



Discordance Between Advanced Cancer Patients' Perceived and Preferred Roles in Decision Making and its Association with Psychological Distress and Perceived Quality of Care

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Accepted: 5 November 2020 / Published online: 11 February 2021
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Abstract

Objective We investigated patient-reported roles of families, physicians, and patients themselves in treatment decision making and whether discordance between perceived and preferred roles is associated with psychological distress and perceived quality of care among patients with cancer.

Methods We analyzed cross-sectional survey data from 599 adults with stage IV solid malignancy in Singapore. Stuart-Maxwell tests were used to compare patients' perceived and preferred roles in decision making. Types of discordance were categorized as follows: involvement at a lesser level than preferred, involvement at a greater level than preferred, and no change in patient involvement. Ordinary least squares regressions examined the associations between types of discordance and patient outcomes, controlling for patient characteristics.

Results Discordance between perceived and preferred roles was observed in 16% of patients. Amongst patients with discordance, 33% reported being involved at a lesser level than they preferred, 47% reported being involved at a greater level than they preferred, and 19% reported discordance where level of patient involvement did not change. Multivariable analyses showed that lesser involvement than preferred and discordance with no change in patient involvement were associated with poorer quality of physician communication ($\beta = -9.478$ [95% confidence interval {CI} -16.303 to -2.653] and $\beta = -9.184$ [95% CI -18.066 to -0.301]) and poorer care coordination ($\beta = -11.658$ [95% CI -17.718 to -5.597] and $\beta = -8.856$ [95% CI -16.744 to -0.968]) compared with concordance.

Conclusions Most patients reported participating at their desired level. Despite this finding, our results suggest that involving patients at a lesser level than they prefer can lead to poorer perceived quality of physician communication and care coordination and that encouraging patient participation is a safe approach to minimizing poor outcomes.

Findings from this study were presented at the 41st Annual North American Meeting of Society for Medical Decision Making in Portland, OR, USA, and at an invited seminar at the Department of Population Health Sciences at Duke University, NC, USA, in October 2019.

The members of the "COMPASS Study Group" mentioned in Acknowledgments section.

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1 Introduction

Shared decision making (SDM) is now widely accepted as the gold standard to promote patient empowerment and care pathways that align with a patient's values and preferences [1]. Previous studies have shown that SDM, particularly active patient participation, is associated with better psychological health outcomes and higher satisfaction with care. However, SDM or an active role in decision making is not desired by all patients with cancer [2–5]. Some patients may not want to take the responsibility of making important decisions at this vulnerable time in their lives [6]. They may lean on their family caregivers [7, 8] and/or physicians [2, 9] to make the decisions for them. Conversely, other patients want to be the ones making the final call on their care plans [10]. If patients are involved in decision making more [11]

Key Points for Decision Makers

Only 16% of patients reported discordance in perceived and preferred roles, suggesting that current clinical practice in Singapore seems to provide an environment for most patients to participate in decision making at their desired level.

Patients who were involved at a greater level than they preferred reported outcomes that did not differ from those who reported concordance. This finding is very reassuring for the advocates of shared decision making in Asian countries, where patients, especially elderly patients, tend to take a backseat in decision making.

Being less involved in decision making than desired was significantly associated with poorer quality of physician communication and care coordination compared with concordance. Our findings suggest that encouraging patient participation is a safer approach to minimizing poor outcomes.

or less [9, 12] than they desire, they may experience anxiety and stress and perceive quality of care (QoC) to be poor. In particular, if they do not participate as much as they desire, they may lose their confidence or be dissatisfied with care as they may end up with a treatment that they do not desire [13].

Previous studies show evidence of discordance between patients' perceived and preferred roles in decision making [14]. Age [15, 16] and education [16] were found to be significant predictors of experiencing discordance. Yet, only a limited number of studies investigated the association between discordance, psychological distress, and satisfaction with consultation or care [13, 17–19]. The findings from these studies have been mixed: only one study found a significant association between discordance and anxiety [13], and one other found a significant association between discordance, depression, and satisfaction with the decision-making process [18]. Also, these studies have focused exclusively on the patient–physician dyad in decision making. More research is needed to understand the relationship between discordance and patient outcomes when decision making is also influenced by family caregivers [20–22]. This is especially the case in Asian societies where adult children often consider caregiving as part of their duty to their parents, and the elderly expect their family members to take care of them, including making medical decisions on their behalf [23].

The objectives of this study were twofold: (1) to examine discordance between patients' perceived and preferred

roles in decision making in the management of advanced cancer (2) to investigate the associations of discordance with psychological distress and perceived QoC. We hypothesized that patients with discordance in decision making will have greater anxiety, more depressive symptoms, and poorer perceived QoC than those who experience concordance between preferred and perceived roles in decision making. We also hypothesized that the type of discordance matters, in that participating in treatment decision making at a lesser level than preferred will be associated with worse outcomes than being involved at a greater level than preferred. The findings from this study can inform development of interventions to implement SDM models where caregivers are important stakeholders and to match patients' perceived roles with their preferred roles in decision making.

2 Methods

2.1 Participants and Study Setting

This cross-sectional study employed baseline data from an ongoing cohort study described elsewhere [24]. From July 2016 to March 2018, patients were recruited from outpatient oncology clinics at National Cancer Centre Singapore and National University Hospital in Singapore. Patients who were Singapore citizens or permanent residents, aged at least 21 years, and diagnosed with stage IV solid cancer were identified from medical records and approached by trained interviewers. They were screened for adequate functional status for participation by scoring an Eastern Cooperative Oncology Group performance status ≤ 2 . The Abbreviated Mental Test was also administered for participants aged ≥ 60 years. The study team approached 1042 eligible patients. Of these, 600 (57%) consented to participate and completed the survey. The main reasons for declining to participate in the study were not being interested in the study, feeling tired or ill, not having enough time for the survey, and caregiver declining to participate on behalf of the patient. One patient who did not answer questions regarding his/her perceived role in decision making was excluded, resulting in an analysis of 599 patients (Fig. 1). The study was approved by the SingHealth Centralized Institutional Review Board (2015/2781).

2.2 Survey Development

The survey instrument was first developed in English. Through cognitive interviews, the survey was tested with ten participants for readability, and framing of the questions was finalized based on the feedback from these interviews. The English version was then translated to Mandarin and Malay,

and then back translated to English by professional translators to cover the three most spoken languages in Singapore. The Mandarin and Malay versions were also reviewed by the bilingual study team members for readability. The survey was administered by trained interviewers who could speak the language of the patient's choice. The following measures were used in the study.

Perceived and preferred roles in decision making Participants were first asked who had been responsible for making the most important treatment decisions and presented with the options of myself, my family, and my doctor (electronic supplementary material [ESM], A). Participants could select as many of the options as they felt were applicable. A second question elicited the role and capacity to which the individual(s) selected in the first question were involved in making decisions. These questions were used to identify the perceived roles in decision making. A similar two-step question format was used to assess patient's preferred roles for these parties in treatment decisions. These questions were adopted from the Cancer Care Outcomes Research and Surveillance (CanCORS) study [25] but modified to incorporate family involvement in addition to that of patients and physicians. Decision-making options were subsequently grouped into six categories: (1) Patient-alone decision making, (2) patient-led decision making (i.e., patient decides after considering their family's and/or physicians' opinion), (3) collaborative decision making (i.e., patient decides with their family and/or physicians), (4) family-led decision making (i.e., patient's family decides after considering patient's and/or physicians' opinion), (5) physician-led decision making (i.e., patient's physicians decide after considering patient's and/or family's opinion), and (6) no patient involvement (i.e., family and/or physicians decide) (ESM B).

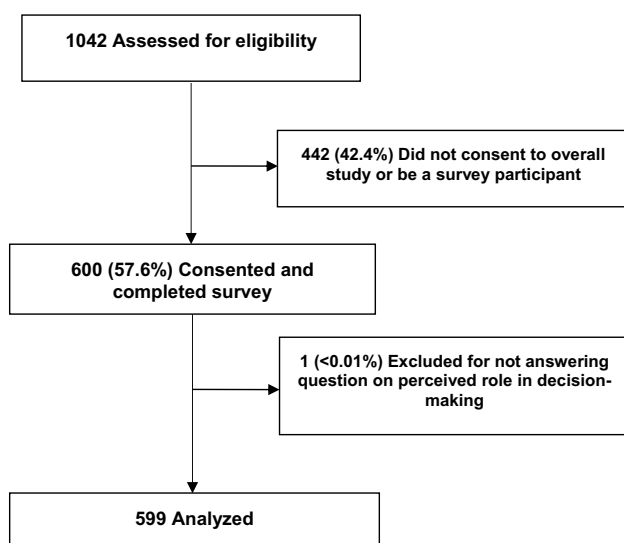


Fig. 1 Participant recruitment flow diagram

Discordance in decision making Discordance was defined as any discrepancy between preferred and perceived roles in decision making. Discordance may occur within the same category or across categories. We classified discordance into three categories: (1) involvement in decision making at a lesser level than preferred, (2) involvement in decision making at a greater level than they preferred, and (3) no change in patient involvement while there is discordance on the role of family and/or physician (e.g., patient decides with their family but prefers making decisions with their physicians).

Psychological distress outcomes Participants completed the Hospital Anxiety and Depression Scale (HADS) that measures anxiety (HADS Anxiety) and depression (HADS Depression). Each subscale has seven items, resulting in total score of 0–21 per subscale. A higher score indicates higher anxiety and depressive symptoms.

Perceived QoC outcomes Patients' experience with physicians and care setting was assessed using questions previously used by the CanCORS study. Items are grouped into two domains: physician communication (QoC-PC) (five items), and healthcare coordination and responsiveness (QoC-CR) (seven items). Items related to the quality of nursing care was not used in the analysis of this paper since it was deemed to be unrelated to the decision-making process. Scores for each domain ranged from 0 to 100, with a higher score indicating better perceived QoC.

Patient characteristics Participants reported their age, ethnicity, marital status, years of education, current working status, and monthly household income. Cancer type was identified through medical records. Symptom burden was measured as the sum of patient-reported symptom severities on a Likert scale from 0 to 4 (not at all, a little bit, somewhat, quite a bit, very much). The list of symptoms, taken from FACIT-PAL-14 [26], were constipation, dryness of mouth, lack of energy, nausea, shortness of breath, weight loss, swelling in parts of body, dry throat, and vomiting.

2.3 Statistical Analysis

We first presented descriptive statistics on patient characteristics and outcomes then on perceived and preferred roles in decision making. We used the Stuart-Maxwell test, which is the appropriate test for comparing multiple correlated (or within-subject) proportions, to compare patients' perceived and preferred roles in decision making.

We also investigated the predictors of discordance between perceived and preferred roles in decision making using a multinomial logit model. The dependent variable was the types of discordance: (1) involved at a lesser level than preferred, (2) involved at a greater level than preferred, (3) no change in patient involvement (reference category: concordance in perceived and preferred levels of involvement in decision making). The independent variables were

medical characteristics (symptom burden and cancer type [respiratory cancer, colorectal and gastrointestinal cancer, breast cancer, genitourinary cancer, gynecologic cancer, and other {reference}]) and sociodemographic characteristics (age, ethnicity [Chinese = 1, Malay/Indian/others = 0], marital status [married = 1, otherwise = 0], education [post-high school or higher education = 1, high school and below = 0], work status [have part-time or full-time job = 1, otherwise 0], and income [Singapore dollar {S\$}4000 per month or higher = 1, otherwise 0]). Gender was not included as it was correlated with types of cancer.

In univariable and multivariable regression analyses, we investigated the association of discordance with psychological distress and perceived QoC. For psychological distress, we employed anxiety and depression (as measured by HADS) as dependent variables. For perceived QoC, we used physician communication and healthcare coordination and responsiveness (as measured by QoC) as dependent variables. The independent variables of interest were types of discordance as described above. We first ran univariable analyses with only variables on the type of discordance. We then ran multivariable analyses controlling for patient medical and sociodemographic characteristics as described above. Assuming linear relationships between the dependent and independent variables, ordinary least squares regressions were used for all univariable and multivariable models. All analyses were conducted using Stata version 14.2.

3 Results

3.1 Patient Characteristics

Table 1 presents patient characteristics. The mean \pm standard deviation (SD) age of patients was 60.4 ± 10.6 years. Less than half of patients were male (46%), had a post-high school education (32%), had part- or full-time jobs (36%), or had a total monthly household income of more than S\$5000 (\$US3606) (26%). The majority of patients were married (73%) and ethnically Chinese (79%). The mean \pm SD symptom burden was 5.05 ± 5.05 . Respiratory cancer (28%) was the most commonly reported, followed by colorectal and gastrointestinal (26%) and breast (16%) cancers. The mean \pm SD scores were quite low for anxiety (2.34 ± 2.77) and depression (2.95 ± 2.92) and quite high for perceived quality of physician communication (90.78 ± 19.12) and care coordination (91.93 ± 17.91).

3.2 Patients' Perceived and Preferred Role in Decision Making

Table 2 shows descriptive statistics on patients' perceived and preferred roles in decision making and Stuart-Maxwell

Table 1 Patient medical and sociodemographic characteristics ($N = 599$)

Demographics	Results
Age	60.4 \pm 10.6
Male	277 (46.2)
Ethnicity	
Chinese	473 (79.0)
Malay/Indians/Others	126 (21.0)
Married	435 (72.6)
Education	
High school or below	409 (69.3)
Above high school	190 (31.7)
Total monthly household income (S\$)	
< 2000	175 (29.2)
2000–2999	84 (14.0)
3000–4999	107 (17.9)
\geq 5000	156 (26.0)
Refused to answer	72 (12.0)
Missing	5 (0.8)
Work status	
Full- or part-time	214 (35.7)
Homemaker/retired/not working	379 (63.3)
Missing	6 (1.0)
Symptom burden	5.05 \pm 5.05
Cancer type	
Respiratory	169 (28.2)
Colorectal and gastrointestinal	154 (25.7)
Breast	96 (16.0)
Genitourinary	78 (13.0)
Gynecologic	53 (8.9)
Others (head and neck, musculoskeletal, neurological, skin and liver)	49 (8.2)
HADS total	5.29 \pm 4.96
Anxiety	2.34 \pm 2.77
Depression	2.95 \pm 2.92
QoC physician communication	90.78 \pm 19.12
QoC care coordination	91.93 \pm 17.91

Data are presented as mean \pm standard deviation or N (%) unless otherwise indicated

HADS Hospital Anxiety and Depression Scale, QoC quality of care, S\$ Singapore dollars

test results for discordance in decision making. The most common perceived role in decision making was collaborative, where patients made decisions together with their family and/or physicians (32%), followed by patient-led decision making (29%). About 15% of patients reported no involvement in decision making, whereas 13% reported making decisions alone. Only 8% of the patients reported that decisions were led by their physicians. Although 4% of the patients reported that decisions were led by their family, 65% of all patients reported family involvement (to

some extent). A similar pattern was observed for patients' preferred roles in decision making, where 32% of patients preferred collaborative decision making and 26% preferred patient-led decision making.

The proportion of patients reporting patient-led decisions was larger than the proportion of patients who preferred this style (29 vs. 26% for perceived and preferred, respectively; $p = 0.009$), and the proportion of patients reporting no involvement in decision making was smaller than the proportion of those who preferred this style of decision making (15 vs. 17% for perceived and preferred roles, respectively; $p = 0.040$).

3.3 Discordance in Perceived and Preferred Roles in Decision Making

Overall, 93 (16%) patients reported discordance in decision making (Table 3). Among patients with discordance, 31 (33%) reported being involved in decision making at a lesser level than they preferred, 44 (47%) reported being involved

at a greater level than they preferred, and 18 (19%) reported discordance where patient involvement did not change. The multinomial logit regression results showed that, compared with experiencing concordance, older patients were less likely to be involved in decision making at a lesser level than they preferred ($\beta = -0.041$ [95% confidence interval {CI} -0.079 to -0.003]), and patients with higher education ($\beta = 0.735$ [95% CI 0.005 – 1.466]) were more likely to be involved at a greater level than they preferred (ESM C). Ethnicity, marital status, work status, income, and symptom burden were not significant predictors of discordance.

3.4 Association of Discordance with Psychological Distress and Perceived Quality of Care

Table 4 presents the results from eight univariable and multivariable regressions, respectively. Univariable regressions revealed that patients who were involved in decision making at a lesser level than they preferred reported greater anxiety ($\beta = 0.906$ [95% CI -0.010 to 1.911]), poorer quality of

Table 2 Descriptive statistics and Stuart-Maxwell test findings on perceived and preferred roles in decision making ($N = 599$)

Roles in decision making	Perceived role	Preferred role	<i>P</i> value
Patient alone			
Patient alone makes decisions	76 (12.7)	81 (13.5)	0.369
Patient led			
Patient makes decisions after considering family's opinion	11 (1.8)	6 (1.0)	0.096
Patient makes decisions after considering doctors' opinion	54 (9.0)	53 (8.9)	0.782
Patient makes decisions after considering their family's and doctors' opinions	109 (18.2)	99 (16.5)	0.041
Total	174 (29.1)	158 (26.4)	0.009
Collaborative			
Patient and patient's family make decisions together	17 (2.8)	14 (2.3)	0.405
Patient and patient's doctors' make decisions together	24 (4.0)	23 (3.8)	0.706
Patient, patient's family, and doctors make decisions together	148 (24.7)	154 (25.7)	0.201
Total	189 (31.6)	191 (31.9)	0.732
Family led			
Patient's family makes decisions after considering patient's opinion	1 (0.2)	1 (0.2)	1.000
Patient's family makes decisions after considering the patient's and doctors' opinions	25 (4.2)	23 (3.8)	0.480
Total	26 (4.3)	24 (4.0)	0.480
Physician led			
Patient's doctors make decisions after considering patient's opinion	19 (3.2)	16 (2.7)	0.180
Patient's doctors make decisions after considering the patient's and the family's opinions	27 (4.5)	29 (4.8)	0.414
Total	46 (7.7)	45 (7.5)	0.763
No patient involvement			
Family alone makes decisions	21 (3.5)	27 (4.5)	0.134
Patient's family makes decisions after considering doctors' opinions	15 (2.5)	16 (2.7)	0.655
Doctors alone make decisions	39 (6.5)	44 (7.4)	0.251
Patient's doctors make decisions after considering family's opinions	1 (0.2)	1 (0.2)	1.000
Patient's family and doctors make decisions together	12 (2.0)	12 (2.0)	1.000
Total	88 (14.7)	100 (16.7)	0.040

Data are presented as N (%)

Table 3 Discordance and types of discordance ($N = 599$)

Discordance	N (%)	95% CI
Concordance	506 (84)	81–87
Discordance	93 (16)	13–19
Types of discordance		
Involved less than preferred	31 (33)	24–44
Involved more than preferred	44 (47)	37–58
No change in patient involvement	18 (19)	12–29

CI confidence interval

physician communication ($\beta = -10.251$ [95% CI -17.146 to -3.356]), and poorer QoC coordination ($\beta = -14.107$ [95% CI -20.509 to -7.706]) compared with those who experienced decision-making concordance. Univariable regressions also revealed that patients who reported discordance with no change in patient role reported poorer quality of physician communication ($\beta = -9.319$ [95% CI -18.258 to -0.381]) and poorer QoC coordination ($\beta = -9.610$ [95% CI -17.909 to -1.311]) compared with those who experienced concordance.

Multivariable analyses that controlled for patient characteristics found that involvement at a lesser level than preferred and discordance with no change in patient role were associated with poorer quality of physician communication ($\beta = -9.478$ [95% CI -16.303 to -2.653] and $\beta = -9.184$ [95% CI -18.066 to -0.301]) and poorer care coordination ($\beta = -11.658$ [95% CI -17.718 to -5.597] and $\beta = -8.856$ [95% CI -16.744 to -0.968]) compared with concordance. Compared with patients who experienced concordance, patients who were involved less than they preferred reported 9.48 (about half of SD) and 11.66 (about two-thirds of SD) lower scores for the quality of physician communication and care coordination, respectively. Similarly, patients who reported discordance with no change in patient role reported 9.18 and 8.86 (about half of SD) lower scores for the quality of physician communication and care coordination, respectively. Full multivariable regression model outputs are shown in ESM D.

4 Discussion

Our findings suggest that the perceived and preferred degree of involvement in decision making varies across patients with advanced cancer. The most common experience in decision making reported by patients was a collaborative approach, followed by a patient-led approach. We found a similar pattern for preferred roles in decision making. Passive (i.e., family-led, physician-led, or no involvement) decision making was reported and preferred by 27% and 28% of patients, respectively. Families were important stakeholders

in making decisions regarding cancer care; yet, the extent to which patients reported their family's involvement in decision making varied substantially. Overall, 65% of patients in our sample reported their families being involved in decision making to a certain extent, including 4% reporting that decisions were led by their families with the patients' and physicians' involvement and a further 4% reporting that decisions were solely made by their families. These figures were higher than those from the CanCORS study, in which family-led decision making was reported by 1.3% and 2.3% for Caucasian patients with cancer and English-speaking Asians, respectively. However, they were one-third of the figures reported for non-English-speaking Asians (12.8%) in the CanCORS study [20].

Overall, 16% of patients reported discordance between perceived and preferred roles in decision making. This is similar to the 20% discordance reported by women with breast cancer in Hong Kong [19] but lower than the 66% reported by patients with cancer in Australia [13]. However, when comparing studies, differences in the questions assessing roles in decision making should be considered. The low level of discordance in our study may be due to the extent of family involvement in patient's decision making, a factor that has not been investigated in previous studies. Future research should investigate discordance in decision making in other countries and the underlying factors for differences across different cultures.

We also found that, among patients with discordance in decision making, more patients reported being involved at a greater level than they preferred compared with those who reported being involved in decision making at a lesser level (47 vs. 33%). This finding should be interpreted through a cultural lens. As stated in the introduction, patients in Asian societies generally expect their family members to take care of them and see this as the duty of the family. This may set patients with an expectation of being passive instead of taking charge of their care management. However, this expectation may not be realized for all those who desire it, as our findings showed.

We also investigated the predictors for types of discordance. Consistent with the previous studies [15, 16], we found that age and education were significant predictors of discordance. Specifically, our findings show that older patients were less likely to be involved at a lesser level than they preferred. This may be due to the authority older individuals have in Asian societies, such that they are not likely to be left out of the decision-making process [27]. We also found that patients with a higher level of education were more likely to be involved at a greater level than they preferred. Individuals with a higher level of education may end up being involved more than desired as they discuss their treatment with their physicians and family caregivers.

Table 4 Univariable and multivariable estimates for discordance in decision making and its association with psychological well-being and perceived quality of care – OLS estimates

Independent Variables	Anxiety		Depressive Symptoms		Physician Communication		Care coordination and responsiveness	
	Coefficient (SE)	95% CI	Coefficient (SE)	95% CI	Coefficient (SE)	95% CI	Coefficient (SE)	95% CI
Univariable Analyses (N = 599)								
Involved less than preferred	0.906* (0.512)	-0.0997 to 1.911	0.857 (0.540)	-0.204 to 1.918	-10.251*** (3.511)	-17.146 to -3.356	-14.107*** (3.260)	-20.509 to -7.706
Involved more than preferred	0.663 (0.435)	-0.191 to 1.517	-0.372 (0.459)	-1.273 to 0.530	0.731 (2.982)	-5.126 to 6.588	-2.755 (2.769)	-8.193 to -2.683
No change in patient involvement	0.832 (0.664)	-0.471 to 2.136	0.472 (0.700)	-0.903 to 1.847	-9.319** (4.551)	-18.258 to -0.381	-9.610** (4.226)	-17.909 to -1.311
Constant	2.223*** (0.123)	1.982–2.465	2.917*** (0.130)	2.662–3.172	91.542*** (0.844)	89.885–93.198	93.155*** (0.783)	91.617–94.693
Adjusted R-squared	0.0056		0.0013		0.0156		0.0330	
Multivariable Analyses^a (N = 599)								
Involved less than preferred	0.514 (0.473)	-0.415 to 1.444	0.666 (0.490)	-0.297 to 1.629	-9.478*** (3.475)	-16.303 to -2.653	-11.658*** (3.086)	-17.718 to -5.597
Involved more than preferred	0.394 (0.403)	-0.398 to 1.187	-0.446 (0.418)	-1.267 to 0.374	2.186 (2.961)	-3.629 to -8.001	-0.489 (2.629)	-5.653 to -4.675
No change in patient involvement	0.908 (0.616)	-0.302 to 2.118	0.675 (0.638)	-0.578 to 1.928	-9.184** (4.523)	-18.066 to -0.301	-8.856** (4.016)	-16.744 to -0.968
Constant	3.643*** (0.834)	2.005–5.282	2.423*** (0.864)	0.726–4.120	99.226*** (6.122)	87.202–111.250	82.531*** (5.437)	71.853–93.209
Adjusted R-squared	0.1676		0.1947		0.0562		0.1517	

CI confidence interval, OLS ordinary least squares, SE standard error

* $p < 0.1$; ** $p < 0.05$; *** $p < 0.01$.

^aMultivariable analyses adjust for sociodemographic characteristics, symptom burden and cancer type. In the multivariable analyses, we included dummy variables for missing data for the income variable (77 missing data) and working status (6 missing data)

Our findings indicate that the type of discordance matters. Being involved in decision making less than desired was significantly associated with poorer quality of physician communication and care coordination compared with concordance. It is possible that patients who were involved less than they desired may have had unanswered concerns or questions or may have felt that their preferences were disregarded by their physicians. In addition, they may have been placed on a treatment regimen that was not consistent with their preferences and values. Conversely, patients who participated as much as or more than they desired were more likely to have raised their concerns and questions to their physicians, received a treatment consistent with their preferences and ultimately were more likely to be satisfied with physician communication and care coordination. Interestingly, a small number of patients reported that the roles of the physicians and/or families were not at the preferred levels, and they reported poorer quality of physician communication and care coordination compared with concordance.

The strengths of this study include its large sample size, inclusion of patients with different types of cancer, and the use of customized questions on decision-making roles to assess the involvement of both families and physicians. Most studies in this area were conducted in Western countries and focus on the patient–physician dyad in decision making. Since families are particularly important stakeholders in decision making in Asian countries, it was necessary that we focused on the triad of patients, physicians, and family members. This study is also one of the few to investigate the association between discordance in perceived and preferred roles, and patient outcomes.

Our study has several limitations. First, our data can only indicate associations and cannot investigate causality between discordance and patient outcomes. Second, although we recognize that patients' perceived and preferred role in decision making may vary based on the type of decision (e.g., chemotherapy, palliative care), we only asked about their role in general decision making. Asking for specific types of decisions would have been cumbersome and tiring for the patients and possibly more susceptible to recall bias than asking for treatment decisions in general. Third, reverse causality between discordance, psychological distress, and perceived QoC outcomes may exist. Finally, patients reported their preferred role in decision making immediately after they reported their perceived role in decision making. This format and timing of survey questions might have led patients to report more concordance in decision making, resulting in the underestimation of the number of patients who may have experienced discordance.

5 Conclusions

Our findings show that current clinical practice in Singapore seems to provide an environment for most patients to participate in decision making at their desired level. Our findings also suggest that patients who were involved at a greater level than they preferred reported no difference in outcomes from those who reported concordance. This finding is very reassuring for the advocates of SDM in Asian countries, where patients, especially those who are elderly, tend to take a backseat in decision making. Our findings suggest that involving patients at a lesser level than they prefer can lead to poorer perceived quality of physician communication and care coordination and that encouraging patient participation is a safer approach to minimizing poor outcomes. Future research should develop tool(s) and strategies that aid healthcare providers to involve patients in decision making.

Electronic supplementary material The online version of this article (<https://doi.org/10.1007/s40271-020-00480-1>) contains supplementary material, which is available to authorized users.

Acknowledgements The authors thank all the patients and caregivers who participated in our study for their time and effort. COMPASS Study Group: Ratna Singh, Rebecca A. Dent, Wee Lee Yeo, Yin Bun Cheung, Rahul Malhotra, Ravindran Kaneshvaran, Alethea Chung Pheng Yee, Noreen Chan, Huei Yaw Wu, Soh Mun Chin, Allyn Yin Mei Hum, Grace Meijuan Yang, Patricia Soek Hui Neo, Nivedita V. Nadkarni.

Declarations

Conflicts of interest Semra Ozdemir, Yubing Tian, Chetna Malhotra, Richard Harding, Gerald Choon Huat Koh, Kumarakulasinghe Naresetnam Barr, Lai Heng Lee, Ssu Wynn Mon, and Eric Finkelstein have no conflicts of interest that are directly relevant to the content of this article.

Ethics approval The study was approved by SingHealth Centralized Institutional Review Board (2015/2781).

Funding The study was funded by the Singapore Millennium Foundation (2015-SMF-0003) and the Lien Centre for Palliative Care (LCPC-IN14-0003).

Data availability Data used in this study are available from the corresponding author upon reasonable request.

Code availability Code used in this study is available from the corresponding author upon reasonable request.

Consent to participate All participants involved provided written consent to participate in this study.

Consent for publication All authors consent to the publication of this manuscript.

Authors' contributions SO identified the research questions and designed the questions used in the study. SO and YT analyzed the data. All authors contributed to the writing and/or critical review of this manuscript.

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