

Research Article

Patients' Decision-Making Preferences for Five Assumptive Clinical Cases

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Submitted: 17 September 2017

Accepted: 04 October 2017

Published: 06 October 2017

ISSN: 2379-9501

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Keywords

• Autonomy; Decision-making degree; Control preference; Family; Clinical case

Abstract

Aim: Ethical issues often arise when people become ill and medical treatment decisions need to be made, however many people do not make such decisions in advance, creating difficulties for family and medical staff. This study aimed to clarify the degree to which Japanese people wished to either self-decide, or involve their family or physician in decision-making, for five clinical assumptive cases. The relationship among the self-decided degree and demographic characteristics was examined.

Materials and methods: Forty-three adults, community residents from Western Japan, who had previously experienced hospital admissions, were selected by convenience and snowball sampling and underwent a structured interview using the Decision-making Degree for Medical Practice Questionnaire. They were asked to imagine they had hypertension, stroke, physical paralysis, early cancer, and terminal cancer, and to state their decision-making preferences for each of these.

Results and discussion: Of the five cases, terminal cancer scored the highest value of decision-making degree for medical practice. The degree of self-decision-making was lower for stroke, whilst for terminal cancer, the self-determination degree of all items was higher than the decision-making degree of family or physician. When making decisions to select medical treatment, even for patients with mild health conditions, opinions of physicians tended to be well-respected. For decision-making regarding care in the terminal phase, the degree of self-decision-making was higher, indicating that participants wanted to spend their remaining time according to their own wishes.

Conclusion: It is vital that the decision-making values and wishes of patients are taken into consideration by health professionals and families. These vary between patients according to context and health conditions, and need to be assessed early in treatment.

INTRODUCTION

Making medical treatment decisions is often a complex process for many people. Ethical dilemmas or issues for treatment teams or families may arise when there is a lack of knowledge about how a patient would like health care decisions to be made. For example, would the patient like (or have liked) to make treatment decisions autonomously? Or in consultation with family or significant others, or with their doctor(s), or both of these parties? Or indeed by either party without consultation? Research has shown that decision-making behavior is a cognitive skill that varies across settings and that patients' preferences for autonomous decision-making are diverse [1]. In addition, it has been strongly suggested that the context of the healthcare system, cultural influences and the presence of the patient's family are greatly involved in a patient's autonomy in medical decision-making [2-6].

As a pre-condition to establishing true informed consent, it is necessary to ensure a patient's autonomy and to reflect their wishes regarding medical practice [7]. In some cases, a patient's

decision-making and participation in consultations may lead to reflection on that patient's wishes, resulting in a good impact on patient and family satisfaction and health condition [8,9]. Nurses have a pivotal role to play in ensuring that patients receive comprehensive information to enable them to make informed decisions regarding various aspects of their medical care and treatment, and to be advocates for them in their decision-making processes. However, it is our experience in many countries and cultures, that often there is little assessment about patients' intentions regarding medical decision-making on hospital admission. Since people's decision-making preferences are diverse, so support based on the situation and context of each particular patient is necessary. There are still many unknown aspects about how a patient chooses to make decisions about medical treatment by themselves (hereinafter referred to as "decision-making degree"). It is thought that tendencies regarding decision-making may vary depending on a patient's particular health condition and specific decisions to be made. Comprehension of the decision-making degree, according to a situation, enhances the efficacy of informed consent, and is most

important when various medical services are offered [10]. This study aimed to clarify the degree to which a patient wished to make medical decisions, by themselves, or with their family or their physician by using five assumptive clinical cases (hypertension, stroke, physical paralysis, early cancer, and terminal cancer) in a structured questionnaire, and the relationship among the self-decided degree and demographic characteristics.

MATERIALS AND METHODS

Sample

Japanese adults, 20 years or older, who had no difficulty in daily communication and had the ability to understand the survey, and gave informed consent, were eligible to be included in this study. They were recruited from a community in western Japan and through convenient and snow-balling sampling.

Data collection

Structured interviews were undertaken using a questionnaire after participants gave informed consent. The interviews began with the researchers obtaining demographic information from each participant regarding their age, gender, hospitalization experience, educational background, and marital status. A survey questionnaire was then administered, the decision-making degree for medical practice. This survey was originally designed by and based on a study by Ende et al. [11], (1989) and revised by Ohki & Fukuhara (1995) [12]. Part 1 has 15 items regarding the degree of general decision-making for medical practice in the five cases above, based on the assumption that the participants suffered from these health conditions. Participants were asked to respond to these items by indicating who should make a decision, themselves, their family or physician with a total possible score of 0-100 points each. Responses were recorded by themselves or the researcher. Part 2 of the survey has four items regarding decision-making for medical care and health issues rated on a 5-point scale ranging from "Absolutely" to "Absolutely Not." Ohki [7] reported moderate internal consistency for the survey: separately α coefficient, $\alpha=0.72$ in hypertension case, $\alpha=0.70$ in stroke case, $\alpha=0.65$ in physical paralysis case, $\alpha=0.78$ in early cancer case, and $\alpha=0.79$ in terminal cancer case, based on an analysis of data obtained from 3,110 participants, men and women 16 years or older throughout Japan. Permission was obtained for the use of Ohki's survey for this study.

A. Case 1: Hypertension: Hypothetical situation for Case 1: "You are diagnosed with essential hypertension though you have not been informed of it yet by a physician." The participants were asked the following questions and to rate their self-opinion, their family's opinion, and the physician's opinion out of total of 100 points: "When should you measure your blood pressure next?" (hereinafter referred to as a "test"); "Will you continue with your work and family life as you have been doing?" (hereinafter referred to as "lifestyle"); "Which medications or which medication-free diet or exercise program will you choose?" (hereinafter referred to as "treatment style").

B. Case 2: Stroke : Hypothetical situation for Case 2: "Suddenly, you felt numbness in your right hand and right foot and were unable to use your muscles while eating, then you were transferred to a hospital by ambulance and were immediately

hospitalized. As a result of a medical examination and tests, you have been diagnosed with a stroke, although you have not been informed of it yet by a physician." The participants were asked the following questions and to rate their self-opinion, their family's opinion, and the physician's opinion out of total amount of 100 points: "How often do you receive brain computed tomography (CT)?" (hereinafter referred to as a "test"); "Will you receive surgical or medical treatment?" (hereinafter referred to as "therapy"); "Will you allow a visitor other than your family to meet with you?" (hereinafter referred to as "lifestyle").

C. Case 3: Physical paralysis: Hypothetical situation for Case 3: "Two or three months have passed and paralysis of the right half of your body has persisted; you are hospitalized since it is hard for you to walk." Participants were asked the following questions and to rate their self-opinion, their family's opinion, and the physician's opinion out of total amount of 100 points: "Will you participate in rehabilitation?" (hereinafter referred to as a "rehab"); "Which treatment will you undergo, hospitalization or ambulatory treatment?" (hereinafter referred to as "treatment style"); "Will you undergo aggressive life-prolonging treatment if you become unconscious?" (hereinafter referred to as "life-prolonging treatment.")

D. Case 4: Early cancer: Hypothetical situation for Case 4: "Your periodic health examination results shows abnormalities in the stomach. In fact, you are diagnosed with early cancer though you have not been informed of it by a physician yet; and there is a sufficient possibility of cure." Participants were asked the following questions and to rate their self-opinion, their family's opinion, and the physician's opinion and to rate their self-opinion, their family's opinion, and the physician's opinion out of total amount of 100 points: "Will you undergo re-examinations?" (hereinafter referred to as a "test"); "Which will you receive: surgical or medical treatment?" (hereinafter referred to as "therapy"); "Will you keep up your work and housework as you have been doing?" (hereinafter referred to as "lifestyle.")

E. Case 5: Terminal cancer: Hypothetical situation for Case 5: "Your periodic health examination results showed abnormalities in the stomach; in fact, you are diagnosed with terminal cancer though you have not been informed of it by a physician yet. Your life expectancy is approximately six months and there is no possibility of a cure in modern medical care." Participants were asked the following questions and to rate their self-opinion, their family's opinion, and the physician's opinion out of total amount of 100 points: "What kind of therapy (including not being treated) will you choose?" (hereinafter referred to as "therapy"); "Which treatment will you undergo: hospitalization or ambulatory?" (hereinafter referred to as "treatment style"); "Will you undergo aggressive life-prolonging treatment if you become unconscious?" (hereinafter referred to as "life-prolonging treatment.")

Data analysis

Data were calculated as the one-way analysis of variance of comparison of mean scores of decision-maker in the five cases and the independent t-test of differences between participants' basic attributes and decision-making of self's preference degree by using the statistical software package, IBM SPSS ver. 19.0.

Table 1 Comparison of mean scores of decision-maker in the five cases (n=43).

	Decision-maker	Self			Family			Physician		
Hypertension Case	Medical practice	Test	Lifestyle	Treatment Style	Test	Lifestyle	Treatment Style	Test	Lifestyle	Treatment Style
	Mean ±SD	25.3±33.7	51.4±26.4	38.4±25.0	4.2±5.9	11.2±10.3	10.7±13.0	70.5±33.5	37.2±25.9	50.9±26.4
	Range	0 - 100	0 - 100	0 - 90	0 - 20	0 - 40	0 - 50	0 - 100	0 - 100	0 - 100
	F-value	8.91 **			6.36 **			14.47 **		
Stroke Case	Medical practice	Test	Therapy	Lifestyle	Test	Therapy	Lifestyle	Test	Therapy	Lifestyle
	Mean ±SD	7.7±15.6	19.5±18.9	39.6±33.0	5.1±7.8	12.6±13.9	17.6±21.2	87.2±19.1	68.1±26.7	42.7±36.2
	Range	0 - 80	0 - 60	0 - 100	0 - 30	0 - 50	0 - 100	10 - 100	0 - 100	0 - 100
	F-value	19.83 **			7.23 **			26.68 **		
Physical paralysis Case	Medical practice	Rehabilitation	Treatment Style	Life-prolong Treatment	Rehabilitation	Treatment Style	Life-prolong Treatment	Rehabilitation	Treatment Style	Life-prolong Treatment
	Mean ±SD	39.4±31.7	39.2±23.7	46.2±34.4	11.0±12.0	22.7±16.2	37.3±28.8	49.5±30.6	38.1±27.7	16.1±19.8
	Range	0 - 100	0 - 100	0 - 100	0 - 50	0 - 50	0 - 100	0 - 100	0 - 100	0 - 80
	F-value	0.74			18.06 **			17.83 **		
Early cancer Case	Medical practice	Test	Therapy	Lifestyle	Test	Therapy	Lifestyle	Test	Therapy	Lifestyle
	Mean ±SD	46.2±34.1	33.5±23.7	56.4±25.5	13.1±18.6	14.2±17.3	18.5±14.5	40.7±34.5	49.1±27.3	25.1±22.7
	Range	0 - 100	0 - 100	10 - 100	0 - 100	0 - 100	0 - 50	0 - 100	0 - 100	0 - 80
	F-value	7.16 **			1.21			7.78 **		
Terminal cancer Case	Medical practice	Therapy	Treatment Style	Life-prolong Treatment	Therapy	Treatment Style	Life-prolong Treatment	Therapy	Treatment Style	Life-prolong Treatment
	Mean ±SD	46.6±31.1	46.3±29.5	53.4±35.4	19.2±21.2	24.8±22.5	31.0±28.4	34.2±29.9	28.9±29.8	15.3±21.4
	Range	0 - 100	0 - 100	0 - 100	0 - 100	0 - 100	0 - 100	0 - 100	0 - 100	0 - 100
	F-value	0.66			2.57			5.43 *		

One-way analysis of variance, * = P < 0.05, ** = P < 0.01

Table 2: Differences between demographic information and decision-making self-preference in five cases.

	Hypertension Case			Stroke Case			Physical Paralysis Case			Early Cancer Case			Terminal Cancer Case		
	Test	Lifestyle	Treatment Style	Test	Therapy	Lifestyle	Rehabilitation	Treatment Style	Life-prolonging Treatment	Tests	Therapy	Lifestyle	Therapy	Treatment Style	Life-prolonging Treatment
Gender															
Female	27.3 ±35.8	47.8 ±27.3	37.0 ±26.0	8.0 ±18.0	16.5 ±17.8	37.8 ±33.8	31.7 ±27.0	36.1 ±25.5	55.2 ±32.6	51.3 ±35.7	30.4 ±27.7	58.7 ±29.0	50.4 ±29.3	51.7 ±30.1	66.1 ±31.0
Male	23.0 ±31.8	55.5 ±25.4	40.0 ±24.3	7.25 ±12.7	23.0 ±20.0	41.8 ±32.7	48.2 ±35.0	42.8 ±21.5	35.8 ±34.3	40.3 ±32.0	37.0 ±18.0	53.8 ±21.2	42.3 ±33.2	39.7 ±28.2	38.8 ±35.2
t-value	-0.42	0.95	0.40	-0.16	1.13	0.39	1.74	0.92	-1.91	-1.06	0.91	-0.63	-0.86	-1.32	-2.71
P-value	0.68	0.35	0.70	0.87	0.26	0.70	0.09	0.36	0.06	0.29	0.37	0.53	0.40	0.19	0.01*
Experience of hospitalization															
Yes	23.8 ±34.1	50.0 ±26.5	37.3 ±24.7	7.1 ±14.5	18.5 ±18.0	41.1 ±34.9	39.6 ±25.5	38.7 ±23.5	41.6 ±33.5	41.3 ±34.3	32.6 ±22.4	52.8 ±24.5	46.0 ±32.0	47.7 ±27.6	49.3 ±36.3
No	31.1 ±33.3	56.7 ±26.9	42.2 ±27.3	10.0 ±20.0	23.3 ±22.9	34.4 ±25.5	38.9 ±26.2	41.1 ±25.7	63.3 ±34.3	64.4 ±27.9	36.7 ±29.2	70.0 ±26.0	48.9 ±28.9	41.1 ±37.2	68.9 ±28.5
t-value	-0.57	-0.67	-0.52	-0.50	-0.68	0.53	0.56	-0.27	-1.72	-1.86	-0.45	-1.85	-0.24	0.59	-1.50
P-value	0.57	0.51	0.61	0.62	0.50	0.60	0.96	0.79	0.09	0.07	0.66	0.07	0.81	0.56	0.14

Independent t-test, P < 0.05, ** = P < 0.01

Ethical considerations

Prior to conducting an interview, we explained the following matters clearly and concretely to the participants, and also gave written study information: the purpose and method of the study, the handling of the completed questionnaire, voluntary participation in the study, and the anonymous nature of the questionnaire. Study approval was obtained from the ethical committee of the Kawasaki University of Medical Welfare, Kurashiki, Okayama, Japan.

RESULTS

The participants were 20 men (46.5%) and 23 women (53.5%) (n=43). The mean age was 58.8 ± 12.5 (range 40–83) years. Of the participants, 34(79.1%) had experienced hospitalization, 41(95.3%) were married and 2(4.7%) were widowed.

Table 1 shows the decision-making degree for medical practice in the five cases (hypertension, stroke, physical paralysis, early cancer, and terminal cancer) and the opinions of the participants, family and physician. Many of the participants in this study were married and had a family. The five cases and the questions about the degree of decision-making that were used in this study are considered relevant to decisions in real clinical settings [7].

In the hypertension, stroke, and early cancer cases, the self as decision-maker in lifestyle scored the highest, 51.4, 39.6, and 56.4 respectively. Those of the physician-degrees in test and treatment were higher more than half than lifestyle and any other self and family degrees. The family-degrees in three cases' medical practices were lowest. Hypertension, stroke, and early cancer cases scored highly on the lifestyle decision by self, and test and treatment decisions by physician. Especially in the case of stroke, many of the items were especially associated with medical doctors making decisions. Thus, the self-decision-making degree was low, because participants wanted to entrust the decision to the judgment of a physician.

The self-degrees in physical paralysis and terminal cancer cases were almost the same degree in rehabilitation and treatment style, but the desire for participants to engage in self-decision-making for life-prolonging treatment in those cases were higher than those of physician and family when the participants supposed they had a sense of control. The degree of self-determination of all items in terminal cancer was higher than the decision-making degree of the family/physician. In the terminal phase of cancer, self-determination degree tended to be higher and the family's wishes are also respected. Participants with end-stage cancer respect their own decision-making abilities

and place emphasis on the goal of self-actualization in the limited time they had left. To address the issues of the family and respect their wishes, posthumous work needs to be done with the family, so that family desires to not have any regrets are taken into account, and there is prevention of physical, psychological, and financial burdens on the family¹³.

In Table 2, the differences between the participants' characteristics such as gender, their hospitalization and decision-making self preferences in the five cases are displayed. Table 3 shows the results of participants' decision-making for medical care and health issues.

For decision-making for medical care, there were many items that participants thought would be decided by themselves, rather than by a physician, which is indicative that the degree of self-determination was high. In addition, the item, 'If you were sick, as your illness become worse, you would want your physician to take greater control', was not applicable to many of the participants in comparison with the other items. Thus, physicians' decisions did not come to be respected, even if the condition became severe.

In this study, the physician's decision-making degree for terminal cancer decreased as compared to early cancer, while the degree of self-decision-making increased. For life-prolonging treatment, the family's decision-making degree also increased, and the more the condition became severe, the more self-decision-making degree tended to be high.

In terms of the association between decision-making degree and participants' basic background characteristics, the degree of decision-making was higher in women than men for all cases of life-prolonging treatment for patients with physical paralysis or terminal cancer. Men showed higher a decision-making degree for lifestyle and treatment style for hypertension, and therapy and lifestyle for stroke. Women seemed to be highly interested in decision-making with their family in the terminal phase of cancer, including matters regarding life-prolonging treatment, while men seem to be highly interested in the impact of disease and treatment on work. Also, for men both the value of lifestyle for hypertension and the decision-making degree for work were higher.

Regarding hospitalization experience, participants who had experienced hospitalization tended to show low decision-making degree for test, therapy, and treatment style, compared with participants who had not experienced hospitalization. For life-prolonging treatment, participants who experienced hospitalization tended to show low decision-making both for physical paralysis and terminal cancer. This seems to be due to a

Table 3 Perceptions about decision-making for medical care and health issues(n=43) no. & %.

	Exactly like that	Almost think	Cannot say	Mostly not	Not at all
The medical decisions should be made by a physician, not by you.	1 (2.3)	4(9.3)	11(25.6)	21(48.8)	6 (14.0)
You should go along with a physician's advice even if you disagree with it.	6 (14.0)	7 (16.3)	15 (34.9)	13 (30.2)	2 (4.7)
When hospitalized, you should not be making decisions about your own medical care.	7(16.3)	4 (9.3)	10 (23.3)	12 (27.9)	10 (23.3)
If you were sick, and your illness become worse, you would want your physician to take greater control.	2 (4.7)	1 (2.3)	11 (25.6)	20 (46.5)	9 (20.9)

change in decision-making degree, because participants realized the importance of self-decision-making after they experienced hospitalization. When patients have a life-threatening condition, they become passive and their decision-making degree decreases^{14), 15)}. When patients come to think strongly that their decisions will be responsible for treatment, participation in and choice of medical practice becomes difficult¹⁶⁾. Thus, even for life-prolonging treatment, patients who experienced decision-making through hospitalization seemed to feel the importance of self-decision-making, which seemed to decrease the degree of decision-making.

This study showed decision-making degrees under various assumptive situations. It is natural that these may change in real decision-making scenarios. As Wendler et al., [17] commented recently there is a paucity of data regarding the preferences of patients about whom they want to make treatment decisions for them if they became unable to make their own decisions. There is a possibility that the intentions of essential decision-making may change when a person actually suffers from a disease [18]. Actual cases differ from assumptive cases in that the person suffers from a disease; the physical and mental burden due to the disease may lead to difficulties in decision-making and complicated factors for individuals may influence decision-making. However, decision-making is often found in clinical settings and may change by the moment, depending on the situation of the individual patient. Advancement of medical technology allows patients and their families to have many options. Additionally, consideration must be given to the diverse nature of decision-making styles. For diverse decision-making in the future, and to support patients by providing options that they desire, further examination of decision-making processes is required through research and debate.

Opportunities exist for support by nurses, doctors and other health professionals across the broad spectrum of decisions that patients and families perceive as serious and important. Such efforts should be tailored to patients' values and should recognize the wide-ranging factors that patients weigh when making decisions.

CONCLUSION

There are limitations to the generalizability of the results of the present analysis of autonomy in the medical decision-making process of 43 participants, since the sample size was small. In this study, decision-making degree of cases under the fictional specific various situations was clarified. However, it is possible that decision-making in actual clinical settings may vary depending on various factors, such as culture and education levels. Therefore, although the participants' decision-making was diverse, the results in this study may not necessarily be applied to actual situations. In clinical settings in which there are more diverse decision-making situations, for both healthcare professionals and patients, it is important to understand patients' intentions in the decision-making process. Thus more research needs to be conducted in this vital area to ensure that patients' wishes are respected and that health professionals, including nurses, are confident and can provide evidence that they are providing the best treatment and care possible and protecting the autonomy of patients.

ACKNOWLEDGEMENTS

We give special thanks to our study participants who gave their valuable time to complete the questionnaire.

CONFLICT OF INTEREST

This study was subsidized by Grant-in-Aid for Scientific Research (C) 21592732, 26463226, Japan Society for the Promotion of Science.

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Cite this article

Ito M, Hattori K, Murakami K, Turale S, Ichihashi T (2017) Patients' Decision-Making Preferences for Five Assumptive Clinical Cases. *Ann Nurs Pract* 4(3): 1086.