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Examining cancer patient preferences during three stages of decision making and family involvement: a multicenter survey study in China

Siyu Yan^{1†}, Danqi Wang^{1,2†}, Qiao Huang¹, Yongbo Wang¹, Manru Fan³, Hongyang Xue³, Linxin Yu³ and Yinghui Jin^{1*}

Abstract

Background Medical decision-making is a complex multi-stage process. Chinese cancer patients' preference for participation in decision-making stages, family involvement and influencing factors remain unclear.

Methods A total of 1,422 cancer patients from four tertiary hospitals in China were included in the cross-sectional survey. Patient Expectation for Participation in Medical Decision-making Scale was used to measure patients' information, deliberation and decisional control preferences. The patient-family Control Preferences Scale was used to measure expected and actual levels of family involvement. Generalized estimation equation was performed to explore factors associated with patients' preferences.

Results 93.0% of patients had a high preference for information exchange, 95.8% for treatment deliberation, and 61.7% for decisional control. Equal participation was most common in family involvement in decision-making, followed by family-led and patient-led. 15.5% of patients reported a discrepancy between expected and actual family involvement. Age, education, marital status, number of adult children, occupation, family income, regular residence, health insurance and time since diagnosis were related to patient preference. Compared to patients with other cancer sites, those with breast [odds ratio (OR) 2.02, 95%CI: 1.47–2.77] and thyroid cancer [OR 2.37, 95%CI: 1.82–3.10] had higher information preference, those with breast [OR 2.98, 95%CI: 2.73–3.26] and esophagus cancer [OR 2.86, 95%CI: 1.13–7.22] had higher deliberation preference, and thyroid cancer patients [OR 1.50, 95%CI: 1.07–2.10] had higher decisional control preference. Patients who expected or experienced equal participation had higher preference at all stages of decision-making than those with family-led involvement. Patients with inconsistent expected and actual family involvement had lower preferences for the deliberation [OR 0.53, 95%CI: 0.36–0.77] and decisional control stages [OR 0.67, 95%CI: 0.56–0.79].

Conclusions Chinese cancer patients generally have high preference for information exchange and treatment deliberation, but varied preferences for decision control, influenced by patients' sociodemographic factors, cancer

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types, time since diagnosis and family involvement. The findings underscore the importance of tailoring medical decision-making processes to individual patient preferences and ensuring family involvement aligns with patient expectations to enhance patient-centered care in China.

Keywords Patient preference, Cancer, Information preference, Deliberation preference, Shared decision making, Family involvement

Background

The best medical decisions should be based on both evidence and patient's values and preferences. Patient-centered care, patient engagement, and shared decision-making (SDM) have been increasingly recognized and emphasized [1–3]. Cancer, as a common life-threatening illness, the burden of its incidence is growing rapidly worldwide [4], as well as in China [5]. In the current landscape and future directions of cancer care and research in China, the adoption of multidisciplinary, comprehensive treatment approaches and precision oncology is emphasized [5]. There are often multiple treatment options with different benefits and risks, and uncertain results. In this situation, understanding and respecting the preferences of cancer patients is particularly important. Studies have shown that patient engagement/SDM could improve satisfaction and adherence, lessen decisional conflict, facilitate accurate risk perceptions, improve care-quality, reduce costs, and result in better outcomes, including within cancer contexts [6–9].

Previous studies have focused on the types of decision-making preferences of cancer patients, such as “active”, “passive” or “shared” measured by the Control Preference Scale [10, 11]. However, decision-making as a complex multi-stage process, patients' preferences at each stage are varied but less investigated. Charles et al. earlier divided the treatment decision making process into three analytical stages: information exchange, deliberation or discussion of treatment preferences, and deciding on the treatment to implement [12, 13]. Flynn et al. pointed out that the concept of deliberation as distinct from decisional control is often ignored entirely [14]. The Patient Expectation for Participation in Medical Decision-making Scale (PEPMDS) has been developed based on Charles's SDM three-stage theory [12], three dimensions measuring preferences for the three stages [15]. It has been widely used in China to investigate patients' participation preferences at different decision-making stages, although it is rarely used internationally [16].

Besides, family caregiver involvement and influence throughout cancer treatment decision-making shouldn't be ignored [17], especially in China [18]. In Chinese legal situation, where it is impossible or inappropriate to do patients' informed consent, the medical staff shall explain it to the patient's close relatives and get their express consent. Charles et al. proposed the conceptual TRIO framework and intentionally distinguished the

decision-making processes of information exchange, deliberation, and actual decision-making to highlight the many roles and impacts family caregivers have when involved in decision-making. However, there is still a lack of empirical research on the impact of family involvement on patients' preferences at various stages.

In developing countries, patient engagement/SDM is still a novel concept [19] and could be hampered by cultural differences [20]. The introduction of the concept of SDM in China can be traced back to 1998. However, the first study of SDM in Mainland China was not published until 2010 [21]. The majority of SDM research in China, approximately 30%, has focused on cancer patients [21]. To date, apart from legal provisions regarding informed consent, there are no formally issued SDM-related policies and SDM has not been accepted as the normal way of making health decisions in Mainland China [20]. Our country's healthcare system is gradually moving towards patient-centered care, and SDM may be a key part of the transformation. Paucity of related research impairs further development of SDM in China [21, 22]. It's time to understand the current willingness of patients to participate in decision-making in China. Therefore, we sought to investigate the preferences of Chinese cancer patients at various decision-making stages using PEPMDs scale, the expected and actual levels of family involvement, and the relations between the latter, sociodemographic, disease factors and the former, in order to broaden the multidimensional perspective of cancer patients' medical decision making.

Methods

Study design and population

We conducted a cross-sectional study using convenience sampling. From April to August 2021, patients treated in the oncology departments of four tertiary hospitals in north and central China were recruited with the help of nursing staff. Inclusion criteria were as follows: (1) age 18 years and older, (2) diagnosed with cancer by healthcare practitioner, (3) able to read and comprehend questionnaires, and (4) no cognitive impairment and know their cancer site. At the beginning of the questionnaire, they were given a unified cover letter stating the purpose of the research, time of the survey and that participation was voluntary. No monetary incentives were offered. The questionnaire survey was conducted anonymously to ensure that respondents feel comfortable providing free

and truthful answers. Patients who declined to sign the informed consent were excluded. Both paper and online questionnaires were prepared for participants to choose one to fill and unified guidance were used. We used the Survey Star online platform (www.wjx.cn) to create and collect online questionnaires and tested the usability and technical functionality of the online questionnaires before fielding them. Respondents were able to review and change their answers through a back button. Two authors converted the paper questionnaires into the online version and cross-checked them. The study was reported following the Checklist for Reporting Results of Internet E-Surveys [23].

Measures

Sociodemographic and clinical variables

Based on the previous findings and our hypothesis, the questionnaire included the following factors that may be related to patient preferences: sociodemographic information including age, sex, education level, marital status, number of adult children, occupation, family per capita monthly income, regular place of residence, religion and health insurance type, as well as disease conditions including the cancer site and time since diagnosis.

Patients' preferences for engagement in medical decision-making

We used the previously published PEPMDS scale in our survey. The item pool for this scale was developed based on existing scales and qualitative interviews with patients, and was refined using the Delphi method to ensure cultural suitability for the Chinese context [15]. Items 1–3 consisted of the dimension of information preference, which measured how much patients want to know about their condition and progress from physicians. Items 4–8 consisted of the dimension of deliberation preference, including measures of preferences for communication before clinical decision and views of various treatment options and corresponding pros and cons. The last dimension consisted of items 9–12 which measured the preferences for medical decision, and used reverse scoring. Considering that cancer patients may be more physically frail than general patients, we simplified the original 5-point Likert-type scale to a 3-point scale in order to reduce their cognitive burden and reduce filling time [24]. Our data identified the scale has good reliability (Cronbach's $\alpha=0.78$ for total, 0.89, 0.93 and 0.74 for three dimensions).

Family involvement in medical decision-making scale

We used the patient-family Control Preferences Scale [10] measuring the extent to which patients expect family members to participate in medical decision-making and to which they actually participate.

Statistical analysis

Continuous variables are presented as mean \pm standard deviation (SD), and categorical variables are presented as frequencies and percentages. To facilitate the interpretation of the results, we used a strategy similar to the previous study [16], converting the score of the dimension to a high/low preference level regarding whether its mean is greater than 2. Considering the possible correlation of patient participation preferences in the same region, the generalized estimation equation was used to fit logistic regression to examine the factors associated with preferences. Considering the possible mediation of clinical factors, the associations between sociodemographic factors and patients' preference were analyzed based on univariable regression. For the effects of cancer site on preference, all the sociodemographic factors collected were adjusted. For the effects of time since diagnosis and number of cancer site on preferences, all the sociodemographic factors and cancer site were adjusted. For the associations between family involvement and patients' preferences, other factors were all included for adjusting. The associations were reported as odds ratios (ORs) with 95% confidence interval (CI). We followed the rule of thumb that logistic regression models should have at least 5 events per variable (EPV) to ensure the model's stability and validity under the consideration of adequate control of confounding [25]. Statistical analyses were performed using SAS software, version 9.4 TS1M6 (SAS Institute Inc., Cary, NC), and a two-sided p-value of <0.05 was considered statistically significant.

Results

Sociodemographic and clinical characteristics

1553 responses were received, 131 of which were excluded according to the inclusion and exclusion criteria. A total of 1422 patients with complete answers were enrolled, and their sociodemographic and clinical characteristics are presented in Table 1. 62.5% of them were female. Their mean age was 51.71 (SD:13.64, range: 19–98 years). Educational levels varied among them, and 43.7% had a less than high school qualification. The majority (90.8%) were married, and 42.9% had one adult child. Most patients regularly lived in towns or cities (68.9%), had insurance by government (89.3%), and had no religion relief (91.7%).

The study population included patients with a variety of cancers, mainly including breast cancer (30.7%), lung cancer (22.3%), thyroid cancer (10.1%), and colorectal cancer (9.6%). The majority (93.0%) had only one cancer. The time since diagnosis of most (64.1%) patients were less than 6 months.

Table 1 Sociodemographic and clinical characteristics of enrolled patients (n = 1422)

Variables	Class	n	Percentage(%)	Variables	Class	n	Percentage(%)
Age	Mean ± SD	51.71 ± 13.64		Regular residence (stay for one year or more)	Towns or cities	980	68.9
	Min-Max	19–98			Rural areas	442	31.1
Sex	Male	533	37.5	Religion belief	No	1304	91.7
	Female	889	62.5		Yes	118	8.3
Education level	Less than high school	622	43.7	Health insurance	Uninsured	55	3.9
	High school	351	24.7		By private (commercial insurance)	14	1.0
Marital status	Bachelor/ junior college or above	449	31.6	Lesion site	By government	1270	89.3
	Married	1291	90.8		By private and government	83	5.8
Number of adult children	Unmarried / divorced / widowed	131	9.2		Lung	317	22.3
	None	216	15.2		Stomach	99	7.0
Occupation	1	610	42.9		Colorectum	137	9.6
	≥ 2	596	41.9		Liver	65	4.6
	Farmers or workers	432	30.4		Breast	436	30.7
	Employees of the company	212	14.9		Esophagus	44	3.1
	Teachers or civil servants	135	9.5		Thyroid	144	10.1
	Individual business	63	4.4		Uterus	42	3.0
	Freelancers	116	8.2		Other	265	18.6
	Retiree	304	21.4	Number of lesion site	1	1322	93.0
Family per capita monthly income* (Yuan)	Unemployed	59	4.1		> 1	100	7.0
	Other	101	7.1	Time since diagnosis	< 1 month	448	31.5
	0–1500	320	22.5		1–6 months	463	32.6
	1501–3000	396	27.9		6–12 months	177	12.4
	3001–5000	358	25.2		1–2 years	145	10.2
	5001–10,000	235	16.5		2–5 years	112	7.9
	> 10,000	113	7.9		≥ 5 years	77	5.4

Family per capita monthly income*: it refers to the total monthly income of the family divided by the total population of the family, in which the total population of the family should include adults, teenagers, young children and the elderly

Patients' preferences for engagement in the medical decision-making process

Patients' participation preferences at different decision-making stages

93.0% of the patients exhibited high information preference, 95.8% had high deliberation preference, while only 61.7% had high decisional control preference, with the latter being significantly lower than the first two. Figure 1 illustrates the counts of patients with high or low preference in the three stages, indicating that the majority of patients had high preference both for information exchange and treatment preference discussions, yet displayed variability in their decision-making preferences. The results for each item on the scale are presented in Appendix 1, Figure S1. Additionally, we observed that different patient subgroups exhibited distinct preferences for participation across the three stages (Appendix 1, Table S1).

Actual and expected family involvement in medical decision-making

Except for the 38 patients who did not remember family involvement in their most recent decision, all patients completed questionnaires regarding family involvement in decision-making. The majority of participants (74.3%) expected that their family would participate equally in

the decision-making with them, which was higher than the actual rate of equal family participation (68.8%). Only a few patients expressed a preference for unilateral decision-making. Regardless of whether it was the actual or expected level of family involvement, the most common scenarios, in descending order, were equal participation, family dominance, fully family decision, patient dominance, and fully patient decision respectively (Fig. 2). To facilitate subsequent analysis, the responses regarding five levels of family involvement were categorized into three levels. 15.5% of participants reported a discrepancy between expected and actual levels of family involvement.

Factors associated with information, deliberation and decisional control preferences

We found that across the three stages of decision-making, older patients exhibited a lower preference for participation, whereas patients with higher levels of education showed greater motivation to engage. Married individuals and those with more adult children both had lower preferences for information and decisional control. Patients with higher family incomes and those residing in urban areas both had higher preferences for information and deliberation. Additionally, occupation and type

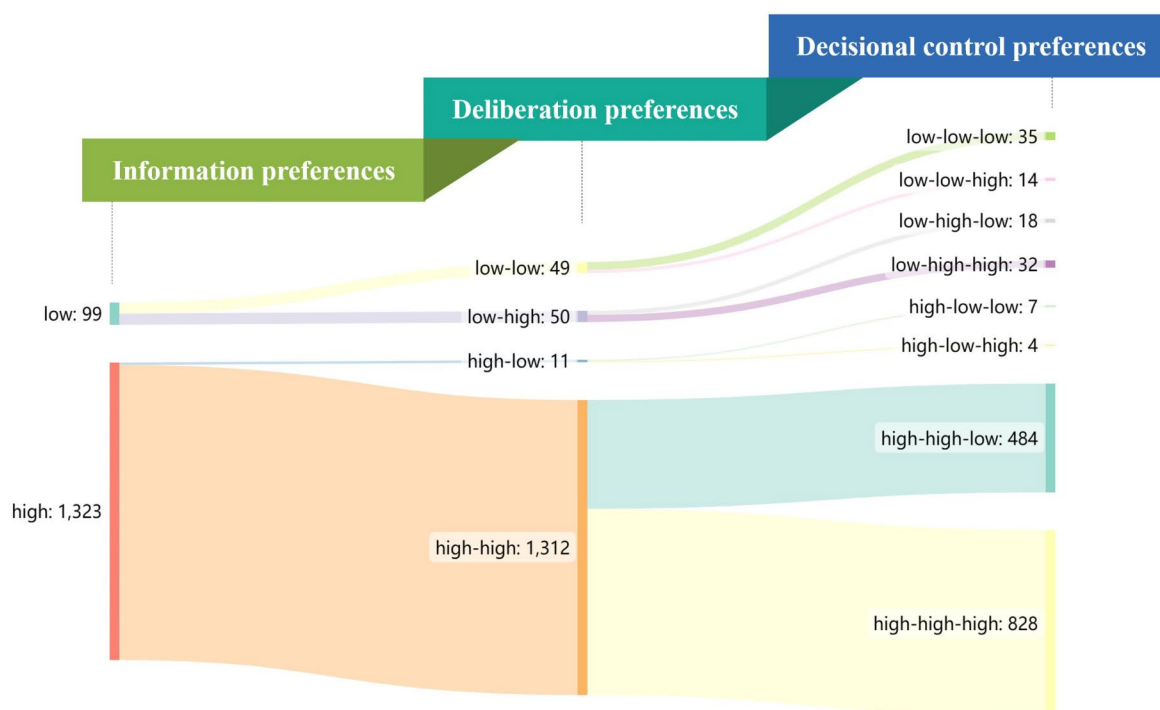


Fig. 1 Counts of patients with low or high preferences for participating at three decision-making stages ($n = 1422$) (Note: low-low means low information preference and low deliberation preference; low-low-low means low information preference, low deliberation preference and low decisional control preference; Other analogies)

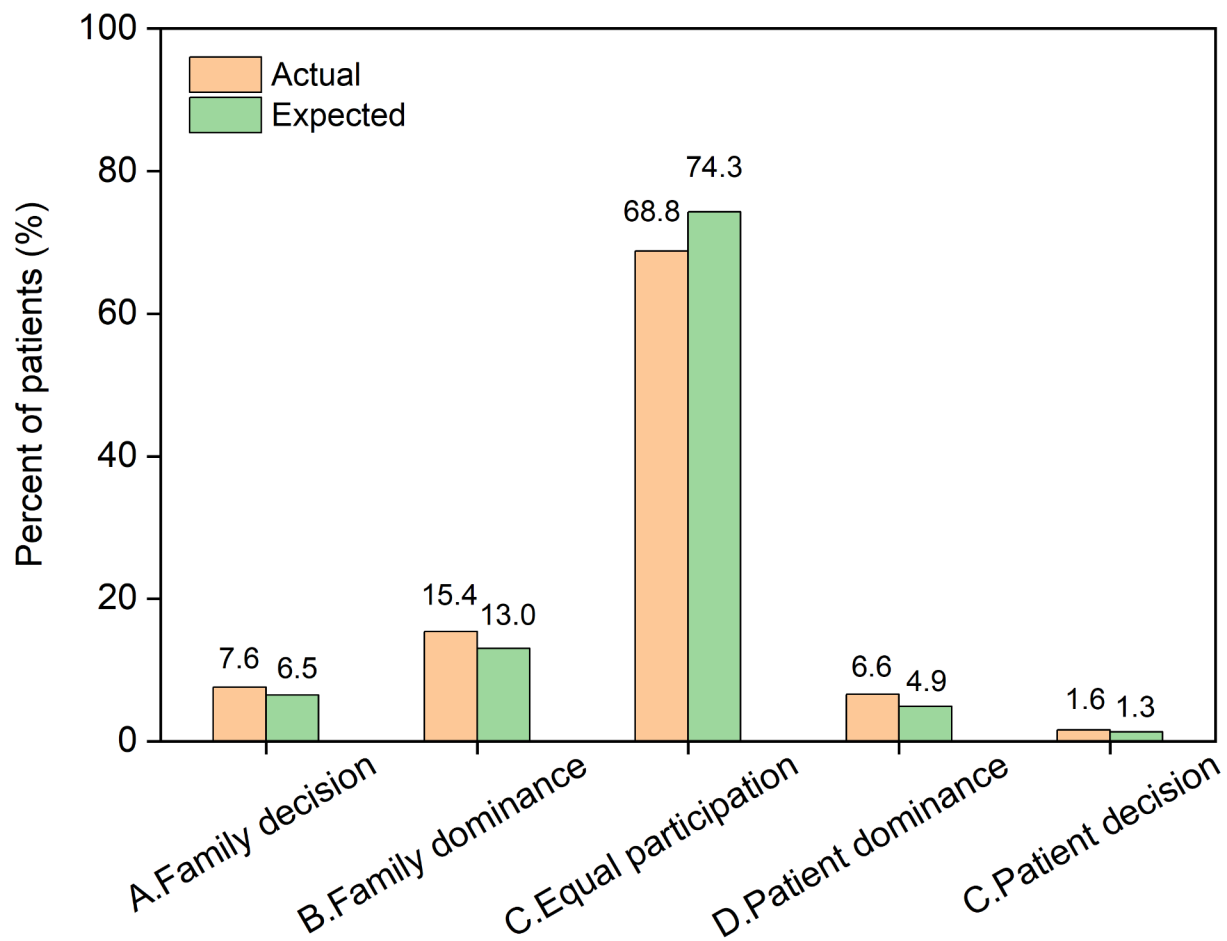


Fig. 2 Patients under different levels of actual and expected family involvement in medical decision-making

Group	Information preference	OR1 (95% CI)	P_value1	Deliberation preference	OR2 (95% CI)	P_value2	Decisional control preference	OR3 (95% CI)	P_value3
Cancer site									
Lung vs other sites	→	0.74 (0.46 to 1.19)	0.213	→	1.06 (0.62 to 1.82)	0.837	→	0.79 (0.52 to 1.20)	0.275
Stomach vs other sites	→	0.51 (0.31 to 0.83)	0.007	→	0.67 (0.37 to 1.22)	0.194	→	1.05 (0.71 to 1.55)	0.812
Colorectum vs other sites	→	0.92 (0.37 to 2.28)	0.852	→	0.47 (0.25 to 0.91)	0.025	→	1.76 (0.61 to 5.04)	0.294
Liver vs other sites	→	2.44 (0.50 to 11.98)	0.273	→	1.67 (0.24 to 11.90)	0.607	→	1.43 (0.88 to 2.30)	0.146
Breast vs other sites	→	2.02 (1.47 to 2.77)	<0.001	→	2.98 (2.73 to 3.26)	<0.001	→	0.71 (0.49 to 1.05)	0.088
Esophagus vs other sites	→	1.52 (0.43 to 5.33)	0.511	→	2.86 (1.13 to 7.22)	0.027	→	1.20 (0.34 to 4.24)	0.778
Thyroid vs other sites	→	2.37 (1.82 to 3.10)	<0.001	→	0.86 (0.46 to 1.59)	0.622	→	1.50 (1.07 to 2.10)	0.019
Uterus vs other sites	→	0.84 (0.72 to 0.98)	0.028	→	0.49 (0.36 to 0.65)	<0.001	→	1.46 (0.63 to 3.37)	0.374
Number of cancer site									
>1 vs 1	→	1.42 (0.46 to 4.37)	0.541	→	2.01 (0.60 to 6.77)	0.259	→	0.94 (0.69 to 1.28)	0.696
Time since diagnosis									
<1 month (as Ref.)	→	—	—	→	—	—	→	—	—
1–6 months	→	0.34 (0.22 to 0.51)	<0.001	→	0.57 (0.34 to 0.95)	0.03	→	0.81 (0.71 to 0.94)	0.004
6–12 months	→	0.30 (0.22 to 0.42)	<0.001	→	0.37 (0.17 to 0.78)	0.01	→	0.70 (0.56 to 0.88)	0.002
1–2 years	→	0.36 (0.14 to 0.91)	0.03	→	0.31 (0.12 to 0.78)	0.013	→	0.78 (0.63 to 0.97)	0.023
2–5 years	→	0.27 (0.23 to 0.33)	<0.001	→	0.36 (0.25 to 0.53)	<0.001	→	0.93 (0.37 to 2.36)	0.884
>=5 years	→	0.38 (0.12 to 1.25)	0.112	→	0.86 (0.27 to 2.73)	0.798	→	0.74 (0.47 to 1.16)	0.184

Fig. 3 Associations between cancer site, number of cancer site, time since diagnosis and patients' preference

of health insurance were also related to patients' preferences at the three decision-making stages (Table S1).

After adjusting for sociodemographic factors, the cancer site was associated to the preference of patients to participate in decision-making (Fig. 3). Compared to

patients with other cancer sites, those with stomach [OR 0.51, 95%CI: 0.31–0.83, $P=0.007$] and uterus cancer [OR 0.84, 95%CI: 0.72–0.98, $P=0.028$] had lower preference for information exchange, whereas breast [OR 2.02, 95%CI: 1.47–2.77, $P<0.001$] and thyroid cancer patients

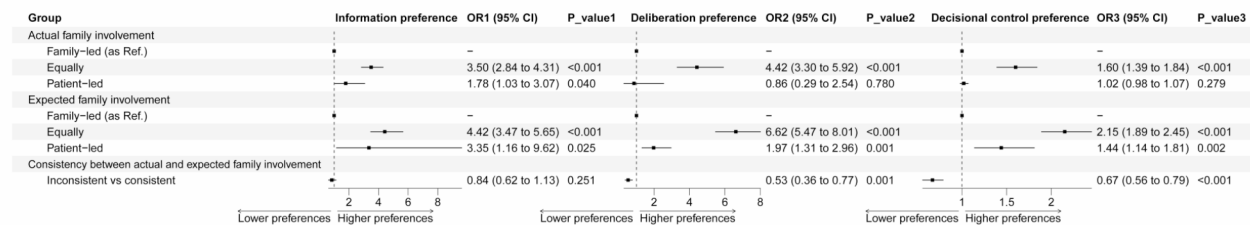


Fig. 4 Associations between actual, expected family involvement, consistency between them and patients' preference in three stage

[OR 2.37, 95%CI: 1.82–3.10, $P < 0.001$] were more proactive. In terms of deliberation of treatment options, colorectum [OR 0.47, 95%CI: 0.25–0.91, $P = 0.025$] and uterus cancer patients [OR 0.49, 95%CI: 0.36–0.65, $P < 0.001$] were less active, whereas patients with breast [OR 2.98, 95%CI: 2.73–3.26, $P < 0.001$] and esophagus cancer [OR 2.86, 95%CI: 1.13–7.22, $P = 0.027$] were more active. For the final decision-making, thyroid cancer patients had higher preference for participation [OR 1.50, 95%CI: 1.07–2.10, $P = 0.019$]. Newly-diagnosed (<1 month) cancer patients had higher information, deliberation and decisional control preferences. The number of cancer site was not significantly related to patients' preference.

The level of family involvement in decision-making was also related to patients' preferences for participation in decision-making (Fig. 4). Regarding actual family involvement, compared to family-led model, equal participation could enhance patients' enthusiasm for information exchange [OR 3.50, 95%CI: 2.84–4.31, $P < 0.001$], deliberation [OR 4.42, 95%CI: 3.30–5.92, $P < 0.001$], and decision-making [OR 1.60, 95%CI: 1.39–1.84, $P < 0.001$]. Patients who anticipated equal participation or a patient-led model expressed a higher desire to participate in all three stages of decision-making. Furthermore, patients who experienced a discrepancy between their expected and actual level of family involvement had lower participation preferences at deliberation [OR 0.53, 95%CI: 0.36–0.77, $P = 0.001$] and decisional control stage [OR 0.67, 95%CI: 0.56–0.79, $P < 0.001$].

Discussion

This cross-sectional study of 1422 Chinese cancer patients showed that the vast majority of patients had high information and deliberation preferences but there was variability in their preferences for the final decision-making, and the majority of patients expected and experienced equal participation from family caregiver in decision-making. Additionally, certain patient characteristics and level of family involvement were associated with their preferences.

Up to 94.3% of patients expressed a preference for receiving information about their condition, which was close to the result (96%) of America reported earlier [14]. Notably, it is usually a challenging issue to tell cancer patients the truth in China [26], but our findings suggest that patients desire to fully understand their health condition. Ensuring sufficient information exchange should be a priority when promoting SDM implementation. Virtually all (95.8%) patients wanted to discuss examination or treatment choices with doctors, exceeding the percentages reported in previous limited reports (62.0%, 73.8%) [14, 16]. Notably, these studies used different scales or items, which may partially account for the observed discrepancies.

The increasing awareness of patient autonomy and the enhancement of health literacy may explain the growing willingness of patients to express and discuss their treatment preferences.

While the vast majority of cancer patients were willing to exchange information and negotiate treatment options, a notable number remain hesitant to participate in the final decision-making, which has also been reported before [14, 16]. Many patients felt that decisions 'required expertise, knowledge and clinical experience that they did not have' [27], and they preferred more involvement in hypothetical decisions where less medical knowledge is required [28]. The first two stages are more concerned with patients' right to information and expression, while the third stage is to make the final decision. Patients may rely on their doctors' authority and fear the consequences of their own decisions, particularly in the context of serious illnesses like cancer. With the advancement of both the quantity and quality of information available for decision making and the improvement of national health literacy, more patients may be willing to be involved in decision control.

Consistent with previous studies [8, 16, 29–32], we validated the effects of age, education, family incomes, occupation, marital status and insurance on patient preferences. Interestingly, married patients or those with more adult children had lower autonomy preference in

information exchange and final decisional control. This may be attributed to these patients having more family members involved in their decision-making, leading to a greater tendency to rely on family input. Notably, patients residing in rural areas had lower information and deliberation preference than those living in towns or cities. A review reported a similar finding and attributed it to the subcultural differences, such as a preference for the more traditional doctor–patient relationship [33]. Additionally, urban patients may have more diverse access to health information, which could enhance their confidence in engaging with their physicians.

In addition, our study found after adjusting for sociodemographic factors, patients' preferences for participation in decision-making still varied by cancer type. Potential explanatory factors include the severity and stage of the disease, health status of patients, available number and type of treatment options, accessibility and quality of information, medical team's attitude towards SDM, and uninvestigated patients' characteristics with specific cancer. However, our study is an exploratory survey across various cancer types, not delving into cancer-specific factors such as treatment modalities and disease stages. Consequently, the variations in patient involvement preferences among different cancer types cannot be definitively explained. We offer the following potential reasons for consideration, and further investigation is needed in the future. In line with previous research [34], we found that breast cancer patients exhibited greater information needs and deliberation willingness compared to patients with other cancer types. This may be attributed to the existence of multiple and controversial treatment options, the impact of treatments to patients' self-image, the existence of active consumer groups, and abundant available information in the public area for breast cancer [35, 36]. Most thyroid cancers are highly curable, with the highest survival rates [37]. Consequently, patients with this cancer are generally in good physical condition, which may explain their preference to engage actively in discussions about their condition and treatment options. It is noteworthy that breast and thyroid cancers are often managed within the same department, and the patients' enthusiasm for SDM may be due to the department's positive attitude and environment towards SDM. Gastric cancer patients usually have lower survival rates, which may lead them to refuse to take information exchange to avoid feeling fatigued or emotionally drained. Patients with colorectal or uterine cancer had lower deliberation preferences, likely due to the more limited or concentrated treatment options available [37]. The significant impact of treatment choices on daily life may account for the higher deliberation preferences observed in patients with esophageal cancer [38]. Our study confirmed that new-diagnosed (<1 month) cancer patients had higher

preferences for involvement in all three decision-making stages. Patients' preferences were likely to change over time as their experience and attitude towards their illness may change [28, 39, 40]. During the early stage of diagnosis, patients may experience great psychological distress, prompting them to be more active in understanding and coping with their cancer [41].

As we hypothesized, in China, influenced by traditional Confucian culture, family members play an important role in patient decision-making. The percentage of both actual and expected family-led decision-making mode was higher than previously reported in multicenter large sample surveys of cancer patients (1.5% and 9.6%), and the similar increase went for equal participation of families and patients in decision-making (47.9% and 49.6%) [10, 17]. Moreover, when family members and patients are equally involved, patients' higher enthusiasm for participation across all three stages of decision-making was observed. Thus, within the traditional family-oriented cultural context of China, the involvement of family members in decision-making should be acknowledged and considered seriously, but the degree of family involvement should be noted to not override the patient's primary role. Because family members may not always fully represent the patient's thoughts and desires, and at times, their opinions may diverge from those of the patient. In the tripartite relationship involving doctors, patients, and family members, the family members can play a supportive role by providing more information and psychological backing [42]. Additionally, effective communication between patients and family members regarding decision-making participation is essential. It is only when the actual level of family involvement aligns with the patient's expectations that the patients are likely to have a greater willingness to participate actively and make decisions that are most beneficial for themselves.

As far as we know, this is the first large-scale, multicenter survey on the participation preferences of cancer patients during the three decision-making stages. Unlike previous studies that primarily focused on one or few cancer types, our research covered a variety of cancer types. Expected and actual family involvement in decision-making were also taken into consideration. However, some limitations should be noted. Firstly, the inherent limitations of cross-sectional research cannot explore the causal sequence. Secondly, participants were from tertiary hospitals in an Asian country, therefore, the findings cannot be directly generalized to cancer patients in primary hospitals and those not going to hospital, and should be carefully when generalizing to other countries and regions with diverse cultural backgrounds. Thirdly, variables such as clinical stage and treatment modalities of specific disease were not investigated, so we cannot provide in-depth analysis in these fields, and further

research is needed based on this exploratory analysis. Fourthly, the survey of preferences was based on a Chinese scale and its international use is relatively limited, and measurement bias should be noted when comparing the results with other questionnaires.

Conclusion

The study indicates that Chinese cancer patients usually have high preference for information exchange and deliberation, but varied preferences for decisional control, which can be affected by patients' sociodemographic factors, cancer type, time since diagnosis, and family involvement. Most Chinese cancer patients expect or are experiencing equal participation with their family members in decision making. Healthcare providers in China should recognize and respond to the strong inclination of cancer patients to participate actively in the information and deliberation stages of the decision-making process. Moderate family involvement that aligns with patient's expectations can effectively enhance the patient's preference for SDM. Proactive strategies need to be developed to cope with a significant proportion of patients with low preference for participating in the final decision, to better achieve SDM and patient-centered care in practice in China.

Abbreviations

CI	Confidence Interval
OR	Odds Ratio
PEPMDS	Patient Expectation for Participation in Medical Decision-making Scale
SD	Standard Deviation
SDM	Shared Decision-Making

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12911-024-02846-z>.

Supplementary Material 1

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Author contributions

SY: Methodology, Formal analysis, Writing - Original Draft; DW: Data Curation, Validation, Writing - Review & Editing; QH: Methodology, Visualization; YW: Writing - Review & Editing; MF, HX and LY: Conceptualization, Investigation; YJ: Conceptualization, Supervision, Funding acquisition. All authors reviewed the manuscript.

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Data availability

The datasets analyzed during the current study are not publicly available due to ethical considerations, but are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

This study received ethical approval from the medical ethics committee of Zhongnan Hospital of Wuhan University (Approved number of ethic committee: 2022002 K). Informed consent was obtained from all individual participants included in the study. The study was carried out following all relevant guidelines and regulations.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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