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의학석사 학위논문

**The Impact of Caregiver's Role Preference on  
Decisional Conflicts and Psychiatric Distresses  
in Decision Making to Help Caregiver's  
Disclosure of Terminal Disease Status**

의사결정 역할에 대한 선호도가  
말기 암 환자 보호자의  
말기 고지 의사결정에서  
의사결정 갈등과 정서적 디스트레스에  
미치는 영향

2017년 1월

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**A thesis of the Degree of Master of Science**

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**Seoul National University**

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**By**

**Shin Hye Yoo**

**A thesis submitted to the Department of Bio-medical  
Informatics in partial fulfillment of the requirements for the  
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University College of Medicine**

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**Approved by Thesis Committee:**

**Professor \_\_\_\_\_ Chairman**

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# ABSTRACT

## The Impact of Caregiver's Role Preference on Decisional Conflicts and Psychiatric Distresses in Decision Making to Help Caregiver's Disclosure of Terminal Disease Status

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**Introduction:** Decision aid facilitates resolution of decisional conflicts and helps patients make informed decision by weighing the benefits and risks of possible choices in difficult decision making in healthcare. However, little is known about relationship between preferred role in decision making and outcomes of decision aid intervention. The objective of this study was to investigate the impact of caregiver's decisional role preference on decisional conflicts and psychiatric distresses in decision making.

**Methods:** 406 of 444 caregivers of terminally ill cancer patients enrolled onto a previous trial determining the efficacy of the decision aid (DA) about disclosure of terminal disease status were included in this analysis. The analysis outcomes were change score of decisional conflicts using the Decision Conflict Scale (DCS) and depression and anxiety using the Hospital Anxiety and Depression Scale (HADS) at 1 and 3 months from baseline. Participants were divided into 4 groups: active caregiver who received DA (active-DA), active caregiver in control group (active-

control), passive caregiver who received DA (passive-DA), and passive caregiver in control group (passive-control). Linear mixed model adjusted for caregiver's marital status, educational status, and income level was conducted to find out the impact of caregiver's decisional role preference on the DCS and the HADS.

**Results:** Among 406 caregivers, 137 (33.7%) showed active role preference, and 269 (66.3%) showed passive role preference. In post-hoc analysis of adjusted differences of change scores between passive-DA and active-DA groups, non-significant differences were observed in DCS. However, at 3 months, change scores of HADS depression subscale increased as 4.43 (95% confidence interval (CI), 0.78-8.07;  $P < 0.007$ ) and those of HADS anxiety subscales increased as 4.14 (95% CI, 0.37-7.91;  $P = 0.021$ ) in passive-DA group than in active-DA group.

**Conclusions:** These findings suggest that information about decision making might be provided with tailored format for how much individual wish to involve in decision making.

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**Keywords:** Cancer, Oncology, Caregivers, Decisional role preference, Information, Decision aid, Decision Conflict

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# INTRODUCTION

## *1. Decision making process*

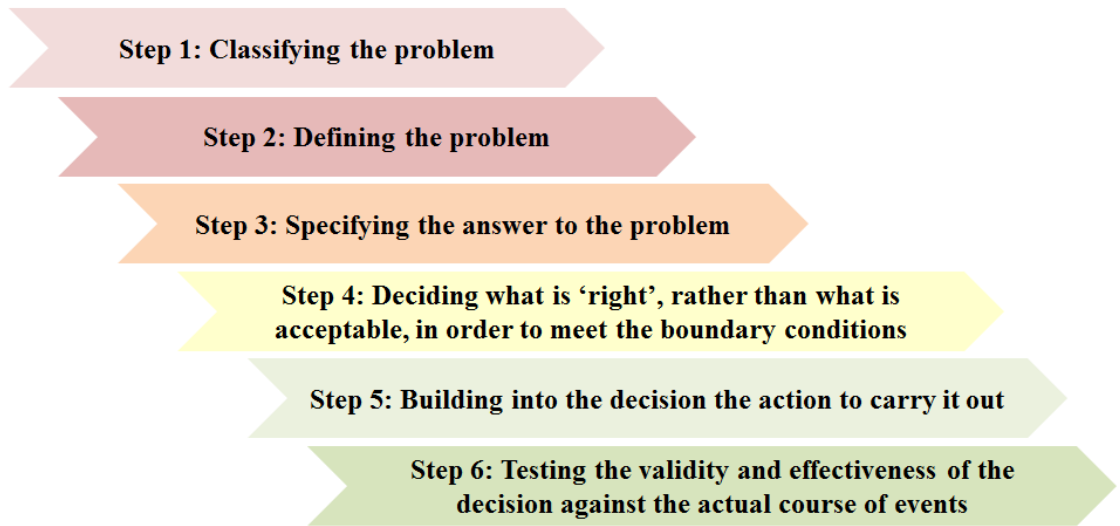
People encounter a chance to make a decision at every moment of life. Decision making is a complex process which results from resolution of decisional conflict as an uncertainty developed when a person makes a choice that has potential gains and losses [1] (Figure 1). To make decision, people weigh risks and benefits of an option and attempt to select a valued option and to minimize the undesired consequences [2]. For these aims, a consumer of information makes judgment and interprets the information on his/her own. Therefore, consequences of decision making can be varied according to different interpretations of an individual even if the same amount, type, and context of information would be supplied. Socio-demographic characteristics and cultural background can influence each individual's experience and interpretation.

In different areas of healthcare, it has been regarded that effective and considerate decision making is essential. Medical decision making topics focus on who should receive screening test for a disease at a risk, whether certain diagnostic test should be performed, which treatment option among surgery, medical treatment, and radiotherapy would be chosen, or how long a medication should be maintained. In the 'preference-sensitive' situation without absolute right or wrong choice, decisions are challenging to assess and often depend on patient values [2].

For widely spread concept of evidence-based medicine [3], two important characteristics have highlighted in the healthcare decision making. The first is

informed decision making, which is based on well-informed situation when a patient knows risks and benefits of all possible options and consequences. As a patient becomes more informed, relationship between patients and healthcare providers has been changed from paternalistic approach to collaborative approach [4]. This approach accommodates patient preferences in the quality of cancer care as mentioned that it should be fit for an individual's need and values in Institute of Medicine (IOM) report *Crossing the Quality Chasm* in 2001 [5]. Not only with explaining to patients that a decision has to be made and discussing options as well as associated benefits and harms, shared decision making [6] elicits patients' ideas, concerns, and expectations, supports them, and asks them for their decisional role preference and come to a decision [7]. Similar steps have been adopted in various shared decision making models (Table 1).

## The Effective Decision Making: 6 steps



**Figure 1 Six steps for the effective decision making**

*\* Modified from the book of Drucker, P. F, 'The effective executive'. 1967*

**Table 1 Classification of steps in various shared decision making processes**

<b>Makoul and Clayman (2006)</b>	<b>Elwyn et al (2012)</b>	<b>Stiggelbout et al (2015)</b>
1. Define or explain problem	1. Choice talk; making sure that patients know that reasonable options are available	1. Explain to patients that a decision has to be made
2. Present options	2. Option talk; the step of providing more detailed information about options	2. Discuss all relevant treatment options and their associated benefits and harms
3. Discuss pros and cons	3. Decision talk; the step of considering preferences and deciding what is best	3. Elicit patients' ideas, concerns, and expectations and support patients in the process of deliberation
4. Assess patient's values or preferences		4. Ask patients for their decisional role preference and come to a decision
5. Discuss patient ability or self-efficacy		
6. Provide doctor knowledge or recommendations		
7. Check or clarify understanding		
8. Make or explicitly defer decision		
9. Arrange follow-up		

*\* modified sources from the Makoul and Clayman (2006) [8], Elwyn et al (2012) [9], and*

*Stiggelbout et al (2015) [7]*



## ***2. Effects of decision aid***

A decision aid is an intervention that provides adequate and potent information of all decisional options and helps an individual make a decision making by thinking of personal values and attitudes toward those options. This intervention has been widely utilized in many areas of healthcare, from screening and diagnosis, through treatment decision making, to end-of-life issues. For example, a decision aid consisting of an educational video and targeted brochure supports promoting colorectal cancer screening in primary care clinics [10]. In addition, many decision aids are designed to target breast cancer patients who face decision making of whether they will take adjuvant chemotherapy added to hormonal therapy after curative surgery or not [11], or whether they will determine types of breast surgery (mastectomy vs breast conserving surgery with reconstruction) [12, 13]. Some decision aids benefit patients with chronic obstructive pulmonary disease to decide to receiving mechanical ventilation or not if they experience respiratory failure [14, 15]. This application of decision aid also has expanded to patients having terminal illness, which is defined as having life expectancy of less than 6 months without active treatment to stop the progress of the disease, and their caregivers [16, 17].

Many studies reported that well-designed decision aid can improve numerous outcomes related to health and decision making [18] (Figure 2). Knowledge related to decision is a typical example that is improved with provision of decision aid [11, 13, 19]. Not only that, a decision aid markedly improves outcomes associated to decision making process including decisional conflicts [12, 13, 15-17, 19], decisional regret [12], and post-decision satisfaction [11, 13, 20]. Furthermore,

actual decision made and preferences for choice become different after receiving a decision aid [10, 13, 15, 17]. Increased treatment adherence with a decision aid [19] implies that this intervention can help patients cope with difficult situations they encounter during the whole management process. In terms of emotional distresses such as anxiety and depression, a decision aid at least makes no difference [13] or diminishes these distresses more than control arm [12, 16]. Eventually, quality of life can be improved by providing decision aid to patients [20]. Enhanced cognitive strategies and emotional changes account for these effectiveness [21]

These positive effects of decision aid have also been shown in many terminal cancer patients and caregiver. They not only suffer from multiple physical symptoms and psychologic and emotional discomforts [22, 23], but also consider discussion about further treatment plans as the most pivotal thing for them [24]. Although whether life-sustaining procedures such as cardiopulmonary resuscitation or mechanical ventilation should be continued or not is the best studied area of research for them [25], the precise perception of terminal illness by a patient should be preceded before discussing the extent of treatment [26]. Although most patients want to be informed of terminal illness status [27, 28], in real, they have poor understanding of their disease [29, 30] and their caregivers disagree with patients' hope [27, 28], especially in Asian culture such as Korea or China [31]. For family caregivers as moderator between physicians and patients about a decision of disclosure of terminal illness, a video-based decision aid that consists of tailored information significantly decreased decisional conflicts and depression of caregivers [16]. This information can benefit family members overcome uncertainty from lack of information [32, 33].

## Effects of Decision Aid

### Choice made

- Improve knowledge
- Increase proportion of people with accurate risk perceptions
- Increase proportion of people choosing an option congruent with their values

### Decision-making process

- Reduce decisional conflict
- Decrease proportions of people who were passive in decision making
- Reduce proportions of people who remained undecided post-intervention
- Raise post-decisional satisfaction
- Decrease anxiety and depression

**Figure 2 Effects of decision aid in medical decision making**

*\* modified from the results of the paper (Stacey D, Légaré F et al, Decision aids for people facing health treatment or screening decisions. Cochrane Database of Systematic Reviews*

*2014 [18])*

### 3. *Decisional role preference*

Although decision aids showed improvement in health-related and decision making-related outcomes, few studies have emphasized the association of preferences for decisional control with those outcomes in decision aid interventions.

Decisional role preference of a participant in decision making is an expression of appraisal how much a person wants to involve, which is the one of essential factors in shared decision making process [7, 34, 35]. Socio-demographic factors such as age, gender, level of income, or educational status, as well as disease-related factors, are known to be associated with patients' preferred role [34, 36-38]. However, consistent results were not unified. Although relatively stable decisional role preferences over time was regarded as intrinsic trait of a person owing [34], discordant studies revealed that these preferences varied owing to endeavors to participate more in decision making [39, 40].

It has been reported that active involvement in decision making is associated with higher satisfaction, lesser level of symptoms and depressive mood, and better quality of life than passive involvement [40, 41]. However, in actual decision making of patients, there is non-negligible discrepancy between preferred and perceived role. The disagreement rate ranged from 39% to 57.6% [38, 40, 42, 43]. This discrepancy may affect outcomes in decision making. Mismatch between preferred and perceived role decreased satisfaction, increased depression, anxiety and fatigue, and worsened treatment adherence and decisional conflicts [44, 45]. Doctors may have poor understanding of their patients' preferences for involvement in decision making, underestimating patients' preferences for discussion about treatment and desire for information [42, 46]. This lack of

understanding would result in the unmet need of patients [47].

Although it is important for physician to consider decisional role preference of patients to deliver patient-centered care and begin the communication for shared decision making, it has not yet been well understood if and how they affect decision making. In addition, previous studies focusing on decisional role preferences have several limitations. First of all, most studies except a few longitudinal ones took the cross-sectional design. Second, studies including preferences for participation merely investigated the prevalence and associated factors [48, 49].

#### ***4. Objective & Hypothesis***

To our knowledge, an impact of decisional role preferences on the effect of decision aid on several outcomes of decision making such as decisional conflicts or psychiatric distresses is unknown. If decisional role preference influences the effect of decision aid, providing decision aid considering preferred role in decision making can be more tailored intervention for participants [38].

Hence, our study aimed to find out how decisional role preference modified the effect of the decision aid on decisional conflict and mood outcome including depression and anxiety, as a sub-analysis of randomized controlled trial which was performed in terminal cancer patient's caregivers. We hypothesized that caregivers who want to involve actively in decision making significantly improved decisional conflicts, depression, and anxiety in experimental arm than in attention control arm, compared to those who do not.

# MATERIALS and METHODS

## *1. Participants*

A randomized controlled trial determining the efficacy of decision aid that focused on caregivers' disclosure of terminal illness was designed from June 2008 to March 2009 at 13 hospitals and National Cancer Center in Korea [16].

Oncologists checked at outpatient clinic if a cancer patient fulfilled the criteria for terminal cancer status as follows: 1) aggressive anti-cancer treatment including surgery, chemotherapy, radiation therapy cannot change the patient's grave course, 2) disease is predicted to be worsened progressively to reach death in a few months, and 3) patients receiving palliative chemotherapy or enrolled in clinical trial for experimental chemotherapy, or patients in stable disease are excluded. However, patients who received acute management of oncologic emergency, control for abrupt symptom, or palliative radiation therapy for improvement of quality of life are not excluded. Physicians explained the objectives of this study to caregivers of patients who was considered as having terminal disease, and project assistant achieved written informed consent with caregivers who understand and agreed with aims of this study. Inclusion criteria for caregivers was 1) understanding the objectives of this study and having informed consent, 2) having physically and mentally sufficient capacity to understand decision making process, 3) older than 18 years old, and 4) who were primary caregiver living with patients. We excluded caregivers who cannot either speak or read Korean, had a serious comorbidity (stroke, heart attack, acute or chronic

respiratory disease, acute or chronic renal disease, or cancer), had a serious psychiatric disorder (schizophrenia; a bipolar, psychiatric, or addictive disorder; or severe emotional distress), or were pregnant.

In total, among 521 potential participants, 77 caregivers (14.8%) refused to participate. The most frequent reason for non-participation was that it was inconvenient or that it took too long time, followed by reasons being too ill, or protection of privacy (Figure 3).

After completing baseline survey, on basis of stratification by caregiver's age (<45, ≥45) and patients' awareness of their terminal status (aware, not aware), randomization was performed with computerized random-number generator, centrally at the National Cancer Center. Finally, remaining 444 caregivers were randomly assigned to either experimental arm (decision aid group) or attention control arm (control group).

Because our study focused on decisional role preference, decisional conflict and mood outcomes, we excluded the data with missing values of decisional role preference at baseline. By the same way, we only included data of caregivers who completed baseline questions about decisional conflict, mood outcome for this analysis.

Before beginning, this study was approved by the individual institutional review boards of all participating institutions (13 hospitals and the National Cancer Center). All procedures were carried out according to the principles of the Declaration of Helsinki.



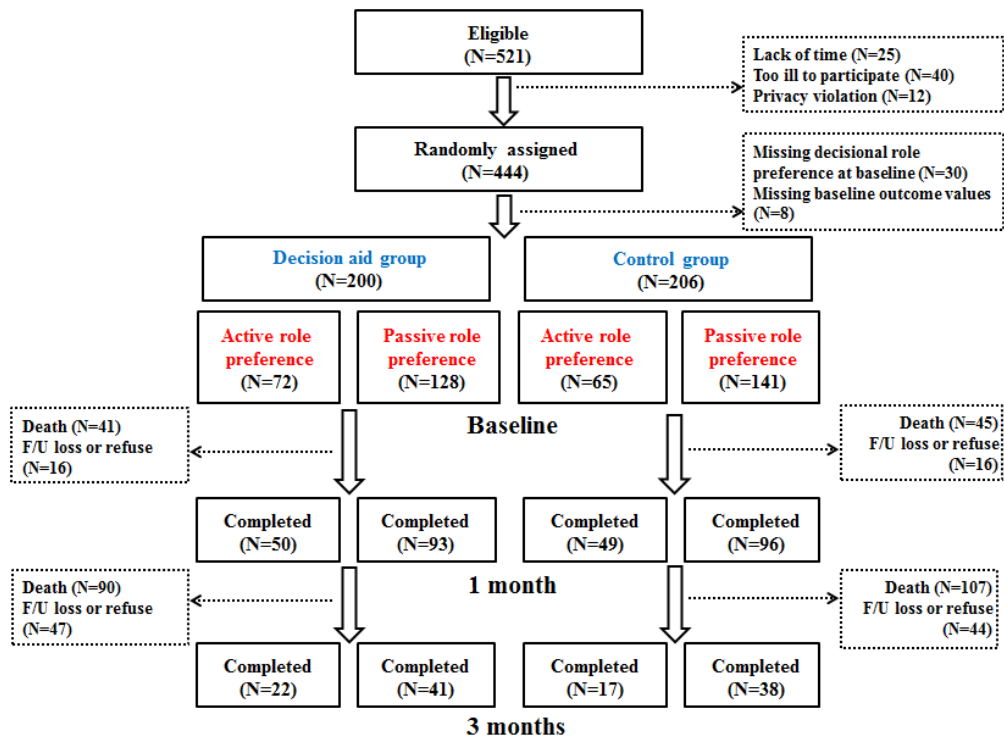


Figure 3 Study flow chart

## **2. *Interventions***

Decision aid group received 20-minute take-home videotape and tailored 43-page workbook entitled “Patients Want to Know the Truth” to make informed choice of disclosure of patient’ terminal illness. Control group was also provided videotape-based material and non-tailored workbook about pain control.

Decision aid consists of a professionally developed video, based on Ottawa decisional support framework [50, 51]. This material fulfilled the criteria for effective decision aid according to International Patient Decision Aid Standards [52]. Conceptual framework of this study was based on social cognitive theory [53]. It focused on cues to action, self-efficacy, and skill development in producing health behavior change. Also, according to transtheoretical model of preparing caregiver’s terminal disclosure, stage of readiness (precontemplation, contemplation, preparation, action, and maintenance/relapse) was applied for providing information. Contents of the materials were described as follows: 1) understanding of dying patients and quality of remaining life, 2) pros and cons of disclosure of terminal illness, 3) protocol for delivering bad news and effective communication, and 4) coping with emotional suffering. Also, definition of terminal disease status, common prognosis and natural courses of terminal cancer patients were explained in the decision aid. During the development of decision aid, we chose videotape and workbook as the most appropriate intervention tool by considering the contents, method of the program, and previous decision aid interventions in the same area. To evaluate the acceptance of the tool, we performed pilot test of the decision aid for focus group consisting of professionals caring cancer patients. In addition, for quality control of the study, all the research

assistants and nurse practitioners were well trained.

The attention control group received a Korean version of a US National Cancer Institute DVD of similar length on pain management entitled Controlling Cancer Pain: A Video for Patients and Families and 29-page educational book on pain control by the Korean Ministry of Health and Welfare entitled Cancer Pain Can Be Controlled.

### **3. Measurement**

This randomized controlled trial measured decision conflicts, depression, anxiety, decisional role preference, and other socio-demographic variables at baseline, and serially rechecked several variables at 1, 3, and 6 months. Decisional conflicts, depression and anxiety were obtained at every check-up, and we used the values at baseline and 1-month, 3-month follow-up.

#### **3.1. Decisional conflict**

We investigated decisional conflict by using the Decisional Conflict Scale (DCS), which format is traditional statement. The DCS [54] is a 16-item questionnaire to assess decisional conflict, which were well validated in different races and countries [55-58] with internal and external validation. For decision making in palliative setting, DCS has been used and well assessed decisional conflicts of cancer patients [56, 58, 59]. Five subscales are included in the questionnaire: Informed subscale assesses conflict how well-informed caregivers felt about their choice, values clarity subscale assesses the clarity of personal values, support subscale assesses the support they had in the decision-making process, uncertainty subscale assesses personal perceptions of the level of uncertainty, and effective decision subscale assesses the likelihood to be implemented and to express satisfaction with the choice. Each question is scored on a 5-point Likert scale (1 means strongly agree, and 5 means strongly disagree). The average score is converted to the equivalent 0-100 scale by subtracting one from the score and multiplying by twenty five. Higher scores indicate more decision-making conflicts.

If missing data was present, we ignored it and calculated the average without it. The internal consistency reliability was estimated with Cronbach's  $\alpha$  coefficient of 0.899.

### ***3.2. Psychiatric distresses (depression and anxiety)***

Mood outcomes revealing psychological distress in caregivers were investigated by utilizing Hospital Anxiety and Depression Scale (HADS) [60]. This 14-item instrument was developed to assess anxiety (seven items) and depression (seven items) among non-psychiatric subjects. This instrument takes only two to five minutes to complete. Each item is rated on a four-point scale. The sum of scores ranges from 0 to 21, with the higher score meaning worse anxiety and depression. In the clinical setting, it is common that a score of 0 to 7 for either subscale could be regarded as being in the normal range, a score of 11 or higher indicating probable presence of the mood disorder and a score of 8 to 10 being just suggestive of the presence of the respective state. We handled incomplete questionnaires according to the developers' recommendations. The Korean version of HADS has been validated [61]. Both anxiety (Cronbach's  $\alpha = 0.85$ ) and depression (Cronbach's  $\alpha = 0.803$ ) scales demonstrated good internal consistency.

### ***3.3. Decisional role preference***

The Control Preferences Scale (CPS) is the most common, self-reported instrument, widely used in assessing decisional role preference which presents the role that patients want to play in treatment decision making [62]. Degner and

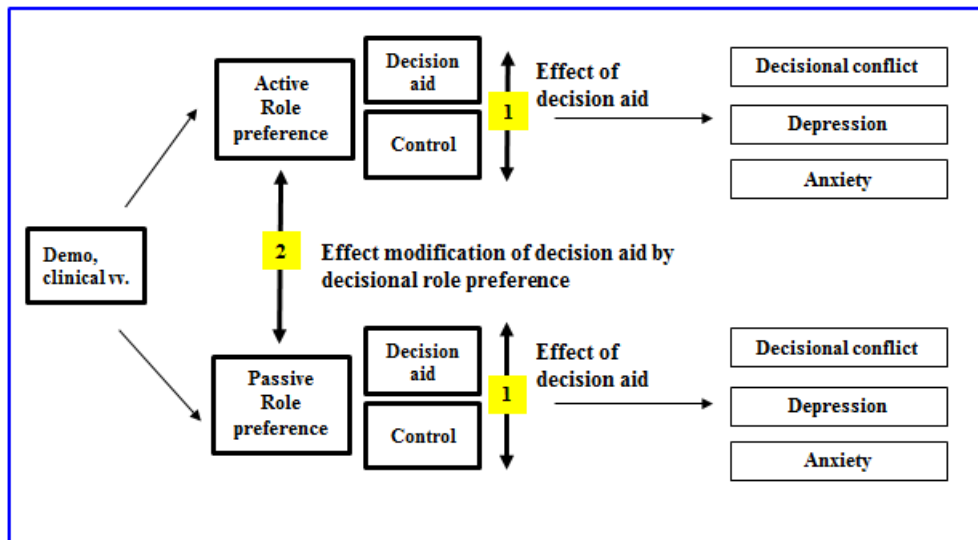
researchers developed this single-item scale in 1994 [63]. Originally, this method was administered as a form of card-sorting method: 5 sort cards of which have a picture and text portraying a different role in decision making on each. The cards are laid out in order, ranging from a fully active role to a fully passive role (Table 2). The respondent is asked to pick the card that best describes how the treatment decision was made. We utilized a pick-one method which was substituted for card-sorting method. This key concept which reflects the patient's role in decision making is included in the Ottawa Decision Support Framework [51]. Regarding three categories consistent with Charles's model of decision-making styles: active, passive and shared, we analytically grouped the original five response options into two groups (active and passive). Choice 1, 2 were categorized into active role preference, and others were into passive role preference.

**Table 2 Categorization of the Control Preference Scale (CPS) [63]**

Term	Description
Fully active role (Choice 1)	I make the final selection about which treatment the patient will receive.
Semiactive role (Choice 2)	I make the final selection of the patient's treatment after considering my patient's opinion.
Collaborative role (Choice 3)	My patient and I share responsibility for deciding which treatment is best for him or her.
Semipassive role (Choice 4)	My patient makes the final decision about which treatment will be used but seriously considers my opinion.
Fully passive role (Choice 5)	I leave all decisions regarding my patient's treatment to him or her.

Other sociodemographic data (patient's age and gender, caregiver's age, gender, marital status, education, religion, income, current job status, residence, and the number of family members) and clinical data (type of malignancy of patients) were obtained from self-reported questionnaire at baseline.

#### 4. Statistical analyses



**Figure 4 Conceptual framework**

The main relationship we intended to explore was the possibilities of effect modification by decisional role preference on differences in change score of decisional conflicts and mood outcomes between experimental and attention control arm (Figure 4). To consider both decisional role preference and type of intervention, participants were divided into four groups (2x2): active caregiver who received decision aid (active, DA), active caregiver who received control intervention (active, control), passive caregiver who received decision aid (passive, DA), and passive caregiver who received control intervention (passive, control).

The primary outcome variables were change score of decisional conflicts and mood outcomes measured at 1-, and 3-month follow-up from baseline, which were the secondary outcome variables of previous RCT [16]. An intent-to-treat analysis was conducted in which all participants will be evaluated as randomized, regardless



of whether they complete to use the decisional aid.

To select candidates for confounder covariates, Student t test and chi-square test were performed to detect potential differences in background variables between experimental and attention control arm, and between active and passive role preference, using a significance level of  $P < 0.10$ . Demographic and clinical variables were handled as categorical variables like this: caregiver's age ( $< 45$  vs  $\geq 45$ ), caregiver's relation (son, daughter, or in-law vs spouse, parent, sibling, or others), marital status (married vs unmarried), religion (yes vs no), location of stay (metropolitan vs rural area), caregiver's level of education ( $\leq$  high school graduate vs  $\geq$  college school graduate), and monthly income ( $< \$300$  vs  $\geq \$300$ ), the number of family members ( $< 3$  vs  $\geq 3$ ), and current job status (yes vs no). Among potential candidates selected, various combinations were tested by entering the actual mixed model, and the most fit model was picked using two kinds of model fit criteria (likelihood ratio test and F-test).

To compare between-group difference of the baseline outcome, general linear model was utilized. If significance between 4 groups was detected in level of  $P < 0.05$ , then post-hoc analysis was performed.

By considering the correlation of repeated observations for a given participant, we used a linear mixed model for estimating the effect of the intervention (between-group) and time (within-group) and the interaction between group and time (interaction). We also adjusted the model for selected covariates from candidates. Those covariates were included as fixed effect, and each person was regarded as random effect. When significant difference of 4 groups in time effect was observed, then post-hoc analysis was conducted using Tukey–Kramer method. Adjusted

differences of change score between caregivers with passive and with active role preference (scores of passive, DA subgroup minus scores of active, DA subgroup) were calculated.

All statistical analyses were carried out using (SAS, Version 9.4: SAS institute, Carey, NC). All statistical tests were 2-sided, and we considered  $P < 0.05$  to be significant, and  $P < 0.10$  to be marginally significant.

# RESULTS

## *1. Participant baseline characteristics*

Socio-demographic and clinical characteristics of 406 terminal cancer patients' caregivers who were involved in this study were shown in Table 3. Out of 406 caregivers, 200 (49.3%) received decision aid, and 206 (50.7%) received usual pain control manual. The rate of follow-up was 70.9% (n=288) at 1 month and 29.1% (n=118) at 3 months. Most of baseline demographic and clinical characteristics except the age of caregivers ( $P=0.009$ ) and patients ( $P=0.054$ ), and current job status ( $P=0.008$ ) were not different between decision aid and control group. The mean age of caregivers was 44 years. Caregivers were mainly female (66.5%) and had low-degree relations such as son, daughter, son-in-law, or daughter in-law (56.2%). The majorities of participants were married (80.3%), graduated high school or lower (59.8%), had religion (68.4%), earned less than \$300 per month (62.8%), lived with less than 3 family members (56.3%), and lived in metropolis (55.8%). The mean age of patients was 61.8 years, and female consists 41.4 percent of patients.

**Table 3 Baseline covariates between decision aid and control group**

	N	%	DA group (N=200)		Control group (N=206)		P
			n	%	n	%	
<b>Caregiver factor</b>							
<b>Age</b>							
≥45	207	51.1	110	53.1	97	46.9	0.099
<45	198	48.9	89	45.0	109	55.0	
<b>Gender</b>							
Male	136	33.5	69	50.7	67	49.3	0.673
Female	270	66.5	131	48.5	138	51.5	
<b>Relation</b>							
Son, daughter, or in-law	228	56.2	110	48.3	118	51.7	0.643
Spouse, parent, sibling, or other	178	43.8	90	50.6	88	49.4	
<b>Marital status</b>							
Married	326	80.3	163	50.0	163	50.0	0.548
Unmarried	80	19.7	37	46.3	43	53.7	
<b>Educational status</b>							
≥College graduate	163	40.2	73	44.8	90	55.2	0.129
≤High school graduate	242	59.8	127	52.5	115	47.5	
<b>Monthly income</b>							
≥\$300	150	37.2	68	45.3	82	54.7	0.240
<\$300	253	62.8	130	51.4	123	48.6	
<b>Current job status</b>							
Yes	173	42.6	72	41.6	101	58.4	0.008
No	233	57.4	128	54.9	105	45.1	
<b>Religion</b>							
Yes	277	68.4	141	50.9	136	49.1	0.295
No	128	31.6	58	45.3	70	54.7	
<b>Location of stay</b>							
Metropolitan	226	55.8	111	49.1	115	50.9	0.904
Rural area	179	44.2	89	49.7	90	50.3	
<b>No. of family members</b>							
≥3	177	43.7	84	47.5	82	52.5	0.495
<3	228	56.3	116	50.9	112	49.1	
<b>Patient factor</b>							
<b>Age</b>							
≥65	195	48.2	106	54.4	89	45.6	0.054
<65	210	51.8	94	44.8	116	55.2	
<b>Gender</b>							
Male	238	58.6	116	48.7	122	51.3	0.802
Female	168	41.4	84	50.0	84	50.0	
<b>Diagnosis</b>							

Poor prognosis (lung, stomach, H&N)	121	29.9	56	46.3	65	53.7	0.453
Good prognosis (Others)	284	70.1	143	50.4	141	49.6	

Abbreviations: DA, decision aid; No., the number of; H&N, head and neck;

\* 'Good prognosis' is defined as having higher, and 'poor prognosis' is defined as having lower 5-year survival rate than that of total cancer types.

## *2. Association of socio-demographic and clinical factors with decisional role preferences*

Out of total 406 caregivers, 137 (33.7%) showed active role preference, and 269 (66.3%) showed passive role preference. Table 4 showed association of demographic and clinical factors with decisional role preference. In univariate analysis, caregivers who were older than 45 years ( $P=0.012$ ), married ( $P=0.035$ ), less educated ( $P=0.097$ ), unemployed ( $P=0.009$ ), and earned less than \$300 per month ( $P=0.072$ ) were likely to want to participate in decision making. Any patient factors did not influence caregiver's decisional role preference.

**Table 4 Association of baseline covariates with decisional role preference**

	N	%	Active role preference (N=137)		Passive role preference (N=269)		P
			n	%	n	%	
<b>Caregiver factor</b>							
<b>Age</b>							
≥45	207	51.1	82	39.6	125	60.4	0.012
<45	198	48.9	55	22.8	143	72.2	
<b>Gender</b>							
Male	136	33.5	46	33.8	90	66.2	0.981
Female	270	66.5	91	33.7	179	66.3	
<b>Relation</b>							
Son, daughter, or in-law	228	56.2	73	32.0	155	68.0	0.405
Spouse, parent, sibling, or other	178	43.8	64	36.0	114	64.0	
<b>Marital status</b>							
Married	326	80.3	118	36.2	208	63.8	0.035
Unmarried	80	19.7	19	23.8	61	76.2	
<b>Educational status</b>							
≥College graduate	163	40.2	47	28.8	116	71.2	0.097
≤High school graduate	242	59.8	89	36.8	153	63.2	
<b>Monthly income</b>							
≥\$300	150	37.2	42	28.0	108	72.0	0.072
<\$300	253	62.8	93	36.8	160	63.2	
<b>Current job status</b>							
Yes	173	42.6	46	26.6	127	73.4	0.009
No	233	57.4	91	39.1	142	60.9	
<b>Religion</b>							
Yes	277	68.4	95	34.3	182	65.7	0.654
No	128	31.6	41	32.0	87	68.0	
<b>Location of stay</b>							
Metropolitan	226	55.8	80	35.4	146	64.6	0.453
Rural area	179	44.2	57	31.8	122	68.2	
<b>No. of family members</b>							
≥3	177	43.7	57	32.2	120	67.8	0.543
<3	228	56.3	80	35.1	148	64.9	
<b>Patient factor</b>							
<b>Age</b>							
≥65	195	48.2	73	37.4	122	62.6	0.139
<65	210	51.8	64	30.5	146	69.5	
<b>Gender</b>							
Male	238	58.6	77	32.3	161	67.7	0.481
Female	168	41.4	60	35.7	108	64.3	
<b>Diagnosis</b>							
Poor prognosis (lung, stomach, H&N)	121	29.9	36	29.8	85	70.2	0.287
Good prognosis (Others)	284	70.1	100	35.2	184	64.8	

Abbreviations: No., the number of; H&N, head and neck;

\* 'Good prognosis' is defined as having higher, and 'poor prognosis' is defined as having lower 5-year survival rate than that of total cancer types.

### 3. *Differences in change scores of decisional conflicts, depression and anxiety between four groups*

Scores of baseline outcomes were not significantly different between 4 subgroups (Table 5).

In unadjusted mixed model, there were no substantial differences between groups at 1 month and 3 months for DCS total score or other DCS subscale scores. For psychiatric distresses, the differences between 4 groups in change scores of depression and anxiety subscale of HADS were significant ( $P=0.001$  for depression subscale;  $P=0.007$  for anxiety subscale).

To control for meaningful confounder covariates, we compared fitness of different mixed models consisting of combination among possible candidates to that of reference model which only included time, group, and interaction between time and groups (Data not shown). As a result, marital status, educational status, and monthly income were finally determined for controlling covariates.

After adjustment for those covariates, similar results were observed as unadjusted ones. There were no significant differences in the change scores for DCS, whereas significant differences in change scores for depression and anxiety of HADS were found ( $P<0.001$  for depression subscale;  $P=0.004$  for anxiety subscale). All the results were shown in Table 6.



**Table 5 Baseline scores of decisional conflict, depression and anxiety according to four groups**

Baseline score	Active, DA (n=72)		Active, control (n=65)		Passive, DA (n=128)		Passive, control (n=141)		P value
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
DCS-total	36.11	13.83	34.08	11.17	35.26	12.51	34.73	13.30	0.806
DCS-informed	42.71	18.13	40.77	16.87	42.51	18.59	40.37	17.54	0.702
DCS-clarity	31.25	13.90	30.13	12.65	31.80	15.79	31.59	15.78	0.899
DCS-support	36.00	19.51	36.79	18.86	34.90	16.02	33.87	17.99	0.692
DCS-uncertainty	34.09	18.94	31.15	14.90	32.36	14.70	32.39	15.62	0.752
DCS-effective decision	36.28	15.22	32.28	14.78	34.86	16.70	35.24	16.06	0.501
HADS-depression	11.22	4.51	10.66	4.33	11.38	4.49	10.97	4.04	0.705
HADS-anxiety	11.47	3.86	11.09	4.26	10.98	4.53	11.33	4.00	0.843

Abbreviations: DA, decision aid; SD, standard deviation; DCS, decisional conflict scale; HADS, Hospital anxiety and depression scale

\* P value is calculated by general linear model and regarded as significant in <0.05 level.

**Table 6 Change scores from baseline in unadjusted and adjusted mixed models**

Change from baseline	Unadjusted mixed model									Adjusted mixed model*									
	Active, DA (n=72)		Active, control (n=65)		Passive, DA (n=128)		Passive, control (n=141)		P (group x time)	Active, DA (n=72)		Active, control (n=65)		Passive, DA (n=128)		Passive, control (n=141)		P (group x time)	
	LS mean	SE	LS mean	SE	LS mean	SE	LS mean	SE		LS mean	SE	LS mean	SE	LS mean	SE	LS mean	SE		
<b>DCS-total</b>																			
1 month	-3.02	1.64	-0.73	1.66	-2.08	1.22	-0.77	1.18	0.820	-3.95	1.84	-1.18	1.78	-2.44	1.31	-1.46	1.33	0.834	
3 months	-2.33	2.40	-2.13	2.65	-4.30	1.72	-1.55	1.78		-3.52	2.58	-2.37	2.75	-4.65	1.80	-1.88	1.89		
<b>DCS-informed</b>																			
1 month	-1.55	2.52	0.10	2.56	-3.65	1.88	-1.06	1.82	0.947	-2.74	2.84	-0.24	2.74	-3.93	2.02	-1.77	2.04	0.928	
3 months	-0.77	3.65	-2.28	4.01	-5.06	2.62	-2.50	2.70		-1.71	3.91	-2.67	4.15	-5.43	2.73	-2.51	2.86		
<b>DCS-clarity</b>																			
1 month	-3.22	2.14	0.32	2.18	-0.68	1.60	-1.31	1.55	0.972	-3.82	2.37	-0.36	2.29	-1.30	1.68	-2.17	1.71	0.949	
3 months	-4.57	3.12	1.16	3.42	-1.28	2.23	-1.43	2.31		-5.74	3.33	0.55	3.55	-1.71	2.32	-2.32	2.44		
<b>DCS-support</b>																			
1 month	-5.41	2.50	-2.38	2.58	-2.27	1.88	2.40	1.82	0.300	-6.57	2.85	-3.40	2.78	-3.07	2.03	1.22	2.05	0.348	
3 months	-3.37	3.43	-5.61	3.73	-7.89	2.47	-1.56	2.53		-4.88	3.73	-6.63	3.91	-8.72	2.60	-2.84	2.72		
<b>DCS-uncertainty</b>																			
1 month	-2.27	2.46	-3.83	2.50	-2.04	1.84	-0.34	1.79	0.170	-0.10	2.77	-2.09	2.68	-0.38	1.97	1.34	2.00	0.144	

3 months	0.63	3.45	-3.51	3.77	-7.47	2.48	0.23	2.55		2.95	3.72	-1.01	3.92	-5.71	2.59	2.35	2.71		
<b>DCS-effective decision</b>																			
1 month	-2.74	2.3	1.18	2.34	-1.42	1.72	-2.73	1.66	0.975	-5.84	2.59	-0.34	2.50	-2.78	1.84	-4.65	1.86	0.975	
3 months	-3.10	3.27	-0.34	3.57	-1.04	2.34	-3.24	2.41		-6.64	3.52	-1.82	3.72	-2.46	2.45	-4.71	2.57		
<b>HADS-depression</b>																			
1 month	1.62	0.62	-0.20	0.63	0.03	0.46	0.22	0.45	0.001	1.47	0.70	-0.46	0.67	0.39	0.49	-0.02	0.50	<0.001	
3 months	-2.16	0.94	0.46	1.10	1.94	0.69	1.32	0.71		-2.61	1.00	0.39	1.14	1.82	0.71	1.32	0.75		
<b>HADS-anxiety</b>																			
1 month	0.88	0.66	0.64	0.66	0.66	0.48	-0.16	0.47	0.007	1.25	0.73	0.68	0.70	0.86	0.51	0.10	0.52	0.004	
3 months	-2.54	0.98	-0.22	1.14	1.62	0.71	0.89	0.74		-2.25	1.04	0.18	1.17	1.89	0.74	1.36	0.77		

Abbreviations: DA, decision aid; LS Mean, least-square mean; SE standard error; DCS, decisional conflict scale; HADS, Hospital anxiety and depression scale

\* Adjusted mixed model was controlled for marital status, education status, and income level of caregivers.

4. *Adjusted differences in change scores of decisional conflicts, depression and anxiety between caregivers who received decision aid with passive role preference and those with active role preference*

In post-hoc analysis of adjusted differences of change scores between subgroups with passive role preference who received decision aid and those with active role preference who also received decision aid (Table 7), non-significant differences were observed in all DCS subscales and overall DCS. However, significant differences were shown for both HADS depression and anxiety subscales at 3 months from baseline. At 3 months, change scores of HADS depression subscale increased as 4.43 (95% confidence interval (CI), 0.78-8.07;  $P<0.007$ ) in passive decision aid group than in active decision aid group, and those of HADS anxiety subscales increased as 4.14 (95% CI, 0.37-7.91;  $P=0.021$ ) in passive decision aid group than in active decision aid group.

**Table 7 Regression-estimated differences in change scores between groups**

<b>(Passive, DA) - (Active, DA)</b>			
	Adjusted difference between change scores	95% CI	adjusted <i>P</i> value
<b>DCS-total</b>			
1 month	1.51	(-4.98, 8.00)	0.996
3 months	-1.13	(-10.42, 8.15)	>0.999
<b>DCS-informed</b>			
1 month	-1.19	(-11.18, 8.81)	>0.999
3 months	-3.72	(-17.77, 10.33)	0.992
<b>DCS-clarity</b>			
1 month	2.53	(-5.83, 10.88)	0.982
3 months	4.04	(-7.93, 16.01)	0.966
<b>DCS-support</b>			
1 month	3.49	(-6.51, 13.49)	0.959
3 months	-3.83	(-17.17, 9.51)	0.986
<b>DCS-uncertainty</b>			
1 month	-0.28	(-10.01, 9.45)	>0.999
3 months	-8.66	(-21.97, 4.65)	0.478
<b>DCS-effective decision</b>			
1 month	3.06	(-6.04, 12.16)	0.967
3 months	4.18	(-8.44, 16.80)	0.969
<b>HADS-depression</b>			
1 month	-1.60	(-4.05, 0.86)	0.477
3 months	4.43	(0.78, 8.07)	0.007
<b>HADS-anxiety</b>			
1 month	-0.38	(-2.94, 2.17)	>0.999
3 months	4.14	(0.37, 7.91)	0.021

Abbreviations: DA, decision aid; 95% CI, 95% confidence interval; DCS, decisional conflict scale; HADS, Hospital anxiety and depression scale

\* Adjusted mixed model was controlled for marital status, education status, and income level of caregivers.

## DISCUSSIONS

Although decision aid substantially improves decisional conflict and psychiatric distress in various healthcare decision-making areas, little is known about influence of decisional role preference on utility of information. Therefore, the study was designed to examine whether decisional role preference differently affected the outcome of the decision aid intervention for the terminal patient's caregiver.

The main finding of this study was that caregiver's preference for decisional control did not make a difference of reduction of decisional conflict with information, but mediated the effect on anxiety and depression. Caregiver who prefers active decisional role did not showed significant difference of decisional conflict over time compared to those who prefers passive role. However, the degrees of anxiety and depression significantly increased at 3 months after receiving decision aid in caregivers with passive decision-making role preference than in those with active preference. These data explained our hypothesis that decisional role preference has an impact on interpretation and utilization of information which is even the same in two subgroups with different preferences.

## 1. *Association of decisional role preference with decisional conflict*

To our knowledge, this is the first study to demonstrate that decisional role preference does not have association with the effect of information on a decrease of decisional conflict. Few previous studies have addressed this issue before. However, our finding of lack of that association is inconsistent with two studies, which implied that role preference for decision-making be one of the factors affecting decisional conflict. France Legare et al [50] investigated the impact of multiple factors including patients' and physicians' decisional role preferences on the gap of decisional conflict between them in a before-and-after study for verifying the efficacy of a workshop implementing the Ottawa Decision Support Frame. As a result, patients who had higher decisional conflicts than physicians were more likely to prefer unilateral role (active or passive) to shared role. This result indicates that decisional role preferences may influence the mutual understanding between patients and physicians. Similarly, in another study conducted by the same researcher [64], larger differences of conflict between women and doctors were observed in postmenopausal women with unilateral role preference than those with shared role in decision making about hormone replacement therapy. However, these two studies compared unilateral role to shared role, not active to passive role, and investigated conflicts between patients and physicians only without absolute degree of decrease within a patient. For these reasons, it is unclear whether a decrease of decisional conflict is related to active or passive preference yet. One cross-sectional study in patients with HIV [44] evaluated the association of role discrepancy between patients and doctors with decisional conflict. In this study, patients who received less than preferred and

those whose physicians determined dominantly despite patient's wish for shared decision making were likely to display higher decisional conflict than those without role discrepancy. However, it is similar to our result that patients who received more than preferred showed no change of decisional conflict. In ACR/ARHP annual meeting held in September 2016, some investigators reported the results of a randomized controlled trial of multimedia patient education tool compared to written information which has attempted to investigate whether decision-making role preferences affect knowledge as a primary outcome, decisional conflict, self-efficacy, and disease management as secondary outcomes [65]. They found patients with passive role preference in the intervention group improved decisional conflicts at 3 months, whereas those with active role preference improved conflicts. This finding might help physicians to identify the modifying effect of decision-making role preferences might be different over time from baseline. More research is needed to further ascertain the relationship between decisional role preferences and decisional conflicts, by considering time-dependent approaches because role preference may change over time [66].



## 2. *Association of decisional role preference with depression and anxiety*

For caregivers who want active involvement in the decision making process, decision aid was likely to help decrease depression and anxiety. In other words, caregivers with passive role preference exhibited more anxious state and overwhelming depressive mood compared to those with active role preference. These findings are congruent with results from two studies investigating the effect of preferences for participation on psychiatric distress. In a longitudinal follow-up of breast cancer patients for 3 years [67], women who want to defer decision-making to their doctors showed significant deterioration of depression, anxiety, anger, and overall distress scores compared to women who want to make decision by their own, adjusting for multiple sociodemographic and clinical factors. Even after correcting for baseline coping response and psychological adjustment, passive preference was the independent factor that increases anxiety. These effects of decision-making preference on psychiatric symptoms were also observed in an observational study conducted in relatives of ICU care patients [68]. The percent of relatives with problematic levels of both anxiety and depression (a score of >10 on HADS anxiety and depression subscale) were significantly higher in those with passive decision-making preferences than those with active or shared preferences. Although, in these two studies, there is possible weakness that the similar amount and relevance of information may not be guaranteed in passive and non-passive groups, our study overcome this limitation by developing potent decision aid.

The mechanism that anxiety and depression is aggravated in a passive caregiver even with adequate information has not been clearly revealed yet. We suggest that an increase of psychiatric distress arises during processes of utilizing a

decision aid. One hypothesis is that the decision aid may be accounted less helpful for decision making in a passive person. According to a study in prostate cancer survivors [69], passive survivors were likely to judge information received as less helpful and not satisfied with information received. It implies that passive preference for involvement in decision making might not be ready for utilization of information even if it is tailored and helpful, impeding a reduction of depression and anxiety. Moreover, patients with passive role preference showed higher level of symptoms, especially fatigue, loss of appetite, and constipation, compared to those with active role preference in a study with patients with higher risk myelodysplastic syndrome [70]. This suffering by symptoms also may affect psychiatric distress in a person who does not want to involve in decision making.

No significant difference in decisional conflicts according to preferences indicates that improved mood conditions such as depression and anxiety affected by preference may not be related to a preceding decrease of decisional conflicts. Further study is needed to investigate factors mediating the relationship between decisional conflict and psychiatric distress.

### ***3. Factors predicting decisional role preference of terminal cancer patient's caregiver***

Little has been known about factors affecting caregiver's decisional role preferences before except a study in Hispanic caregivers in USA and Latin America showing that low educational status was associated with passive role preference for patient's decision making [37]. Although many studies about patient's role preference [34, 36] revealed younger age, higher education and higher income level were associated with active role preference, in our study, older caregivers seemed to involve more actively in the decision making in terminal setting. This can be explained by Confucianism in Asian culture including Korea [71] that the oldest person among caregivers usually has the hegemony of decision making. Interestingly, caregivers who have lower educational status, have lower monthly income, and do not have current job are relatively free of barriers against care burden, so that they are available enough to accompany their patients at admission or outpatient clinic visit and prefer more involvement in decision making.

However, unlike patients who make a decision by their own, caregivers should make a decision for patients, not for them. Therefore, patient-related factors should be considered for predicting caregiver's role preference. Because, in our study as well as other study [37], only three patient factors such as age, gender, and diagnosis were included in analysis investigating the association, it is not sufficient to identify the factors that influence the decisional role preference. Further research should be designed with this limitation.

#### 4. *Clinical and Practical Implications*

There are several possible clinical and practical implications for these findings. First of all, the influence of decisional role preference on depression and anxiety with decision aid indicates that this preference make the interpretation of information received different. In previous decision aid interventions researchers have taken a unilateral approach that allows physician to provide well-designed information to patients. Little has been investigated whether interactive provision of information with regard to preference for decisional role. We suggest that further decision aid in medical decision making be developed, provided, and evaluated with consideration of preference and interactive feature. With development of information and communication technology, web-based and smartphone-based interactive approach would be helpful for achieving true meaning of shared decision making, which is called "*the intersection of patient-centered communication skills and evidence-based medicine*" [72] and is evolved from provision of tailored information only.

Second, offering decision aid to a recipient who defers decision making to others may be harmful for its effects on depression and anxiety. This implies that simple, unilateral provision of information make the recipient recognize it as a burden and pressure. When a clinician gives caregivers information for decision making about patients in clinical practice, we propose that it should be cautiously performed.

Third, we suggest that the influence of decisional role preference on outcomes in decision aid intervention should be verified in patients. Although our study aimed at caregiver's role preference because the decision of terminal disclosure

should be made by caregivers, few studies except one focusing on the impact of preference in a multimedia-based educational intervention in patients with rheumatologic disease [65] have been investigated for this issue. Further studies are needed to establish whether this association of role preference with psychiatric distress would be present in patients.

## ***5. Strengths and Limitations of this study***

Overall, our research has an interesting objective that decisional role preference may benefit differently decisional conflict and mood outcomes. To our knowledge, this object has not been studied much before. Moreover, we controlled multiple factors for the analyses in prospective design which was randomized controlled trial, which enables to exclude possible bias of retrospective or cross-sectional study design. Finally, it is meaningful that our study focused on terminal disclosure, which is the beginning of patient-caregiver-physician communication in terminal care. This can benefit to easily remain discussion about other decision making topics such as withholding the futile management.

Nevertheless, our study has several limitations. First, at the time when the original decision aid intervention was designed, we did not reflect decisional role preference on the development process. Although our study was sub-analysis of the original trial, decision aid which consists of this preference should be utilized in further study. Second, the intervention in our study only targets narrow decision making of terminal disclosure to cancer patients in caregivers. Generalizability may be insufficient to prove the potential effect of decisional role preference in different types of disease such as non-malignant chronic disease or in other populations such as patients or physicians. Further study is needed to deal with other topics of decision making expanding from terminal disclosure as well. Third, we did not include various patient-related factors into our analysis. Although we have attempted to select the most influential confounders in analysis, those factors should be included in further study especially for decision making of caregivers.

Fourth, despite its design as randomized controlled trial, non-negligible numbers of missing values from baseline to 3 months occurred, and lower response rate and missing data could have brought about the selection bias. However, we understand how difficult to follow up the terminal cancer patient's caregiver whose loved one had approximately 6 months of remaining expectancy. Although we tried several times with different ways to contact participants, psychiatric distress and burden of care may affect their no-response and influence the study outcomes. Finally, lower power than one as planned before the study may arise because of missing (n=30) data of decisional role preference. However, we assured that there was no specific missing pattern, which was regarded not against the assumption of missing completely at random.

## CONCLUSIONS

Regardless of several limitations, our study supported that decisional role preference modified the effect of decision aid on depression and anxiety in terminal cancer patient's caregiver.

To develop more interactive decision aid beyond the current decision support tools, we suggest that physicians should be encouraged to involve caregivers in the terminal setting of cancer patients to establish a partnership and elicit their preferences. In addition, tailored information should be provided with consideration of how much an individual wish to involve in decision making.



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# 국문 초록

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**서론:** 의사결정 지원도구는 의료 영역에서의 어려운 의사결정 과정에서 의사결정 갈등을 감소시키고 가능한 선택의 이득과 위험을 파악하여 환자가 정보를 받은 의사결정을 내릴 수 있도록 돕는 역할을 한다. 그러나 이러한 의사결정 지원도구의 효과와 의사결정 역할에 대한 선호도 간의 관계에 대해서는 아직 알려진 바가 많지 않다. 이 연구에서는 보호자가 말기 암 환자에게 말기라는 사실을 알리는 의사결정을 돕는 의사결정 지원도구의 효과에 보호자의 의사결정 역할의 선호도가 어떻게 영향을 미칠 수 있는지 살펴보았다.

**방법:** 2008년 6월부터 2009년 3월까지 국내 13개 병원 및 국립암센터에서 말기 암 환자의 보호자가 연구에 참여하여 예후에 대한 상의 및 말기 고지를 돕는 의사결정 지원도구를 제공받은 실험군과 암성 통증 조절에 대한 정보를 제공받은 대조군으로 분류되었다. 연구에 참여한 총 444명 중, 우리는 연구 참여 시점에서의 의사결정 역할에 대한 선호도와 의사결정 갈등, 정서에 대한 정보가 누락되지 않은 총 406명의 환자를 대상

으로 분석하였다. 의사결정 갈등은 DCS를 이용하여, 정서는 HADS를 이용하여 조사되었고, 연구 참여 시점으로부터 1개월, 3개월 추적 관찰 시점에서 각 결과의 점수 차이를 분석의 주요 결과로 선택하였다. 보호자의 의사결정 역할에 대한 선호도가 의사결정 갈등, 정서에 대한 의사결정 지원도구의 효과에 영향을 주는지 선형 혼합 모델을 통하여 의사결정 역할 선호도에 영향을 줄 수 있는 요인을 보정하여 관계를 도출하였다.

**결과:** 406명의 보호자 중에서, 137명이 적극적인 의사결정 역할 선호도를 보였으며 269명이 소극적인 역할 선호도를 보였다. 역할 선호도에 영향을 미치는 인자 중 보호자의 결혼 여부, 교육 수준, 소득 수준을 선형 혼합 모델의 교란 변수로 결정하였다. 중재 종류 및 의사결정 역할 선호도 여부에 따라 네 군으로 나누었을 때, DCS의 점수 차이는 네 군 간에 유의한 차이가 없었고 HADS 우울 및 불안 점수 차이는 네 군 간의 유의한 차이가 있었다. 의사결정 지원도구를 받은 군 중 소극적 역할 선호도를 보이는 군과 적극적 역할 선호도를 보이는 군에서 점수의 차이를 보정한 모델에서 비교하였을 때, DCS의 점수 차이에는 유의한 차이가 없었으나 HAD 우울 및 불안 점수는 모두 3개월 추적 관찰 시에 적극적 역할 선호도를 보이는 군에 비해 소극적 역할 선호도를 보이는 군에서 통계적으로 유의하게 각각 4.43 (95% 신뢰도 구간, 0.78-8.07;  $P<0.007$ ), 4.14 (95% 신뢰도 구간, 0.37-7.91;  $P=0.021$ ) 만큼 증가하는 것으로 보였다.

**결론:** 전체적인 결과를 종합하여 볼 때, 말기 암 환자의 보호자에서 의사결정 지원도구를 제공할 때에 의사결정 역할에 대한 선호도에 따라 의사결정 갈등에는 차이가 없으나 우울, 불안에 미치는 효과가 달라질 수

있다. 의사결정에 참여하고자 하는 정도를 고려하여 상호작용을 할 수 있는 방식으로 대상자에게 정보를 제공하는 것이 향후 중요할 것으로 예상된다.

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**Keywords:** 암, 종양학, 보호자, 의사결정 역할 선호도, 정보, 의사결정 지원 도구, 의사결정 갈등

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