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Chapter

Effect of a Video-Supported Nurse-Led Advance Care Planning for Older Adults with Frailty: A Randomized Controlled Trial

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Abstract

This chapter reports the results of a parallel, double-blinded randomized controlled trial to examine the effect of video-supported nurse-led advance care planning (ACP) as compared with a health education program plus an ACP promotion leaflet on end-of-life decision-making outcomes in older adults with frailty. Outcomes were assessed at 1 month and 6 months after the intervention via telephone. Between December 2018 and January 2020, 449 older adults were screened for eligibility. The trial was terminated early after 105 subjects had been assigned (intervention: 51; control: 54) because of the COVID-19 pandemic and the end of the funding period. No significant between-group difference was found in the retention rate at 1 (41.2% vs. 38.9%) and 6 months (35.3% vs. 44.4%). In the intention-to-treat analysis, the ACP group reported a higher but non-significant advance directive completion rate (5.9% vs. 1.9%) and a significantly higher mean score in quality of communication about end-of-life care at 1 month [estimated difference: 8.73 (1.16–16.30)]. There was no evidence of a difference in favorable outcomes of subjects receiving the video-supported, nurse-led ACP compared with those receiving active control. Results might have been confounded by high attrition, poor intervention completion, and reduced sample size due to the early termination of the study.

Keywords: advance care planning, advance directives, decision aids, decision-making, end-of-life communication, frailty, older adult

1. Introduction

End-of-life (EOL) care has been defined as care “to assist patients who are facing imminent or distant death to have a quality of life possible till the end of their life regardless of their medical diagnosis, health condition or ages” [1]. EOL care encompasses not only the provision of medical support but also social, emotional, and spiritual support [2]. Discussing EOL care can help create a shared understanding of the patient's

values and care preferences, which can lead to a plan of care that is congruent with these values and preferences [3].

Advance care planning (ACP) is a process of communication aimed at helping individuals proactively make decisions on their EOL care when they are mentally competent [4]. Previous studies consistently reported that ACP is beneficial to patients, family members, healthcare professionals, and the healthcare system. With honest and open ACP conversations, a better understanding of patient's wishes and preferences is gained, thereby increasing their satisfaction with the care that they receive [5, 6]. Other studies found that early ACP conversations lead to the avoidance of aggressive medication interventions, which can improve the patient's quality of life and help family members adjust to their bereavement [7, 8]. ACP can also facilitate healthcare professionals' understanding of patient's goals of care; thus, healthcare professionals can be more certain about what action to offer [9]. Having early ACP can lead to better utilization of healthcare resources. It has resulted in a reduction in hospitalizations and in the increased use of hospice and palliative care services [10, 11]. A recent systematic review of 132 randomized controlled trials (RCTs) concluded that ACP interventions improve patient outcomes including quality of patient-physician communication, preference for comfort care, decisional conflict, patient-care-giver congruence in preference, and ACP documentation [12].

Frailty has been referred to as a complex chronic condition where patients experience more than one chronic illness, have a decreased ability to engage independently in the activities of daily living and are at an increased risk of morbidity and mortality [13, 14]. A recent systematic review of population-level studies from 62 countries across the world estimated that 12% of older adults are suffering from frailty [15]. Thus, ACP is especially important for older patients with frailty. Previous studies summarized EOL care needs of older adults with frailty, which included domains in physical health (e.g., pain management), psychosocial needs, functional status, care-related outcome (e.g., satisfaction with care), and preference of care [16, 17]. Frailty generally causes gradual and slow progression of decline, creating difficulty for healthcare professionals to predict patients' prognosis and identify their EOL phase, especially for frail patients who do not have a recognized life-limiting illness [18]. As a result of the unpredictable prognosis in patients with frailty, there are calls for initiating ACP conversations to discuss goals of care and preferences to make advance care plans in these patients. Having these conversations may increase patient's awareness of the benefits of palliative care [19].

However, technical medical terms, such as cardiopulmonary resuscitation (CPR), antibiotics, and intravenous infusion, are to be covered when discussing common treatment options for EOL care in the ACP conversations. The procedures for these medical treatments are usually described in an abstract, hypothetical way, but the related content may not be understandable for laymen, especially those with limited health literacy. Meta-analytic evidence showed that video-based interventions present a promising way to promote patient's preferences for these EOL care treatment options and knowledge related to ACP but not in the completion of advance directives (AD) [20]. Thus, the addition of a video on EOL care treatment options to support clinical communication in the ACP conversation can further enhance the quality of ACP conversations in EOL care communication.

The aim of the study was to compare the effectiveness of two structured ACP programs with different intensities (one focuses on communication and AD with video decision aids, whilst the other focuses on AD promotion only) on EOL

decision outcomes of older adults with frailty and their carers. In this chapter, we only report results from the patients because the sample size for carers was too small for analysis.

2. Methods

2.1 Study design and participants

The trial was a parallel, double-blinded, prospective RCT with blinded assessment at 1-month and 6-month follow-up conducted at one geriatric medical ward in Hong Kong. The trial protocol was approved by the research ethics committees of the participating hospital and the university of the principal investigator. Written informed consent was obtained from all the participants and family members who joined the study. Participants were assured their right to withdraw from the study at any time without reprisal. The method and protocol of the trial have been reported elsewhere [21].

We recruited eligible subjects at a medical ward of a public hospital in Hong Kong using convenience sampling. The participating hospital is a major hospital providing geriatric medicine and palliative medicine service in the serving district. Hospital nurses referred potentially eligible patients who were about to be discharged to our research assistant (RA1) for eligibility screening. Eligible patients were invited to join the study with signed written consent after an explanation. The inclusion criteria for patients were (1) in-patients, (2) 60 years old or above, (3) fulfilling at least one criterion of the FRAIL scale [22], (4) being clinically stable, (5) able to communicate in Chinese, and (6) cognitively intact (mini-mental state examination [MMSE] > 17) [23]. The exclusion criteria were patients who (1) had already signed an AD or (2) had been referred to a palliative care service during the study period. Consented patients were then asked to nominate an informal caregiver who would likely be a substitute decision-maker for them in future health care. RA1 then approached the nominated caregiver and explained the study to him/her. The inclusion criteria for caregivers were (1) 18 years old or above and (2) able to communicate in Chinese. We recruited patient-caregiver dyads in which patients could join without a caregiver but caregivers could not join without a corresponding patient in the study.

2.2 Randomization and masking

Randomization was conducted based on a 1:1 ratio for each treatment arm. A statistician who was not involved in subject recruitment and data collection generated the random allocation list using a computer-generated randomizer. Allocation concealment was implemented by the use of sealed envelopes. Each consented dyad was randomly assigned to either the intervention group to receive a video-supported, nurse-led ACP program or the control group to receive a health education program plus a leaflet promoting ACP after completing the baseline assessment. The envelope was opened by RA1. After randomization, RA1 scheduled the first home visit within 1 week with the participants and sent the participants' information to the nurse who was responsible for the delivery of the corresponding treatment accordingly, with RN1 delivering the ACP intervention and RN2 responsible for the health education

program. This procedure can ensure that both the interventionists (RN1 and RN2) were blinded to group allocation. Given that both treatment groups cover ACP elements to a different extent, the participants should also be blinded to their group allocation.

2.3 Intervention material

The interventions for the two groups followed the published study protocol [21]. The two structured ACP interventions had two 1-h sessions and were delivered at the patient's home on a weekly basis.

For the intervention group (ACP), participants (the patient and caregivers, if any) received a video-supported, nurse-led ACP program developed using the patient-centered approach. The home-based ACP program involved two 1-h sessions covering four main elements: understanding illness; values and beliefs about care preferences; health prognosis of the disease; and introducing the idea and arrangement of AD. In addition, a 3-min video covering treatment options of EOL care in Hong Kong was shown when discussing health prognosis of disease in the ACP conversations. A personal workbook on ACP was provided to summarize the ACP conversations for participants' records. The nurse who delivered the program had more than 5 years of clinical experience and was trained to facilitate the ACP conversation in a 2-day training workshop.

For the control group (control), participants received a health education program about specific symptoms or diseases provided by another nurse. A leaflet about ADs with contact information for signing AD was distributed at the end of the second session.

2.4 Data collection

After obtaining written consent, baseline data were collected by RA1. RA1 then randomly assigned the consented participants to either the control or the intervention group by opening the sealed envelope. Participants were followed up at 1 and 6 months after intervention via telephone by another trained RA2 who was blinded to group allocation. A designated private physician was recruited for AD completion in the study.

2.5 Outcome measures

Details of primary and secondary outcomes were described in the published study protocol [21]. In brief, completion of AD was the primary outcome. Those patients who were willing to sign an AD was referred to a designated private physician for completion. The AD form used in the study was adapted from a previous version of the modified directive model by the Hong Kong Hospital Authority [21, 24] with permission.

We also collected data on the following three secondary outcomes from patients and reported their results in the chapter. (1) Patients' decisional conflict in making decisions related to future care was measured by the SURE test [25]. The SURE test has four items in a "Yes/No" format, and its total score can range from 0 to 4, with higher scores indicating higher levels of certainty regarding decision-making. (2) The quality of communication on EOL care with healthcare professionals was measured with the subscale "quality of communication about end-of-life care" (QoC-EOL) of the quality of communication questionnaire developed by Engelberg and colleagues [26, 27]. The subscale has seven items measuring a participant's perception of quality

of the ACP communication on an 11-point Likert scale ranging from 0 (the very worst I could imagine) to 10 (the very best I could imagine). There are two additional options for selection: “didn’t have the related communication” and “don’t know” (to indicate that they were unsure of how to rate the facilitator on a particular skill). For QoC-EOL, we imputed “0” for the two additional options based on the assumption that the failure to complete or address an item warranted a low score because all of the included items were identified as important aspects of EOL care communication [27]. Scores of the seven in the scale were summed up to create the total score with a possible range of 0–70. (3) Patient’s knowledge of ACP (ACP knowledge) was measured by a self-developed knowledge questionnaire consisting of five items covering the purposes of AD, EOL discussion, and issues related to ACP. The ACP knowledge score can range from 0 to 5, with higher scores indicating better knowledge. Good content validity (CVI > 0.9) and internal consistency (0.84) were obtained based on the data from a previous local study [28]. At the 1-month follow-up, patient’s satisfaction with the treatment received was measured by an item on a 0–10 VAS scale. In addition, intervention patients were asked to rate their comfort level of watching the 3-min video on treatment options of EOL care on a 0–10 VAS scale.

2.6 Statistical analysis

The analysis was conducted on the intention-to-treat population whenever applicable. The sample size calculation was based on the primary outcome of AD completion, with a power of 80% at a 5% level of significance using a chi-square test and a 20% attrition rate at 6 months to detect a difference of 14.8% (16.5% for the intervention group and 1.7% for the control group) [28]. After the start of subject recruitment, the required sample size was revised from 298 to 148, with approval from the funding body because of computational error in the original calculation.

Demographic data were summarized and compared with the group difference at baseline by using chi-square tests for categorical variables and Mann–Whitney U tests for continuous variables. For the primary outcome variable, we compared the proportion of AD completion between the intervention and the control group using Fisher’s exact test. We used the Mann–Whitney U test to compare the SURE, QoC-EOL, and ACP knowledge score changes between groups, as well as to compare their scores at 1 and 6 months between groups. Furthermore, we conducted generalized estimating equations (GEEs) to examine the differences in the mean changes between the two groups in the secondary outcomes, with adjustment for imbalances in characteristics at baseline. The interaction term of group by time was included to assess the corresponding changes in the outcome variable at the follow-up time points with respect to baseline. All statistical tests, performed using SPSS version 26.0 (IBM Corp., Armonk, NY, USA), were two-sided, and $p < 0.05$ was considered statistically significant. This trial was registered with Chinese Clinical Trial Registry ChiCTR-IOR-17012341.

3. Results

3.1 Subject recruitment and characteristics

Between December 2018 and January 2020, we assessed 449 patients for trial eligibility. However, subject recruitment was suspended since January 2020 due to

the outbreak of the COVID-19 pandemic, leading to the cessation of all research activities in the study hospital and home-based intervention delivery in the RCT. The RCT was terminated prematurely by May 2022 due to the end of funding after two extensions of the study period. During this period, a total of 143 (31.8%) older adults with frailty were eligible for study inclusion, and 105 (73.4%) provided informed consent and were enrolled in the RCT, with 51 allocated to the ACP group and 54 to the control group (**Figure 1**). Of the 51 patients in the ACP group, 40 (78.4%) patients joined the study without caregivers and 11 had caregivers. During the study period, 33 had received the ACP intervention, 20 refused to receive the intervention (mostly because of the social event in 2019 in Hong Kong), 1 passed away and 5 were pending for intervention due to the COVID-19 situation. Video on treatment options of EOL care was shown in 30 cases in the ACP group (90.9%). No adverse event was reported during the sensitive discussion in the ACP conversations. Of the 54 patients in the control group, 39 (72.2%) of them joined the study without caregivers and 15 had caregivers, and 31 (57.4%) had received the health education program, 8 refused, 10

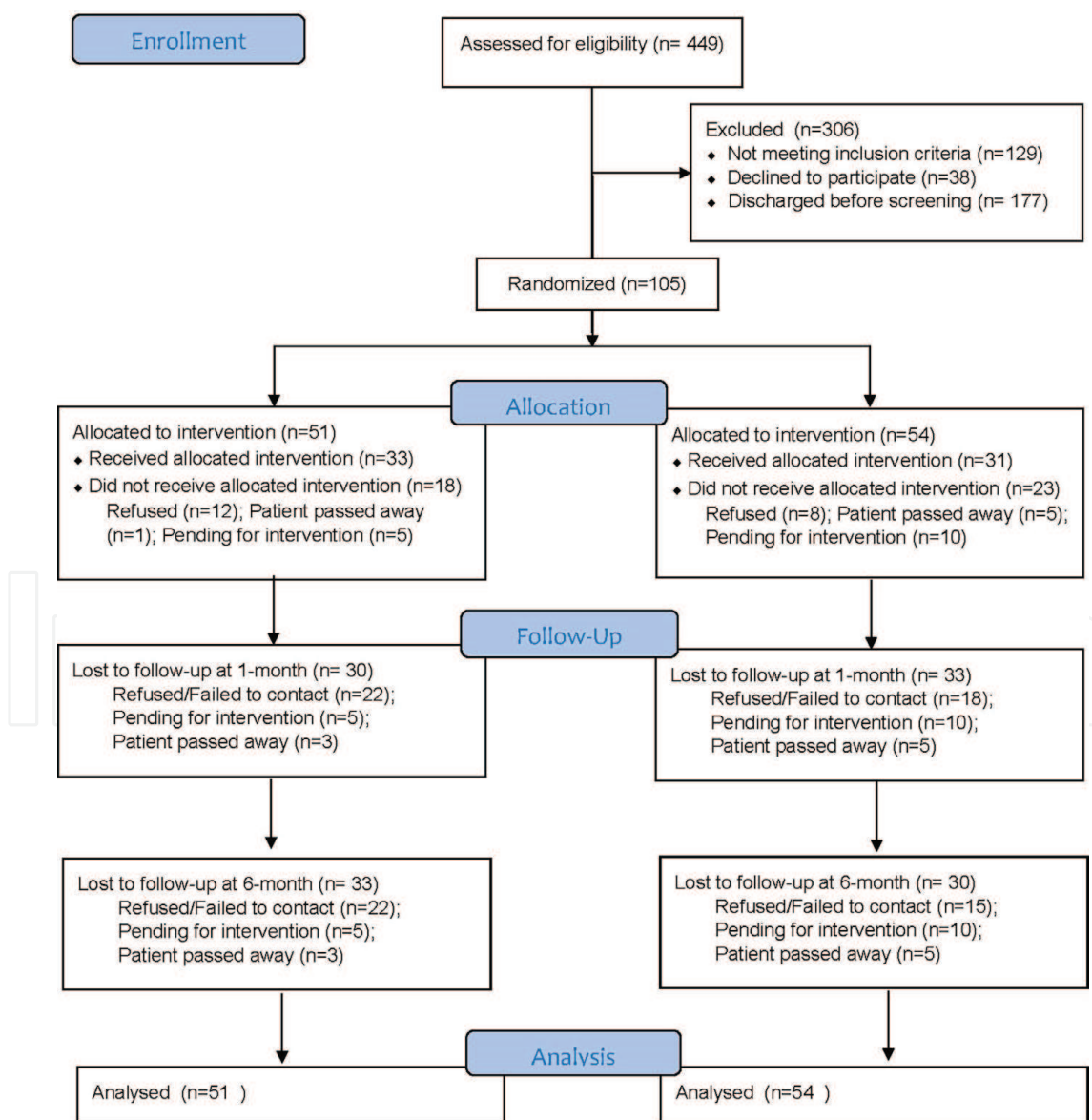


Figure 1.
Flow diagram of the trial.

were pending intervention, and 5 passed away. The overall attrition rate was 60.0% at both follow-up time points, and there was no statistical difference in the attrition rate between the two groups at 1 (ACP: 58.8% vs. Control: 61.1%, $p = 0.819$) and 6 months (64.7% vs. 55.6%, $p = 0.344$).

Baseline patient characteristics are presented in **Table 1**. The study sample included mainly males (62.9%, $n = 66$), married (60.0%, $n = 63$), not living alone (81.9%, $n = 86$), had religion (56.2%, $n = 59$), and had primary education or below (52.4%, $n = 55$). The patients had a median (interquartile range [IQR]) age of 82.0 (74.0, 85.0) years and a median MMSE score of 24.0 (21.0, 27.0). On the basis of the possible range of 8–24, the patients reported high levels of daily activities of living with a median of 20.0 (16.0, 23.0) and instrumental daily activities of living with a median of 16.0 (10.5, 22.0). Baseline characteristics were generally balanced in the study sample, except for the FRAIL score, in which the ACP group patients were less frail with a median of 2.0 (1.0, 3.0) than the control group patients whose median was 3.0 (2.0, 4.0), with a p -value of 0.006. For the secondary outcome variables, all the patients in the sample reported extremely low scores in all three secondary outcomes at baseline: QoC-EOL with a median of 0 (0.0, 0.0), SURE with a median of 0.0 (0.0, 3.0) and ACP knowledge with a median of 1.0 (1.0, 2.0).

Table 2 shows the bivariate analysis results, and **Table 3** illustrates the logistic regression results for the primary outcomes and GEE results for the secondary outcomes of the trial, with the adjustment for FRAIL score at baseline and whether the patients had received the assigned group treatment. For the primary outcome, we found no evidence of a difference in the proportion of patients who had signed an AD during the study period (3 [5.9%] of 51 patients in the ACP group vs. 1 [1.9%] of 54 in the control group, odds ratio [OR] 3.31, 95% CI (0.33, 32.93). The result remained unchanged after adjusting for the effects of baseline FRAIL score and whether the patients had completed the allocated treatment (adjusted OR 3.32, 95% CI (0.33, 32.79); **Tables 2 and 3**).

For the perceived quality of communication on EOL care, the median (IQR) in QoC-EOL score at 1 month was 15.0 (0.0, 22.0) in the ACP group and 0.0 (0.0, 12.0) in the control group. The difference in the median score at 1 month between the two groups was statistically significant ($p = 0.048$), but the significant result diminished at 6 months. The median (IQR) score in QoC-EOL at 6 months was 0.0 (0.0, 7.0) in the ACP group and 0.0 (0.0, 0.0) in the control group. The median (IQR) change in the QoC-EOL score from baseline to 1 month was 10.0 (0.0, 22.0) in the ACP group and 0.0 (0.0, 12.0) in the control group, whilst the median change from baseline to 6 months was 0.0 (0.0, 6.3) in the ACP group and 0.0 (0.0, 0.0) in the control group. Mann–Whitney U test results showed no evidence of differences in the median change in QoC-EOL at both follow-up time points (**Table 2**). However, we observed a significant between-group difference in the change in QoC-EOL score. Patients in the ACP group reported a higher QoC-EOL score at 1 month than those in the control group, with an estimated mean difference (95% CI) of 8.73 (1.16, 16.30) after controlling for the effects of baseline FRAIL score and whether the patients had received the allocated treatment in GEE analysis (**Table 3**).

For decisional conflict, the two groups exhibited an increase in SURE score to a similar extent, with a median of 1.0 at 1 month and 4.0 at 6 months (p -values >0.8). The median (IQR) change from baseline to 1 month was 0.5 (−0.8, 1.8) in the ACP group and 0.0 (−1.0, 0.0) in the control group, and that from baseline to 6 months was 3.0 (0.0, 3.0) in the ACP group and 1.0 (−0.5, 2.5) in the control group (**Table 2**). The GEE results also supported that there was no evidence of differences in the mean

	Total (n = 105)	ACP (n = 51)	Control (n = 54)	p-value
Demographic characteristics				
Gender				0.982
Male	66 (62.9)	32 (62.7)	34 (63.0)	
Female	39 (37.1)	19 (37.3)	20 (37.0)	
Education				0.980
Some education	24 (22.9)	12 (23.5)	12 (22.2)	
Primary	31 (29.5)	16 (31.4)	15 (27.8)	
Secondary	32 (30.5)	15 (29.4)	17 (31.5)	
Tertiary or above	15 (14.3)	7 (13.7)	8 (14.8)	
Missing data	3 (2.9)	1 (2.0)	2 (3.7)	
Marital status				0.828
Married	63 (60.0)	29 (56.9)	34 (63.0)	
Single	9 (8.6)	4 (7.8)	5 (9.3)	
Widowed	30 (28.6)	16 (31.4)	14 (25.9)	
Divorced	3 (2.9)	2 (3.9)	1 (1.9)	
Living alone				0.696
Yes	19 (18.1)	10 (19.6)	9 (16.7)	
No	86 (81.9)	41 (80.4)	45 (83.3)	
Had religion				0.893
Yes	59 (56.2)	29 (56.9)	30 (55.6)	
No	46 (43.8)	22 (43.1)	24 (44.4)	
Age (years)	82.0 (74.0, 85.0)	81.0 (75.0, 84.0)	82.0 (73.0, 86.3)	0.546
MMSE score	24.0 (21.0, 27.0)	25.0 (21.0, 26.0)	24.0 (21.0, 27.0)	0.611
FRAIL score	3.0 (2.0, 3.0)	2.0 (1.0, 3.0)	3.0 (2.0, 4.0)	0.006
ADL score	20.0 (16.0, 23.0)	22.0 (16.0, 24.0)	20.0 (15.8, 23.0)	0.395
IADL score	16.0 (10.5, 22.0)	16.0 (10.0, 23.0)	16.0 (10.8, 21.0)	0.604
Secondary outcome				
QoC-EOL score	0.0 (0.0, 0.0)	0.0 (0.0, 0.0)	0.0 (0.0, 0.0)	0.865
SURE score	0.0 (0.0, 3.0) ^a	0.0 (0.0, 3.0)	0.0 (0.0, 3.0) ^a	0.949
ACP Knowledge score	1.0 (1.0, 2.0) ^c	2.0 (1.0, 2.5) ^b	1.0 (1.0, 2.0) ^b	0.429

Note: Data are n (%) or median (Interquartile range). MMSE = Mini-Mental State Examination; QoC-EOL: Quality of communication about end-of-life care; ^a Data of 1 patient was missing; ^b Data of 2 patients were missing; ^c Data of 4 patients were missing.

Table 1.
Patient demographic characteristics and secondary outcome measures at baseline.

change in the SURE scores from baseline to 1 month and to 6 months in the two groups after controlling for the effect of baseline FRAIL score and whether they had received the allocated treatment (**Table 3**).

For ACP knowledge, the control group exhibited higher median scores than the ACP group at both 1 and 6 months. However, the median change in ACP knowledge was 0 in both groups from baseline to 1 month, whereas the median (IQR) change

Outcome	ACP	Control	p-value
Primary outcome			
AD completion	3 (5.9%; n = 51)	1 (1.9%; n = 54)	0.281
Secondary outcome			
QoC-EoL score			
at 1 month	15.0 (0.0, 22.0; n = 21)	0.0 (0.0, 12.0; n = 21)	0.048
at 6 months	0.0 (0.0, 7.0; n = 18)	0.0 (0.0, 0.0; n = 24)	0.271
from baseline to 1 month	10.0 (0.0, 22.0; n = 21)	0.0 (0.0, 12.0; n = 21)	0.194
from baseline to 6 months	0.0 (0.0, 6.3; n = 18)	0.0 (0.0, 0.0; n = 24)	0.599
SURE score			
at 1 month	1.0 (0.0, 2.8; n = 20)	1.0 (0.0, 2.0; n = 19)	0.828
at 6 months	4.0 (2.0, 4.0; n = 9)	4.0 (2.0, 4.0; n = 6)	0.888
from baseline to 1 month	0.5 (-0.8, 1.8; n = 20)	0.0 (-1.0, 0.0; n = 19)	0.338
from baseline to 6 months	3.0 (0.0, 3.0; n = 9)	1.0 (-0.5, 2.5; n = 6)	0.504
ACP knowledge			
at 1 month	1.0 (1.0, 3.0; n = 21)	1.5 (1.0, 2.0; n = 20)	0.955
at 6 months	1.0 (0.8, 3.3; n = 14)	2.0 (1.0, 3.0; n = 12)	0.693
from baseline to 1 month	0.0 (-1.0, 1.0; n = 21)	0.0 (0.0, 1.8; n = 20)	0.262
from baseline to 6 months	0.0 (-1.0, 1.0; n = 13)	0.5 (-0.8, 2.0; n = 12)	0.130

Note: Data are n (%) or median (Interquartile range). QoC-EoL: Quality of communication about end-of-life care.

Table 2.
 Primary and secondary outcomes.

Outcome	Adjusted OR (95%CI)	p-value
AD completion	3.32 (0.33–32.79)	0.307
	Beta coefficient (95%CI)	p-value
QoC-EOL		
Group		
ACP	0.29 (-0.66, 1.24)	0.549
Control	Reference	
Time		
Baseline	Reference	
1 month	5.89 (1.79, 9.99)	0.005
6 months	1.28 (-0.98, 3.54)	0.267
Group x Time interaction		
ACP x 1 month	8.73 (1.16, 16.30)	0.024
ACP x 6 months	1.29 (-5.70, 8.28)	0.717
SURE		
Group		
ACP	-0.03 (-0.65, 0.60)	0.930

Outcome	Adjusted OR (95%CI)	p-value
Control	Reference	
Time		
Baseline	Reference	
1 month	0.09 (-0.51, 0.69)	0.769
6 months	0.78 (-0.65, 2.21)	0.286
Group x Time interaction		
ACP x 1 month	0.22 (-0.76, 1.21)	0.657
ACP x 6 months	0.42 (-1.25, 2.08)	0.623
ACP Knowledge		
Group		
ACP	0.14 (-0.30, 0.57)	0.538
Control	Reference	
Time		
Baseline	Reference	
1 month	0.32 (-0.23, 0.87)	0.257
6 months	0.53 (-0.23, 1.28)	0.175
Group x Time interaction		
ACP x 1 month	-0.15 (-0.98, 0.68)	0.727
ACP x 6 months	-0.70 (-1.76, 0.35)	0.191

Note: CI = confidence interval; FRAIL score and completion of intervention were added in the models.

Table 3. Results of logistic regression on primary outcome and generalized estimating equations on secondary outcomes.

from baseline to 6 months remained at 0 (-1.0, 1.0) in the ACP group and was increased by 0.5 (-0.8, 2.0) in the control group (Table 2). The GEE results showed that the mean values of ACP knowledge remained stable in the two groups over time, and there was no evidence of a difference in the mean changes in the ACP knowledge score between the two groups at both 1-month and 6-month follow-up (Table 3).

Amongst the 64 patients who completed 1-month follow-up, the level of satisfaction with the received treatment was high in both the intervention group (median [IQR]) (8.0 [5.3, 10.0], n = 33) and the control group (8.0 [5.0, 10.0], n = 31), with no statistically significant difference between the groups (p = 1.0). For the 30 interventional patients who had watched the 3-min video on EOL care treatment options, the median (IQR) in the comfort level was also high at 7.0 (4.0, 8.0).

4. Discussion

On the basis of the prespecified intention-to-treat analysis, the trial did not show a benefit of the video-supported nurse-led ACP program over the health education program plus an ACP promotion leaflet for end-of-life decision-making outcomes. However, our results might have been confounded by the poor implementation of the study because of three reasons: (1) the slowing down of research activities due

to the social event in 2019 in Hong Kong, (2) the complete halt of all research activities due to the outbreak of the COVID-19 pandemic in January 2020, and (3) end of the funding period of the study, which eventually led to the early termination of the trial. These events limited our final sample size to only 105 (70.9%) of our planned target of 148 patients, together with the large attrition rates in the two follow-up time points in both groups, resulting in an underpowered analysis. Moreover, the fact that one-third of the patients were not screened for eligibility before discharge might have introduced selection biases that contributed to our observed findings.

In this study, the completion rates of AD in both treatment groups were low compared with previous RCTs, with a range of 0–37.9% in the intervention group and 0.4–23.9% in the control group [29]. The recent systematic reviews on the efficacy of ACP based on 132 RCTs concluded that it improved ACP documentation, with 34 out of 54 included studies (63%) showing significant and positive results [12]. However, amongst these 54 RCTs, only three were conducted in Asian countries [28, 30, 31]. Together with a more recent RCT in Singapore, mixed results on ACP/AD documentation were found: two showed significant improvement in the outcome [28, 30], and the other two had non-significant results [31, 32]. Compared with our previous RCT on ACP conducted in Hong Kong with significant results on ACP/AD documentation [28], we did not observe a difference in the AD completion rate between the two groups although we have added the 3-min video decision aid in the ACP intervention in the current study. The mixed results of RCTs could be explained by the difference in the target patient group. The two RCTs with significant results targeting subjects with limited life expectancy (elderly in nursing homes and patients with advanced serious illness and their proxies) and the two with non-significant results included advanced cancer patients and patients visiting primary care clinics. In this study, we included older adults with frailty who were healthy and had long life expectancies; thus, they would be less likely to see the clinical relevance or urgency of ACP conversations [33, 34]. In our qualitative analysis of ACP conversations who did not complete AD after the ACP intervention, we also found that the older adults generally accepted that getting old and becoming frailer is a natural process instead of feeling anxious about death [35]. They believed they were still healthy and reluctant to discuss EOL issues and indicated they would be willing to engage in ACP conversations when they became terminally ill. The RCT in Singapore with primary care patients also indicated that they were too young to consider completion of AD [32]. Discussing death-related issues is still taboo in many Asian cultures [36]. The findings from these RCTs, including the current trial, provide some support regarding the optimal time for ACP in the Asian context: ACP conversations with patients who are not approaching their end of life may be too inappropriate when these patients still consider themselves healthy, although more studies are required to provide a firm conclusion to this assertion. Nevertheless, we clearly need other initiatives that promote EOL discussion in Asian countries. For example, a community action approach to promote early ACP conversation through public education by shifting ACP from a health issue to a “normal” conversation to reduce the negative feeling related to death advocated in the literature could be an option [37].

This work is the first trial in the Asian region examining the effect of an ACP intervention on the quality of communication in EOL care. In our study, we observed a significantly greater increase in the median QoC-EOL score from baseline to 1 month after intervention in the ACP group than those in the control group based on the GEE results. Although subject to a large type 2 error, the observation of the increase in quality of communication was consistent with previous studies reporting

that ACP interventions can improve the quality of patient-physician communication [12]. However, in the current study with a range of 0–70, the highest median in the observed QoC-EOL score was 15 at 1 month in the ACP group, which was still extremely low. Despite high acceptable levels of satisfaction with the received treatment in both groups, the low median in QoC-EOL scores in this study reflected that the promotional leaflet alone in the control group and the stand-alone two-session ACP intervention in the intervention group might not be sufficient to improve the quality of the communication. A recent RCT also showed that video-alone intervention does not engage individuals in high-quality ACP [38]. The communication on EOL care was determined to be of low quality in this study because of the rareness of its occurrence. A recent systematic review found a low rate (0–5%) of EOL care communication in hospitalized frail older adults, even though 74–84% of older inpatients with capacity were receptive to ACP [39]. A lack of communication on EOL care between healthcare professionals and older adults with frailty seems to be a worldwide problem. On-going discussions and deliberation with a healthcare provider in promoting patient-physician communication on EOL care are necessary [38].

Similar to QoC-EOL, the increases in SURE scores from baseline to 1 and 6 months were greater in the ACP group than in the control group, but the differences in the changes were not statistically significant. The result was contradictory to the findings from a systematic review of ACP interventions [12] that decisional conflict was reduced significantly in 64% (9) of the 14 RCTs that had assessed this outcome including the previous RCT in Hong Kong [28]. The nonsignificant result might be due to the underpowered feature of the study. Another possible reason is the low level of prognostic awareness in the participants. As reported previously, many of the participating older adults in our study believed they were still healthy, and they would be willing to participate in an EOL conversation when they became terminally ill [35]. Hence, they were not likely to make any decision about their EOL care at the present moment. Previous studies showed that low levels of prognostic awareness are associated with difficulty in initiating conversation in older adults [40]. The three RCTs targeting patients with advanced illnesses in the Asian region that had examined this outcome reported mixed results; two studies that included ACP conversations showed that ACP intervention improved decisional conflict [28, 41], whereas another study that used video/booklet without active counseling showed non-significant results [42]. In addition, a previous study reported that individuals with a high ability to understand health information have low decisional conflict [43]. The low intensity of the ACP conversations in the current study might not be sufficient to gain and understand EOL care information for our participants who were comparatively healthy, and it might lead to uncertainty in making EOL care-related decisions.

Conversely, participants in the ACP group reported no change in their ACP-related knowledge median scores after the intervention, whereas those in the control group reported a slight increase in the median scores at 1 and 6 months after the intervention. There was no statistical difference in the changes in ACP knowledge, but the trend of the changes favored the control group. Although we did not have any particular explanation for such an observation, we suspected that this observation might be because of the measurement tool itself. The ACP knowledge has five items with good content validity and internal consistency; however, other psychometric properties, such as factorial and construct validities, have not yet been tested [21]. Thus, the current findings might be subject to measurement error. We recommend that the psychometric properties of the scale be fully examined before its use.

Our study had limitations. The main study limitation was that the trial did not meet recruitment goals, and the analysis was underpowered. The small sample size was a consequence of unexpected events of the social event in 2019 in Hong Kong and the COVID-19 pandemic since 2020; the former had substantially slowed down, and the latter completely hindered all the research activities in the territory. High attrition rates also contributed to the small sample size for analysis. The two follow-up surveys were unavoidably conducted via telephone due to the social event in Hong Kong and the COVID-19 pandemic during the study period that had made face-to-face administration of the questionnaire impossible, even though we realized that the participating older adults could not hear well on the phone and tended to provide missing data. Future studies should consider the face-to-face mode for data collection with older adults with frailty. Another limitation was the arrangement of the completion of AD with a designated private physician. Given that the participants of the study targeted older adults with frailty, it would be troublesome for them to pay an extra visit to the clinic of the private physician to sign the AD even if they were willing to do so. There are many barriers to such a visit, including transportation, traveling fee, and companion for the trip. Although we were willing to provide support to these three barriers for the visit, it became impossible because of the social event in 2019 and the location of the clinic.

5. Conclusions

In conclusion, in our trial, a video-supported, nurse-led ACP intervention did not significantly increase the completion of ADs in older adults with frailty who were discharged from hospital in Hong Kong. The optimal time for ACP conversations with Chinese older adults with frailty depends largely on personal perception of health, which deserves further studies.

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Conflict of interest

The authors declare no conflict of interest.

Notes/thanks/other declarations

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References

- [1] Izumi S, Nagae H, Sakurai C, Imamura E. Defining end-of-life care from perspectives of nursing ethics. *Nursing Ethics*. 2012;**19**(5):608-618. DOI: 10.1177/0969733011436205
- [2] Driessen A, Borgstrom E, Cohn S. Placing death and dying: Making place at the end of life. *Social Science & Medicine*. 2021;**291**:113974. DOI: 10.1016/j.socscimed.2021.113974
- [3] Sinuff T, Dodek P, You JJ, Barwich D, Tayler C, Downar J, et al. Improving end-of-life communication and decision making: The development of a conceptual framework and quality indicators. *Journal of Pain and Symptom Management*. 2015;**49**(6):1071-1080. DOI: 10.1016/j.jpainsymman.2014.12.007
- [4] Rietjens JAC, Sudore RL, Connolly M, van Delden JJ, Drickamer MA, Droger M, et al. European association for palliative care. Definition and recommendations for advance care planning: An international consensus supported by the European Association for palliative care. *Lancet Oncology*. 2017;**18**(9):e543-e551. DOI: 10.1016/S1470-2045(17)30582-X
- [5] Gonella S, Basso I, Clari M, Di Giulio P. A qualitative study of family carers views on how end-of-life communication contributes to palliative-oriented care in nursing home. *Annali dell'Istituto superiore di sanita*. 2020;**56**(3):315-324. DOI: 10.4415/ANN_20_03_09
- [6] You JJ, Dodek P, Lamontagne F, Downar J, Sinuff T, Jiang X, et al. Accept study team and the Canadian researchers at the end of life network (CARENET): What really matters in end-of-life discussions? Perspectives of patients in hospital with serious illness and their families. *Canadian Medical Association Journal*. 2014;**186**(18):E679-E687. DOI: 10.1503/cmaj.140673
- [7] Mack JW, Cronin A, Keating NL, Taback N, Huskamp HA, Malin JL, et al. Associations between end-of-life discussion characteristics and care received near death: A prospective cohort study. *Journal of Clinical Oncology*. 2012;**30**(35):4387-4395. DOI: 10.1200/JCO.2012.43.6055
- [8] Wright AA, Zhang B, Ray A, Mack JW, Trice E, Balboni T, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *Journal of the American Medical Association*. 2008;**300**(14):1665-1673. DOI: 10.1001/jama.300.14
- [9] Fulmer T, Escobedo M, Berman A, Koren MJ, Hernández S, Hult A. Physicians' views on advance care planning and end-of-life care conversations. *Journal of the American Geriatric Society*. 2018;**66**(6):1201-1205. DOI: 10.1111/jgs.15374
- [10] Brinkman-Stoppelenburg A, Rietjens JA, van der Heide A. The effects of advance care planning on end-of-life care: A systematic review. *Palliative Medicine*. 2014;**28**(8):1000-1025. DOI: 10.1177/0269216314526272
- [11] Martin RS, Hayes B, Gregorevic K, Lim WK. The Effects of advance care planning interventions on nursing home residents: A systematic review. *Journal of the American Medical Directors Association*. 2016;**17**(4):284-293. DOI: 10.1016/j.jamda.2015.12.017
- [12] Malhotra C, Shafiq M, Batcagan-Abueg APM. What is the evidence

for efficacy of advance care planning in improving patient outcomes? A systematic review of randomized controlled trial. *BMJ Open*. 2022;**12**:e060201. DOI: 10.1136/bmjopen-2021-060201

[13] Abbasi M, Rolfson D, Khera AS, Dabravolskaj J, Dent E, Xia L. Identification and management of frailty in the primary care setting. *Canada Medical Association Journal*. 2018;**190**(38):e1134-e1140. DOI: 10.1503/cmaj.171509 Erratum in: *Canada Medical Association Journal*. 2019;**191**(2):e54

[14] Carter C, Leanza F, Mohammed S, Upshur R, Kontos P. A rapid scoping review of end-of-life conversations with frail older adults in Canada. *Canadian Family Physician*. 2021;**67**(11):e298-e305. DOI: 10.46747/cfp.6711e298

[15] O'Caomh R, Sezgin D, O'Donovan MR, Molloy DW, Clegg A, Rockwood K, et al. Prevalence of frailty in 62 countries across the world: a systematic review and meta-analysis of population-level studies. *Age and Ageing*. 2021;**50**(1):96-104. DOI: 10.1093/ageing/afaa219

[16] Crooms RC, Gelfman LP. Palliative care and end-of-life considerations for the frail patient. *Anesthesia and Analgesia*. 2020;**130**(6):1504-1515. DOI: 10.1213/ANE.0000000000004763

[17] Stow D, Spiers G, Matthews FE, Hanratty B. What is the evidence that people with frailty have needs for palliative care at the end of life? A systematic review and narrative synthesis. *Palliative Medicine*. 2019;**33**(4):399-414. DOI: 10.1177/0269216319828650

[18] Cohen-Mansfield J, Skornick-Bouchbinder M, Brill S. Trajectories of end of life: A systematic review.

The Journals of Gerontology, Series B, Psychological Sciences and Social Sciences. 2018;**73**(4):564-572. DOI: 10.1093/geronb/gbx093

[19] Cardona-Morrell M, Lewis E, Suman S, Haywood C, Williams M, Brousseau AA, et al. Recognising older frail patients near the end of life: What next? *European Journal of Internal Medicine*. 2017;**45**:84-90. DOI: 10.1016/j.ejim.2017.09.026

[20] Jain A, Corriveau S, Quinn K, Gardhouse A, Vegas DB, You JJ. Video decision aids to assist with advance care planning: A systematic review and meta-analysis. *British Medical Journal Open*. 2015;**5**:e007491. DOI: 10.1136/bmjopen-2014-007491

[21] Leung DYP, Chan HYL, Yau SZM, Chiu PKC, Tang FWK, Kwan JSK. A video-supported nurse-led advance care planning on end-of-life decision-making among frail older patients: Protocol for a randomized controlled trial. *Journal of Advanced Nursing*. 2019;**75**:1360-1369. DOI: 10.1111/jan.13959

[22] Morley JE, Malmstrom TK, Miller DK. A simple frailty questionnaire (FRAIL) predicts outcomes in middle aged African Americans. *Journal of Nutrition, Health & Aging*. 2012;**16**:601-608. DOI: 10.1007/s12603-012-0084-2

[23] Fan TW. Brief cognitive mental status tests for psychometric outpatients — A pilot study. *Journal of Hong Kong College Psychiatry*. 1992;**2**:69-78

[24] Hong Kong Hospital Authority. Sample of advance directives form [Internet]. 2020. Available from: <https://www.ha.org.hk/haho/ho/psrm/ADformEng1.pdf> [Accessed: 2022-10-17]

[25] Légaré F, Kearing S, Clay K, Gagnon S, D'Amours D, Rousseau M. Are

- you SURE?: Assessing patient decisional conflict with a 4-item screening test. *Canada Family Physician*. 2010;**56**(8):e308-e314
- [26] Curtis JR, Engelberg RA, Nielsen EL, Au DH, Patrick DL. Patient-physician communication about end-of-life care for patients with severe COPD. *The European Respiratory Journal*. 2004;**24**(2):200-205. DOI: 10.1183/09031936.04.00010104
- [27] Engelberg R, Downey L, Curtis JR. Psychometric characteristics of a quality of communication questionnaire assessing communication about end-of-life care. *Journal of Palliative Medicine*. 2006;**9**(5):1086-1098. DOI: 10.1089/jpm.2006.9.1086
- [28] Chan HY, Ng JS, Chan KS, Ko PS, Leung DY, Chan CW, et al. Effects of a nurse-led post-discharge advance care planning programme for community-dwelling patients nearing the end of life and their family members: A randomised controlled trial. *International Journal of Nursing Studies*. 2018;**87**:26-33. DOI: 10.1016/j.ijnurstu.2018.07.008
- [29] Houben CHM, Spruit MA, Groenen MT, Wouters EFM, Janssen DJA. Efficacy of advance care planning: A systematic review and meta-analysis. *Journal of the American Medical Directors Association*. 2014;**15**:477-480. DOI: 10.1016/j.jamda.2014.01.008
- [30] Chiu Wu CH, Perng SJ, Shi CK, Lai HL. Advance care planning and advance directives: A multimedia education program in community-dwelling older adults. *Journal of Applied Gerontology*. 2020;**39**(8):811-819. DOI: 10.1177/0733464819831596
- [31] Wen FH, Chen CH, Chou WC, Chen JS, Chang WC, Hsieh CH, et al. Evaluating if an advance care planning intervention promotes do-not-resuscitate orders by facilitating accurate prognostic awareness. *Journal of the National Comprehensive Cancer Network*. 2020;**18**(12):1658-1666. DOI: 10.6004/jnccn.2020.7601
- [32] Xu C, Yan S, Chee J, Lee EPY, Lim HW, Lim SWC, et al. Increasing the completion rate of the advance directives in primary care setting – A randomized controlled trial. *BMC Family Practice*. 2021;**22**:115. DOI: 10.1186/s12875-021-01473-1
- [33] Bernard C, Tan A, Slaven M, Elston D, Heyland DK, Howard M. Exploring patient-reported barriers to advance care planning in family practice. *BMC Family Practice*. 2020;**21**(1):94. DOI: 10.1186/s12875-020-01167-0
- [34] Combes S, Gillett K, Norton C, Nicholson CJ. The importance of living well now and relationships: A qualitative study of the barriers and enablers to engaging frail elders with advance care planning. *Palliative Medicine*. 2021;**35**(6):1137-1147. DOI: 10.1177/02692163211013260
- [35] Wan Z, Chan HYL, Chiu PKC, Lo RSK, Cheng HL, Leung DYP. Experiences of older adults with frailty not completing an advance directive: A qualitative study of ACP conversations. *International Journal of Environmental Research and Public Health*. 2022;**19**(9):5358. DOI: 10.3390/ijerph19095358
- [36] Cheng SY, Lin CP, Chan HY, Martina D, Mori M, Kim SH, et al. Advance care planning in Asian culture. *Japanese Journal of Clinical Oncology*. 2020;**50**:976-989
- [37] McIlfatrick S, Slater P, Bamidele O, Muldrew D, Beck E, Hasson F. It's almost superstition: If I don't think about it,

- it won't happen'. Public knowledge and attitudes towards advance care planning: A sequential mixed methods study. *Palliative Medicine*. 2021;**35**(7):1356-1365. DOI: 10.1177/02692163211015838
- [38] Douglas ML, Simon J, Davison SN, Biondo P, Ghosh S, Kassam A, et al. Efficacy of advance care planning videos for patients: A randomized controlled trial in cancer, heart, and kidney failure outpatient settings. *Medical Decision Making*. 2021;**41**(3):292-304. DOI: 10.1177/0272989X20985836
- [39] Hopkins SA, Bentley A, Phillips V, Barclay S. Advance care plans and hospitalized frail older adults: A systematic review. *BMJ Supportive & Palliative Care*. 2020;**10**(2):164-174. DOI: 10.1136/bmjspcare-2019-002093
- [40] Carlini J, Bahudin D, Michaleff ZA, Plunkett E, Shé ÉN, Clark J, et al. Discordance and concordance on perception of quality care at end of life between older patients, caregivers and clinicians: a scoping review. *European Geriatric Medicine*. 2022;**13**(1):87-99. DOI: 10.1007/s41999-021-00549-6
- [41] Malhotra C, Sim D, Jaufeerally FR, Hu M, Nadkarni N, Ng CSH, et al. Impact of a formal advance care planning program on end-of-life care for patients with heart failure: Results from a randomized controlled trial. *Journal of Cardiac Failure*. 2020;**26**(7):594-598. DOI: 10.1016/j.cardfail.2020.01.015
- [42] Yun YH, Kang E, Park S, Koh SJ, Oh HS, Keam B, et al. Efficacy of a decision aid consisting of a video and booklet on advance care planning for advanced cancer patients: Randomized controlled trial. *Journal of Pain and Symptom Management*. 2019;**58**(6):940-948.e2. DOI: 10.1016/j.jpainsymman.2019.07.032
- [43] Pecanac KE, Brown RL, Kremsreiter HB. Decisional conflict during major medical treatment decision-making: A survey study. *Journal of General Internal Medicine*. 2021;**36**(1):55-61. DOI: 10.1007/s11606-020-06125-1