

# BMJ Open Patient involvement in decision-making: a cross-sectional study in a Malaysian primary care clinic

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## ABSTRACT

**Objective:** Shared decision-making has been advocated as a useful model for patient management. In developing Asian countries such as Malaysia, there is a common belief that patients prefer a passive role in clinical consultation. As such, the objective of this study was to determine Malaysian patients' role preference in decision-making and the associated factors.

**Design:** A cross-sectional study.

**Setting:** Study was conducted at an urban primary care clinic in Malaysia in 2012.

**Participants:** Patients aged >21 years were chosen using systematic random sampling.

**Methods:** Consenting patients answered a self-administered questionnaire, which included demographic data and their preferred and actual role before and after consultation. Doctors were asked to determine patients' role preference. The Control Preference Scale was used to assess patients' role preference.

**Primary outcome:** Prevalence of patients' preferred role in decision-making.

**Secondary outcomes:** (1) Actual role played by the patient in decision-making. (2) Sociodemographic factors associated with patients' preferred role in decision-making. (3) Doctors' perception of patients' involvement in decision-making.

**Results:** The response rate was 95.1% (470/494). Shared decision-making was preferred by 51.9% of patients, followed by passive (26.3%) and active (21.8%) roles in decision-making. Higher household income was significantly associated with autonomous role preference ( $p=0.018$ ). Doctors' perception did not concur with patients' preferred role. Among patients whom doctors perceived to prefer a passive role, 73.5% preferred an autonomous role ( $p=0.900$ ,  $\kappa=0.006$ ).

**Conclusions:** The majority of patients attending the primary care clinic preferred and played an autonomous role in decision-making. Doctors underestimated patients' preference to play an autonomous role.

## INTRODUCTION

Several studies have shown that patient involvement in decision-making is poor

## Strengths and limitations of this study

- This study is one of the few performed in Asia looking specifically at patients' preferred role in decision-making.
- Systematic random sampling was used to provide a good representation of the clinic attendees, which makes the results generalisable to the study population.
- This study was conducted in a primary care clinic based in a teaching hospital located in an urban area. The findings may not be representative of the general population in the community.
- The questionnaire was given to patients and doctors before consultation, which may have resulted in a change in the doctors' behaviour during the consultation.
- Although face and content validation was performed for the Control Preference Scale, reliability testing and further validation using convergent or discriminatory validation methods may be necessary to determine the validity of the questionnaire.

worldwide.<sup>1-4</sup> The Department of Health in the UK has come up with the policy 'Liberating the NHS: no decision about me, without me' to increase patient involvement in decisions about their care.<sup>5</sup> The Affordable Care Act in the USA has incorporated shared decision-making into the Public Health Services Act to improve the quality of care provided to patients.<sup>6</sup> There is an increasing emphasis on patient involvement in healthcare decision-making, and patient involvement may have an impact on treatment adherence and clinical outcomes.<sup>7</sup>

The common treatment decision-making models include paternalistic, professional-as-agent, informed decision-making and shared decision-making models. Patients play a passive role in the paternalistic model. In the professional-as-agent model, the doctor makes the decision for the patient assuming he/she

had the same preferences as the patient, thus making the doctor the sole decision-maker. The informed decision-making model incorporates the idea of information sharing with the patient who makes the decision solely at the end. In the shared decision-making model, both the patient and the doctor take turns to be involved in the decision-making process and agree to the treatment decision. In this case, both are responsible for the final decision.<sup>3</sup>

However, patient involvement in decision-making varies worldwide. In Europe, a large population-based study revealed that 51% of patients preferred shared decision-making, followed by doctors as the main decision-makers (26%) and patients having a primary role in decision-making (23%).<sup>8</sup> In this study, among patients who had had a consultation, only slightly more than half of them participated in the consultation and decision-making. This suggests that many European patients wanted a more autonomous role in decision-making and there was a gap between patients' role preference and their experience.<sup>8</sup> However, not all patients wish to be involved in the decision-making process. In 2002, it was found in the US population-based General Social Survey that 52% of participants preferred to leave the final decision to their doctors. However, the majority (96%) of participants wanted to discuss options and share their opinions about clinical management with doctors.<sup>9</sup> This component of decision-making was valued by patients. Briel *et al*<sup>10</sup> conducted a study in Switzerland to determine patients' decisional role preference in the context of an acute illness. In this study, the majority (66%) of patients preferred a doctor-centred approach. There might be differences in role preference in patients with different types and duration of illnesses. Patient involvement in decision-making also varied depending on the different issues in management. Between 2007 and 2008, a study carried out in the Netherlands showed that patients who were referred for diagnostic purposes had less involvement in choosing their healthcare provider than those who were referred for treatment.<sup>11</sup>

In Asia, a previous study conducted in Japan in 1996 suggested that Japanese played a passive role during consultations. This study showed that older patients ( $\geq 65$  years of age) trusted their doctors to make the decision. Only 19.6% of patients made the decision on their own to undergo a coronary angiography procedure.<sup>12</sup> A more recent study was conducted in 2004 to determine the role preference among 134 diabetic patients attending a single outpatient clinic in Kyoto who were randomly assigned to one of three case study vignettes (pneumonia, gangrene or cancer). The majority preferred a collaborative role (71%), followed by passive (17%) and active (12%) roles. Those who answered the cancer vignettes were less likely to prefer an active role and were more likely to prefer family involvement in decision-making than those who did not respond to the cancer vignettes. This suggests that

patients who previously preferred a more paternalistic approach want to play a more active role in decision-making.<sup>13</sup> Malaysia is a multi-ethnic, multi-cultural, middle-income developing country in Asia. Although the population is becoming more affluent, they still share common Asian values. There have been no published studies on patients' role preference in decision-making in the Malaysian primary care setting.<sup>14</sup> Thus, this study was performed to determine patients' role preference in decision-making and the factors associated with it.

## OBJECTIVES

### Primary objective

To determine patients' preferred role in decision-making in the primary care clinic at the University of Malaya Medical Centre.

### Secondary objectives

1. To determine the patient's actual role in decision-making during consultations.
2. To determine the association between patients' preferred role in decision-making and their sociodemographic factors.
3. To determine the association between doctors' perceptions of patients' role preference and patients' actual role preference in decision-making (ie, whether the doctors were able to identify patients' actual role in decision-making).

## Hypothesis

1. Patients attending the primary care clinic preferred a passive role in decision-making.
2. Patients are passively involved during the consultation.
3. There is an association between patients' sociodemographic factors (age, gender, ethnicity, marital status, education level, occupation, total household income and perceived health status) and the doctors' and patients' preferred role in decision-making.
4. There is no association between doctors' perception of patients' role preference and patients' actual role preference in decision-making.

## METHODS

This was a descriptive cross-sectional study conducted at an academic primary care clinic in Kuala Lumpur, Malaysia in September 2012. All patients above 21 years of age attending the clinic during this 1-month period were eligible to be included in the study. All doctors working in the clinic during this study period consented to participate. Patients with acute psychosis, dementia or mental disability and those who were unable to understand English, Malay, Chinese or Tamil were excluded.

A sample size of 460 patients was required to participate in this study. This was calculated using the Kish formula, based on an estimated 51% of patients who

wish to be involved in decision-making with the CI of 95% and  $\pm 5\%$  precision, taking into consideration 20% of patients refusing to participate in the study. The estimated prevalence of patients who prefer shared decision-making (51%) was based on the prevalence found in a study performed in Europe in 2002.<sup>8</sup> Based on the formula, a sample size of 385 patients was needed. After addition of an estimated 20% for non-respondents, an additional 75 participants was added, making the final sample size 460.

The patient-preferred decisional role was measured using the Control Preference Scale (CPS) questionnaire.<sup>15</sup> This determines 'the degree of control the individual wants to assume when decisions are being made about medical treatment'. The CPS was used in four sections of the questionnaire (figure 1). Face and content validation of the questionnaire was conducted. Face validation was performed by three non-healthcare personnel, and content validation by three experts in this field. The questionnaire was translated into Malay, Chinese and Tamil, and back-translated to English, by independent individuals. All four versions of the questionnaire were tested in a pilot study with 30 individuals who had no difficulty in understanding and answering all the questions.

During data collection, the questionnaire was given to patients before and after consultation with the doctor. The pre-consultation questionnaire consisted of sociodemographic data and two questions to determine the patient's role preference (question 1) and family involvement (question 2) in decision-making; the post-consultation questionnaire had one question to determine the patient's actual role during consultation (question 3). The doctors completed one questionnaire after consultation to determine their perception of patients' role preference (question 4).

Eligible participants were identified at the clinic triage counter. The statistical software Epical 2000 was used to select a single-digit number from 0 to 9 for the day. All patients whose last number in their four-digit queue number corresponded to the chosen number for the day were approached to participate in the study (eg, if the chosen number for the day was 5, patients with queue numbers 1005, 1015, 1025, etc were invited). Patients who fulfilled the inclusion criteria were given the patient information sheet to read. Once they had agreed to participate, written consent was taken, and they were asked to complete the pre-consultation questionnaire. After consultation, the doctor and the patient each completed a separate questionnaire.

The dependent variable was the patient's role preference in decision-making. The independent variables were age, sex, ethnicity, socioeconomic status, education level and doctor's qualification. Categorical variables were summarised as percentages, and continuous variables as mean and SD or median. To test the association between variables, bivariate analysis of categorical variables was performed using  $\chi^2$ .  $\kappa$  was used to determine

agreement between doctors' perceived patients' role preference and patients' preferred role. Ethics approval was obtained from the University of Malaya Ethics Committee (reference number 830.16).

## RESULTS

A total of 494 patients were approached, of which 470 provided their consent—a response rate of 95.1%. Two patients who agreed to participate and completed the questionnaire did not return after the consultation to answer the post-consultation questionnaire. These two patients were excluded in the calculation of prevalence of patients' role preference in decision-making after consultation, but were included in the other analyses.

Sociodemographic characteristics of the patients, reasons for seeing a doctor, duration of disease and doctors' qualifications are shown in table 1. The median duration of a patient's illness was 180 days. The highest number of patients was seen by family medicine trainees with <10 years of practice. Table 2 shows the association between patients' sociodemographic characteristics and their preferred role in decision-making. Only total household income was associated with patients' role preference in decision-making, where patients with lower household income ( $\leq$ MYR999 (999 Malaysian Ringgits)) were more likely to prefer a passive role in decision-making.

The study involved 47 doctors. The median age of the doctors was 33 years ranging from 28 to 61 years and the majority were female, Malay, had less than 10 years of practice, and did not have a postgraduate qualification. Most were 3rd and 4th year postgraduate family medicine trainees (MMed in Family Medicine) (table 3).

The patients' role preference in decision-making and their actual role during the consultation are shown in table 4. Nearly three-quarters of the patients preferred an active or shared decision-making role before consultation, but only 70% felt that they played this role during the consultation. The doctors perceived that most of the patients preferred either a shared role (39.6%) or a passive role (39.4%) in decision-making. Almost half of the patients (49.1%) preferred to have shared decision-making together with their family.

Table 5 shows that there was no significant association between doctors' perception of patients' preferred decisional role and patients' preferred role in decision-making. The  $\kappa$  value was low, indicating that there was a lack of agreement between patients' role preference and doctors' perception of patients' role preference in decision-making.

## DISCUSSION AND CONCLUSION

### Discussion

The three key findings of this study are (1) the majority of patients preferred an autonomous (active and shared) role in decision-making, (2) only total household income was associated with patients' role



Question 1: Control Preference Scale

- Option 1: "I prefer to make the final treatment selection about which treatment I receive".
- Option 2: "I prefer to make the final selection of my treatment after seriously considering my doctor's opinion".
- Option 3: "I prefer that my doctor and I share responsibility for deciding which treatment is best for me".
- Option 4: "I prefer that my doctor make the final decision about which treatment will be used but seriously consider my opinion".
- Option 5: "I prefer to leave all decisions regarding my treatment to my doctor".

Question 2: Modified CPS for family involvement in decision-making

- Option 1: "I prefer to make the final treatment selection about which treatment I receive".
- Option 2: "I prefer to make the final selection of my treatment after seriously considering my family's opinion".
- Option 3: "I prefer that my family and I share responsibility for deciding which treatment is best for me".
- Option 4: "I prefer that my family make the final decision about which treatment will be used but seriously consider my opinion".
- Option 5: "I prefer to leave all decisions regarding my treatment to my family".

Question 3: Modified CPS for patients' actual role during consultation

- Option 1: "I made the final decision about which treatment I would receive".
- Option 2: "I made the final selection of my treatment after seriously considering my doctor's opinion".
- Option 3: "My doctor and I shared responsibility for deciding which treatment is best for me".
- Option 4: "My doctor made the final decision about which treatment would be used but seriously considered my opinion".
- Option 5: "My doctor made all the decisions regarding my treatment".

Question 4: Modified CPS for doctor's perceived patients' role preference during consultation

- Option 1: The patient prefers to make the final treatment selection about which treatment he/she receives.
- Option 2: The patient prefers to make the final selection of the treatment after seriously considering the doctor's opinion.
- Option 3: The patient prefers that the doctor and the patient share responsibility for deciding which treatment is best for him/her.
- Option 4: The patient prefers that the doctor makes the final decision about which treatment will be used but seriously consider the patient's opinion.
- Option 5: The patient prefers to leave all decisions regarding the treatment to the doctor.

**Figure 1** Questionnaire used for the study.

preference and (3) there was a gap between patients' expectation and doctors' perception of patients' role preference.

More than half of the patients preferred shared decision-making (before consultation), but fewer than that (45.3%) felt that the decision was shared during the consultation. This finding is very similar to a population-based study conducted in Europe, which found that 51% of respondents preferred shared decision-making.<sup>8</sup> It was found in another population-based study conducted in the USA in 2005 that 52% of patients preferred to leave decision-making to their physicians.<sup>9</sup> It was found in a study carried out in Japan that 71% of patients preferred shared decision-making.<sup>13</sup> The authors postulated that the high preference for shared decision-making was due to the study population who were diabetic with relatively good adherence to treatment. Therefore, they were more likely to be actively involved in the management of their illness.<sup>7</sup> In contrast, a study conducted in Switzerland showed that two-thirds of the patients preferred a doctor-centred approach.<sup>10</sup> In that study, the participants were adults with acute respiratory tract infection. These two studies indicate that the characteristics of the presenting illness

are important in determining patients' decisional role preference. However, healthcare providers should not assume that they can predict a patient's role preference. They should assess each patient's role preference individually and tailor patient care accordingly.

There was a significant association between total household income and patients' preferred decisional role. Patients who had a lower total household income of less than MYR1000 preferred a more passive role in decision-making than those from a higher total household income group. This was similar to the finding by Chewing and Sleath<sup>16</sup> from the USA in 1996, where patients from a higher income group preferred an active role in decision-making. Patients with a lower total household income often have limited healthcare access and options, and they tend to believe that the doctor would be the best person to decide for them after taking into consideration the cost of treatment. Conversely, the higher income groups have more options to choose from, as cost would not be an issue for them.

No significant association was found between doctors' perceptions of patients' preferred role in decision-making and patients' actual role preference. This is

**Table 1** Sociodemographic characteristics of the patients

Characteristic	Total patients (n=470)
Age (years)	
< 35	98 (20.8)
36–54	156 (33.2)
≥55	216 (46.0)
Sex	
Male	199 (42.3)
Female	271 (57.7)
Ethnicity	
Malay	171 (36.4)
Chinese	153 (32.6)
Indian	116 (24.7)
Others	30 (6.3)
Marital status	
Single	86 (18.3)
Married	326 (69.4)
Divorced/widow/widower	58 (12.3)
Occupation	
White collar job	115 (24.5)
Blue collar job	89 (18.9)
Retired	136 (28.9)
Unemployed	30 (6.4)
Housewife	100 (21.3)
Total household income (MYR)	
≤999	69 (14.7)
1000–2999	190 (40.4)
3000–4999	107 (22.8)
≥5000	104 (22.1)
Educational level	
No formal/primary	97 (20.6)
Secondary	197 (41.9)
Technical/vocational/diploma	73 (15.5)
Tertiary	103 (22.0)
<b>Disease-associated factors</b>	<b>Total respondents (n=470)</b>
Reason for seeing the doctor	
Symptoms, complaints	268 (57.0)
Diagnosis, screening, prevention	34 (7.2)
Treatment, procedures, medication	0 (0)
Test results	0 (0)
Diagnoses, disease	168 (35.8)
Duration of illness (days), median (range)	180 (1–12 775)
Number of patients seen by doctors according to the doctors' qualification	
Masters year 1	115 (24.5)
Masters year 2	73 (15.5)
Masters year 3	149 (31.7)
Masters year 4	87 (18.5)
Lecturer	4 (0.9)
Service medical officer	42 (8.9)
Number of patients seen by doctors according to the number of years of doctors' practice	
<10	348 (74.0)
10–19	80 (17.0)
≥20	42 (8.9)

Unless otherwise indicated, values are n (%).  
MYR, Malaysian Ringgit.

**Table 2** Association between patients' sociodemographic characteristics/number of years of doctors' practice and patients' preferred role in decision-making

Characteristic	Passive* (n=123)	Autonomous† (n=347)	p Value	$\chi^2$
Age (years)				
<35	24 (24.5)	74 (75.5)	0.762	0.543
36–54	39 (25.0)	117 (75.0)		
≥55	60 (27.8)	156 (72.2)		
Sex				
Female	74 (27.3)	197 (72.7)	0.513	0.428
Male	49 (24.6)	150 (75.4)		
Ethnicity				
Malay	47 (27.5)	124 (72.5)	0.317	3.529
Chinese	32 (20.9)	121 (79.1)		
Indian	35 (30.2)	81 (69.8)		
Other	9 (30.0)	21 (70.0)		
Marital status				
Single	24 (27.9)	62 (72.1)	0.135	4.008
Married	78 (23.9)	248 (76.1)		
Divorced/widow/widower	21 (36.2)	37 (63.8)		
Occupation‡				
White collar job	33 (28.7)	82 (71.3)	0.794	1.683
Blue collar job	20 (22.5)	69 (77.5)		
Retired	33 (24.3)	103 (75.7)		
Unemployed	8 (26.7)	22 (73.3)		
Housewife	29 (29.0)	71 (71.0)		
Total household income (MYR)			<b>0.018</b>	<b>10.017</b>
≤999	27 (39.1)	42 (60.9)		
1000–2999	53 (27.9)	137 (72.1)		
3000–4999	21 (19.6)	86 (80.4)		
≥5000	22 (21.2)	82 (78.8)		
Education level				
No formal/primary	27 (27.8)	70 (72.2)	0.532	2.198
Secondary	54 (27.4)	143 (72.6)		
Technical/vocational/diploma	14 (19.2)	59 (80.8)		
Tertiary	28 (27.2)	75 (72.8)		
Number of years of practice of doctors				
<10	85 (24.2)	263 (75.6)	0.348	2.114
10–19	25 (31.3)	55 (68.8)		
≥20	13 (31.0)	29 (69.0)		

Values are n (%).

Bold indicates significance.

\*Passive: passive role preference (options 4 and 5; see fig 1).

†Autonomous: shared and active role preference (options 1–3; see fig 1).

‡Occupation of the patients was categorised based on the Malaysian Standard Classification of Occupations 2008 by the Ministry of Human Resources, Malaysia.

MYR, Malaysian Ringgit.

similar to a study conducted by Cox *et al*<sup>17</sup> in the UK, where it was found that general practitioners' perceptions of patients' role preference in decision-making were inaccurate in most cases. Doctors tend to underestimate patients' preferred level of involvement. It was noted that the general practitioners accurately assessed

**Table 3** Sociodemographic characteristics of the doctors

Characteristic	Total respondents (n=47)
Age (years)	
Mean±SD	35.1±7.2
Range	28–61
Median	33
Sex	
Male	11 (23.4)
Female	36 (76.6)
Ethnicity	
Malay	29 (61.7)
Chinese	4 (8.5)
Indian	8 (17.0)
Others	6 (12.8)
Number of years of practice	
Mean±SD	10.1±6.8
Range	4–35
Median	8
Postgraduate qualification	
Yes	4 (8.5)
No	43 (91.5)
Current working position	
Masters year 1	10 (21.3)
Masters year 2	6 (12.8)
Masters year 3	12 (25.5)
Masters year 4	12 (25.5)
Lecturer	3 (6.4)
Service medical officer	4 (8.5)
Number of years of practice	
<10	33 (70.2)
10–19	10 (21.3)
≥20	4 (8.5)
Range	4–35

Unless otherwise indicated, values are n (%).

patients' preferences in only 32% of the consultations.

This study showed that most of the patients preferred to share their decision with their family (49.1%). This was consistent with the study conducted in Japan, where 42% preferred family involvement in the pneumonia vignette, 41% for the gangrene vignette and 70% for

**Table 4** Patients' preferred role in decision-making

	Pre-consultation (n=468)	Post-consultation
	How do you prefer to make a decision during consultation?	n (%) How did you make your decision during consultation?
Autonomous		
Active	102 (21.8)	113 (24.1)
Shared	243 (51.9)	212 (45.3)
Passive	123 (26.3)	143 (30.6)
Total	468 (100.0)	468 (100.0)

Values are n (%).

Active, options 1 and 2; Shared, option 3; Passive, options 4 and 5.

**Table 5** Association between patients' role preference (before consultation) and doctor's perceived patients' role preference in decision-making (during consultation)

	Patients' role preference			p Value
	Passive	Autonomous	Total	
Doctor's perception of patients' role preference				
Passive	49 (26.5)	136 (73.5)	185 (100.0)	0.900
Autonomous	74 (26.0)	211 (74.0)	285 (100.0)	
Total	123 (26.2)	347 (73.8)		

$\kappa=0.006$ ,  $p=0.900$ .

the cancer vignette. The Japanese culture stresses the interconnectedness of a person, especially within the family. In Japan, patients may require cooperation of their families for the fulfilment of their treatment decisions. Hospital admission may impose heavy workloads on their family; as such, the family's consent and commitment are important considerations for Japanese patients.<sup>13</sup> The Malaysian culture may be similar to the Japanese culture.

This study is one of the few studies in Asia looking specifically at patients' preferred role in decision-making. Systematic random sampling was used to provide a good representation of the clinic attendees, which makes the results generalisable to the study population. However, there are a few limitations of this study. First, it was conducted in a primary care clinic based in a teaching hospital located in an urban area. The findings may therefore not be representative of the general population in the community. Future surveys involving a larger population in the community will provide the true prevalence of patients' role preference in Malaysia. Second, the questionnaire was given to patients and doctors before consultation. This may have resulted in a change in the doctors' behaviour during the consultation. However, there was no association between the patients' role preference and the doctors' perception of patients' role preference. This implies that the agreement in the usual clinical setting may be even lower without the prompting of these questions. Finally, although face and content validation was conducted for the CPS, further validation using convergent or discriminatory validation methods may be necessary to determine the validity of the questionnaire. However, the patients did not express any difficulty in understanding and answering the questions during the pilot and actual study.

This study challenges the assumption that Asian patients prefer a passive role in healthcare decision-making. Further qualitative and quantitative studies should be conducted with patients and doctors to find ways to actively engage patients in clinical consultations. In addition, more emphasis should be given to train healthcare professionals in acquiring skills to support patients in making an informed decision. This may be achieved by incorporating the shared decision-making

model into the undergraduate and the postgraduate curricula across all disciplines.

## CONCLUSION

The majority of patients in this study preferred an autonomous role, and a high proportion of them wanted family involvement in decision-making. There is still a gap between patients' expectation and doctors' perception of patients' role preference. This study has shed light on patients' role preference and its associated factors in the context of a primary care setting in Malaysia. It provides evidence that physicians must actively involve patients in decision-making in their daily clinical practice.

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