






BMJ Open What role do patients prefer in medical decision-making?: a population-based nationwide cross-sectional study

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ABSTRACT

Objective To assess patients' preferred roles in healthcare-related decision-making in a representative sample of the Portuguese population.

Design Population-based nationwide cross-sectional study.

Setting and participants A sample of Portuguese people 20 years or older were interviewed face-to-face using a questionnaire with the Problem-Solving Decision-Making scale.

Outcomes The primary outcome was patients' preferred role for each vignette of the problem-solving decision-making scale. Sociodemographic factors associated with the preferred roles were the secondary outcomes.

Results 599 participants (20–99 years, 53.8% women) were interviewed. Three vignettes of the Problem-Solving Decision-Making scale were compared: *morbidity*, *mortality* and *quality of life*. Most patients preferred a passive role for both the problem-solving and decision-making components of the scale, particularly for the *mortality vignette* (66.1% in the analysis of the three vignettes), although comparatively more opted to share decision in the decision-making component. For the *quality of life vignette*, a higher percentage of patients wanted a shared role (44.3%) than with the other two vignettes. In the problem-solving component, preferences were significantly associated with area of residence ($p<0.001$) and educational level ($p=0.013$), while in the decision-making component preferences were associated with age ($p=0.020$), educational level ($p=0.015$) and profession ($p<0.001$).

Conclusions In this representative sample of the Portuguese mainland population, most patients preferred a practitioner-controlling role for both the problem-solving and decision-making components. In a life-threatening situation, patients were more willing to let the doctor decide. In contrast, in a less serious situation, there is a greater willingness to participate in decision-making. We have found that shared decision-making is more acceptable to better-educated patients in the problem-solving component and to people who are younger, higher educated and employed, in the decision-making component.

Strengths and limitations of this study

- This is a cross-sectional study. The questionnaire was applied face-to-face in a representative sample of the Portuguese population from mainland Portugal (599 participants).
- The sample was selected by a geographical region quota method, the Nomenclature of Territorial Units for statistical purposes, while considering the distribution of gender, age and area of residence.
- This study only included mainland residents, thus excluding Madeira and Azores, which might be a limitation.

INTRODUCTION

The consultation model and healthcare practice have evolved from a paternalistic perspective towards the current approach of integrating patient preferences and values while engaging patients actively in their healthcare decisions.^{1 2}

Shared decision-making is a process of decision throughout which the patient: (1) understands the risk of the condition being addressed, (2) understands benefits, harms, uncertainty and alternatives related to the decision, (3) weights the values the decision elicits in himself and (4) engages in the decision-making process to a comfortable extent.³ For most medical decisions, there is not a single best option^{2 4}—this is the field of shared decision-making.

According to the latest Cochrane review of 105 trials, the use of decision aids to support preference-sensitive decisions can increase patient knowledge, make people feel clearer about their values, reduce decisional conflict and promote an active patient role in decision-making.⁵ Shared decision-making process is also associated with anxiety reduction and improvements in patients' satisfaction and health outcomes.⁶

The effect of this consultation model in Length of Stay and Costs Among Hospitalized Patients is still a controversial issue. Some studies suggest that it does not affect,⁷ or may even increase,⁸ length of hospital stay and health costs. However, it is important to note that even if there is an increase in associated costs, if these are reflected in better patient satisfaction and an improvement in health outcomes, they can be seen as a benefit.

On the other hand, it is also important to note that involving patients in decision-making does not mean that physicians have to accept any request from them, in order to prevent conflicts and malpractice issues. The field of quaternary prevention must be a priority. Shared decision-making should not be an excuse to defensive medical practices.

Nevertheless, not all patients wish to actively participate in health-related decisions to the same extent. As for patients' role preferences, in a systematic review of 115 studies, patients preferred shared decision-making with the physician in 63% of the studies; 21% patients preferred to delegate decisions. It is noteworthy that shared decision-making was preferred to a great extent in more recent studies and patients with cancer.⁹

Heterogeneity in role preferences has been well demonstrated in different studies.¹⁰⁻¹⁵ Shared decision-making seems to be preferred by women and younger and better-educated patients.^{16 17} The preferred role might also be affected by demographic variables, health status, the experience of illness and ethnicity.^{11 17}

Further understanding of patient preferences is likely to make an important contribution to truly patient-centred care. The Problem-Solving Decision-Making scale measures preferred roles in health-related decision-making.¹⁸ We translated and validated this scale for the Portuguese population.¹⁹ To our knowledge, the roles preferred by the Portuguese patient population in medical decision-making have not been studied previously. Since this type of decision-making in the consultation can bring healthcare closer to patients' values, it is important to study them in order to improve the healthcare we can offer to our population. By better understanding the preferences of our patients, we can offer them more targeted and better-quality care.

This study aimed to assess Portuguese patients' preferred roles in healthcare decision-making using a representative sample of the Portuguese population.

METHOD

Study design and setting

Cross-sectional study using a representative sample of the Portuguese population living in mainland Portugal. Data collection occurred from January to March 2019, applying a questionnaire in face-to-face interviews.

Participants

Participants were considered eligible if living in mainland Portugal and aged 20 years or older. People were

excluded from the study if they had a cognitive or physical disability that made it impossible to perform a face-to-face interview, they were residents of a collective residence, or they refused to provide informed consent to participate.

The Nomenclature of Territorial Units for statistical purposes (NUTS II) geographical region quota method was used to select the sample considering the distribution of gender, age and area of residence. Interviews were conducted in all district capitals to ensure their proportionality among the population of mainland Portugal. The 'random route' sampling process was applied to randomly select households. Some interviews were allocated to each interviewer, and the route to follow was established through a completely random choice of the street, door number and floor. In each household, one individual was randomly selected using the last birthday method (the person with the most recent birthday on the date of the interview was selected). On weekdays, fieldwork took place between 17:00 and 21:00, while on weekends and holidays, it took place between 11:00 and 21:00. This was done to maximise the probability of finding as many people as possible in the household. Whenever contact with the household was not possible, additional attempts were made, and if there was still no response, the household was replaced with a new one using the same randomisation and random-route methods.

At the beginning of each interview, verbal informed consent was obtained from all participants. The interviewers were required to read a text indicating the voluntary nature of the participation, the expected duration of the questionnaire and the possibility of ending participation at any point. Voluntary participation, anonymity and confidentiality of the data were all ensured.

Questionnaire

The questionnaire contained three sections: questions about the health status of the respondent, the Problem-Solving Decision-Making scale and sociodemographic questions. The Problem-Solving Decision-Making scale was developed by Kraetschmer and colleagues and validated in English.²⁰ The scale presents three short vignettes: the *morbidity vignette*, the *mortality vignette* and the *quality of life vignette*, each with six tasks. For each task, respondents are asked, 'Who should decide?'. The answers are categorised according to a 5-point Likert scale: 1—the doctor alone, 2—mostly the doctor, 3—doctor and you equally, 4—mostly you and 5—you alone. [Table 1](#) shows the scale with its vignettes and tasks.

The Problem-Solving Decision-Making scale was translated into Portuguese and validated in a previous study.¹⁹ The translation was carried out based on the Principles of Good Practice for the Translation and Cultural Adaptation Process for Patient-Reported Outcomes Measures.²¹ First, we obtained permission from author to translate and validate the questionnaire for the Portuguese population. Two independent translations of the questionnaire were produced (by two native speakers of Portuguese, fluent in English, with a health and research background and

Table 1 Problem-Solving Decision-Making scale

Morbidity vignette: ‘Suppose you often experience a burning sensation when you go to the bathroom. You usually have to push to begin to urinate and sometimes dribbling occurs after urination.’

Mortality vignette: ‘Suppose you had mild chest pains for 3 days and decided that you should visit your doctor about this.’

Quality of life vignette: ‘Suppose you and your partner have been trying for pregnancy, but have been unsuccessful for more than a year.’

(Choose one number for each question)

	Doctor alone	Mostly the doctor	Doctor and you equally	Mostly you	You alone
Diagnosis: Who should determine (diagnose) what the likely causes of your symptoms are?	1	2	3	4	5
Options: Who should determine what the treatment options are?	1	2	3	4	5
Risks and benefits: Who should determine what the risks and benefits for each treatment option are?	1	2	3	4	5
Probability: Who should determine how likely each of these risks and benefits are to happen?	1	2	3	4	5
Utility: Given the risks and benefits of these possible treatments, who should decide how acceptable those risks and benefits are for you?	1	2	3	4	5
What is done: Given all the information about risks and benefits of the possible treatments, who should decide what treatment option should be selected?	1	2	3	4	5

experience in translating documents) and reconciled by the research team. The back-translation was done by a professional translator (native speaker of English and fluent in Portuguese) and compared with the original. Finally, the questionnaire was applied to a group of 15 people (relatives and/or colleagues of the first author of this paper) to verify that there were no problems of interpretation and to assess the time required for the application of the questionnaire. After analysing the results of the questionnaire application, no changes were required, and the final version was prepared.

Then, to validate the translated scale, two types of validity were analysed: face validity and validity of the internal structure of the scale. To test face validity of the final version of the translated questionnaire, a pilot study was carried out on 20 people with data analysis to verify the adequacy of the questions and answers. To test the internal structure validity, the questionnaire was applied to a sample of 301 people, and then the technique of principal component analysis was applied. For reliability testing of the Portuguese Problem-Solving Decision-Making scale, the internal consistency was evaluated via Cronbach’s alpha. The validation of the Portuguese scale agreed with the literature. The scale can be divided into problem-solving and decision-making components.¹⁸ The translated scale demonstrated good internal consistency allowing its use in future studies.

Replies were recorded manually in each questionnaire by the interviewers. To assure quality control, all the surveys were monitored by a data collection supervisor, and at least 20% of the interviews were randomly supervised by members of the investigation team.

Study size

The sample size of 599 participants has been calculated to estimate proportions while considering a significance level of 5%, a conservative scenario of 50% for the sample proportion, an infinite population, and an error margin of approximately 4%.

Variables and data analysis

Qualitative variables are described by their absolute and relative frequencies, n (%). Quantitative variables are described by the mean, SD and minimum and maximum values ($M \pm SD$, min, max), if normally distributed, or by the median (M) and respective 95% CI, if non-normally distributed. The normality of the variables is analysed by observation of the respective histograms. To verify sample representativeness, we performed Chi-Square Goodness of Fit Tests. To compare ordinal variables, the Mann-Whitney test was used for two independent samples, and the Kruskal-Wallis test was used for more than two independent samples. The Bonferroni correction was used for dealing with multiple testing. Multiple regression analysis was performed to adjust the variables statistically significant. The graphs presented were made in Excel V.2016 or R software.²² Data analysis was performed in SPSS V.25. Values of $p \leq 0.05$ were considered significant.

Responses to each vignette were divided into two components, in accordance with previous literature^{18 19 23}: component I or problem-solving (diagnosis, options, risks and benefits and probability) and component II or decision-making (utility and what is done). Also, similar to a previous study,¹² for each of the tasks of the two components, the scores (1–5) assigned by the respondents were redefined into three control categories: wishing to

'hand over' the responsibility to the doctor (scores 1 and 2); wishing to 'share' the responsibility with the doctor (score=3) and wishing to 'retain' the responsibility (scores 4 and 5). The 'average' variables were calculated using the mean score of all problem-solving and decision-making tasks separately for each participant.

Public involvement statement

The public was not involved in the development of the research questions.

RESULTS

Participants and descriptive data

The average age of the 599 participants was 51.9 years, ranging from 20 to 99, and the majority were women (53.8%) and of Portuguese nationality (95.5%). Most (54.9%) were married, and 35.2% had completed high school. Regarding work, 46.9% worked for others, and the majority of those had a profession working in the tertiary professional sector (83.4%). The reported health status was mainly good (45.9%). The sociodemographic characteristics of the sample and the Portuguese population are presented in [table 2](#).

To check sample representativeness, we performed Chi-Square Goodness of Fit Tests. Our sample is a representative sample of the Portuguese population in terms of sex (p value=0.446), age groups (p value=0.612) and area of residence (NUTS II) (p value=0.964), the variables that we control for stratification.

MAIN RESULTS

Morbidity vignette

Most patients preferred 'doctor alone' or 'mostly doctor' to control all the tasks of the morbidity vignette, concerning both the 'problem-solving' (97%) and 'decision-making' (66%) domains. Around one-third (30.7%) showed a preference to share the decision concerning 'what is done' ([table 3](#)).

Detailed results can be found in online supplemental appendix table 1.

Mortality vignette

The 'handover' control category was preferred for the conjunct of both problem-solving (99%) and decision-making tasks (66%). A preference for a shared decision on 'what is done' was present in 29.4% ([table 4](#)).

Detailed results are found in online supplemental appendix table 2.

Quality of life vignette

Although, in line with the responses to other vignettes, most participants preferred to hand over all the tasks for problem-solving (96%) and decision-making (55%) ([table 5](#)), concerning this quality of life scenario, the 'retain' category registered more preference than in the other two vignettes, namely, 21.2% of the responses regarding 'what is done' fall in the 'retain' category.

Table 2 Sociodemographic characteristics of the sample, N=599

Characteristic	Study sample	Portuguese population
Nationality, n (%)		
Portuguese	572 (95.5)	
Foreign	27 (4.5)	
Stateless (without nationality)	0 (0)	
Does not know	0 (0)	
Age (years), $\bar{x} \pm \text{sx} \pm \text{s}$, min, max	51.9 \pm 18.0, 20, 99	
Age (years), n (%)*, p value=0.612		
20–24	37 (6.2)	582 065 (5.5)
25–29	39 (6.5)	656 076 (6.2)
30–34	43 (7.2)	773 567 (7.3)
35–39	50 (8.3)	824 683 (7.8)
40–44	59 (9.8)	773 098 (7.3)
45–49	55 (9.2)	770 294 (7.3)
50–54	54 (9.0)	722 360 (6.8)
55–59	52 (8.7)	677 651 (6.4)
60–64	49 (8.2)	634 741 (6.0)
65–69	44 (7.3)	551 701 (5.2)
70–74	38 (6.3)	496 438 (4.7)
≥75	79 (13.2)	961 925 (9.1)
Sex, n (%)*, p value=0.446		
Male	277 (46.2)	5 046 600 (47.8)
Female	322 (53.8)	5 515 578 (52.2)
Marital status, n (%)*, p value<0.001		
Not married	133 (22.2)	4 272 977 (40.5)
Married	329 (54.9)	4 924 870 (46.6)
Married (in the situation legally separated from persons and property) or Divorced	70 (11.7)	593 667 (5.6)
Widowed	67 (11.2)	770 664 (7.3)
Higher educational level completed, n (%)†, p value<0.001		
None	14 (2.3)	596.0 (6.7)
Elementary school—first cycle (4th year)	135 (22.5)	1966.3 (22.2)
Elementary school—second cycle (6th full year)	58 (9.7)	933.7 (10.5)
Elementary school—third cycle (9th full year)	114 (19.0)	1766.4 (20.0)
High school (12th year)	211 (35.2)	1934.5 (21.9)
Higher education	67 (11.2)	1655.0 (18.7)
Main occupation, n (%)†, p value<0.001		

Continued

Table 2 Continued

Characteristic	Study sample	Portuguese population
Works on their own	100 (16.7)	789.7 (7.7)
Work for others	281 (46.9)	4056.5 (39.5)
Student	16 (2.7)	801.1 (7.8)
Doing military service	0 (0)	
Homemaker	8 (1.3)	378.3 (3.7)
Retired	156 (26.0)	1774.5 (17.3)
Unemployed	38 (6.3)	365.9 (3.6)
Does not know	0 (0)	
Profession, n (%)†, p value<0.001		
No job	218 (36.4)	365.9 (3.6)
Job	381 (63.6)	4866.7 (47.4)
Does not know	0 (0)	
Professional sector, n (%)†, p value<0.001		
Primary	2 (0.5)	294.2 (6.0)
Secondary	61 (16.1)	1209.2 (24.8)
Tertiary	317 (83.4)	3363.3 (69.1)
Area of residence (NUTS II), n (%)†, p value=0.964		
Norte	220 (36.7)	3 572 583 (36.5)
Centro	140 (23.4)	2 216 569 (22.7)
AM Lisboa	167 (27.9)	2 846 332 (29.1)
Alentejo	43 (7.2)	705 478 (7.2)
Algarve	29 (4.8)	438 864 (4.5)
Health status, n (%)		
Very good	61 (10.2)	
Good	275 (45.9)	
Reasonable	216 (36.1)	
Bad	44 (7.3)	
Very bad	3 (0.5)	

*PORDATA 'Censos 2011', n=105 562 178.

†PORDATA 2018 data, n=10 276 617.

NUTS II, Nomenclature of Territorial Units for statistical purposes.

Detailed results are found in online supplemental appendix table 3.

ANALYSIS OF THE THREE VIGNETTES

Although there are differences in terms of preference for each vignette separately, we decided to analyse the three vignettes together to allow for a comparison with the existing literature since Deber *et al* performed a similar data analysis.^{12 14} All the mean scores on the Problem-Solving Decision-Making scale were inferior to 3 (online supplemental appendix table 4), indicating a preference for a practitioner controlling role. Also, considering the

Table 3 Morbidity vignette proportion of scores in each control category (N=599)

	Control categories, %		
	Hand over (<3)	Share (3)	Retain (>3)
Problem-solving			
Diagnosis	460 (76.8)	120 (20.0)	19 (3.2)
Options	572 (95.5)	25 (4.2)	2 (0.3)
Risks and benefits	543 (90.7)	53 (8.8)	3 (0.5)
Probability	508 (84.8)	78 (13.0)	13 (2.2)
Average	581 (97)	15 (3)	3 (1)
Decision-making			
Utility	363 (60.6)	182 (30.4)	54 (9.0)
What is done	341 (56.9)	184 (30.7)	74 (12.4)
Average	394 (66)	132 (22)	73 (12)

distribution of Problem-Solving Decision-Making scale scores by control category for the three vignettes together, of the 12 problem-solving scores (three vignettes times, four tasks), 99.6% were between 1 and 3. In contrast, in the decision-making component, this percentage drops to 78.7%, showing that patients have some desire to participate in this component (online supplemental appendix table 5).

In order to classify patients' preferred roles, we used a methodology previously applied by Deber *et al*.¹⁴ The average-PS (problem-solving) and average-DM (decision-making) variables shown in online supplemental appendix table 5 were recoded into three control categories: 'hand over' (score <3); 'share' (score ≥3 and <4) and 'keep' (score ≥4). These score groups were used to place the patients in one of three preferred role categories: 'passive' (handing over both problem-solving and decision-making); 'shared' (handing over or sharing problem-solving but share or keep decision-making) and 'autonomous' (keeping problem-solving and sharing

Table 4 Mortality vignette proportion of scores in each control category (N=599)

	Control categories, %		
	Hand over (<3)	Share (3)	Retain (>3)
Problem-solving			
Diagnosis	536 (89.5)	55 (9.2)	8 (1.3)
Options	583 (97.3)	14 (2.3)	2 (0.3)
Risks and benefits	554 (92.5)	40 (6.7)	5 (0.8)
Probability	523 (87.3)	66 (11.0)	10 (1.7)
Average	591 (99)	4 (1)	4 (1)
Decision-making			
Utility	377 (62.9)	161 (26.9)	61 (10.2)
What is done	352 (58.8)	176 (29.4)	71 (11.9)
Average	398 (66)	133 (22)	68 (11)

Table 5 Quality of life vignette proportion of scores in each control category (N=599)

	Control categories, %		
	Hand over (<3)	Share (3)	Retain (>3)
Problem-solving			
Diagnosis	494 (82.5)	86 (14.4)	19 (3.2)
Options	549 (91.7)	46 (7.7)	4 (0.7)
Risks and benefits	533 (89.0)	60 (10.0)	6 (1.0)
Probability	498 (83.1)	85 (14.2)	16 (2.7)
Average	573 (96)	18 (3)	8 (1)
Decision-making			
Utility	308 (51.4)	176 (29.4)	115 (19.2)
What is done	280 (46.7)	192 (32.1)	127 (21.2)
Average	332 (55)	140 (23)	127 (21)

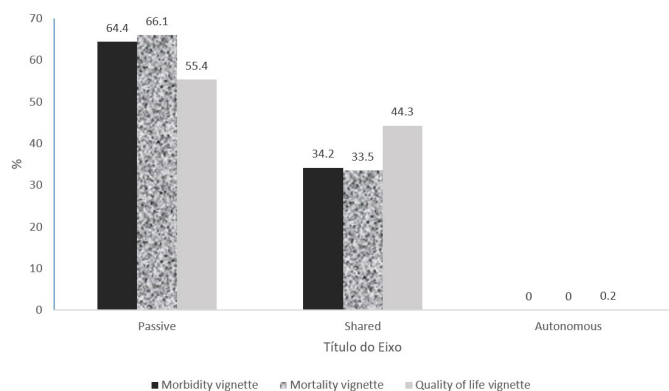
or keeping decision-making) (online supplemental appendix table 6).

Figure 1 shows the preferred roles' proportions of scores for the three vignettes. Patients most often left the decision to the doctor in the mortality vignette, with 66.1% of the patients being passive. In contrast, the quality of life vignette had a higher percentage of patients who wanted a shared role (44.3%) and was the only one in which there were people in the autonomous category (0.2%).

Detailed results are found in online supplemental appendix tables 4–7.

Factors influencing patients' preferred roles

We investigated the variations in participation preferences according to individual differences using Mann-Whitney or Kruskal-Wallis tests. In the problem-solving component, differences in preferences were statistically significant for area of residence ($p<0.001$) and educational level ($p=0.013$). Higher educated people wanted a more participative role in the consultation. The Alentejo area seemed to want a more participative role, while people from AM Lisboa and Algarve seemed to leave the decisions to their doctors. In a multivariate analysis, these variables remain statistically significant when adjusted for one another.

**Figure 1** Preferred roles of the three vignettes.

In the decision-making component, differences in preferences were statistically significant for age ($p=0.020$), educational level ($p=0.015$) and profession ($p<0.001$). Younger, higher educated and employed people seemed to want a more participative role in consultation. In a multivariate analysis, the variable profession is non-statistically significant when adjusted for the other two variables ($p=0.421$).

Detailed results are found in online supplemental appendix figures 1–4.

DISCUSSION

Key findings

For the three vignettes (morbidity, mortality and quality of life), patients preferred a practitioner-controlling role for both problem-solving and decision-making tasks, although comparatively more opted to share decision in the decision-making component. Of note, a higher proportion of participants revealed to prefer a controlling role concerning the quality of life vignette's decision tasks in comparison with the other two vignettes. In this representative sample of the Portuguese population, for the problem-solving component, preferences were significantly associated with area of residence and educational level, while for the decision-making component preferences associated with age, educational level and profession.

Comparison with the existing literature

Our results are similar to Deber *et al*¹² in demonstrating that there are differences between the problem-solving and decision-making components. The patients prefer to leave the problem-solving tasks to their doctor but want to be involved in decision-making tasks, showing a desire for information. This supports the argument that patients want to actively participate in making decisions about their own care.

In a 2012 systematic review on patient preferences for shared decisions, in 63% of the included studies, there was a preference to participate in medical decisions, while in 21% of the studies most participants preferred to delegate decisions.⁹ Our results seem to be in accordance with this last proportion of studies. We hypothesise that the Portuguese population may still be less ready to share healthcare decisions with physicians. This may be due to low health literacy and low numeracy, which can pose barriers to share decision-making; some patients from disadvantaged cultural backgrounds are not used to participating in medical decisions.^{9 24}

Of note, the included studies used different scales, which could also explain the differences. Nevertheless, in the same systematic review, considering four analyses of articles that used the problem-solving decision-making scale, in 80% of studies, the majority of patients preferred to participate in decisions, a higher proportion in comparison with our results.

A 2020 exploratory study in an orthopaedic surgery clinic found that patients preferred semipassive roles in 92% of decisions assessed.²⁵ A study with seriously ill-hospitalised patients showed a preferred variable role concerning decision control.²⁰ Our findings are also in line with another study using the problem-solving decision-making scale, in which very few participants wished an autonomous role.²⁶

Regarding which factors are associated with patients' preferred involvement in the problem-solving and decision-making process, our findings are in line with other study using the same scale, which found education to be significantly associated with the desire to participate in health decisions.²⁷ However, we found no significant differences between different genders, unlike other studies.^{11 17 28}

Strengths and limitations

Our study participants are a representative sample of the Portuguese mainland population, yet island residents were excluded, which might be a limitation. We cannot exclude social desirability bias, as interviews were face-to-face, although interviewers were previously trained to apply the questionnaire and had no previous relationship with participants.

Implications for practice and research

Shared decision-making with physicians is supported by robust evidence,⁵ yet as our findings suggest most patients still prefer to handover their healthcare decisions. Physicians' training to adequately engage in shared decision-making with their patients should be introduced early in Medicine curricula as well in practice guidelines for preference-sensitive healthcare decisions.

More longitudinal studies are needed to deepen our understanding of how the patient's preferred role might change with changes in health status and through the course of a disease.

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Data availability statement All data relevant to the study are included in the article or uploaded as supplementary information.

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