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PAPER

Attitudes Toward Family Involvement in Cancer Treatment Decision Making: The Perspectives of Patients, Family Caregivers, and Their Oncologists

Dong Wook Shin^{1,2} | Juhee Cho^{3,4,5} | Debra L. Roter⁵ | So Young Kim^{6,7} | Hyung Kook Yang⁶ | Keeho Park⁶ | Hyung Jin Kim⁸ | Hee-Young Shin⁹ | Tae Gyun Kwon^{10,11} | Jong Hyock Park^{6,7*}

¹Department of Family Medicine and Health Promotion Center, Seoul National University Hospital, Seoul, Korea

²Cancer Survivorship Clinic, Seoul National University Cancer Hospital, Seoul, Korea

³Cancer Education Center, Samsung Comprehensive Cancer Center, School of Medicine and SAHIST, Sungkyunkwan University School of Medicine, Seoul, Korea

⁴Department of Epidemiology, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA

⁵ Department of Health, Behavior, and Society, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA

⁶National Cancer Control Institute, National Cancer Center, Goyang, Korea

⁷College of Medicine/Graduate School of Health Science Business Convergence, Chungbuk National University, Cheongju, Korea

⁸Department of Urology, Chonbuk National University Medical School, Jeonju, Korea

⁹ Department of Biomedical Science, Chonnam National University Medical School, Gwangju, Korea

¹⁰ Department of Urology, Kyungpook National University School of Medicine, Daegu, Korea

¹¹ Joint Institute for Regenerative Medicine, Kyungpook National University Hospital, Daegu, Korea

Correspondence

College of Medicine/Graduate School of Health Science Business Convergence, Chungbuk National University, Cheongju 361-763, Korea Email: jonghyock@gmail.com

1 | INTRODUCTION

Abstract

Background To investigate how cancer patients, family caregiver, and their treating oncologist view the risks and benefits of family involvement in cancer treatment decision making (TDM) or the degree to which these perceptions may differ.

Patients and Methods A nationwide, multicenter survey was conducted with 134 oncologists and 725 of their patients and accompanying caregivers. Participant answered to modified Control Preferences Scale and investigator-developed questionnaire regarding family involvement in cancer TDM.

Results Most participants (>90%) thought that family should be involved in cancer TDM. When asked if the oncologist should allow family involvement if the patient did not want them involved, most patients and caregivers (>85%) thought they should. However, under this circumstance, only 56.0% of oncologists supported family involvement. Patients were significantly more likely to skew their responses toward patient rather than family decisional control than were their caregivers (P < .003); oncologists were more likely to skew their responses toward patient rather than family decisional control than caregivers (P < .001). Most respondents thought that family involvement is helpful and neither hamper patient autonomy nor complicate cancer TDM process. Oncologists were largely positive, but less so in these ratings than either patients or caregivers (P < .002).

Conclusions Patients, family caregivers, and, to a lesser degree, oncologists expect and valued family involvement in cancer TDM. These findings support a reconsideration of traditional models focused on protection of patient autonomy to a more contextualized form of relational autonomy, whereby the patient and family caregivers can be seen as a unit for autonomous decision.

KEYWORDS

autonomy, cancer, communication, decision making, family caregiver

Family caregivers not only provide emotional and physical support in the care of cancer patients¹ but also play an important role in treatment decision making (TDM).^{2,3} Family members often

accompany patients to a physician visit^{2,4,5} and help the patients obtain and understand information relevant to treatment decisions.^{2,5} Patients often want to discuss treatment decisions with family members,⁶ and their decisions and preferences are often influenced by them.^{6,7}

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Previous literature regarding cancer TDM has largely reflected individual patient preferences for decision-making control.^{1,12} While studies from Canada,⁶ Germany,¹³ and Korea¹⁰ suggest that most patients and family caregivers agree that the family should be involved in cancer TDM, these studies have not investigated these preferences in terms of perceived benefits or harms of family involvement. Moreover, none of the studies addressing family involvement in TDM have investigated the perspectives of treating oncologists and the degree to which their perspectives might differ from those of their patients and family caregivers. The current study was designed to contribute to this literature by examining the perspectives regarding family involvement in cancer TDM of patients, family caregivers, and the treating oncologist. Our study was theoretically guided by interpersonal health care process model emphasizing triadic patient-family-provider exchanges.¹⁴

2 | METHODS

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2.1 | Study design and subjects

This study was performed as part of the Cancer Patient Experience Study, which has been conducted annually nationwide to develop comprehensive supportive care in Korea. In 2012, the 5th Cancer Patient Experience survey examined matched physician-patient-caregiver triads to explore and compare their views on cancer care. The National Cancer Center and 12 government-designated Regional Cancer Centers participated in the survey. The study was approved by the institutional review board of the National Cancer Center.

Ten board-certified oncologists were approached in each of 13 cancer centers across Korea and asked to recruit their patients, along with a caregiver, to the study. Of the 144 oncologists invited, 134 (93%) agreed to participate in the study. Inclusion criteria for patients were (1) \geq 18 years of age, (2) histologically confirmed to have cancer, (3) currently receiving cancer treatment or follow-up care, and (4) physically and mentally able to complete study questionnaires. Caregivers were included if they were at least 18 years of age. Patient-caregiver dyads were enrolled only if both agreed to participate in the study.

2.1.1 | Patient and caregiver recruitment

The oncologists provided a brief overview of the study to consecutive sample of eligible subjects and referred those who were interested to the research coordinator. The coordinator explained the study in more detail and obtained written informed consent. Among the 960 dyads invited to participate, 725 dyads (75.5%) agreed and completed the survey. Consenting patients and family members were instructed to

complete the questionnaires independently and shown to separate areas of the waiting room to avoid consultation. Oncologists recruited 6 dyads on average (range: 1-15).

2.2 | Measures

Questionnaires examining attitudes toward family involvement in cancer TDM were linked as patient-caregiver-oncologist triads. A modified version of the Control Preferences Scale¹⁵ was used to measure preferences for family involvement in cancer TDM, as used in other studies.^{10,16} Respondents were asked to respond to two 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 and oncologist version) cancer treatment when [(first ending) treatment is curative and decisions are needed in regard to surgery chemotherapy or radiotherapy] [(second ending) when treatment is palliative and decisions are made after recurrence or metastasis]."

Five response options are as follows:

- 1. The patient makes the treatment decision on his or her own;
- The patient makes the treatment decision after hearing the family's opinion;
- 3. The patient and the family decide together;
- The family makes the treatment decision after hearing the patient's opinion;
- 5. The family makes the treatment decision.

Original questions were drafted by the investigators to address perceived benefit/harm of family involvement in cancer TDM as follows: Respondents were asked to rate the degree to which family involvement is (3-point Likert scale: harmful, neither harmful or helpful, or helpful) in regard to communication, treatment decisions, and psychological support. Respondents were also asked to indicate their degree of agreement (4-point Likert scale) with the following statements regarding family involvement in cancer TDM: It hampers patient autonomy, complicates the cancer TDM process, and leads to a harmonious decision, and Families have the right to be involved.

Sociodemographic and medical information was obtained from study participants and primary cancer diagnosis, disease stage, and time since diagnosis was retrieved from the hospital information systems.

2.3 | Statistical analysis

Responses to each question were cross-tabulated and the mean values were computed for each group. The differences between groups were tested by paired *t*/McNemar tests (for matched patient-caregiver comparison) or Student's *t*/chi-square tests (for patient-physician and caregiver-physician comparison), as appropriate for continuous/categorical variables. All statistical analyses were conducted using STATA version 13.0 (StataCorp., TX, USA); *P* value <.05 was considered statistically significant.

3 | RESULTS

3.1 | Subject characteristics

Patients averaged 60 years of age and a slight majority (55%) were female. Most patients (85%) were married and somewhat more than half reported a monthly income of <2 million KRW (US\$ 2000) (58%) and greater than a high school education (52%). Colorectal, stomach, breast, and lung cancers were the most common diagnoses; 45% of the patients were receiving active treatment and about one-third were being seen for a routine follow-up after completion of treatment. Disease was staged as local (36.0%), regional (31.7%), and distant/metastatic (30.8%). Caregivers were mainly spouses (60.3%) and adult children (28.6%). Adult children caregivers were better in terms of education and financial security than the patients (Table A1).

The participating oncologists were primarily surgical (51%) and medical oncologists (44%) with an average of 12 years since board certification. They were predominantly male (80%) and averaged 43 years of age (Table A2).

3.2 | Attitudes toward family involvement among patients

Nearly all respondents in each group (>90%) thought the family should be involved in cancer TDM. When asked if the oncologist should allow family involvement in cancer TDM if the patient did not want them involved, most patients and caregivers (>85%) thought they should. Oncologists were less likely to support family involvement than either patient or caregiver in this case (56.0%, Ps < .001) (Table 1).

3.3 | Decision control preferences according to treatment phase

Overall, patients were significantly more likely to skew their responses toward patient rather than family decisional control than were their caregivers (P < .003 for both curative and palliative care); oncologists were also more likely to skew their responses toward patient rather than family decisional control than caregivers (P < .001 for both curative and palliative care). A similar finding is also evident for the comparison between patients and oncologists; in this case, however, the difference is statistically significant for curative care (P = .001) and suggestive for palliative care (P = .061) (Table 2).

There were no differences in decision control preferences of patients and caregivers when considering curative vs palliative care (patients rating for curative care 2.78 vs palliative care 2.80, P > .3; caregiver ratings for curative: 2.89 vs palliative: 2.92, P > .2). Oncologists, however, gave more importance to the family's role in decision control in palliative relative to curative care (2.66 vs 2.54, P = .004).

3.4 | Perceived benefit/harm of family involvement

Most respondents thought that family involvement in cancer TDM is helpful as displayed in Table 3. The great majority of respondents thought family involvement was helpful in regard to communication, treatment decisions, and psychological support (positive endorsements ranged from 76% to 93%). Although the majority of oncologists endorsed family involvement as helpful to communication and treatment decisions, they were significantly less positive in their ratings than either patients or caregivers (P < .002). Ratings of helpfulness of family involvement for psychological support were nearly identical for patients, caregivers, and oncologists. Cronbach alpha values for 3-item questionnaire to measure perceived benefit/harm were .86, .80, and .61 for patients, caregiver, and oncologists, respectively.

3.5 | Attitudes toward family involvement in TDM process

Overall patients and caregivers were more positive in their attitudes toward family involvement in cancer TDM than oncologists. As reflected in Table 4, these ratings were significantly more positive in regard to family involvement not hampering patient autonomy, complicating the decision-making process or in regard to the family's right to be involved (all $P_{\rm S}$ < .001). Only in response to the statement that family involvement leads to a more harmonious decision is there no difference across the triads.

4 | DISCUSSION

In this Korean study of patient-caregiver-oncologist triads, we investigated attitudes and preferences toward family involvement in the cancer TDM. All three members of the surveyed triad endorsed family involvement in cancer TDM, as helpful and positive; however, oncologists were somewhat less positive in their attitudes toward the utility of family involvement than patients or family caregivers.

Consistent with previous reports that cancer patients valued their family caregivers' opinion^{2,16} and wanted them to be involved in cancer TDM,^{13,17,18} patients in our survey similarly expected their family members to be involved in cancer TDM. The great majority of caregivers also thought that they should be involved in the cancer TDM, consistent with the literature. In a US study with localized prostate cancer patients, most family members strongly agreed that their role included making treatment decisions (65%-79%).¹⁶

Oncologists were generally positive about family involvement in cancer TDM, again consistent with previous studies in which they recognize that family members' opinion influences treatment choice,^{4,5} and lack of support from family could lead to suboptimal treatment.¹⁹ Indeed, most US physicians discuss treatment options with the family caregivers and encourage them to ask questions.¹⁶ However, compared with the patients and family caregivers, they were more likely to support patient control in cancer TDM. Relatedly, physicians were less likely to agree with the helpfulness of family involvement for communication and decision making and more likely to worry about potential threat to patient autonomy and complicated process from family involvement. Physicians were educated with the medical ethics of patient autonomy during medical school and might have experienced adverse effect of excessive family involvement in their practice.^{5,20}

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TABLE 1 Attitudes Toward Family Involvement Among Patients, Caregivers, and Physicians

	Patients	(N = 725)	Caregiver	s (N = 725)	Physician	is (N = 134)	Difference (P value)		e)
	n	%	n	%	n	%	Patient- caregiver	Patient- physician	Caregiver- physician
Do you think th	e family shoul	d be involved	l in the cance	r treatment de	ecision?				
Yes	687	94.8	706	97.4	132	98.5	.009	.164	.713
No	36	5.0	18	2.5	2	1.5			
Missing	2	0.3	1	0.1	0	0.0			
Do you think the want it?	e health care p	roviders shou	uld allow the f	amily be invol	ved in cance	r treatment deo	cision even when	the patient himself	or herself does not
Yes	629	86.8	617	85.1	75	56.0	.265	<.001	<.001
No	91	12.6	105	14.5	58	43.3			
Missing	5	0.7	3	0.4	1	0.8			

P-value: McNemar test (patient-caregiver); chi-squared test (patient-physician, caregiver-physician).

TABLE 2 Decision Control Preferences in Curative and Palliative Phase Among Patients, Caregivers, and Physicians

	Patie (N = 7	PatientsCaregiversPhysicians(N = 725)(N = 725)(N = 134)		icians 134)	Difference (P value) ^a				
	n	%	n	%	n	%	Patient- caregiver	Patient- physician	Caregiver- physician
Decision control preference in curative p	hase								
Patient solely decides (score = 1)	70	9.7	39	5.4	5	3.7			
Patient decides considering family opinion (score = 2)	104	14.3	103	14.2	53	39.6			
Patient and family decide together (score = 3)	476	65.7	490	67.6	74	55.2			
Family decides considering patient's opinion (score = 4)	56	7.7	77	10.6	2	1.5			
Family solely decides (score = 5)	16	2.2	13	1.8	0	0.0			
Missing	3	0.4	3	0.4	0	0.0			
Mean, SD	2.78	0.81	2.89	0.73	2.54	0.60	.003	.001	<.001
Decision control preference in palliative	phase								
Patient solely decides (score = 1)	69	9.5	42	5.8	2	1.5			
Patient decides considering family opinion (score = 2)	102	14.1	91	12.6	47	35.1			
Patient and family decide together (score = 3)	455	62.8	469	64.7	79	59.0			
Family decides considering patient's opinion (score = 4)	69	9.5	93	12.8	6	4.5			
Family solely decides (score = 5)	16	2.2	13	1.8	0	0.0			
Missing	14	1.9	17	2.3	0	0.0			
Mean, SD	2.80	0.83	2.92	0.75	2.66	0.59	.002	.061	<.001
Difference between curative-palliative (p-value) ^b	0.354		0.189		0.004				

Abbreviation: SD, standard deviation.

^aP-value: Paired t test (patient-caregiver); T test (patient-physician, caregiver-physician).

^bP-value: Paired t-test.

Patients and family caregivers preferred shared decision between the patient and family caregivers irrespective of the nature of care being delivered (ie, curative or palliative). This is consistent with studies suggesting that patients' role preference in cancer TDM showed little variability over time and remains consistent regardless of situations.²¹ Similar stability was found in the decision control preference of terminally ill patients in the United States and Belgium.^{18,22} Oncologists, however, were significantly more positive about family involvement in palliative care than curative care. This might be because family involvement in cancer TDM happens more frequently within palliative setting than curative care settings, when patients' physical and mental conditions are deteriorated and caregiving burden increases.^{17,18}

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Most patients and caregivers in our study thought that the family should be involved in cancer TDM even if a patient did not want their family involvement. This may raise concern for possible subversion of

TABLE 3 Perceived Benefit/Harm of Family Involvement Among Patient, Caregivers, and Physicians

	Patients (N = 725)	Caregivers	(N = 725)	Physicians	(N = 134)	Difference (P-value)		lue)
	n	%	n	%	n	%	Patient- caregiver	Patient- physician	Caregiver- physician
Family involvement is fo	r communio	ation.							
Harmful (score = 1)	9	1.2	9	1.2	5	3.73			
Neither harmful nor helpful (score = 2)	44	6.1	55	7.6	18	13.4			
Helpful (score = 3)	668	92.1	660	91.0	111	82.8			
Missing	4	0.6	1	0.1	0	0.0			
Mean, SD	2.91	0.3	2.90	0.3	2.79	0.5	.337	<.001	.002
Family involvement is fo	r treatment	decision.							
Harmful (score = 1)	6	0.8	6	0.8	2	1.5			
Neither harmful nor helpful (score = 2)	59	8.1	59	8.1	30	22.4			
Helpful (score = 3)	657	90.6	660	91.0	102	76.1			
Missing	3	0.4	0	0.0	0	0.0			
Mean, SD	2.90	0.3	2.90	0.3	2.75	0.5	1.000	<.001	<.001
Family involvement is fo	r psycholog	ical suppor	rt.						
Harmful (score = 1)	6	0.8	3	0.4	1	0.8			
Neither harmful nor helpful (score = 2)	38	5.2	46	6.3	10	7.5			
Helpful (score = 3)	677	93.4	675	93.1	123	91.8			
Missing	4	0.6	1	0.1	0	0.0			
Mean, SD	2.93	0.3	2.93	0.3	2.91	0.3	.840	.458	.501
Scale score									
Cronbach alpha	0.86		0.80		0.61				
Mean, SD	2.92	0.28	2.91	0.26	2.82	0.32	.657	<.001	<.001

Abbreviation: SD, standard deviation.

P-value: Paired t test (patient-caregiver); T test (patient-physician, caregiver-physician).

patients' interests to that of the family caregivers. However, such response suggests that they recognize their interests are likely to be highly interconnected and interdependent and important treatment decisions affect family caregivers as well as the patients.²³⁻²⁵ For example, patients' requests of life-prolonging treatment or dismissal of a home health care aide would increase caregiver burden,^{23,24} and it is not clear whether patients' own willingness to make a decision in this instance could override what is best for both patients and family.^{23,24,26}

On the contrary, oncologists were less likely to support family involvement in cancer TDM in such situation. Oncologists might have bad experience of family involvement in cancer TDM without patients consent. Or they might consider patients' autonomy as a prior than family involvement. While different views and expectations between patients and family caregivers regarding cancer TDM can be practical challenge for the health care professionals (HCPs), our previous study showed that the majority of patients and family caregivers reported that their cancer TDM preferences and experiences were in accord¹⁰ even when the preferences are discordant between the patients and the caregivers. This implies that harmonious decision making can be achieved in most cases without complete agreement on decisional leadership.¹⁰ A UK study found that, while family caregivers influence on the decision-making process and on the decision itself, they usually left the final decision to the patients.²³ Therefore, HCPs can try to support them to optimize the family involvement when there is an initial discordance in their preferences.

All three groups believed that family involvement is helpful for communication, treatment decision, and psychological support. To date, little evidence is available regarding whether family involvement in cancer TDM improves clinical outcomes in cancer care. While direct comparison is not appropriate, patients who are engaged in cancer TDM process had better compliance, higher satisfaction, and higher quality of life.^{27–29} In addition, some evidence from primary care suggests that family involvement facilitated patients TDM and enhanced patient autonomy,^{30–32} although it is unclear if such findings also apply to oncology context. Future research is warranted on whether family involvement improves clinical outcomes in cancer care, and how to optimize the level and way of family involvement in cancer TDM.

Dominated by bioethical precepts calling for the protection of patient autonomy, the focus has largely been on the dyadic interaction between patients and physicians.^{13,23} In such model, family caregivers are sometimes viewed with suspicion and as a threat to patient autonomy,^{9,13} diminishing and demeaning their role.^{13,33} The current study, however, challenges such a model and suggests that it does not correspond with the view and experiences of patients and their caregivers or their physicians. An extended model of shared decision

TABLE 4 Attitudes Toward Family Involvement in Treatment Decision Making Process: View of Patients, Caregivers, and Physicians

	Patients (N = 725)	Caregivers	(N = 725)	Physicians	(N = 134)	Difference (P value)		ıe)
	Mean	SD	Mean	SD	Mean	SD	Patient- caregiver	Patient- physician	Caregiver- physician
Family involvement in can	cer TDM ha	impers pati	ient autonom	ıy.					
Strongly disagree (score = 1)	220	30.3	140	19.3	6	4.5			
Disagree (score = 2)	278	38.3	300	41.4	52	38.8			
Agree (score = 3)	175	24.1	236	32.6	75	56.0			
Strongly agree (score = 4)	46	6.3	44	6.1	1	0.8			
Missing	6	0.8	5	0.7					
Mean, SD	2.07	0.90	2.26	0.84	2.53	0.60	<.001	<.001	<.001
Family involvement compl	licates cance	er TDM pro	ocess.						
Strongly disagree (score = 1)	248	34.2	170	23.5	6	4.5			
Disagree (score = 2)	313	43.2	380	52.4	82	61.2			
Agree (score = 3)	122	16.8	134	18.5	41	30.6			
Strongly agree (score = 4)	34	4.7	38	5.2	5	3.7			
Missing	8	1.1	3	0.4					
Mean, SD	1.92	0.84	2.06	0.79	2.34	0.62	<.001	<.001	<.001
Family involvement leads	to harmonio	ous decision	า.						
Strongly disagree (score = 1)	14	1.9	8	1.1	0.00	0.0			
Disagree (score = 2)	37	5.1	27	3.7	5	3.7			
Agree (score = 3)	439	60.6	503	69.4	103	76.9			
Strongly agree (score = 4)	231	31.9	185	25.5	26	19.4			
Missing	4	0.6	2	0.3	0.00	0.0			
Mean, SD	3.23	0.63	3.20	0.55	3.16	0.46	.204	.198	.430
Families have right to be i	nvolved in c	ancer TDN	1.						
Strongly disagree (score = 1)	6	0.8	6	0.8	3	2.2			
Disagree (score = 2)	29	4.0	23	3.2	24	17.9			
Agree (score = 3)	421	58.1	467	64.4	93	69.4			
Strongly agree (score = 4)	265	36.6	225	31.0	14	10.5			
Missing	4	0.6	4	0.6	0.00	0.0			
Mean, SD	3.31	0.59	3.26	0.56	2.88	0.60	.081	<.001	<.001

Abbreviations: SD, standard deviation; TDM, treatment decision making.

P-value: Paired t test (patient-caregiver); T test (patient-physician, caregiver-physician)

making that includes the broader scope of triadic relationship may be more reflective of the clinical realities and preferences.^{5,10,13,23,26} We therefore suggest the need to develop a greater appreciation for the relational and reciprocal nature of patient-family caregiver relationship in cancer TDM^{23,26} and consider an evolution of the current concept of patient autonomy to a more contextualized form of relational autonomy,^{13,23,34} where the patient *and* family caregivers can be seen as a unit for autonomous decision.³⁵

Family caregivers who are not integrated into the decision-making units would be limited in supporting patient decision making. Despite this, clinical guidelines^{36,37} and communication training for HCPs³⁴ currently lack guidance for optimizing positive family involvement in cancer TDM.³⁸ This limitation is also characteristic of most patient coaching interventions for TDM.³⁹ Only 1 communication activation program of which we are aware has been directed to both patients and family caregivers who accompany them to their medical visit and found that the program was highly valued and associated with positive changes in visit communication.⁴⁰ More research is needed to develop effective strategy for optimizing family involvement in cancer TDM to improve decision quality, family communication, and health outcomes.^{3,10,13}

Several limitations of the study are noteworthy. First, we only invited dyads and those who were not accompanied by family caregiver or did not want them involved in the study were excluded, which makes this study susceptible to selection bias. Second, we did not consider the issue of multiple caregivers who share tasks and might have significant input into treatment decisions. Third, study measures, the modified control preference scale and investigator-developed questionnaire, were not formality tested for reliability and validity. For example, the Cronbach alpha for physician group for perceived benefit/harm was only .61, which is below the usual standard for reliability. Fourth, our cross-sectional study could not determine the stability of preference for family involvement over time. Fifth, cultural differences in communication style influence decisional role preference,^{7,16,21,41,42} and our study needs to be interpreted in the cultural context of Korea, in which family-centered decision making has been traditionally common under the influence of Confucianism.⁴³ The preferences for family involvement in TDM from our study (>90%) seem to be somewhat higher than those from the Western studies (58% in the United States^{7,16} or 69% in Belgium¹⁸). However, in Western countries, family caregivers also have both the right and responsibility to be involved in TDM, particularly in the care of the vulnerable elderly patients⁴⁴ and those patients with long-term illness such as cancer or dementia.²³

In conclusion, our study adds to the evidence that patients, family caregivers, and oncologists valued and expected family involvement in TDM. A theoretical framework and clinical strategy need to be developed based on relational perception rather than individual perception of autonomy.

CONFLICT OF INTEREST

None.

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REFERENCE

- Hinds PS, Feetham SL, Kelly KP, Nolan MT. "The family factor" knowledge needed in oncology research. *Cancer Nurs.* 2012;35:1–2.
- Jones RA, Taylor AG, Bourguignon C, et al. Family interactions among African American prostate cancer survivors. *Fam Community Health*. 2008;31:213–220.
- 3. Laidsaar-Powell RC, Butow PN, Bu S, et al. Physician-patient-companion communication and decision-making: a systematic review of triadic medical consultations. *Patient Educ Couns*. 2013;91:3–13.
- Tariman JD, Doorenbos A, Schepp KG, Becker PS, Berry DL. Patient, physician and contextual factors are influential in the treatment decision making of older adults newly diagnosed with symptomatic myeloma. *Cancer Treat Communications*. 2014;2:34–47.
- Laidsaar-Powell R, Butow P, Bu S, Fisher A, Juraskova I. Oncologists' and oncology nurses' attitudes and practices towards family involvement in cancer consultations. *Eur J Cancer Care (Engl)*. 2016. doi: 10.1111/ecc.12470
- Davison BJ, Gleave ME, Goldenberg SL, Degner LF, Hoffart D, Berkowitz J. Assessing information and decision preferences of men with prostate cancer and their partners. *Cancer Nurs*. 2002;25:42–49.
- Hobbs GS, Landrum MB, Arora NK, et al. The role of families in decisions regarding cancer treatments. *Cancer*. 2015;121:1079–1087.
- Zhang AY, Zyzanski SJ, Siminoff LA. Differential patient-caregiver opinions of treatment and care for advanced lung cancer patients. *Soc Sci Med.* 2010;70:1155–1158.
- Kai J, Beavan J, Faull C. Challenges of mediated communication, disclosure and patient autonomy in cross-cultural cancer care. *Brit J Cancer*. 2011;105:918–924.

- Shin DW, Cho J, Roter DL, et al. Preferences for and experiences of family involvement in cancer treatment decision-making: patient-caregiver dyads study. *Psycho-Oncology*. 2013;22:2624–2631.
- 11. Hillyer GC, Hershman DL, Kushi LH, et al. A survey of breast cancer physicians regarding patient involvement in breast cancer treatment decisions. *Breast.* 2013;22:548–554.
- 12. O'Brien MA, Ellis PM, Whelan TJ, et al. Physician-related facilitators and barriers to patient involvement in treatment decision making in early stage breast cancer: perspectives of physicians and patients. *Health Expect*. 2013;16(4):373–384.
- Schafer C, Putnik K, Dietl B, Leiberich P, Loew TH, Kolbl O. Medical decision-making of the patient in the context of the family: results of a survey. *Supp Care Cancer*. 2006;14:952–959.
- Wolff JL, Roter DL. Family presence in routine medical visits: a metaanalytical review. Soc Sci Med. 2011;72:823–831.
- Degner LF, Sloan JA, Venkatesh P. The Control Preferences Scale. Can J Nurs Res. 1997;29:21–43.
- Rim SH, Hall IJ, Fairweather ME, et al. Considering racial and ethnic preferences in communication and interactions among the patient, family member, and physician following diagnosis of localized prostate cancer: study of a US population. *Int J Gen Med.* 2011;4:481–486.
- Nolan MT, Hughes MT, Kub J, et al. Development and validation of the family decision-making self-efficacy Scale. *Palliat Supp Care*. 2009;7:315–321.
- Pardon K, Deschepper R, Stichele RV, et al. Preferences of patients with advanced lung cancer regarding the involvement of family and others in medical decision-making. *J Palliat Med.* 2010;13:1199–1203.
- Wan-Chow-Wah D, Monette J, Monette M, et al. Difficulties in decision making regarding chemotherapy for older cancer patients: a census of cancer physicians. Crit Rev Oncol/Hematol. 2011;78:45–58.
- Al Mutair A, Plummer V, O'Brien AP, Clerehan R. Attitudes of healthcare providers towards family involvement and presence in adult critical care units in Saudi Arabia: a quantitative study. J Clin Nurs. 2014;23:744–755.
- Singh JA, Sloan JA, Atherton PJ, et al. Preferred roles in treatment decision making among patients with cancer: a pooled analysis of studies using the Control Preferences Scale. Am J Manag Care. 2010;16:688–696.
- Sulmasy DP, Hughes MT, Thompson RE, et al. How would terminally ill patients have others make decisions for them in the event of decisional incapacity? A longitudinal study. J Am Geriatr Soc. 2007;55:1981–1988.
- 23. Gilbar R. Family involvement, independence, and patient autonomy in practice. *Med Law Rev.* 2011;19:192–234.
- Whitlatch C. Informal caregivers: communication and decision making. Am J Nurs. 2008;108:73–77. quiz 77
- Laidsaar-Powell R, Butow P, Bu S, et al. Family involvement in cancer treatment decision-making: a qualitative study of patient, family, and clinician attitudes and experiences. *Patient Educ Counsel*. 2016;99:1146–1155.
- Hardwig J. What about the family? Hastings Center Report. 1990;20:5– 10.
- Lantz PM, Janz NK, Fagerlin A, et al. Satisfaction with surgery outcomes and the decision process in a population-based sample of women with breast cancer. *Health Serv Res.* 2005;40:745–767.
- Hack TF, Degner LF, Watson P, Sinha L. Do patients benefit from participating in medical decision making? Longitudinal follow-up of women with breast cancer. *Psycho-Oncology*. 2006;15:9–19.
- Street RL Jr, Voigt B. Patient participation in deciding breast cancer treatment and subsequent quality of life. *Med Decision Making: Intern* J Soc Med Decision Making. 1997;17:298–306.
- Clayman ML, Roter D, Wissow LS, Bandeen-Roche K. Autonomyrelated behaviors of patient companions and their effect on decisionmaking activity in geriatric primary care visits. *Soc Sci Med*. 2005;60:1583–1591.

 Ishikawa H, Roter DL, Yamazaki Y, Hashimoto H, Yano E. Patients' perceptions of visit companions' helpfulness during Japanese geriatric medical visits. *Patient Educ Counsel*. 2006;61:80–86.

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- Ishikawa H, Roter DL, Yamazaki Y, Takayama T. Physician-elderly patient-companion communication and roles of companions in Japanese geriatric encounters. Soc Sci Med. 2005;60:2307–2320.
- Ballard-Reisch DS, Letner JA. Centering families in cancer communication research: acknowledging the impact of support, culture and process on client/provider communication in cancer management. *Patient Educ Counsel*. 2003;50:61–66.
- Burkhalter JE, Bromberg SR. Family-oncologist communication in cancer patient care. *Cancer Investigat*. 2003;21:915–923.
- Siminoff LA, Rose JH, Zhang A, Zyzanski SJ. Measuring discord in treatment decision-making; progress toward development of a cancer communication and decision-making assessment tool. *Psycho-Oncology*. 2006;15:528–540.
- Blank T, Graves K, Sepucha K, Llewellyn-Thomas H. Understanding treatment decision making: contexts, commonalities, complexities, and challenges. Annals Behav Med. 2006;32:211–217.
- Makoul G, Clayman ML. An integrative model of shared decision making in medical encounters. *Patient Educ Counsel*. 2006;60:301–312.
- Cherlin E, Fried T, Prigerson HG, Schulman-Green D, Johnson-Hurzeler R, Bradley EH. Communication between physicians and family caregivers about care at the end of life: when do discussions occur and what is said? J Palliat Med. 2005;8:1176–1185.
- Stacey D, Kryworuchko J, Bennett C, Murray MA, Mullan S, Legare F. Decision coaching to prepare patients for making health decisions: a

systematic review of decision coaching in trials of patient decision AIDS. *Med Decis Making*. 2012;32(3):E22-E33.

- 40. Wolff JL, Roter DL, Barron J, et al. A tool to strengthen the older patient-companion partnership in primary care: results from a pilot study. J Am Geriatr Soc. 2014;62:312–319.
- Williams SW, Hanson LC, Boyd C, et al. Communication, decision making, and cancer: what African Americans want physicians to know. J Palliat Med. 2008;11:1221–1226.
- Whitlatch CJ, Judge K, Zarit SH, Femia E. Dyadic intervention for family caregivers and care receivers in early-stage dementia. *Gerontolog.* 2006;46:688–694.
- 43. Shin DW, Lee JE, Cho B, Yoo SH, Kim S, Yoo JH. End-of-life communication in Korean older adults: with focus on advance care planning and advance directives. *Geriatr Gerontol Intern.* 2016;16:407–415.
- Wolff JL, Roter DL. Hidden in plain sight: medical visit companions as a resource for vulnerable older adults. Arch Intern Med. 2008;168:1409– 1415.

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APPENDIX

 TABLE A1
 Characteristics of Patient-Caregiver Dyads (N = 725)

Patient characteristics (N = 725)	Caregiver characteristics (N = 72						
Age (years)	60.2	12.5	Age (years)	51.3	13.4		
Gender			Gender				
Male	329	45.4	Male	310	42.8		
Female	396	54.6	Female	415	57.2		
Marital status			Marital status				
Married	615	84.9	Married	612	84.5		
Unmarried	109	15	Unmarried	112	15.5		
Educational status (years)			Educational status (ye	ars)			
<9	345	47.6	<9	200	27.6		
9-12	236	32.6	9-12	256	35.3		
>12	139	19.2	>12	266	36.7		
Missing	5	0.7	Missing	3	0.4		
Income, USD			Income, USD				
<2000	423	58.3	<2000	292	40.3		
≥2000	293	40.4	≥2000	420	57.9		
Missing	9	1.2	Missing	13	1.8		
Cancer type, primary			Relationship to patien	ts			
Stomach	118	16.3	Spouse	437	60.3		
Lung	98	13.5	Others	288	39.7		
Liver	52	7.2	Adult child	207	28.6		
Colon	130	17.9	Parents	39	5.4		
Breast	103	14.2	Others	42	5.8		
Cervix	50	6.9	Living with patients				
Others	174	24	Yes	535	73.8		
SEER stage (current)			No	190	26.2		
In situ and local	261	36					
Regional	230	31.7					
Distant	223	30.8					
Unknown/missing	14	1.9					
Treatment situation							
Under initial treatment	324	44.7					
On regular follow-up after treatment	237	32.7					
On regular follow-up after cure	39	5.4					
Under treatment for metastasis or recurrence	107	14.8					
Don't know	14	0.4					
Others (eg, treatment for second primary cancer)	3	0.1					

TABLE A2 Characteristics of Oncologists (N = 134)

Physician characteristics (N = 134)		
Age	43.5	7.8
Gender		
Male	107	79.9
Female	27	20.1
Specialty		
Medical oncologist	59	44
Surgical oncologist	68	50.8
Radiotherapy oncologist	7	5.2
Years after board certification		
Mean, SD	12.3	7.5

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