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Effects of a structured, family-supported, and patient-centred advance care planning on end-of-life decision making among palliative care patients and their family members: protocol of a randomised controlled trial

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Abstract

Background Advance care planning (ACP) is a well-recognized quality indicator for palliative care. Despite two decades of effort, previous studies showed that ACP-related documentation and end-of-life discussion rates remain low for palliative care patients. Although ACP is about self-determination and autonomy, studies consistently show the importance of family involvement in adult patient's medical decision-making. Yet, research on ACP interventions with structured components targeting family member remained limited. The current study aims to evaluate the effectiveness of a structured, family-supported, patient-centred ACP programme for adult palliative care patients and their families.

Methods This is a 2-arm parallel group randomized controlled trial with follow-ups at 6 and 12 months. One hundred and seventy eligible palliative care patients and their families are planned to be recruited from three hospitals, and randomized to either a structured, family-supported, patient-centred ACP programme (ACP-Family) or usual ACP care (ACP-UC) arm. The ACP-Family intervention consists of 2 sessions. The primary outcome is family's prediction accuracy of patient's treatment preferences at 6 months. Secondary outcomes include proportions of new ACP documentations and family-reported perception of whether the patient's end-of-life (EOL) care preference was respected; patient's decisional conflict; quality of communication; family's decision-making confidence; family's anxiety and depression; and patients' and family members' satisfaction of the intervention. Outcomes of the two groups will be compared using regressions and linear mixed-effects models.

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Discussion This study will provide rigorous scientific evidence on the effectiveness of a structured and well-design family-supported, patient-centred ACP programme for adult palliative care patients and their family members in the hospital setting. If the ACP-Family proves to be effective, it will provide a structured and systematic approach to facilitate ACP discussions involving family members. This will respond to local needs and inform international ACP practice.

Trial registration ClinicalTrials.gov Identifier: NCT05935540.

Keywords Advance care planning, Family, Palliative care, End of life care

Background

Palliative care emphasizes meeting the needs of patients to improve the quality of life of the patients and their family, who face life-threatening illnesses [1]. Advance care planning (ACP) is a process to enable individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences [1]. The ultimate goal of ACP rests on improving the rate of preference-concordant care, which can be achieved either by documenting a patient's wishes regarding end-of-life (EOL) care and treatment preferences or appointing a substituted decision maker who will make decisions that respect the patients' wishes when the patients become incapable of making their own decisions. ACP is well recognized as an important component of palliative care [2, 3]. It has been argued that referral to palliative care may prompt the start of EOL discussions, as both the patients and their family have great potential to see the clinical relevance of ACP [4].

Yet, ACP-related documentation and EOL discussion rates are still low for palliative care patients – the AD documentation rate for palliative care patients was 15.5% whereas 60–90% of patients with life-threatening illnesses reporting never having discussed EOL care issues with their clinicians [5, 6]. The percentage might be even lower in Hong Kong, as only 3,275 AD documents were recorded in 30 hospitals in 2017 [7]. With the demand for palliative care rising, the Hong Kong Hospital Authority has recently developed a strategic service framework for palliative care and is advocating ACP as one of the four key elements in a cluster-based future service model for adult palliative care [8]. Recent local studies showed family members' prediction accuracy of patient's treatment preferences were still low ranging from 40 to 56% after ACP discussion [9]; and poor awareness of ACP in the community [10]. These figures highlight the needs to promote ACP in Hong Kong.

The importance of involving family members in ACP discussions has been acknowledged recently, as studies have consistently shown that patients in both Western and non-Western populations want to consider the opinions of family members to support them in making decisions regarding EOL care and treatment options [4]. However, under the current medical model, individual autonomy is fundamental to Western notions of ACP, causing the discussions usually be focused mainly between patients and healthcare providers [11]. Yet, similar to patients, family members may also be unprepared to discuss ACP. They have to clearly understand patients' values and beliefs regarding care preferences, and the rationale for making decisions on EOL wishes, in order to prepare themselves to act as substituted decision makers. Inevitably, technical medical terms will be used in the discussions to describe the illness and treatment options, and medical knowledge will be needed to make decisions on care. Recently, there is a trend to involve family members in ACP studies. A few studies had included a structured component targeting family members in their ACP programmes while many might have a flexible component for family members [12–14]. While flexibility could be used to tailor the intervention to meet individual needs, it could also be possible that insufficient intervention or even no intervention had been delivered to family members, especially when the family members felt stressed and unprepared for ACP discussions, or were unaware of the need to raise questions on substituted decision making. This might have undermined the interventional effects on both patient and family outcomes. Indeed, a previous RCT by Green and colleagues provides support for this claim: superior concordance was not found among patients and family members went through an online ACP decision aid *together but without professional support* compared to patients went through the process alone [15]. This study finding provided some support to the claim that leaving patients and family to discuss ACP among themselves may not be beneficial. Without support from healthcare professionals, two undesirable outcomes may occur: (1) The family members inaccurately predict the patients' treatment preferences because they do not clearly understand the patients' values and the rationale for making decisions on EOL care and (2) they feel stressed as substituted decision markers, especially when the decision contradicts their own personal values, preferences, needs and emotions [4, 16]. There is a need to include a component for family members that are delivered in a structured and systematic way in ACP discussions to equip them in the preparation for acting as substituted decision makers for their relatives so as to improve ACP outcomes, therefore we developed a structured, family-supported, patient-centred (ACP-Family) programme to address this research gap.

The main research questions are:

a) Compare to usual care, is the ACP-Family programme effective in improving prediction accuracy of patient's treatment preferences, new ACP documentation and whether family-reported patient's EOL care preferences was respected for deceased patients in palliative care patients and family members?
b) Compared to usual care, is the ACP-Family programme effective in improving family members' decision-making confidence, anxiety, depression, and quality of communication regarding EOL?
c) Compare to usual care, is the ACP-Family programme effective in promoting patients' certainty in decision making and quality of communication regarding EOL?

Methods/design

Aim, study design and setting

This study is a 2-arm parallel group randomized controlled trial (RCT) with follow-ups at 6 and 12 months, aiming to examine the effectiveness of a structured, family-supported, patient-centred ACP programme for adult palliative care patients and their families (ACP-Family) comparing to usual ACP care (ACP-UC). Subjects will be recruited from medical wards of three hospitals which provide palliative care in the serving community in Hong Kong. Flowchart of the study is shown in Fig. 1.

Participants and sample size calculation

Patients will be eligible if they are (1) aged ≥ 18, (2) receiving palliative care at the study hospitals, (3) able to communicate in Cantonese, and (4) cognitively intact (Abbreviated Mental Test score ≥ 7) [17] at the time of recruitment. Patients will be excluded if they are engaging in ACP discussions with healthcare professionals in the hospital at the time of recruitment. Patients will be asked to nominate a family member (or a friend) who is likely to make substituted decisions for them in future health care issues to participate in the study. Family members will be eligible if they are: (1) aged ≥ 18 and (2) able to communicate in Cantonese. This study will recruit both cancer and non-cancer patients. Consecutive sampling will be used, as it is a practical and commonly used sampling method in studies conducted in hospital setting. The study will be conducted in compliance with the principles of the Declaration of Helsinki. The study has started subject recruitment in one of the hospitals in September 2023.

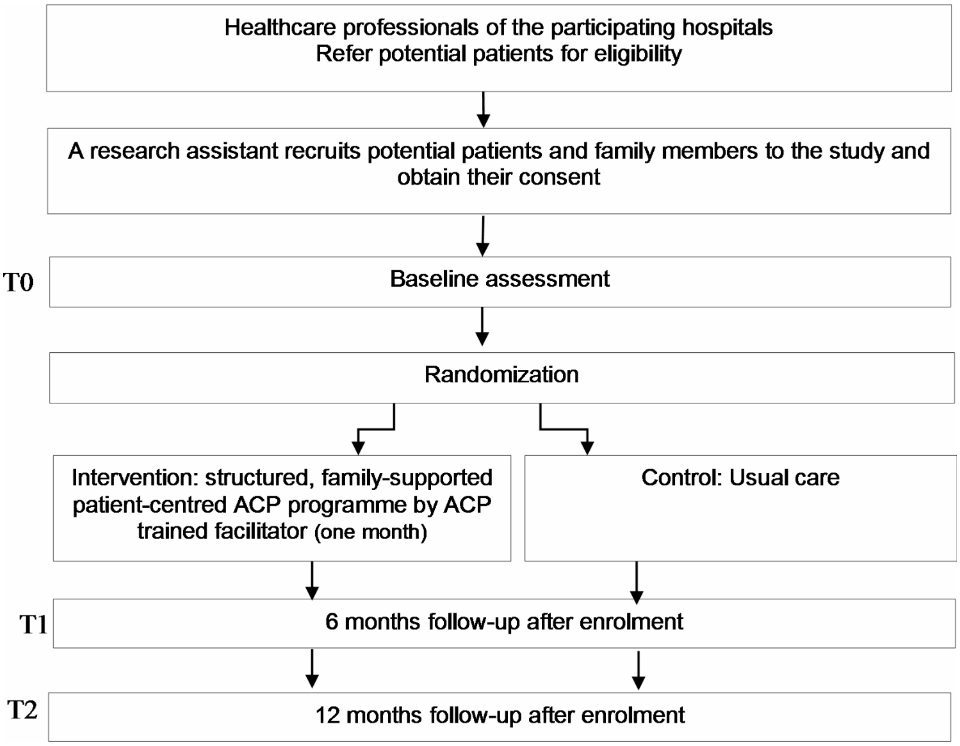

Fig. 1 Flowchart of the study

Sample size calculation is based on studies using individual-based ACP programme on prediction accuracy of patient's treatment preference at 6 months among severely ill patients. We are aiming for 170 dyads (i.e., 85 dyads per arm), which would provide 80% power to detect an effect size of 0.54 (Cohen's *d*) in overall prediction accuracy between the study arms with 35% attrition rate at 6 months (*t* statistic, two-sided $\alpha = 0.05$, G*Power 3.0). The expected effect size was derived from two previous studies [9, 18] whose studies resembles our own in many aspects. The tested interventions are of comparable intensity and duration and targeting severely ill patients. Attrition rates at 6 months ranged 20.9–34.3% in these two studies.

Study procedures

Randomization and masking

Patients will be randomized to either the ACP-Family or ACP-UC arm by block randomization with varying block sizes. A separate sequence of group identifies based on computer-generated random codes using a 1:1 allocation were prepared and placed in serially numbered opaque sealed envelopes by an independent person prior to the start of recruitment.

Recruitment, baseline assessment, and allocation

Physicians/nurses of the hospital will identify potentially eligible patients under their care and refer them to the research team. A group of research assistants in charge of recruiting subjects (RA1) then approach these patients individually and screen for eligibility. If the patient is eligible and willing to join the study, RA1 will ask the patient to nominate a family member who will be involved in their EOL decision-making (substituted decision maker). RA1 will then approach the family member and screen for eligibility. After providing their written informed consents, the dyad will self-complete the baseline assessment questionnaire (T0) independently, with assistance from RA1 if necessary. RA1 then will randomly assign the dyad to either the ACP-Family or the ACP-UC arm using the pre-prepared envelopes. For those dyads assigned to the ACP-Family arm, RA1 will schedule the first session of the intervention within one week, and information of the dyads will be sent to a trained ACP facilitator of the study (RN) to receive the ACP-Family programme. For those assigned to the ACP-UC arm, they will receive usual care of the respective hospital.

Study arms

Intervention: structured, family-supported, patient-centered ACP programme (ACP-Family group)

Treatment in the ACP-Family group will consist of two sessions to be delivered within one month in a face-to-face format as long as the patient is still in the hospital. The treatment will be continued in the patient's home if the patient is discharged before the two sessions are completed. To protect the privacy, the treatments will be delivered in a designed room as far as possible. Using a person-centered approach, the structured, family-supported, patient-centered ACP programme is developed based on the intervention in our previous RCT, where the component for family members will be delivered in a structured and systematic way, rather than in an unstructured, optional format (Table 1) [19]. This will be achieved by restructuring the corresponding content into a component targeting family members. The original protocol consists of four elements, namely (1) patients' understanding of their illness, (2) patients' values and beliefs underpinning care preferences, (3) possible health conditions in the future, and (4) introducing the idea of AD and its arrangement. The newly restructured component is named (5) construction of the role of substituted decision maker. Based on the experience obtained from the previous RCT and reference to clinical reviews on the discussion of goals for care with hospitalized patients with serious illnesses [20, 21], three topics will be covered: (i) inviting family member to share their own values and attitudes towards EOL care and views of the patient's EOL care preferences, (ii) discuss their understanding about being a substitute decision maker and explore potential concerns and (iii) encourage the patient and family member to discuss the amount of leeway for substitute decision-making, with the professional support from the ACP facilitator. A 3-min video on EOL treatment options will be shown to help patients and family members to clearly understand the related topic [22]. However, there will be no restriction on the order of the five topics to be discussed during the intervention.

Regarding the time, based on our previous RCT and other studies on ACP with seriously ill patients and their family in both hospital and community settings [13, 19, 22], two 60–90 min sessions should be long enough to cover all of the topics of the intervention while allowing enough time for discussion. Additional sessions of ACP will be delivered on request. A nurse, who has had at least five years of clinical experience with training in ACP, will deliver the intervention. At the end of the intervention, a personal ACP workbook summarizing the ACP process will be given to the patient-family dyad for record. The dyad will be asked to put the ACP workbook in a plastic folder for repeat ACP discussions in the future, if needed. If the patient wishes to sign an AD or have ACP discussions with his/her doctor at any time after the intervention, the ACP facilitator will arrange an additional session for signing. If participants experience negative emotions caused by the sensitive issues during the discussion, the sessions will be stopped and they will be referred to our research team members immediately,

Table 1 Components of structured family-supported patient-centred ACP programme

Component	Discussion focus	Suggested points for discussion
1	Assess understanding of and experience with the illness	- Invite patients to share their experiences about their recent health condition, and previous experiences of using or witnessing the use of life-sustaining treatments. - Assess the patient's understanding of their current health status, prognosis and potential complications.
2	Clarify patient's personal values and beliefs underpinning care preferences.	- Invite patients to share and reflect on their: - life purpose and meaning; - views concerning death; - religious beliefs, if any; - end-of-life care expectations
3	Identify possible conditions in the future in the context of patient's health. Show the video decision aid	- Discuss different health problems that may arise in the future, for example: - long-term use on life-sustaining treatment, such as mechanical ventilation, renal dialysis, tube feeding…etc; - loss of consciousness; - totally dependent in activities of daily living; - stop breathing/heart beating. - Clarify expectations towards future care in the context of the above health conditions. - Provide information about the potential benefits and burdens of different medical treatments in the context of different anticipated health deterioration.
4	Introduce the idea of advance directives ad discuss the arrangements in the aftermath of death	- Discuss the pros and cons of making an advance directive. - Assist the patient to formulate an individual advance directive if they agree to. - Discuss about aftermath plan, such as burial arrangement, memorial services…etc.
5	Construct the role of substituted decision maker	- Discuss the role of substituted decision maker and who could be the substituted decision maker - Emphasize the importance of respecting patient's value and beliefs and build consensus about EOL care among family members - Figure out patient's EOL care preference and strengthen family member's skill in decision making - Clarify some common concerns among family members on EOL care issues

who are either nurses or geriatricians with substantial experience in palliative care, and provide counselling if needed. These participants will be further referred to Comfort Care Concern, a non-governmental organization, for professional early bereavement counselling if necessary.

Usual Care with ACP (ACP-UC group)

An ACP programme (ACP-UC) is available to all palliative care patients in the hospitals under usual care. This ACP-UC covers similar elements as the structured, family-supported, and patient-centred ACP programme in the ACP-Family group except (1) a structured component to support the family members to construct their role in substituted decision making and (2) the 3-min video to show EOL treatment and care options during the conversation. The ACP-UC programme is not mandatory but will be initiated by ACP-trained nurses in the hospital if they think the patients are ready for ACP discussion, which only occasionally occurred due to the limited manpower in the hospitals.

Measures

The primary outcome is family's prediction accuracy of patient's treatment preferences at 6 months. Secondary outcomes include proportions of new ACP documentations and family-reported perception of whether the patient's end-of-life care preference was respected, patient's decisional conflict, and quality of communication, and family's decision-making confidence, anxiety, depression and quality of communication.

Data collection is scheduled at three time points: baseline before randomization (T0), and at 6 (T1) and 12 months (T2) after enrollment. If a patient has died, the family member will be asked to confirm the type of medical care received by the patient at EOL. All the variables are measured at both follow-ups except proportion of family-reported perception of whether the patients' EOL care preferences was respected. Another group of RA (RA2), blinded to the allocation, will conduct the two follow-ups at 6 and 12 months with the dyads (separately) in face-to-face format if the patient is still in the hospital or by telephone if the patient has been discharged. Most of the questionnaires have been validated and used in our previous RCTs [19, 22]. A list of the project telephones will be distributed to the dyads after consent to promote retention and complete follow-ups. The summary of instruments assessing outcomes of patient and family member is shown in Table 2.

Family's prediction accuracy of patient's treatment preferences

Patients and family members will be asked independently to indicate patient's preferences regarding three life-sustaining treatments (cardiopulmonary resuscitation, mechanical ventilator and tube feeding) based on

Table 2 Summary of instruments to assess outcomes of patients and family members

Outcome and variable	Instrument	Completed by		Measurement time point		
		Patient	Family	Baseline	6 m	12 m
Family's prediction accuracy of patient's treatment preferences	Assessment form adapted from Respecting Choices programme	√	√	√	√	√
New ACP documentation	Medical record / patient or family-reported	√	√		√	√
Wishes known and respected	Two items[18]		√		√	√
Communication about end-of-life care	Quality of Communication	√	√	√	√	√
Decisional conflict	SURE	√		√	√	√
Decision making confidence	Decision Making Confidence Scale		√	√	√	√
Anxiety and depression	HADS		√	√	√	√
Satisfaction of the interventional components	VAS	√	√	√	√	√

three options (want to attempt, refuse or uncertain) in two hypothetical EOL scenarios (being terminally ill and in persistent vegetative state or a state of irreversible coma). An accuracy score will be calculated by summing the number of treatment decisions for which responses from the patient and family member are identical, and then dividing by the total number of decisions ($n=6$), all equally weighted. This measure has been used in a previous RCT conducted in Hong Kong [19].

Proportion of new ACP documentation

AD will be retrieved from medical record or ACP discussion recorded reported by the patients or family member. A composite variable of any ACP documentation (forms and/or discussion) will be created.

Proportion of family-reported whether the patient's EOL care preference was respected for deceased patients

For deceased patients, their family members will be asked to respond to two items (whether EOL wishes were discussed and whether they were met) and a binary variable will be generated [23].

Patient's decisional conflict

Patient's decisional conflict in making decisions related to future care will be measured by the SURE test scale [24]. Patients will be asked to rate their future care on four items using a Yes/No format. An overall SURE score will be calculated, with a possible range 0–4 and higher scores indicating less decisional conflict. Good construct validity and reliability of the Chinese version of the scale were demonstrated [25].

Quality of communication regarding EOL

Patient-healthcare provider and family-healthcare provider quality of communication about EOL care will be measured using the corresponding subscale of the validated Quality of Communication Questionnaire [26]. Patients and family members will be asked to rate how good their physician is at each of the 7 communication skills about EOL discussion. An overall score will be computed, with higher score indicating better quality of communication. A Chinese version of the scale has been validated [27].

6. Decision-making confidence

Family's decision-making confidence in EOL decision making for their patients will be measured by the 5-item Decision Making Confidence Scale [28]. Family members will be asked to indicate their level of comfort in the surrogate role on a 0–4 points Likert scale, with higher scores indicating higher levels of confidence. The scale has been translated into Chinese and used in a previous study [22] and a Cronbach alpha value of 0.944 was obtained.

Anxiety and depression

Family's anxiety and depression will be assessed by the widely used 14-item Hospital Anxiety and Depression Scale (HADS) [29]. The HADS consists of two subscales: anxiety (7 items) and depression (7 items) with scores range 0–21 and higher scores indicating higher levels in anxiety and depression, respectively. A Chinese version of HADS has good psychometric properties [30].

Patients' and family members' satisfaction of the intervention

Patients and family members in the ACP-Family arm will be asked to rate their satisfaction about the discussion, the video shown, the ACP facilitator and the involvement of the family member (for patient only) using one item on a 0–10 Visual Analogue Scale separately [31].

Demographic characteristics

For both patients and family members, information of age, gender, marital status, educational level, living status, religious status, and self-rated health, and types of diseases of the patients (cancer vs. non-cancer) will be collected at baseline.

Data analysis

The data will be double entered. Intention to treat with all available data will be applied in all the analyses whenever applicable using SPSS with a significance level at 5%. Independent *t*-tests for continuous variables and chi-square tests for categorical variables examine comparability of groups in terms of demographics produced by randomization. Demographic variables that are statistically different between the two groups will be accounted for in subsequent analyses. The effectiveness of the ACP-Family programme on prediction accuracy of patient's treatment preferences at 6 months (primary outcome) will be evaluated by regression on outcome value at 6 months with "group" as an independent variable and controlled for baseline value of the outcome. For new ACP documentations at 6 and 12 months and proportion of family-reported whether the patient's EOL care preference was respected for deceased patients, Fisher's exact tests will be used for comparison. The effectiveness of the ACP-Family programme on continuous secondary outcomes (prediction accuracy, family members' decision-making confidence, anxiety and depression, and patients' perceived quality of community regarding EOL and decisional conflict) from T0 to T2 will be evaluated by linear mixed-effects models (MIXED procedure), because it could account for intra-correlation between repeatedly measured data and accommodates missing data caused by dropouts if missing data are random. Significant coefficient of "group" in regression, Fisher's exact tests and significant "time x group" interaction term in MIXED will support the hypotheses on the effects of the ACP-Family programme. Additional analyses will be performed to check the influence of potential confounding effect of disease type (cancer vs. non-cancer) on outcomes by adding the variable in the analyses as a covariate. Satisfaction of the ACP-Family intervention will be summarized by mean and standard deviation.

Training and quality assurance

To avoid potential contamination across study arm in the hospitals, we will recruit one patient-family dyad in each of the cubicles within each ward and provide one treatment at a time, with no new dyads be recruited before the patient is discharged in order to maintain separation between arms. In addition, the dyads in both arms will be asked not to share or discuss the content of the treatment they receive during their stay in the hospital.

Before the start subject recruitment, nurses who has clinical experience ≥ 5 years will be trained to be ACP facilitators and to implement the intervention. A two-day training workshop, including a tutorial, a video-showing, a case scenario discussion, and a role play session, adapted from a series of our previous studies [19, 22, 32], will be provided by the research team to equip the nurses with the knowledge and skills necessary for conducting ACP. The nurse will then deliver the ACP intervention to two patient-family dyads to ensure the quality of the intervention to be delivered under the supervision of one of the investigators, who is an expert in ACP training. All sessions in the ACP-Family arm will be audio-recorded with the consent from the participants and checked by the research team. Additionally, to ensure the reliability of RAs, a pilot test on collecting the data of 5 dyads will be conducted by both RA and principle investigator for comparison. If a 95% agreement in response coding is not achieved, addition training to RA will be provided.

Discussion

ACP provides patients, family members and healthcare providers an opportunity to understand the patient's wishes and preferences for future care and have a shared decision-making, which may enhance the preference-concordant care and quality of life of the patients and their families [1, 33]. Although its significance has been well documented, the optimal strategy of embedding ACP into clinical practice, especially increasing the ACP documentation rate and improving family's prediction accuracy of patient's treatment preferences [9, 10], is crucial to be further explored. In terms of the significant role of family members in ACP process and they often feel unprepared to the discussion, supporting them through a structured ACP programme will be potentially beneficial. The findings are expected to add to the literature supporting the effectiveness of a structured, family-supported, and patient-centred ACP programme.

The current intervention has been well connected with our previous RCTs [19, 22] and further enhanced by adding a new component targeting family members. It will adopt a standardized procedure with five predefined components and be facilitated by trained nurses, which will enhance its validity. Recruiting subjects from multiple sites will increase the generalizability of the study findings. Meanwhile, it will keep flexibility in the sequence of discussed topics, which makes the ACP programme more operable in the clinical practice. Including both cancer and non-cancer patients responds to local policy initiatives and may meet the needs of a wider range of palliative care patients. We have also acknowledged the differences of the two groups and will perform additional analyses to determine the possible confounding effect on outcomes. The examination of various outcome variables in our study using both objective and subjective assessment tools will provide a thorough, multifaceted understanding of the effects of the programme. As a result, conclusions about potential future interventions, additional study, and the viability of comparable trials will be possible.

Limitations

This study has some limitations that require further consideration. First, we face the difficulty in data completion at the primary endpoint because of the long follow-up time and the loss of patients due to death and thus the possibility of unwillingness to complete the survey in family members after the death of their loved ones. We therefore collaborate with hospital clinicians to inform us when the patients have passed away and we will acknowledge the death of the patients when we contact their relatives for follow-up. In addition, we distribute a list of telephone numbers of the project to participants after enrollment of the study for communication in order to boost participation rate. Second, blinding of group allocation is another concern as both the facilitators who conduct the ACP-Family intervention and the participants cannot be blinded. Yet, we have attempted to blind the participants as far as possible with the dyads in the control group are told that they will be approached for ACP conversations when their attending physicians have time to do so.

Conclusion

We proposed a randomized controlled trial to investigate the effectiveness of a structured, family-supported, and patient-centred advance care planning on end-of-life decision making among palliative care patients and their family members. This study will provide an evidence-based approach to involve family members in the ACP discussion.

Dissemination policy

Results will be disseminated through national conferences and publications.

Abbreviations

ACP	Advance care planning
ACP-Family	Structured, family-supported, patient-centred ACP programme
ACP-UC	Usual ACP care
EOL	End-of-life
AD	Advance directives
CT	Randomized controlled trial
RA	Research assistant
HADS	Hospital Anxiety and Depression Scale

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Author contributions

D.L. is principal investigator, formulated the research question, conceptualized the study design, conceived, and contributed the manuscript. J.C. and H.C. are co-investigators and contributed to its design and the intervention manual. H.C. wrote the intervention manual and supervises the intervention. J.C. coordinates the study and helped writing the intervention manual. R.L., K.L., P.L. and N.N. are co-investigators, coordinate subject recruitment at study sites and contributed to the manuscript. All authors have read and approved the manuscript.

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Data availability

Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

This study protocol was approved by the Human Subjects Ethics Sub-committee of the Hong Kong Polytechnic University (HSEARS20200114002) and the Joint Chinese University of Hong Kong-New Territories East Cluster Clinical Research Ethics Committee (CREC Ref. No. 2023.109-T). The study will be conducted accordance with the Declaration of Helsinki. Informed written consents are obtained from all the participants before data collection.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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