

Promoting advance care planning in people with early dementia and their family caregivers

CY Yeung *, HYL Chan

KEY MESSAGES

1. Advance care planning (ACP) allows people with early-stage dementia to plan for future care before they lose mental capacity.
2. A dyadic-based ACP programme facilitates discussions on future care between people with early-stage dementia and their family caregivers in a community care setting.
3. After the ACP programme, people with early-stage dementia reported significantly higher levels of self-efficacy and readiness for ACP. Concordance regarding end-of-life care preferences between participants and their

family caregivers also significantly improved.

4. More services are needed to support the completion of advance directives in the community.

Hong Kong Med J 2025;31(Suppl 3):S23-6

HMRP project number: 03180198

CY Yeung, HYL Chan

The Nettersole School of Nursing, Faculty of Medicine, The Chinese University of Hong Kong, Hong Kong SAR, China

* Principal applicant and corresponding author: cyyeung@cuhk.edu.hk

Introduction

People with dementia experience increasing dependency due to declining physical and cognitive functions and decision-making abilities as the disease progresses. Consequently, the promotion of advance care planning (ACP) at an early stage of dementia is highly recommended.¹ Support of dementia-caregiver dyads and respect for the autonomy of people with dementia in decision-making are main aspects of person-centred dementia care. However, ACP discussions are often deferred due to a lack of knowledge about dementia, limited awareness and support for ACP, and concerns about provoking negative emotions. This study aimed to promote ACP among people with early-stage dementia and their family caregivers in a community care setting in Hong Kong.

Methods

This was a multicentre, single-group, quasi-experimental, pretest-posttest study. A 3.5-hour ACP facilitator training session was provided to staff members of participating centres who then delivered the Have a Say (HAS) programme along with the research team. A set of ACP facilitator training materials and an ACP booklet were developed. Participating centres screened and invited potential participants who were Cantonese-speaking Chinese adults aged ≥ 55 years with early-stage dementia (stage 3 or 4 on the Global Deterioration Scale) and their designated family caregivers to participate on a dyadic basis.

The HAS programme was based on the

Bandura's self-efficacy model and the shared decision-making model, designed to enhance self-efficacy and readiness for ACP among people with early-stage dementia and to support shared decision-making on future care among the dementia-caregiver dyad and healthcare professionals.^{2,3} Details of the intervention have been reported elsewhere.⁴

The primary outcome was the ACP engagement level of participants with early-stage dementia. The secondary outcome was dyadic concordance regarding end-of-life care preferences. Outcomes were measured at baseline, immediately post-intervention, and 1-month post-intervention; they were analysed using generalised estimating equation models.

Results

In total, 124 staff members from 17 participating centres attended ACP facilitator training workshops. Among them, 29 (23.4%) delivered the HAS programme. Five (29.4%) of the 17 participating centres intended to integrate the HAS programme into their existing services.

Overall, 100 dyads of people with early-stage dementia (mean age, 78.5 years) and their caregivers (mean age, 64.6 years) were recruited from the 17 participating centres (Table 1). Among these dyads, 90% completed the HAS programme; attrition rates were 11% immediately post-intervention and 19% at 1-month post-intervention. Of the 89 dyads who completed the satisfaction survey, 77% of people with early-stage dementia and 83% of family caregivers reported satisfaction with the HAS programme.

TABLE 1. Characteristics of people with early-stage dementia and their family caregivers.

Characteristic	People with early-stage dementia (n=100)*	Caregivers (n=100)*
Sex		
Male	50 (50.0)	25 (25.0)
Female	50 (50.0)	75 (75.0)
Age, y	78.5±7.7 (55-96)	64.6±13.8 (24-89)
Marital status		
Married/cohabitated	72 (72.0)	75 (75.0)
Single	1 (1.0)	21 (21.0)
Widowed/separated/divorced	27 (27.0)	4 (4.0)
Education status		
Below primary	31 (31.0)	11 (11.0)
Primary	31 (31.0)	29 (29.0)
Secondary	33 (33.0)	40 (40.0)
Tertiary or above	5 (5.0)	20 (20.0)
Religion		
With	51 (51.0)	-
Without	49 (49.0)	-
Global Deterioration Scale score		
Stage 3	42 (42.0)	-
Stage 4	58 (58.0)	-
Living status		
Alone	11 (11.0)	-
With family members	89 (89.0)	-
Living status		
With care recipient	-	80 (80.0)
Not with care recipient	-	20 (20.0)
Relationship with care recipient		
Spouse	-	59 (59.0)
Child	-	40 (40.0)
Other	-	1 (1.0)
Working status		
Full-time	-	24 (24.0)
Part-time	-	7 (7.0)
Unemployed	-	69 (69.0)

* Data are presented as No. (%) of participants or mean±standard deviation (range)

In generalised estimating equation models, the overall ACP engagement score and subscale scores for 'self-efficacy' and 'readiness' significantly increased among people with early-stage dementia both immediately and at 1-month post-intervention relative to baseline (all $P<0.001$, Table 2). Participants reported completing fewer ACP behaviours that involved discussions with doctors and signing official documents than those that involved

their medical decision-makers (Table 3). Dyadic concordance regarding end-of-life care preferences also significantly improved both immediately and at 1-month post-intervention (all $P<0.001$).

Discussion

The HAS programme was well accepted by dyads of people with early-stage dementia and their caregivers, with a high completion rate and satisfaction level. This may be attributed to the involvement of health and social care providers as ACP facilitators. The HAS programme emphasises a person-centred approach, allowing ACP facilitators to address participants' informational and emotional needs.

The attrition rate in this study was lower than the 17.8% at 1-month post-intervention and 34.3% at 6-month post-intervention from a previous study involving people nearing end of life in Hong Kong.⁵ This is likely because participants in our study were relatively healthier. Earlier initiation of ACP is essential to ensure that patients can actively participate in the planning process.

The HAS programme significantly improved both self-efficacy and readiness for ACP among people with early-stage dementia. Nonetheless, most remained in the contemplation stage of ACP behaviours and had not yet planned or completed ACP actions, particularly those involving discussions with doctors or signing official documents. This may be attributed to the lack of healthcare services supporting completion of advance directives in the community, which could have hindered readiness to officially record medical decisions and end-of-life care preferences. Another possible explanation is that variability in life expectancy among people with early-stage dementia made it difficult to determine an appropriate time for ACP. The dyads may have uncertainty regarding end-of-life care decisions.¹ Therefore, behavioural changes beyond the contemplation stage may require additional guidance or resource support to facilitate ACP.

The results of this study highlight the importance of involving family caregivers in the ACP process. Dyadic concordance regarding end-of-life care preferences significantly improved over time, consistent with findings from a previous study that showed significant improvement at 6-month post-intervention.⁵

This study had some limitations. The absence of randomisation and a control group prevented confirmation of intervention effects from the HAS programme on ACP engagement and dyadic concordance regarding end-of-life care preferences. The use of convenience sampling may have introduced selection bias, limiting generalisation of the findings to individuals who actively engage with community care services. Participants may have

TABLE 2. Advance care planning (ACP) outcomes among people with early-stage dementia across three time points (n=100).

Outcome	Score*	Time effect β (95% confidence interval)	P value
Overall ACP engagement			
Baseline	1.44 (0.86)	-	-
Immediately post-intervention	2.65±0.83	1.07 (0.87-1.26)	<0.001
1-month post-intervention	2.53±0.89	0.94 (0.73-1.15)	<0.001
Self-efficacy subscale			
Baseline	2.20±1.23	-	-
Immediately post-intervention	3.61±0.99	1.42 (1.13-1.70)	<0.001
1-month post-intervention	3.42±1.13	1.24 (0.92-1.56)	<0.001
Readiness subscale			
Baseline	1.00 (0.17)	-	-
Immediately post-intervention	2.17±0.94	0.89 (0.69-1.09)	<0.001
1-month post-intervention	2.09±0.99	0.80 (0.57-1.03)	<0.001
Life Support Preferences Questionnaire			
Baseline	1.59±1.54	-	-
Immediately post-intervention	2.54±1.62	0.93 (0.56-1.31)	<0.001
1-month post-intervention	2.56±1.74	0.97 (0.56-1.38)	<0.001

* Data are presented as mean±standard deviation or median (interquartile range)

TABLE 3. Stages of change for each advance care planning (ACP) behaviour among people with early-stage dementia across three time points (n=100).

Stage of change	Baseline*	Immediately post-intervention*	1-month post-intervention*
1. Formally asking someone to be their medical decision maker			
Pre-contemplation: have never thought about it	74 (74.0)	20 (20.0)	28 (28.0)
Pre-contemplation: have thought about it, but not ready to do it	7 (7.0)	16 (16.0)	7 (7.0)
Contemplation: thinking about doing it in the next 6 months	1 (1.0)	0	1 (1.0)
Preparation: planning to do it in the next 30 days	0	0	0
Action: already done	18 (18.0)	51 (51.0)	44 (44.0)
2. Talking with their doctor about their preferred medical decision maker			
Pre-contemplation: have never thought about it	95 (95.0)	64 (64.0)	55 (55.0)
Pre-contemplation: have thought about it, but not ready to do it	2 (2.0)	16 (16.0)	21 (21.0)
Contemplation: thinking about doing it over the next few visits	1 (1.0)	2 (2.0)	1 (1.0)
Preparation: planning to do it at the next visit	0	2 (2.0)	1 (1.0)
Action: already done	2 (2.0)	3 (3.0)	3 (3.0)
3. Signing official papers to name their medical decision maker			
Pre-contemplation: have never thought about it	96 (96.0)	63 (63.0)	57 (57.0)
Pre-contemplation: have thought about it, but not ready to do it	3 (3.0)	15 (15.0)	13 (13.0)
Contemplation: thinking about doing it in the next 6 months	0	2 (2.0)	2 (2.0)
Preparation: planning to do it in the next 30 days	1 (1.0)	0	1 (1.0)
Action: already done	0	7 (7.0)	8 (8.0)
4. Talking to their decision maker about their end-of-life medical care			
Pre-contemplation: have never thought about it	82 (82.0)	24 (24.0)	31 (31.0)
Pre-contemplation: have thought about it, but not ready to do it	6 (6.0)	8 (8.0)	9 (9.0)
Contemplation: thinking about doing it in the next 6 months	0	0	2 (2.0)
Preparation: planning to do it in the next 30 days	0	1 (1.0)	2 (2.0)
Action: already done	12 (12.0)	54 (54.0)	37 (37.0)

* Data are presented as No. (%) of participants

TABLE 3. (cont'd)

Stage of change	Baseline*	Immediately post-intervention*	1-month post-intervention*
5. Talking to their doctor about their end-of-life medical care			
Pre-contemplation: have never thought about it	95 (95.0)	68 (68.0)	56 (56.0)
Pre-contemplation: have thought about it, but not ready to do it	2 (2.0)	15 (15.0)	24 (24.0)
Contemplation: thinking about doing it over the next few visits	0	0	0
Preparation: planning to do it at the next visit	1 (1.0)	2 (2.0)	1 (1.0)
Action: already done	2 (2.0)	2 (2.0)	0
6. Signing official papers to document their end-of-life medical care preferences			
Pre-contemplation: have never thought about it	97 (97.0)	62 (62.0)	57 (57.0)
Pre-contemplation: have thought about it, but not ready to do it	2 (2.0)	15 (15.0)	12 (12.0)
Contemplation: thinking about doing it in the next 6 months	0	3 (3.0)	1 (1.0)
Preparation: planning to do it in the next 30 days	1 (1.0)	0	2 (2.0)
Action: already done	0	8 (8.0)	9 (9.0)

been better prepared for ACP or less opposed to it. The dyadic nature of the study also excluded those without family support. Follow-up assessments were conducted via telephone, which may have influenced participants' responses by their partners.

Conclusion

The substantial involvement of participating centres and frontline healthcare professionals suggests interest in integrating the HAS programme into existing services. Regular ACP training should be provided to frontline health and social care staff, in collaboration with doctors, to facilitate the completion of advance directives and discussions regarding documented care preferences across various healthcare settings.

Funding

This study was supported by the Health and Medical Research Fund, Health Bureau, Hong Kong SAR Government (#03180198). The full report is available

from the Health and Medical Research Fund website (<https://rfs2.healthbureau.gov.hk>).

References

1. Rietjens JAC, Sudore RL, Connolly M, et al. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *Lancet Oncol* 2017;18:e543-51.
2. Bandura A. Self-efficacy: toward a unifying theory of behavioral change. *Psychol Rev* 1977;84:191-215.
3. Elwyn G, Frosch D, Thomson R, et al. Shared decision making: a model for clinical practice. *J Gen Intern Med* 2012;27:1361-7.
4. Yeung CC, Ho KH, Chan HY. A dyadic advance care planning intervention for people with early-stage dementia and their family caregivers in a community care setting: a feasibility trial. *BMC Geriatr* 2023;23:115.
5. Chan HY, Ng JS, Chan KS, 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. *Int J Nurs Stud* 2018;87:26-33.