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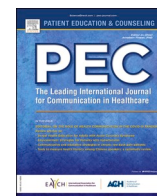
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# Patients' preferred and perceived decision-making roles, and observed patient involvement in videotaped encounters with medical specialists

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## ABSTRACT

**Objective:** To assess how patients prefer and perceive medical decision making, which factors are associated with their preferred and perceived decision-making roles, and whether observed involvement reflects patients' perceived role.

**Methods:** We asked 781 patients visiting a medical specialist from 18 different disciplines to indicate their preferred and perceived decision-making roles. Patient involvement in videotaped consultations was assessed with the OPTION5 instrument.

**Results:** Most patients preferred and perceived decision making as shared (SDM; 58% and 43%, respectively), followed by paternalistic (26% and 38%), and informative (16% and 15%). A large minority ( $n = 103$ , 21%) of patients preferring shared or informative decision making ( $n = 482$ ) experienced paternalistic decision making. Mean (SD) OPTION5 scores were highest in consultations which patients perceived as informative (26.0 (19.7)), followed by shared (19.1 (17.2)) and lowest in paternalistic decision making (11.8 (13.4)  $p < 0.001$ ).

**Conclusions:** Most patients want to be involved in decision making. Patients perceive that the physician makes the decision more often than they prefer, and perceive more involvement in the decision than objective assessment by an independent researcher shows.

**Practice implications:** A clearer understanding of patients' medical decision-making experiences is needed to optimize physician SDM training programmes and patient awareness campaigns.

## 1. Introduction

Shared decision making (SDM) is a process in which medical decisions are made in a collaborative way between physicians and patients, in which information is provided about the available options with their benefits and harms, and the patient's values, preferences and circumstances are taken into consideration [1]. SDM is an important link in the integration of evidence-based medicine and patient-centred communication skills, to provide optimal patient care [2]. The process of SDM allows the physician's medical expertise to meet the patient's expertise regarding their personal life [1]. The justification for the SDM model primarily comes from ethical principles of care, including respecting the patient's autonomy and doing no harm [3–5]. Asking patients what their preferences are regarding a decision alerts them that there is a choice to be made and allows them to participate in that choice

if they wish. When patients are more involved in the decision-making process, they are more satisfied with the decision taken, which increases their likelihood of following through with the actions related to the decision and, hence, with their adherence to the agreed-upon treatment [6].

Although SDM is increasingly championed as the preferred model of decision making in medical encounters, its implementation in routine medical care remains problematic [7–10]. A number of observational studies have shown low levels of patient involvement in daily clinical practice [11,12]. Research on the barriers that hamper further implementation of SDM has focused on the physician's perspective on the decision-making process. It has been shown, for instance, that many physicians think that they already apply SDM [8,13]. They also feel their patients either do not want to be involved in the decision-making process or are too sick or too emotional to be capable to participate

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meaningfully in decision making [14]. Although SDM aims to promote patient involvement in reaching a decision that suits them best, there is a paucity of evidence on the patients' perspective on its limited implementation in medical care. It has been well established that most patients prefer SDM, [15,16] but there is scant literature on how patients perceive the actual decision-making process in everyday clinical practice. The available studies that investigated patient perception of decision making in consultations were conducted in specific settings (such as breast cancer or dialysis care) and the participating physicians in these studies were either trained in SDM or worked in a department running an SDM implementation program [16–23]. Thus, patients' perceptions of the decision-making process in everyday clinical practice encounters are largely unknown.

A thorough understanding of how patients perceive the decision-making process in medical encounters may offer a novel perspective on understanding the problems in SDM implementation, and can be useful in developing effective SDM training programs for physicians and improving awareness campaigns for patients. Therefore, we studied how patients prefer and perceive the decision-making process in a large sample of hospital based consultations across medical specialties, and we assessed to what extent the perception was affected by patient, consultation and physician characteristics. We also assessed whether the observed degree of patient involvement reflected the patients' perceived role in decision making.

## 2. Methods

### 2.1. Setting

We analysed video-recorded outpatient encounters between medical specialists and their patients in Isala Hospital, a large general teaching hospital in the Netherlands. The sample of videotaped consultation was obtained between November 2018 and April 2019. We distinguished the main decision from all other decisions in each consultation (decision type). The main decision was defined as the decision that directly related to the chief complaint reported by the patient during the consultation with the specialist. We chose the patients' main decisions for our analyses because we assumed that patients had these in mind when they reported their perceived decision-making role.

### 2.2. Participants

We recruited the participating medical specialists from respondents to our previous cross-sectional survey in which we assessed their perceptions on the decision-making process [13,24]. All medical specialists who had participated in our survey study were invited via e-mail by the first author to participate in this observational study with videotaped encounters. Participating physicians were not recruited based on specific characteristics. We approached consecutive patients at each medical specialist's regular scheduled outpatient clinics. We aimed to include a minimum of 10 encounters per physician, which is recommended to obtain a reliable estimate of healthcare professionals' patient involvement behavior [25]. To protect the privacy of patients, only the physicians were visibly recorded on video; the patient was only captured on audio. All participants, physicians and patients, provided written informed consent.

### 2.3. Outcomes and instruments

#### 2.3.1. Patients' preferred and perceived decision-making roles

Directly after the medical consultations, patients were asked to complete the control preference scale (CPS). The CPS was designed to assess patients' perceived and preferred decision-making roles in a medical consultation [26]. It has been validated across several patient and clinical contexts and has shown good reliability [27]. The responses to these questions were classified as paternalistic (physician decides),

shared, or informative (patient decides) decisions, [13] see [supplementary material](#), Table A.

#### 2.3.2. Patient satisfaction

To assess the effect of a possible discrepancy between perceived and preferred decision-making roles on satisfaction, we asked the patients, directly after the medical consultation, to complete a satisfaction questionnaire containing the Net Promoter Score (NPS), which is the standard patient satisfaction questionnaire used in Dutch hospitals, including Isala. The NPS assesses the likelihood that a patient would recommend the physician to someone else, on a scale ranging from 0 to 10 (higher scores meaning the patient is more likely to recommend the physician to another person) [28]. We report the mean NPS on the 11-point scale, because the original cut-off points for the NPS categorization have been shown to be inappropriate in the Dutch setting [28]. Participating patients completed both the CPS and the NPS on their own, without supervision. The first author or a research assistant were available at the outpatient clinic for assistance or clarification if required.

#### 2.3.3. Patient involvement in the decision-making process

We used the validated Observing Patient Involvement (OPTION5) instrument to assess the extent to which extent the participating medical specialists involved patients in the decision-making process (for the items, see [supplementary material](#), Table B) [29]. Each OPTION5 item is scored on a 5-point Likert scale ranging from zero (not observed) to four (executed to a high standard). The sum of these items is the total score (range 0–20). Following the instrument's coding manual, we rescaled the total scores to a range of 0–100 [29]. We used the consultation's main decision OPTION5 scores for analysis purposes. In view of the large number of encounters, two researchers were used for the scoring process (EMD and RH, a linguistics master student). Both were trained in the application of the OPTION5 scoring system. To ensure interrater reliability, both researchers independently scored the first 29 videotaped encounters, and compared and discussed differences until consensus was reached. They then independently coded 179 subsequent encounters and achieved excellent interrater agreement (intraclass correlation coefficient 0.938 [95% confidence interval (CI) 0.921–0.951]). The remaining consultations were coded by either one of the researchers.

### 2.4. Statistical analysis

We used chi-squared tests to compare proportions and Student's *t*-tests to compare group means. Multivariable logistic regression analysis was used to assess correlates of the patients' perceived decision-making role. For the logistic regression analysis, we recoded the patients' perceived decision-making role into two groups based on their CPS response: perceived active role (informative or SDM role) versus no active role (paternalistic role). We evaluated the effect on patients' perceived decision-making role of the following variables: patients' gender, presence of a companion (spouse, family or friend), consultation duration, consultation type (new patient or follow-up consultations), type of problem (cancer or no cancer), decision category (diagnostic (gathering additional information), treatment, or follow-up decision), and the physician's discipline (medical or surgical) [30]. We analysed patients' age both as a continuous variable and as an ordinal variable, categorised as paediatric patient (aged <18 years), patient aged 18–65 years and patient  $\geq 65$  years. The OPTION5 instrument is ordinal by design, but in most studies OPTION5 scores have been analysed as a continuous variable using parametric statistical techniques [29]. We assessed the differences in OPTION5 scores between groups using both nonparametric and parametric analyses. Since these analyses showed comparable results and to facilitate comparison with other studies, further data analysis was carried out using parametric tests only. The OPTION5 scores were not entered into logistic regression models because of the nested nature of this variable, with multiple observations

for each participating medical specialist. For all analyses, the alpha level was set at 0.05. All analyses were performed using SPSS (version 26).

### 2.5. Ethics

The Ethical Review Board of Isala Hospital approved the study (file number 180706). All participating medical specialists and patients provided written informed consent.

## 3. Results

### 3.1. Demographics

Overall, 41 medical specialists (28 male (68%), mean (SD) age 47.9 (8.0) years) from 18 specialties (23 from medical and 18 from surgical disciplines) and 781 patients (15–24 per medical specialist) participated in our study. After excluding 36 consultations because of insufficient audio quality and 18 preoperative anaesthesiology consultations in which no decisions were made, a total of 727 consultations and 1564 decisions were available for analysis. The median (range) number of decisions per consultation was two (1–6). None of the participating medical specialists had received SDM training prior to participation in this study. There were 347 male patients (48%); their mean (SD) age was 48.6 (24.6) years. There were 239 consultations with new patients (33%) and 488 follow-up consultations (67%). The mean (SD) duration of the consultations was 15 (9) minutes.

### 3.2. Patients' preferred decision-making role

Most patients (n = 387, 58%) wanted to share their medical decisions with their physician, 176 (27%) preferred the physician to decide and 95 (16%) wanted to make the decision themselves (Table 1). Paediatric patients (aged <18 years) with their parent(s) and patients aged 18–65 years less frequently expressed a preference for SDM (n = 73/132, 55% and n = 186/352, 53%, respectively) than patients ≥ 65 years (n = 154/233, 66%, p = 0.023). Patients' gender, type of consultation (new patient vs follow-up visit), type of problem (cancer vs no cancer), and presence of a companion had no effect on the patients' decision-making preference (all p-values >0.114, Table 2).

### 3.3. Patient's perceived decision-making role

Patients' perceived decision-making roles, as assessed by CPS, are presented in Table 1. Almost half of the patients perceived that the decision was made with the physician (n = 307, 47%), 253 (38%) perceived that the medical specialists decided for them, and 98 patients reported they had made the decision themselves (15%). The relationship of patient and consultation characteristics to patients' perceived decision-making role is presented in Table 2. Patients perceived the decision making as SDM considerably more often with treatment decisions than with other decision categories (p < 0.001), and slightly more often when they were new patients or when the consultation lasted longer (Table 3). In logistic regression analysis, patient and consultation characteristics had no effect on patients' perceived decision-making role. The only variable significantly related to patients' perceived decision-making role was decision category (SDM more likely with

treatment than with other decisions, odds ratio 2.13, 95%CI 1.48–3.06, p < 0.001).

Discrepancy between preferred and perceived decision-making roles In 481 (73%) consultations, the patient's perceived decision-making role was the same as their preferred decision-making role. Patient and consultation characteristics had no effect on the agreement of perceived and preferred decision-making role (all p-values > 0.091). In the group of 387 patients who preferred SDM, 103 patients (21%) experienced decision making to be paternalistic, see Table 1. The 481 patients (73%) whose perceived decision-making role was the same as their preferred decision-making role had slightly higher NPS score (mean 8.9, SD 1.0) than the 171 patients (27%) who perceived another decision-making role than their preferred role (mean 8.7, SD 1.0, 95% CI of difference 0.01–0.40, p = 0.044).

### 3.4. Observed patient involvement (OPTION5)

In comparison to a systematic review of earlier studies, in which mean (SD) OPTION5 scores were 23 (14), [21] overall patient involvement in the present study was low, with mean (SD) OPTION5 scores of 16.8 (17.1). Although 47% of patients perceived the decision-making process as shared and another 15% perceived they had made the decision themselves. We observed the highest degree of patient involvement (mean (SD) OPTION5 scores) in consultations in which patients perceived the decision making as informative 26.0 (19.7), followed by shared 19.1 (17.2), and lowest for paternalistic decision making (11.8 (13.4), p < 0.001).

## 4. Discussion and conclusion

### 4.1. Discussion

Most patients in our study wanted to be involved in decision making, and make the decision together with their physician (SDM) or by themselves (informative decision making). Although most patients perceived that they were involved in making the decision, patients reported that the physician made the decision for them, although their preferred role was to be involved in the decision-making process (Table 1). The perceived decision-making role was independent of patient and consultation characteristics, except for decision category (higher perceived patient involvement in treatment decisions than in diagnostic or follow-up decisions).

The large majority of the patients in our study (70%) perceived the decision-making role in their consultation with the medical specialist to match their preferred decision-making role, which is in line with a review of 22 studies that assessed the match between patients' preferred and experienced participation in (mainly cancer) treatment decisions [31]. The statistically significant difference in satisfaction (NPS) score between patients whose perceived decision-making role did or did not corresponded to their preferred role was too small to be clinically relevant. In agreement with earlier work, the power of our study to detect meaningful differences in NPS scores between different patient groups was hampered by ceiling effects, because many patients provided the maximum NPS score [28].

Interestingly, elderly patients (> 65 years of age) expressed a preference for SDM more often than patients 18–65 years and paediatric

**Table 1**  
Preferred and perceived decision-making role.

Patients' self-reported decision-making role		Perceived role					Total	
		Paternalistic	SDM	Informative		N	(% within preferred role)	
Preferred role	Paternalistic	150 (85%)	20 (11%)	6 (4%)		176	(27%)	
	SDM	92 (24%)	267 (69%)	28 (7%)		387	(58%)	
	Informative	11 (12%)	20 (21%)	64 (67%)		95	(15%)	
Total N (% within perceived role)		253 (38%)	307 (47%)	98 (15%)		658	(100%)	

**Table 2**  
Patient-reported preferred role in the decision-making process and the effect of patient and consultation characteristics.

Patient and consultation characteristics	Patient-reported preferred decision-making role*							p-value
	Paternalistic N (%)		SDM N (%)		Informative N (%)		Total	
Patient gender								0.493
Male	95	(28%)	197	(58%)	49	(14%)	341	
Female	95	(25%)	216	(58%)	65	(17%)	376	
Patient age (years)								0.039
Mean (SD)	45.2	(24.5)	50.5	(24.6)	47.6	(23.8)	717	
Patient age (category)								0.023
< 18 year	40	(30%)	73	(55%)	19	(14%)	132	
18 – 65 year	102	(29%)	186	(53%)	64	(18%)	352	
≥ 65 year	48	(21%)	154	(66%)	31	(13%)	233	
Type of consultation								0.868
New patient	63	(27%)	134	(56%)	40	(17%)	237	
Follow-up consultation	127	(27%)	279	(58%)	74	(15%)	480	
Companion								0.114
Present	118	(26%)	254	(56%)	82	(18%)	454	
Not present	72	(27%)	159	(61%)	32	(12%)	263	
Type of problem								0.484
Cancer	17	(23%)	41	(56%)	15	(21%)	73	
No-cancer	173	(27%)	372	(58%)	99	(15%)	644	
Total	190	(26%)	413	(58%)	114	(16%)	717	NA

\* The Control Preference Scale is used to assess the preferred and experienced role of decision making of the patients direct after their consultation with the medical specialist. Abbreviations: SDM = shared decision-making, NA = not applicable.

**Table 3**  
Patient-reported perceived decision-making role and the effect of patient and consultation characteristics.

Patient and consultation characteristics	Patient-reported perceived decision-making role*							p-value
	Paternalistic N (%)		SDM N (%)		Informative N (%)		Total	
Patient gender								0.168
Male	135	(42%)	145	(45%)	42	(13%)	322	
Female	120	(35%)	164	(48%)	56	(17%)	340	
Patient age (years)								0.808
Mean (SD)	48.1	(24.8)	47.6	(25.0)	49.4	(23.6)	662	
Patient age (category)								0.435
< 18 year	49	(39%)	64	(50%)	14	(11%)	127	
18 – 65 year	130	(39%)	143	(44%)	55	(17%)	328	
≥ 65 year	76	(37%)	102	(49%)	29	(14%)	207	
Type of consultation								0.011
New patient	77	(34%)	102	(45%)	46	(21%)	225	
Follow-up consultation	178	(41%)	207	(47%)	52	(12%)	437	
Companion								0.398
Present	153	(37%)	197	(47%)	66	(16%)	416	
Not present	102	(42%)	112	(45%)	32	(13%)	146	
Type of problem								0.940
Cancer	26	(40%)	29	(45%)	10	(15%)	65	
No-cancer	229	(38%)	280	(47%)	88	(15%)	597	
Consultation duration (minutes)								0.015
Mean (SD)	14.2	(9.1)	16.3	(8.7)	16.0	(10.0)	662	
Consultation duration								0.158
≥ 5 min longer than planned	32	(36%)	38	(43%)	19	(21%)	89	
Within scheduled time	223	(39%)	271	(47%)	79	(14%)	573	
Decision category								< 0.001
Treatment	165	(33%)	245	(50%)	83	(17%)	493	
Diagnostic or follow-up	90	(53%)	64	(38%)	15	(9%)	169	
Total	255	(38%)	309	(47%)	98	(15%)	662	NA

\* The Control Preference Scale is used to assess the preferred and experienced role of decision making of the patients direct after their consultation with the medical specialist. Abbreviations: SDM = shared decision-making, NA = not applicable.

patients (aged <18 years) with their parent(s) (Table 2). This challenges the common assumption that elderly patients prefer paternalistic decision making, [14,31] and underscores the importance of discussing with the patient what role they want to have in the decision-making process instead of assuming that the physician knows which decision-making role patients prefer.

There was a considerable discrepancy between the patients' self-reported perceived decision-making role and the degree of patient involvement as observed by an independent trained observer (OPTION5). Overall, in comparison to earlier studies, [21] the OPTION5 score that we recorded were low, even in consultations which patients

perceived as SDM. One possible explanation is that there are factors in the consultation that influence the patient's experience, which are not part of the SDM process as evaluated by the observer assessment, like rapport building, the expression of empathy by the physician, or time management of the consultation. Another explanation could be that parts of the decision-making process had already been carried out in previous consultations, which would result in seemingly low OPTION5 scores, despite the patient involvement in previous consultations [1,32]. We were surprised that the observed patient involvement was highest in consultations in which the patients had experienced that they had made the decision themselves (informative model). This suggests that patients

feel more room to make the medical decision themselves when physicians show more SDM behaviour. The discrepancy that we observed between how patients perceived the decision-making role in consultations and the observed patient involvement as assessed by an independent researcher using the validated OPTION5 instrument expands those of previous studies in selected care centres with doctors trained in SDM [16–23]. It should be noted that these two instruments (CPS and OPTION5) were designed for different purposes, and none of the studies comparing results from these instruments (including our own) have investigated or confirmed that they capture comparable aspects of the decision-making process as perceived by patients (CPS) or independent observers (OPTION5). With some caution, therefore, the results of the present study suggest that in everyday clinical practice, patients may have a different perception of the decision-making process in consultations than is reflected in the physician's decision-making behaviour as assessed by an independent observer. These results raise the issue of what patients exactly understand by SDM. In view of the fact that SDM has been developed for patients, to respect their autonomy and to promote that their views and preferences are taken into account when making medical decisions about their health, [1,3–5,33,34] it is striking that the large majority of SDM models (75%) have been designed and developed without patient involvement [34]. Surprisingly little is known about how patients actually perceive and judge the decision-making process in consultations about their health issues. An interview study with 23 patients in general practice showed that patients experience a decision as shared when they came to a mutually agreed decision with their doctor, suggesting the outcome of agreement is more important to them than the communication process that they experienced [35]. In another interview study, 30 cancer patients mentioned asking questions, expressing their thoughts, feelings and opinions, considering options, and deciding or delegating the decision to their oncologist as key parts of a shared decision [36]. In addition, it has been argued that a large part of the decision-making process takes place outside of the medical consultation, with patients and their families acquiring information online or from their social network, deliberating their options, and developing their preferences over time [32]. Despite these limitations of studying the SDM process during single consultations, patients rely to a considerable degree on information provided by their health care professionals, and may expect a treatment recommendation from their physician [14,35–37]. Evidence suggests that choice awareness, the part in which the physician acknowledges that a decision needs to be made and that both parties should take part in this process, is of key importance to empowering patients to participate in the decision-making process [34,38,39].

#### 4.1.1. Strengths and limitation of this study

The main strength of this study is that we assessed the relationship between patients' self-reported perceived decision-making role in medical consultations and the actual observed and independently assessed degree of physician-driven patient involvement in a large sample of clinical decisions in consultations with patients visiting medical specialists, who were not specifically trained in SDM, from 18 different disciplines. Our results therefore reflect medical decisions in outpatient consultations across disciplines in everyday clinical practice. The use of validated methods supports the robustness of our findings.

A number of limitations relate to the instruments we used. Firstly, the use of patient self-report measures may be at risk of social desirability bias [40]. Secondly, CPS and OPTION5 focus on different parts of the decision-making process, with the CPS focusing more on who made the final decision, the OPTION5 more on the entire process of patient involvement. This may partly explain the discrepancy between the CPS replies and the OPTION5 scores. Thirdly, patients' preferences of the decision-making process were assessed with CPS scores after the visit, which are likely to have been affected by the actual events occurring in the consultation room or by the patient's experience of the decision-making process, which we also asked them to record. It is

therefore likely that hindsight bias limits the reliability of our data on the patient's preferred decision-making role, and that our way of recording preferred and perceived decision-making role simultaneously after the consultation may have inflated the agreement between these two variables in our study. For future studies, we recommend assessing patients' decision-making preference before the consultation, and their perception of the decision-making process after the consultation. Fourthly, putting a camera in the consultation room may have influenced participants' behaviour, potentially prompting participating physicians to show more SDM behaviour. However, so far, there is no indication that videotaping consultations has a measurable effect on physicians' behaviour [41,42]. Fifthly, in comparison to earlier studies, the OPTION5 scores in our study were relatively low, limiting our study's power to identify statistically significant associations between OPTION5 scores and other variables. Finally, this study was performed in a single Dutch hospital, limiting generalizability of results to other hospitals and settings.

#### 4.2. Conclusion

In this large sample of medical encounters between patients and medical specialists in a large general teaching hospital in the Netherlands, most patients want to be involved in medical decisions. A large minority of patients preferring to be involved in the decision-making process perceived paternalistic decision making, with the physician making the decision for them, but these results may have been affected by hindsight bias. Patients perceive more involvement in the decision than objective assessment by an independent researcher shows, calling into question what patients actually perceive as patient involvement.

#### 4.3. Practice implications

The finding that patients feel involved while an independent researcher observes little involvement is remarkable and calls for a careful exploration of patients' perspectives on and experiences of the decision-making process. Qualitative research methods, with in-depth interviews with individual patients or patient focus groups, appear to be the most appropriate approach to exploring this issue. A clearer understanding of the patient's experience in and views on the process of medical decision making may contribute to a better understanding of the halting implementation of SDM.

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#### CRedit authorship contribution statement

EMD designed the study, collected data, analysed data, and was the principal author of the manuscript. AMS assisted in the design of the study, the interpretation of the data, and the editing of the manuscript. PLPB designed the study, supervised data analysis and interpretation, and edited the manuscript. The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.

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### Conflict of interest

The grant from Isala Hospital Innovation and Research Fund covers the salary of the main researcher (EMD) through her PhD trajectory; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

### Declarations of interest

None.

### Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.pec.2022.03.025](https://doi.org/10.1016/j.pec.2022.03.025).

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