent), we believe that patients and their carer if any will also be blinded to their group allocation.

Data collection

Patient-carer dyads complete the baseline questionnaires before randomization (T0), and then complete questionnaires approximately 1 month (T1) and 6 months (T2) after intervention. All patients and carers will self-complete the questionnaires with RAs available for assistance at each time point (Table 2).

Primary outcome

Completion of AD: Patients who want to sign an AD will be referred to a designated physician with ACP experience and complete an AD which is adapted from the modified directive model form by Hospital Authority of Hong Kong (2014).

Secondary outcomes

(a) Goals for EOL care were known will be measured using The End-of-Life Care Preferences Questionnaire (Chan et al., 2018) which was developed based on the Life-Support Preferences Questionnaire (Ditto et al., 2001). Patients will be asked to indicate their preferences regarding (i) three kinds of life-sustaining treatments (cardiopulmonary resuscitation, mechanical ventilation and tube feeding) based on three options (want to attempt, refuse or uncertain) and (ii) care goals (comfort-oriented, prolongation of life at all costs or uncertain) in the context of two common clinical situations of ‘being terminally ill’, and ‘in persistent vegetative state or a state of irreversible coma’. Carers will also be asked to predict the patient’s preferences by completing the same assessment form.

(b) Decisional conflict in making decisions related to future care will be measured by the SURE test (Légaré et al., 2010). Patients will be asked to rate their future care on four items using a Yes/No format. Good construct validity and reliability of the scale were demonstrated.

(c) Communication about end-of-life care will be measured using the corresponding subscale of the validated Quality of Communication Questionnaire (Engelberg, Downey & Curtis, 2008). Patients will rate how good the ACP facilitator is at each of the seven communication skills about EOL discussion on a scale of 0 (the very worst) -10 (the very best).

(d) Knowledge of Advance Care Planning: Patient's knowledge of ACP will be assessed using a self-developed Knowledge Questionnaire. The scale consists of five items which address the purposes of ADs, EOL discussion, and issues related to ACP. The scale has good content validity (CVI>0.9) and internal consistency (0.84).

(e) Healthcare service utilization: Patient's medical records will be retrieved retrospectively at T2 to review their healthcare service utilization over the study period, including the number of visits to the emergency department, unplanned hospital admission, length of stay, and investigation, procedures and treatment received.

(f) Decision-making confidence: Carer's confidence in EOL decision making for their patients will be measured by the 5-item Decision Making Confidence Scale (Song, Ward & Lin, 2012). Carers will be asked to indicate their level of comfort in the potential surrogate role on a 5-point Likert scale. A good reliability of the scale (Cronbach's alpha = 0.85) was reported in a previous study (Song et al., 2010).

(g) Anxiety and depression: Carers' anxiety and depression will be assessed by the validated Chinese version of the 14-item Hospital Anxiety and Depression Scale (HADS) (Wang, Chair, Thompson & Twinn, 2009). The HADS consists of two subscales: anxiety (seven items) and depression (seven items) with scores range 0-21.

(h) Satisfaction of the intervention: Patients and carers will be asked to rate their satisfaction about the discussion received using one item on a 0-10 VAS scale.

(i) Comfort watching the video: Both patients and carers in the intervention group will be asked to rate their using one item on a 0-10 VAS scale.

(j) Demographic characteristics: For both patients and carers, we collect information of age, gender, marital status, educational level, living status, religious status, financial assistance from the Government, functional status (both activities of daily living (ADL) and instrumental activities of daily living (IADL)), types of chronic diseases and self-rated health. Their relationship will also be recorded. The Activities of Daily Living (ADL)-Staircase Scale will be used to measure ADL and IADL. Good psychometric properties of the scale was shown in a sample of Chinese patients with heart failure (Leung et al., 2014).

Qualitative data and Fidelity of the ACP programme: All the sessions of the ACP and the health education programmes received by the patients and carers will be audio-recorded. The interventionists will take field notes during the discussion process. Fidelity of the ACP programme will be checked by recording the length of the two sessions of the ACP programme separately, whether the video was shown during the intervention.

Planned analyses

Quantitative Data: Intention-to-treat with all available data will be applied in all the analyses whenever applicable. Descriptive statistics summarize demographic characteristics of the patients and carers. Independent t-tests for continuous variables and chi-square test for categorical variables examine comparability of groups in terms of demographics produced by randomization. Confounding variables will be accounted for in subsequent analyses. The effectiveness of the video-support ACP programme on frail elders and their carers will be evaluated by comparing the study outcomes from T0 to T2 between the two groups using generalized estimating equation (GEE) methods with appropriate link functions (Objectives 1-4). Kappa statistics examine congruence in responses between patients and carers at T0-2 (Objective 5). Additional subgroup analyses using GEE will be performed for (1) patient-related study outcomes by whether a carer is involved or not, and (2) carer-related outcomes by bereavement (whether the patient died or not) separately. All the statistical analyses will be performed using SPSS with a significant level at 5%.

Qualitative data: The audio records will be transcribed verbatim. Inductive content analysis analyze the qualitative data to address Objective 6 (Elo & Kungas, 2007). The analysis will focus on the manifest content regarding communication patterns and its relationship with shared decision making in the process. Codes will be identified and classified into subcategories and then into categories according to their concurrence or antecedents. Finally, the themes of the data will be identified. The themes, categories and subcategories will be reviewed by two members in the research team to improve the credibility. The analysis will first be done separately by whether a carer is involved, and the results will further be compared and contrasted for similarity and differences in communication patterns and shared decision making. The identified patterns of communication will be quantified and included in GEE analyses (Sandelowski, 2000).

Ethical considerations

The research ethics committee of the participating hospital has granted ethical approval for the study. Patients and carers have every right to stop the conversation or withdraw from the study at any time without reprisal. If the patients/carers have negative emotions caused by the sensitive discussion, the discussion will be stopped and counselling will be provided by the ACP facilitator to acknowledge their reactions. These patients/carers will be further referred to Comfort Care Concern for professional early bereavement counselling if necessary. The intervention will be continued even if the patients are hospitalized during the study period because changes in health status can influence care preferences.

Validity and reliability

The psychometric properties of the scales is described above. Any difference in baseline characteristics between groups will be accounted for in the statistical analysis.

DISCUSSION

Respecting patients' wishes about end-of-life (EOL) care is considered as an essential part of high quality medical care. Advance care planning (ACP) facilitates communication among the patient, their family/carers, and healthcare providers to enable a shared understanding on patient's EOL care preferences before they become incapacity for decision making. Nurses are one of the major care providers in the healthcare system, representing the largest group of professional staff in healthcare organizations. Nurses are at the best position to promote ACP because they are equipped with sufficient medical knowledge that enables them to facilitate the discussion on EOL treatment options that is relevant to the elder's own health condition. Furthermore, nurses have frequent contacts with patients in both hospital and community settings, that they can facilitate ACP discussion during home visits as patients and their carers are expected to be more acceptable to have such discussion in a comfortable place such as the home setting.

This study aims to establish best practice in ACP and AD completion within the current Hong Kong framework for frail elders by testing a well designed and tested audio-visual means to overcome limitations in health literacy to support improved EOL planning with better ACP and more AD completion using a double-blinded randomized controlled trial. It is hypothesized that more AD completion and occurrence of discussion regarding EOL care in patients at 6-months will be obtained in the video-supported ACP group. The results of the proposed study will shed light to the implementation of structured ACP programmes in routine healthcare service in response to the ongoing growth in the need for quality EOL care.

Limitations

There are several potential limitations to the study. Subject recruitment can be challenging because of the inclusion of patient-caregiver dyad in the study. In addition, we may not be able to avoid participation bias as the participation to the study is voluntary that dyads who are more receptive to the concept of advance care planning are more likely to join the study. Our patients are those who are old and frail, and at a high risk of sudden deterioration and becoming mentally incompetent, and hence the attrition rate may be high; however, the research design outlined should control for this limitation.

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