

Patient's Cognitive Function and Attitudes towards Family Involvement in Cancer Treatment Decision Making: A Patient-Family Caregiver Dyadic Analysis

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Purpose

Older patient populations commonly have cognitive impairment, which might impact decisional capacity. We examined patients and family caregivers preferences for family involvement in treatment decision making assuming different level of cognitive impairment, and sought to explore the factors associated with the preferences and the degree to which patients and family members agree on preferences.

Materials and Methods

A total of 358 elderly cancer patient and caregiver dyads were recruited from the 11 cancer centers in Korea and were asked to express their preferences for family involvement in treatment decision making using hypothetical scenarios with three different levels of cognitive status (intact, mild impairment, and severe impairment).

Results

Both patients and family caregivers preferred greater family dominance in treatment decision making with the increasing the level of cognitive impairment (39.7%, 60.9%, and 86.6% for patients and 45.0%, 66.2%, and 89.7% for caregivers in each scenarios). Patient and family caregiver concordance in decisional control preference was small for all three scenarios (weighted $\kappa=0.32$, $\kappa=0.26$, and $\kappa=0.36$, respectively). Higher patient education was associated with preference for patient dominance in treatment decision in conditions of both mild and severe cognitive impairment. The association of higher patient education and patient-caregiver preference concordance was positive with intact cognition, while it was negative with severe cognitive impairment.

Conclusion

Decision control preferences were affected by hypothesized cognitive status of the patients. Findings from our study would be helpful to develop effective strategy for optimizing family involvement in cancer treatment decision in the context of deteriorating cognitive function of the patients.

Key words

Neoplasms, Family involvement, Cognitive function, Treatment decision, Caregivers

Introduction

The ability to engage in the process of medical decision making is contingent on a patient's capacity to understand and use medical information to make treatment decisions consistent with one's values and preferences [1]. While cognitive function is an important component of capacity, with the exception of end-of-life decisions [2,3], relatively little research has focused on how patients and family members approach treatment decisions under conditions of cognitive impairment.

Older patient populations commonly suffer some degree of cognitive impairment (CI) as a result of the normal aging process and comorbid medical conditions, as well as the potentially transitory effects of dehydration, medication side effects, anxiety, and depression. These patients are also at high risk for a cancer diagnosis; studies report that between 24% and 38% of elderly cancer patients have CI [4,5]. This impairment is likely to diminish decision making capacity at diagnosis, and late effects of cancer treatment (e.g., brain irradiation or chemotherapy [6-8]), is likely to further affect subsequent medical decisions.

While cancer treatment decision making is challenging for everyone, elderly patients face the additional burden of choosing among treatment options with diminished cognitive capacity and their families struggle with how best to support and protect them. This study was designed to contribute to the small literature in this area by examining preferences and agreement for family involvement in treatment decision making from the perspective of patients and family caregivers when presented with treatment scenarios in which a patient has no, mild, or severe cognitive impairment. We also sought to explore the factors associated with preferences for patients' active participation in treatment decision making and the degree to which patients and family members agree on preferences.

Materials and Methods

1. Study participants

Cancer patients 60 years or older and their caregivers were eligible for the the 2014 Cancer Patient Experience (CaPE) Survey, a nationwide, multicenter survey of the experience of cancer patients and their caregivers. We recruited participants from the National Cancer Center and other 10 regional cancer centers in Korea. Patients accompanied by family caregivers in outpatient waiting areas were recruited by

trained research assistants who explained the survey purpose and procedures. Inclusion criteria for patients were as follows: (1) age 60 or older, (2) diagnosis of stomach, lung, or colorectal cancer, (3) currently receiving cancer treatment or follow-up care, and (4) in sufficient physical and mental health to complete the study questionnaire as judged by the trained research assistants. Patients who were diagnosed with dementia were excluded from the study.

After patients agreed to participate in the survey, adult family caregivers (age ≥ 18) accompanying the patient to their cancer visit were also asked to participate in the survey. Patients and family members were instructed to complete the questionnaires independently and shown to separate areas of the waiting room to avoid consultation. For this study, we used patient-caregiver linked data.

2. Measures

Patients and family members were asked to express their preferences for family involvement in cancer treatment decision making using hypothetical scenarios with three different levels of cognitive status (intact, mild impairment, and severe impairment). As in previous studies [2,3,9,10], a modification of the Decision Control Preferences Scale [11] was used to examine patient and family decisional control preferences. The response categories included: 1 (the patient makes the treatment decision on his/her own); 2 (the patient makes the treatment decision after hearing the family's opinion); 3 (the family makes the treatment decision after hearing the patient's opinion); and 4 (the family makes the treatment decision on their own). A pilot test with 10 patient-family member dyads confirmed that the questions and response options were clearly understood by the subjects.

Response options were on a 4-point ordinal scale reflecting the theoretical position that decision-making is unlikely to be equally shared [12] and the tendency of Asian respondents to choose a middle response style [13]. Respondents were asked to respond to three versions of the following question: "What do you think the desirable level of family involvement is in deciding your (patient version) or the patient's (caregiver version) cancer treatment when you (patient version) or the patient (caregiver version) has ([first ending] intact cognition) ([second ending] mild cognitive impairment) ([third ending] severe cognitive impairment).

Socio-demographic and medical information was obtained from study participants and the medical records of the patients were reviewed to collect information on American Joint Committee on Cancer (AJCC) cancer stage, treatments, and other medical information.

3. Statistical analyses

Patient and family caregiver responses to the decision preference questions were arrayed and examined by Friedman test to determine if there is difference in distribution between the dyads and between the different hypothetical scenarios (intact vs. mild impairment and mild vs. severe impairment). Next, we evaluated patient-family caregiver agreement on decisional control preference when presented with scenarios for intact cognition, mild impairment, or severe impairment by calculating percent agreement and kappa scores. Cases with missing response of either patients or family caregiver were excluded from the denominator. We also explored the association between patient and family caregiver characteristics and decisional control preferences with multivariate logistic regression, by dichotomizing responses into active patient (patient lead) or active family (family lead) as was done in previous studies [2,9]. All data analyses were conducted using STATA ver. 14.0 (StataCorp., College Station, TX).

4. Ethical statement

The study was approved by the Institutional Review Board of National Cancer Center (IRB No. NCCNCS13787) and performed in accordance with the principles of the Declaration of Helsinki. Written informed consents were obtained.

Results

1. Subject characteristics

A total of 358 patient and caregiver dyads enrolled in the study and completed provided complete survey information. Patients were on average 71 years of age, and 62% were male and slightly less than one-third had at least a college education (Table 1). Of total, 42.5% and 38.5% were stomach and colorectal cancer patients and disease was staged as AJCC stage I (42.5%), II (17.3%), III (35.8%), and IV (1.7%). More than half of the patients (54.2%) were diagnosed within 1 years of the survey date, and most received surgery (85.2%). Family caregivers were predominantly spouses (50.8%) and adult children (46.7%) and two-thirds of patients lived with their family caregiver.

2. Decision control preferences and cognitive status

As displayed in Fig. 1, there were significant differences in decision control preferences across levels of cognitive impair-

Table 1. Characteristics of patient-caregiver dyads

Patient characteristic	No. (%) (n=358)
Age, mean±SD (yr)	71.1±6.2
Sex	
Male	222 (62.0)
Female	136 (38.0)
Educational status	
High school or less (< 12 yr)	248 (69.3)
College and above (≥ 12 yr)	110 (30.7)
Income status	
< 2 million KRW	263 (73.5)
≥ 2 million KRW	79 (22.1)
Missing	16 (4.5)
Health insurance status	
National Health Insurance	347 (96.9)
Medical aid	9 (2.5)
Others	2 (0.6)
Cancer type	
Stomach	150 (42.5)
Lung and bronchus	68 (19.0)
Colorectal	138 (38.5)
AJCC cancer stage	
I	162 (45.3)
II	62 (17.3)
III	128 (35.8)
IV	6 (1.7)
Time since diagnosis, mean±SD (yr)	1.1±0.6
< 1 yr	194 (54.2)
1-2 yr	153 (42.7)
> 2 yr	11 (3.1)
Treatment received	
Surgery	305 (85.2)
Chemotherapy	175 (49.3)
Radiotherapy	53 (15.4)
Caregiver characteristics	
Age, mean±SD (yr)	56.0±13.7
Sex	
Male	119 (33.2)
Female	239 (66.8)
Educational status	
High school or less (< 12 yr)	242 (67.7)
College and above (≥ 12 yr)	115 (32.1)
Missing	1 (0.3)
Income status	
< 2 million KRW	171 (47.8)
≥ 2 million KRW	177 (49.4)
Missing	10 (2.8)

(Continued to the next page)

Table 1. Continued

Patient characteristic	No. (%) (n=358)
Relationship to the patients	
Spouse	182 (50.8)
Adult children	167 (46.7)
Son	69 (19.3)
Daughter	63 (17.6)
Daughter in law	32 (8.9)
Son in law	3 (0.8)
Brother/Sister	9 (2.5)
Caregiving duration	
Mean±SD	1.7±2.8
< 1 yr	206 (60.4)
1-2 yr	100 (29.3)
> 2 yr	35 (10.3)
Missing	17 (4.4)
Living with the patients	
Yes	226 (63.1)
No	131 (36.6)
Missing	1 (0.3)

SD, standard deviation; KRW, Korean won; AJCC, American Joint Committee on Cancer.

ment; moreover, these differences were largely consistent for both patients and caregivers. More specifically, when considering treatment decisions under circumstances of intact cognitive function, 35% patients (n=125) and 36.0% caregivers (n=129) preferred that patients lead with input from family members while patients were more likely than caregivers to prefer that decisions are patient directed (25% [n=90] vs. 18% [n=66]) while caregivers were more likely to prefer that decisions were family lead with patient input than patients (39% [n=139] vs. 30% [n=108]). Under the condition of mild cognitive impairment, 45% (n=162) of patients and 55% (n=196) of caregivers preferred the family lead decisions with patient input. Finally, under the condition of severe cognitive impairment, the majority of patients (57% [n=207] and 49% [n=177]) of caregivers preferred to have the family make treatment decisions. A sizeable minority of patients (29%, n=103) and caregivers (40%, n=144) thought that families should lead these decisions with patient input.

3. Concordance among responses

Percentage agreement between patients and caregivers in responses to each scenario were 46.5%, 49.0%, and 60.8%, respectively. The weighted kappa reflecting patient and family caregiver concordance in decisional control preference was small but statistically significant for all three scenarios ($\kappa=0.32$, $\kappa=0.26$, and $\kappa=0.36$, respectively) (Table 2).

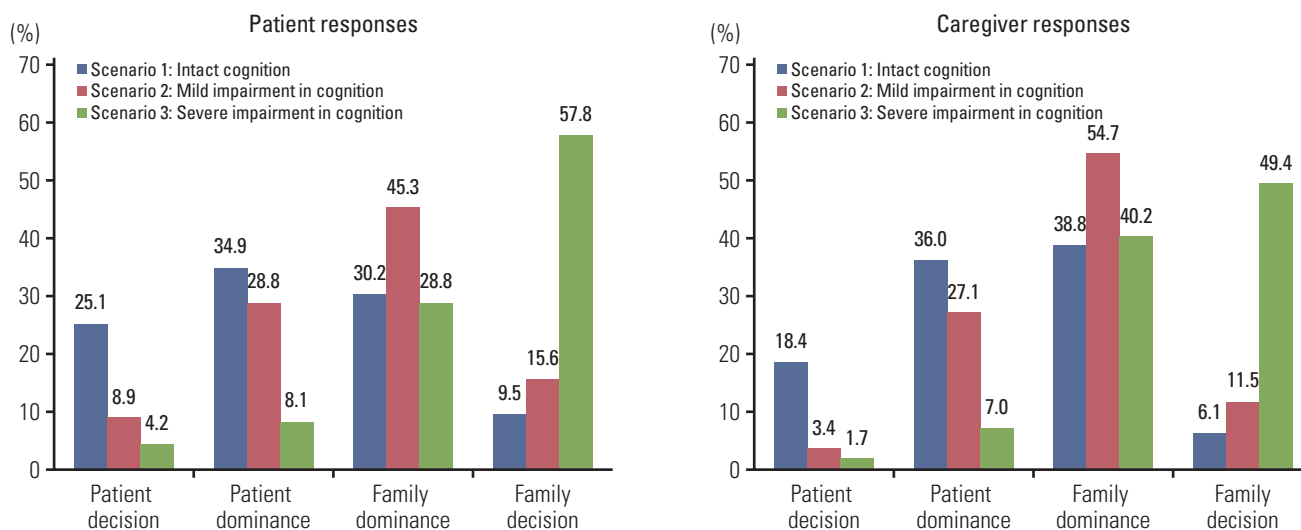


Fig. 1. Distribution of patient and caregiver responses to decision control preferences question by patients' hypothetical cognitive status. There was no significant difference in the level of decision control preference between patient and caregivers for all three scenarios ($p > 0.05$). There was significant difference in the level of decision control preference between scenarios (scenario 1 vs. scenario 2 and scenario 2 vs. scenario 3, $p < 0.05$, respectively).

Table 2. Concordance of patient and caregiver responses to decision control preferences question by patients' hypothetical cognitive status

Patient responses	Caregiver responses					Concordance		
	Patient decision	Patient dominance	Family dominance	Family decision	Missing response	Total	Agreement (%)	Weighted κ
Scenario 1: Intact cognition								
Patient decision	33 ^{a)}	35	20	1	1	90	46.48	0.319
Patient dominance	23	59 ^{a)}	36	7	0	125		
Family dominance	9	27	65 ^{a)}	6	1	108		
Family decision	1	7	18	8 ^{a)}	0	34		
Missing response	0	1	0	0	0	1		
Total	66	129	139	22	2	358		
Scenario 2: Mild impairment in cognition								
Patient decision	4 ^{a)}	12	13	2	1	32	48.98	0.258
Patient dominance	2	43 ^{a)}	51	2	5	103		
Family dominance	4	36	101 ^{a)}	17	4	162		
Family decision	2	6	28	20 ^{a)}	0	56		
Missing response	0	0	3	0	2	5		
Total	12	97	196	41	12	358		
Scenario 3: Severe impairment in cognition								
Patient decision	3 ^{a)}	2	7	3	0	15	60.74	0.363
Patient dominance	0	7 ^{a)}	13	7	2	29		
Family dominance	3	10	64 ^{a)}	26	0	103		
Family decision	0	6	60	138 ^{a)}	3	207		
Missing response	0	0	0	3	1	4		
Total	6	25	144	177	6	358		

Weighted kappa values are statistically significant for all scenarios ($p < 0.05$). ^{a)}Agreement between patient and caregiver in the dyads.

Table 3. Factors associated preferences for patients' active participation and agreement between dyads

Characteristic	Patient responses			Caregiver responses			Agreement between dyads		
	By hypothesized cognitive status		Severe impairment	By hypothesized cognitive status		Severe impairment	By hypothesized cognitive status		Severe impairment
	Intact	Mild impairment		Intact	Mild impairment		Intact	Mild impairment	Severe impairment
Patient									
Age, per year	0.94 (0.91-0.97)	0.96 (0.92-0.99)	0.96 (0.91-1.01)	-	-	-	1.02 (0.97-1.07)	1.01 (0.96-1.06)	1.03 (0.96-1.11)
Female	0.66 (0.41-1.05)	0.63 (0.39-1.02)	0.72 (0.33-1.57)	-	-	-	0.87 (0.5-1.53)	1.03 (0.58-1.82)	1.66 (0.71-3.91)
Higher education (≥ 12 yr)	1.25 (0.75-2.09)	1.82 (1.11-2.99)	3.05 (1.53-6.09)	-	-	-	1.82 (1.02-3.26)	0.67 (0.40-1.15)	0.44 (0.22-0.86)
Caregiver									
Age, per year	-	-	-	1.02 (0.99-1.05)	0.98 (0.95-1.02)	1.00 (0.94-1.05)	1.02 (0.98-1.06)	1.02 (0.98-1.06)	1.01 (0.95-1.08)
Female	-	-	-	1.66 (1.04-2.67)	0.93 (0.56-1.55)	1.94 (0.76-4.93)	1.41 (0.83-2.40)	1.31 (0.76-2.24)	1.25 (0.57-2.77)
Higher education (≥ 12 yr)	-	-	-	1.55 (0.92-2.60)	1.46 (0.84-2.53)	2.98 (1.21-7.35)	0.97 (0.55-1.72)	1.26 (0.71-2.21)	0.76 (0.35-1.65)
Spouse	-	-	-	0.78 (0.34-1.80)	1.96 (0.78-4.92)	2.13 (0.45-9.97)	0.81 (0.23-2.83)	0.78 (0.23-2.67)	0.61 (0.10-3.82)

Agreement between dyads was defined after dichotomization of the patients and caregiver responses into patients' active participation (patient decision and patient dominance combined) vs. not (family dominance and family decision combined). Multivariate logistic regression analyses included patient variables (age, sex, and education) for patient responses, caregiver variables (age, sex, education, spouse vs. others) for caregiver responses, and both for agreement between dyads.

4. Patient and Caregiver factors associated with decision control preferences

As reflected in Table 3, older patients preferred less active participation in treatment decisions under conditions of intact cognition and mild impairment. Patients with higher levels of education preferred to dominate or lead decisions in contrast to less educated patients in conditions of both mild and severe CI with an odds ratio (OR) of 1.82 and 3.05, respectively.

Also displayed on Table 3 are two findings related to patient and caregiver agreement on decisional preferences. Higher education of patients was significantly associated patient-caregiver preference concordance when intact cognition was assumed; however, the association changed direction under conditions of severe CI such that the more highly educated the patient, the lower the agreement with caregivers regarding decisional preferences. Interestingly, more highly educated caregivers also preferred greater levels of patient decisional control under circumstances of severe impairment relative to less well educated caregivers (OR, 2.98).

Discussion

In this nationwide study of 358 cancer patients and their family caregivers, we systematically investigated preferences for family involvement in cancer treatment decision making when presented with scenarios across conditions of cognitive status. Under conditions of intact cognitive function, patients relative to caregivers were more likely to endorse patient directed decision making and less likely to endorse family led decisions. Both patients and family caregivers expressed a preference for greater family dominance in treatment decision making as the level of CI increased. While roughly half of patients and caregivers expressed a preference for the family to lead decisions, with patient input, under conditions of mild impairment, roughly 30% of both patients and caregivers preferred that patients lead decisions, with family input. In contrast, under the condition of severe impairment, about half of both patients and caregivers preferred that decisions be family directed; in this instance, however some 30% of patients and 40% of caregivers thought that family should lead the decision with patient input.

It seems quite natural that family take over the treatment decisions when CI is severe and likely to hinder decision making capacity [14], and is consistent with the findings from an observational study in which dementia family caregivers took a dominant or exclusive role in treatment deci-

sions as cognitive function declined [15,16].

Between 46% and 61% of patient and family dyads agreed on decision control preferences across scenarios, suggesting that a failure to agree is common and could be a source of family conflict, as has been observed in geriatric studies [17]. It is well known that family caregivers do not have an accurate sense of patients' values and preferences [1]; furthermore, the agreement rates found in this study are comparable to ultrasonographic findings of patient and family caregiver agreement on preferences for family involvement in decision making when considering conditions in which the patient is conscious (56%) or unconscious (46%) [2].

While patients appear to recognize the need for the family to lead treatment decisions under conditions of cognitive deterioration, many patients express a preference for continued involvement in making decisions about their own treatment and care [1,18,19]. Despite preferences to the contrary, actual involvement is often limited even at levels of mild impairment with family caregivers directing treatment decisions without patient input in consultation with physicians [18,20]. In some cases patients are excluded from participating in decisions because caregivers believe they are reducing patient burden and a source of distress [21], although a number of studies suggest that people with CI are usually able to communicate their values and preferences and can be active participants in treatment decisions [16,22]. Other studies suggest that some persons with dementia fear their future cognitive decline and subsequent loss of autonomy, and avoid involvement in treatment decisions [23,24], perhaps as a self-protective mechanism [16].

Health care providers often rely on family members to make treatment and care decisions for patients with cognitive impairment, but current legal and ethical standards (e.g., The Mental Capacity Act 2005 in England and Wales) requires the safeguarding of the rights of people with limited capacity to make their own decisions for as long as possible [21].

Our study found that younger and more highly patients preferred greater decisional control, consistent with previous studies similarly finding that younger and better educated dementia patients remain involved in treatment decisions [15,18]. Female gender of caregiver was associated with preference for greater involvement of patients in treatment decisions, while male gender of the patients was negatively associated with it with marginal statistical significance. Such conflicting direction of influence of gender on treatment decisions involvement was also noted in previous studies [18,25], and may reflect the traditional gender role in households in which most medical decisions are made by male [16]. Spouse caregivers showed some non-significant trends toward more active patient engagement in decision making, also consistent with previous studies with dementia [18,25]. Consistency with previous empirical studies, we believe that

the hypothetical scenarios presented in the current study are likely to reflect actual practice.

One interesting finding of our study was that higher education of patients was associated with higher agreement in intact scenario, but changed to higher disagreement in CI scenarios. Patients with higher education tend to actively participate in the decision, and their wish agree with the family caregivers general willingness to involve them in treatment decisions [25]. However, patients want to remain involved in treatment decisions even when their cognitive function declines, while caregivers want to take a custodial role under this circumstance.

The clinical implications of our findings are that providers need to anticipate transitions in decisional preference among patients and their caregivers as cognitive status declines and that they may be able to support their patients and their families during this period in a variety of ways. First, screening and periodic assessment of CI using validated instruments to assess capacity, such as MacArthur Competency Assessment Tool for Treatment (MacCAT-T) [1,26], carries information that patients and their family caregivers want and need as they consider transitions in cognitive status and what that might mean for how treatment decisions are made. This is critically important since estimates of patients' decisional capacity only weakly correlates with objective assessment [1] and a determination of decisional capacity can achieve the proper balance between patient autonomy and best interest.

Second, clinicians can help patients and family caregivers to involve patients as much as possible by using simple language, repeating key points, asking targeted questions and obtaining verbal feedback about their understanding. Family caregiver can be also helped by information, emotional support, or communication skill training. Several interventions have been shown to be effective in improving the shared decision-making process among dyads of patients with dementia and their family caregivers [27-29].

Finally, the study findings indicate the need for regular assessments of patients' values and preferences to improve communication about treatment decisions within the patient-caregiver dyad from the early stages of cognitive impairment. CI in elderly cancer patients is usually progressive and can change rapidly due to complications from cancer or its treatment underscoring the need to discuss issues such as the goals of care, treatment preference, advance directives and surrogate decision makers while the patient still has capacity.

Several methodological limitations are noteworthy. First, the elderly cancer patients who were accompanied by family caregivers may be different in sociodemographic characteristics (e.g., age, education, and health status) than patients who chose not to participate or were not accompanied by a caregiver. These differences could influence their decisional control preferences. Secondly, we did not consider the issue

of multiple caregivers who may share caregiving tasks and participate in treatment decisions. Third, our analytic framework was focused on dyadic relationship between patients and family caregivers, and did not consider the clinicians who are also important stakeholders in treatment decisions. Fourth, our study is based on scenarios and preferences expressed in response to hypothetical situations which may differ from those made under actual circumstances. Nevertheless, it is likely that the patients who show a preference for greater decisional involvement will be more involved in actual treatment decisions [30]. Moreover, all advance care planning needs to be based on the use of hypothetical situations by their very nature. Fifth, while our study is geographically nationwide, we could not determine representativeness of our sample as we could not collect information on the non-participants. However, participation rates in the CaPE surveys conducted in similar settings in previous years were estimated to be between 70% and 80%. Finally, our study was conducted in South Korea, which has a tradition of Confucianism that individuals defer to the family in matters that consider the well-being of all members of a family. While a number of findings are consistent with those reported in Western studies, the generalizability across cultures should be further investigated.

Elderly patients now comprise the majority of cancer patient population in developed countries and are fast growing in developing countries. CI is common and may complicate treatment decision making process and threat patient autonomy. However, unfortunately, few guidelines are available for clinicians to guide treatment decision making of the elderly cancer patients with CI and their family caregivers. Findings from our study would be helpful to develop effective strategy for optimizing family involvement in cancer treatment decision in the context of deteriorating cognitive function of the patients.

Conflicts of Interest

Conflict of interest relevant to this article was not reported.

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