



The Effects of Advance Care Planning on Decision Conflict and Psychological Distress: A Systematic Review and Meta-Analysis of Randomized Controlled Trials

Young-Ran Yeun, Ph.D.

Department of Nursing, Kangwon National University, Samcheok, Korea

Purpose: Advance care planning (ACP) is widely understood to improve end-of-life care. This systematic review and meta-analysis aimed to examine the effects of ACP interventions on decision conflict and psychological distress. **Methods:** A search of PubMed, CINAHL, CENTRAL, EMBASE, KISS, KoreaMed, and RISS was conducted in November 2020. The study included randomized controlled trials. Data were pooled using fixed- and random-effects models. **Results:** Fourteen studies were identified that cumulatively included 1,548 participants. ACP interventions were effective in alleviating decision conflict ($d=-0.53$; 95% CI: -0.83 to -0.23), depression ($d=-1.22$; 95% CI: -1.71 to -0.74) and anxiety ($d=-0.76$; 95% CI: -1.12 to -0.39). **Conclusion:** ACP interventions have significant positive effects on reducing decision conflict and psychological distress. A high level of bias was shown related to allocation concealment and blinding. The results of this study are expected to be useful for end-of-life care providers to improve the effectiveness of ACP interventions.

Key Words: Advance care planning, Psychological conflict, Psychological distress, Hospice care

Received February 24, 2021
Revised June 23, 2021
Accepted June 24, 2021

Correspondence to
Young-Ran Yeun
ORCID:
<https://orcid.org/0000-0002-5393-4312>
E-mail: yeunyr@kangwon.ac.kr

INTRODUCTION

The Act on Hospice and Palliative Care and Decisions on Life-Sustaining Treatment for Patients at the End of Life has been in place since 2018 in South Korea to protect human dignity and values, and advance directives and physician orders for life-sustaining treatment (POLST) are now actively in use. According to the National Agency for the Management of Life-Sustaining Treatment, however, only 33.4% of total deaths involved written advance directives or POLST, and 96.5% of advance directives or POLST were not made by patients themselves, but rather by patients' families using statements and agreements [1].

Patients with malignant or chronic diseases face a variety of issues as they near the end of their lives. Aside from medical problems, patients may face family-related tensions and conflicts between medical personnel and family members that can result in medical disputes [2]. Advance care planning (ACP) is a communicative process through which patients' preferences for end-of-life care and medical treatment are outlined if patients are expected to be unable to make such decisions on their own in the future [3]. This usually entails discussing the disease's prognosis and various treatment options, preparing an advance directive, and appointing a surrogate to make medical decisions [4]. Decision conflict is a state of confusion over which choices to make to minimize risk or avoid failure

according to an individual's personal values during the decision-making process [5]. A high degree of decision conflict can have a negative impact on quality of life and cause anxiety, stress, and regret [6]. From a health service perspective, medical disputes can increase the possibility of patients missing their optimal treatment windows [7]. Thus, to improve the quality of end-of-life care and related medical services, it is important to concentrate on decision conflict. If ACP is undertaken ahead of time, the patient is more likely to receive care according to his or her wishes at the end of life, and communication between family and medical personnel is likely to improve, leading to less conflict and distress [8,9]. Psychological distress refers to a state of emotional or mental suffering due to demands or stressors that are difficult to cope with in daily life, and it manifests as depression, anxiety, and hopelessness [10]. Depression and anxiety tend to worsen the general condition of patients related to treatment, decrease satisfaction with health services, and cause decision conflict [11]. As a result, depression and anxiety should be regularly assessed and managed. Carrying out ACP has been found to increase knowledge of end-of-life care without reducing hope, increasing despair, or inducing anxiety in patients with advanced cancer [12,13].

The impact of ACP interventions has been much debated over the last few years. However, few reviews have examined the effects of ACP on decision conflict and psychological distress. Most systematic reviews of ACP have studied the implementation of ACP interventions, the execution of advance directives, end-of-life treatment instructions such as do-not-resuscitate (DNR) orders, and communication-related variables [14–18]. The aim of this review and meta-analysis was to collect evidence related to the effects of ACP interventions on decision conflict and psychological distress.

METHODS

1. Study design

This study is a systematic literature review and meta-analysis that aimed to investigate the effects of ACP interventions on decision conflict and psychological distress.

2. Eligibility criteria

The participants, intervention, comparisons, outcomes, setting, and study design (PICO-SD), which were the key considerations for the literature selection, were as follows. The participants (P) were patients with malignant or chronic diseases. The intervention (I) was any ACP intervention that included end-of-life discussions about a living will, durable power of attorney, or DNR or do-not-hospitalize (DNH) orders. End-of-life discussions are conversations among professionals, patients, and relatives concerning a patient's wishes and decisions related to the end of life. Durable power of attorney ensures that, in the event of a medical emergency or mental dysfunction, another person will execute the patient's health plans on his or her behalf. Comparisons (C) were made between participants who received an ACP intervention and those who did not receive an ACP intervention or received only a placebo intervention. The outcomes (O) were decision conflict, depression, and anxiety. Depression and anxiety were assessed to measure psychological distress. The settings (S) were hospitals, nursing homes, outpatient clinics, and communities. The study design (D) was randomized controlled trials (RCTs). The exclusion criteria for the studies in this review were the presence of children as participants; outcome variables other than decision conflict, depression, or anxiety; a non-RCT study design; and an inability to obtain the mean and standard deviation of the measured results.

3. Literature search

The data were selected from papers published from the databases' inception and extending to November 2020. The electronic databases used for the literature search were PubMed, CINAHL, CENTRAL, EMBASE, KISS, KoreaMed, and RISS. MeSH terms, the text of titles, and abstracts were applied when relevant in the search formula. The search terms were as follows: (advance care plan* OR advance care direct* OR advance health care plan* OR advance medical direct* OR advance medical plan* OR future care plan*) AND (end of life OR living will* OR power of attorney OR DNH OR DNR) AND (hospice OR life prolonging OR life support OR life sustaining OR palliative OR advanced OR severely OR serious OR malignant OR chronic) AND (decision making

OR decision* conflict OR distress OR depression OR anxiety) AND (intervention OR therapy OR programme OR program OR trial OR randomized OR controlled).

4. Data extraction

In the first stage of data selection, an electronic database was searched in order to identify relevant papers. In the second stage, duplicate data were excluded by checking the author names, publication years, titles, and journal names of the collected papers. In the third stage, related data were selected by applying the inclusion and exclusion criteria to the titles and abstracts of the collected papers. In the fourth and last stage, the final data were selected after reviewing the full texts of the papers. Information on the selected trials was maintained in a coding table in which the author, year of publication, country of publication, number of participants, age and gender ratios of the participants, type of intervention, setting, intervention provider, status of involvement of family members or surrogates, comparative intervention, outcome variables, measurement tools, and mean and standard deviation were recorded for each paper.

5. Methodological quality

The methodological quality of the trials was evaluated using the risk of bias (RoB) tool, which reviews bias for six items: random sequence generation, allocation concealment, blinding of participants and personnel, blinding of outcome assessment, incomplete outcome data, and selective reporting [19]. For each source, the RoB was judged as low, unclear, or high.

6. Ethical consideration

This study was exempted from review by the institutional review board (IRB No. KNU 2021-02-012).

7. Data analysis

The effect size and homogeneity of ACP interventions were analyzed using the Review Manager Version 5.3 program (RevMan, The Cochrane Collaboration, Oxford, UK). When homogeneity was confirmed, the effect size was calculated using a fixed-effect model, and when heterogeneity was confirmed, the effect size was calculated using a random-effect model. The statistical significance of the effect size was deter-

mined based on the overall effect test, a confidence interval (CI) of 95%, and a significance level of 5%. The homogeneity of studies was tested using the Higgins I^2 statistic, and publication bias was tested using a funnel plot.

RESULTS

1. Literature search

In the first stage of data selection, 1,297 articles from the databases were screened. In the second stage, duplicate articles were excluded, after which 563 articles remained. In the third stage, 149 papers were selected based on the inclusion and exclusion criteria, focusing on the titles and abstracts of papers. In the fourth stage, the full texts of the remaining studies were reviewed, and 14 studies were finally selected (Figure 1).

2. Study characteristics

Ten (71.4%) of the 14 studies were conducted in the USA and four (28.6%) in other countries.

Eleven trials were performed in a hospital setting and three in a community setting. There were 1,548 participants in total, 798 of whom were in an experimental group and 750 of whom were in a control group. The median sample size was 98 participants, with a range of 18 to 230 participants. Six papers (42.9%) examined interventions that were conducted by nurses who received professional ACP training, and nine trials (64.3%) included family members or surrogates in the inter-

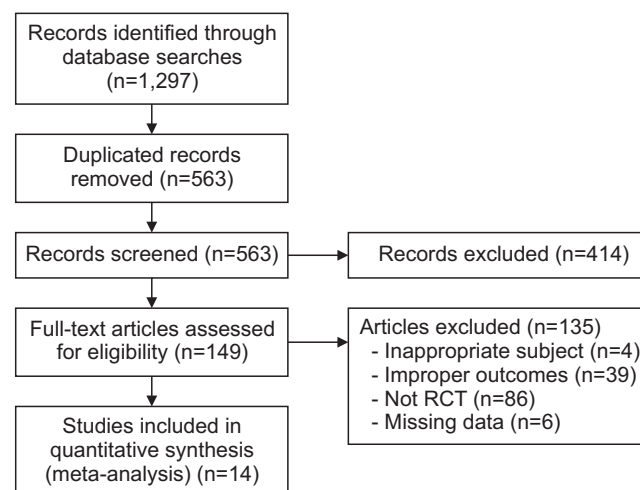


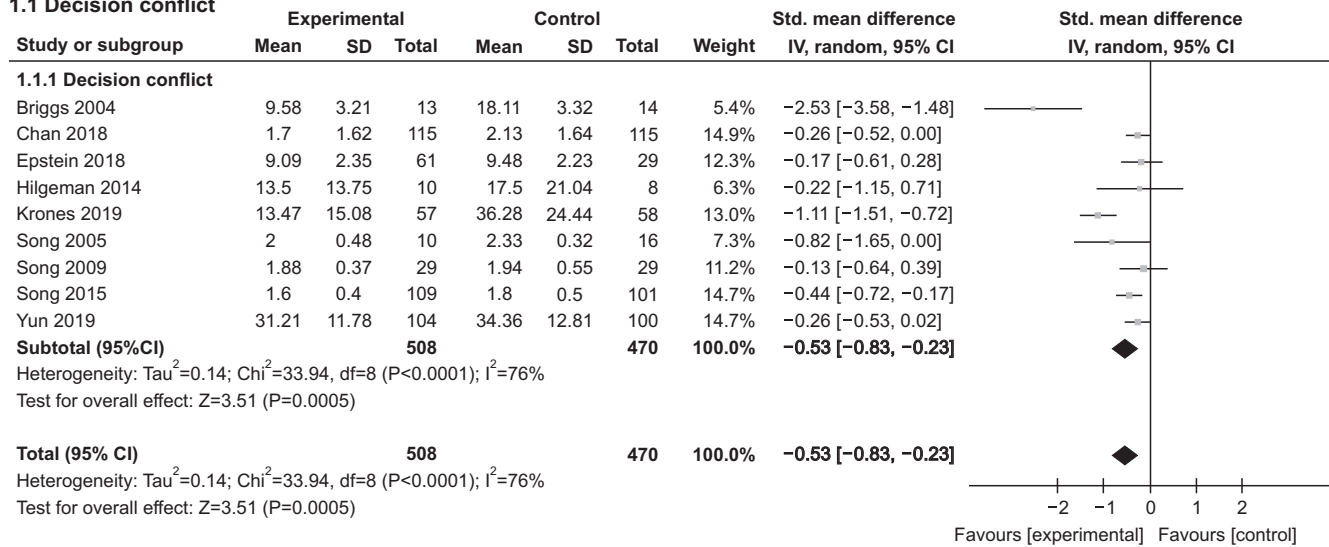
Figure 1. Flow diagram of the study selection process.

Table 1. Characteristics of the Included Studies.

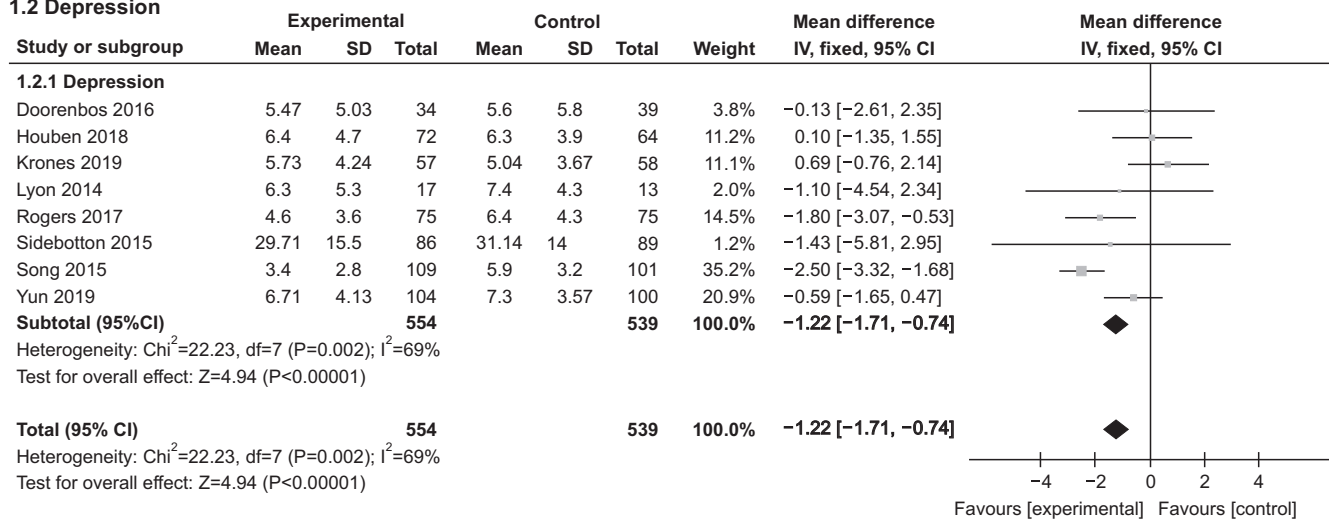
First author and year (Appendix no.)	Country	Participants			Interventions			Involvement of family or surrogate	Comparison	Main outcome measures		
		Disease	eN	cN	Mean age	Male (%)	Setting				Provider	Length (min)
Briggs 2004 (1)	USA	CHF, ESRD, OHS	13	14	68.7	59.3	Hospital	ACP facilitator	50~60	Yes	UC	DCS
Chan 2018 (2)	Hong Kong	Malignant or advanced chronic diseases	115	115	77.7	68.3	Community	Nurse	NM	Yes	UC	SURE
Doorenbos 2016 (3)	USA	Heart failure	34	39	58.1	76.3	Outpatient clinic	Nurse	NM	No	UC	PHQ, GAD
Epstein 2018 (4)	USA	Advanced GI cancers	61	29	67.9	70	Outpatient clinic	Oncologist	NM	No	UC	DCS
Hilgeman 2014 (5)	USA	Dementia	10	8	82.8	31.6	Community	ACP facilitator	NM	Yes	Minimal support	DCS, EQ-5D
Houben 2018 (6)	Netherlands	Advanced COPD	72	64	67.4	53.3	Community	Nurse	90	Yes	UC	HADS-A, HADA-D
Krones 2019 (7)	Switzerland	Severely ill	57	58	64.3	76.5	Hospital	ACP facilitator	60~90	Yes	UC	DCS, HADS-A, HADA-D
Lyon 2014 (8)	USA	Cancer	17	13	16.3	60	Hospital	ACP facilitator	NM	Yes	Providing ACP educational materials	BAI, BDI
Rogers 2017 (9)	USA	Heart failure	75	75	70.9	52.7	Outpatient clinic	ACP facilitator	NM	No	UC	HADS-A, HADA-D
Sidebottom 2015 (10)	USA	Heart failure	86	89	73.4	52.5	Hospital	PC team	NM	No	UC	PHQ
Song 2005 (11)	USA	Undergoing cardiac surgery	16	16	68.9	53.2	Hospital	Nurse	20~45	Yes	UC	IDKG, DCS, SAI
Song 2009 (12)	USA	ESRD	29	29	57.9	56.8	Outpatient clinic	Nurse	60	Yes	UC	DCS
Song 2015 (13)	USA	ESRD	109	101	62.1	42.9	Outpatient clinic	Nurse	NM	Yes	UC	DCS, HADS-A, HADA-D
Yun 2019 (14)	South Korea	Advanced cancer	104	100	57.6	38.7	Hospital	Video and book	20	No	Providing ACP educational materials	DCS, HADS-A, HADA-D

ACP: advance care planning, AD: advance directive, BAI: beck anxiety inventory, BDI: beck depression inventory, CHF: chronic heart failure, COPD: chronic obstructive pulmonary disease, DCS: decisional conflict scale, EQ-5D: EuroQol-5, ESRD: end-stage renal disease, GAD: generalized anxiety disorder, GI: gastrointestinal, HADS-A: hospital anxiety and depression scale, anxiety subscale, HADS-D: hospital anxiety and depression scale, depression subscale, IDKG: investigator-developed knowledge questionnaire, KAD: knowledge of AD, KDS: kessler distress scale, NM: not mentioned, OHS: open heart surgery, PC: palliative care, PHQ: patient health questionnaire, SAI: Spielberg's state anxiety inventory, SURE: sure of myself: understand information: risk-benefit ratio: encouragement screening test, UC: usual care.

1.1 Decision conflict



1.2 Depression



1.3 Anxiety

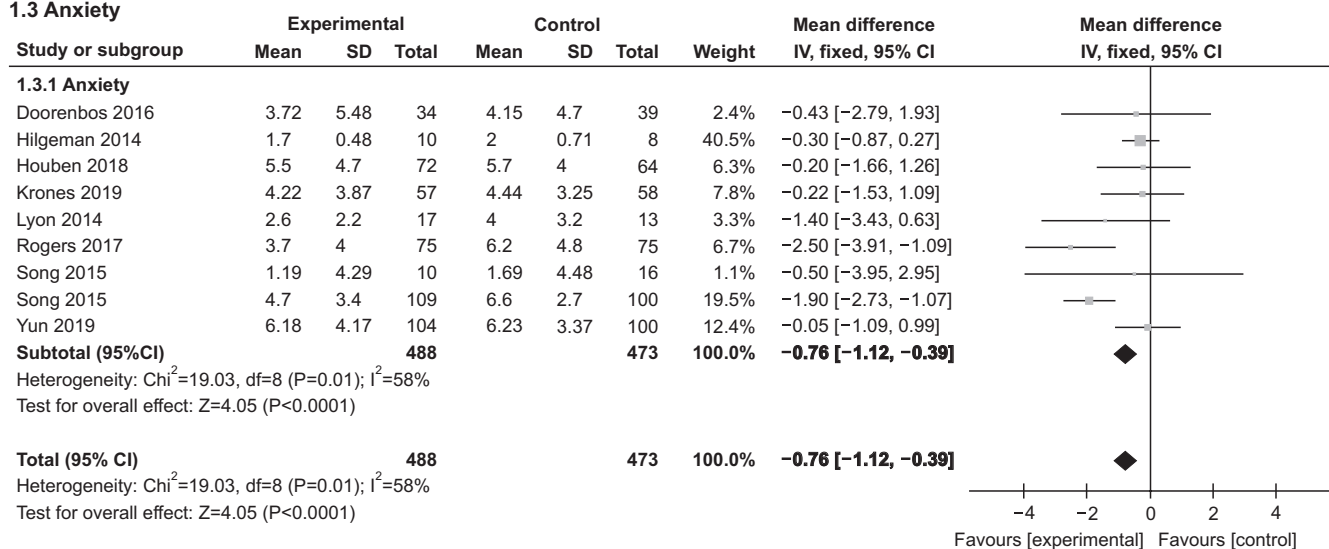


Figure 2. Forest plot of the effect size of advance care planning interventions on decision conflict, depression, and anxiety.

vention (Table 1, Appendix 1).

3. ACP effects

Nine studies examined the effects of ACP interventions on decision conflict. The effect size was medium (-0.53 [95% CI: -0.83 to -0.23]), and the heterogeneity was high ($I^2=76%$). Eight trials investigated the effects of ACP on depression, and a large effect size was found (-1.22 [95% CI: -1.71 to -0.74]) with moderate heterogeneity ($I^2=69%$). Nine papers examined the relationship between ACP and anxiety, with an effect size of -0.76 (95% CI: -1.12 to -0.39) and moderate heterogeneity ($I^2=58%$) (Figure 2).

The following moderators were used to perform subgroup analysis for all pooled effect sizes: setting, provider, and family or surrogate involvement. ACP interventions were more effective in hospital or clinic settings than in community settings. Implementation by nurses was the most effective, and interventions that included family members or surrogates were more effective than those that were conducted with the patient alone (Table 2). Publication bias was not detected for any of the variables.

4. Methodological quality

Seven trials (50.0%) reported adequate methods of random sequence generation, and 13 papers (92.9%) explained the reasons for incomplete outcome data. Allocation concealment was performed in only one trial (7.1%). Blinding of participants was not possible in nine trials due to the nature of the interventions, thus resulting in a high risk of performance bias. Selective reporting was adequately addressed in all studies (Figure 3).

DISCUSSION

Previously, there was no firm evidence on the effects of ACP interventions on decision conflict and psychological distress. This literature review and meta-analysis examined 14 RCTs that included 1,548 participants and found that ACP interventions were effective for alleviating decision conflict, depression, and anxiety.

This review is the first meta-analysis to examine the effects of ACP interventions on decision conflict and psychological

Table 2. Moderation Analyses for Decision Conflict and Mental Health.

Category	Discussion conflict				Depression				Anxiety			
	n	SDM	95% CI	I ²	n	SDM	95% CI	I ²	n	SDM	95% CI	I ²
Setting	7	-0.63	-1.01, -0.25	81	7	-1.39	-1.90, -0.87	68	7	-1.17	-1.67, -0.67	56
	2	-0.25	-0.50, -0.00	0	1	0.10	-1.35, 1.55	-	2	-0.29	-0.82, 0.25	0
Provider	4	-0.35	-0.52, -0.17	2	3	-1.74	-2.42, -1.06	82	4	-1.35	-20.3, -0.68	39
	3	-1.25	-2.28, -0.22	81	3	-0.75	-1.67, 0.17	69	4	-0.60	-1.08, -0.12	66
Family or surrogate involvement	2	-0.23	-0.46, 0.00	0	2	-0.64	-1.67, 0.40	0	1	-0.05	-1.09, 0.99	-
	7	-0.67	-1.07, -0.27	80	4	-1.37	-1.99, -0.74	84	6	-0.73	-1.14, -0.32	56
	2	-0.23	-0.46, -0.00	0	4	-1.01	-1.77, -0.25	0	3	-0.85	-1.64, -0.07	74

ACP: advance care planning.

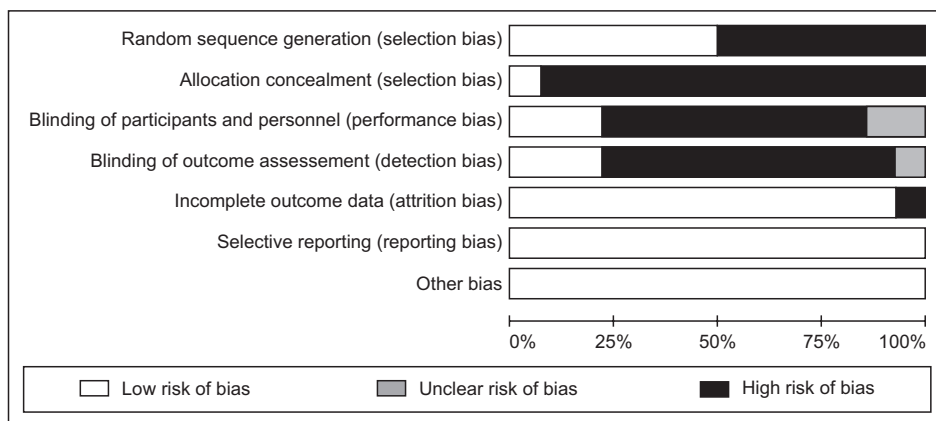


Figure 3. Assessment of methodological quality.

distress among patients suffering from a malignant or chronic disease. ACP interventions initially tended to focus on the execution of advance directives. However, after evidence was found that advance directives do not significantly enhance end-of-life care [20,21], ACP for patients has evolved to concentrate more on preparing patients for decision-making related to treatment at the end of life while minimizing psychological distress. For example, Song et al. [22] found that participants in an ACP intervention (Sharing Patient’s Illness Representations to Increase Trust, SPIRIT) were interested in addressing end-of-life care since, rather than focusing on the execution of advance directives, SPIRIT encouraged patients to consider and discuss the possibility of decision-making about future care, as well as how they would feel about care options at the end of life.

Patients with a malignant or chronic disease suffer from physical side effects such as fatigue and functional regression, as well as emotional discomfort such as feelings of failure due to changes in body image and anxiety about end-of-life care [23]. Many of the studies on ACP interventions included in our analysis identified the concerns and preferences of patients concerning their disease state or end-of-life care through conversation or discussion [22,24,25]. Reducing stimulation by examining the reasons why patients experience depression or anxiety and presenting patients with adequate information to address these issues has been found to be successful in reducing psychological distress. This finding aligns with those of a study by Nishikawa et al. [26] that found that an ACP intervention contributed to an increase in discussions about the ACP process between medical personnel and patients, thus reducing

depression in patients.

The meta-analysis of decision conflict showed a high degree of heterogeneity, and the meta-analysis of psychological distress showed a moderate degree of heterogeneity. Subgroup analysis was performed to further examine these findings, but heterogeneity remained high in some subgroups. Therefore, further research is needed to understand these meta-analysis results. A subgroup analysis showed that involving family members or surrogates in ACP interventions is more effective than conducting ACP interventions involving the patient alone. The importance of family members or surrogates has been recognized since they are often involved in key care decisions at the end of life [27,28]. In a family-centered system such as that of Korea, the opinions of patients are often excluded from the decision-making process or ignored when they run contrary to the family’s wishes [29,30]. When patients, families, and medical personnel share opinions through ACP interventions, patients and family members are better able to voice their opinions and reach a consensus. ACP interventions should be able to provide medical professionals with guidelines for starting discussions with patients and their families about end-of-life or life-sustaining care that patients and their families are hesitant to address.

In the methodological quality evaluation of the trials included in this systematic review, 92.9% of studies did not show allocation concealment. To investigate the pure effects of ACP interventions, efforts to reduce selection bias, such as the use of centrally controlled randomization and sequentially numbered containers, should be made. It was also found that study participants or outcome measurers were blinded in only 35.7%

of the studies included in our analysis. Blinding is a method for preventing bias in performance and result confirmation in research. This figure suggests that double-blind experimental studies should be conducted in the future to better evaluate the effectiveness of ACP interventions.

This study is notable since it is the first to examine the impact of ACP interventions on decision conflict, anxiety, and depression and provides evidence for the development and implementation of ACP in the future. The limitations of this study are as follows. First, the long-term effects of ACP interventions could not be analyzed since the meta-analysis was performed using data on the effects of ACP interventions mea-

sured immediately after ACP had been completed. Second, exploring the source of variation in the exact effect sizes of ACP interventions was difficult since the full content of many of the trials included in the study was not available. The intensity of the ACP interventions should also be considered in future studies.

CONFLICT OF INTEREST

No potential conflict of interest relevant to this article was reported.

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