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RHEUMATOLOGY | RESEARCH ARTICLE

Preference for shared decision-making in Japanese patients with rheumatoid arthritis

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Abstract: Purpose: The goal of this study was to examine preference for collaborative decision-making in Japanese patients with rheumatoid arthritis (RA). Patients and methods: A national online survey identified five hundred Japanese patients with RA who met study eligibility criteria. Subjects were queried regarding their preference for shared decision-making (SDM), using a questionnaire developed by Baars et al. to evaluate preference for SDM among Dutch patients. Participants in this study were asked to identify a number of clinical and socioeconomic characteristics, medical history, and treatment details. Multivariable regression analyses were applied to determine factors that were related to patient preference for SDM. Results: The study showed that 52% of patients surveyed considered shared medical decision-making "Very important" on a 4-item Likert scale. Females and patients with RA in Japan who are treated with biologic agents are more likely to have a preference for SDM. On the other hand, patients with a comorbidity of depression are less likely to prefer SDM. Conclusion: A majority of Japanese patients with RA prefer a collaborative role in medical decision-making. Treatment with biologic agents is associated with a higher likelihood of preference for SDM.

Subjects: Quality of Life; Health Communication; Rheumatology

Keywords: decision-making; patient preference; rheumatoid arthritis; biological products

ABOUT THE AUTHORS

Jorg Mahlich and Rosarin Sruamsiri are health economists at Janssen Japan, where they conduct projects on health economics and outcomes research. Health Technology Assessment and value based pricing of pharmaceuticals are also part of their research agenda.

PUBLIC INTEREST STATEMENT

Conventional wisdom says that physicians in Japan are less prepared to involve patients in treatment decisions because Japanese patients prefer to adopt a rather passive approach to health care counseling. However, our study on preferences for shared decision-making of Japanese patients with rheumatoid arthritis reveals that the vast majority of Japanese patients prefer a collaborative decision-making process with their physician. This preference was marked in patients treated with a biologic agent. The study also suggests that patients who bear a larger cost burden, such as those patients with lower annual household income, are more interested in SDM. The results of the study provide fertile ground for further research about SDM that will improve persistence and subsequent positive outcomes.









1. Introduction

Shared decision-making (SDM) is the process of interaction with patients who wish to be involved with their healthcare providers in making medical decisions. This concept is increasingly being embraced by the healthcare community (Smith, Pandit, Rush, Wolf, & Simon, 2016). There has also been a recent emphasis on the importance of patient participation in the decision-making process among patients with rheumatoid arthritis (RA) who are initiating treatment with a biologic; a need was identified for more open communication about treatment options, which may encourage a more appropriate, timely transition to biologic therapy (Bolge, Goren, Brown, Ginsberg, & Allen, 2016). These discussions are most often initiated by the patient's rheumatologist (Kalkan, Roback, Hallert, & Carlsson, 2014). An effective line of communication during the SDM process has been linked to improved patient satisfaction and better adherence to therapy (Lindhiem, Bennett, Trentacosta, & McLear, 2014). Current recommendations for treatment of patients with RA prioritize the need for SDM between patient and rheumatologist (Singh et al., 2016; Smolen et al., 2014). It was argued that this process includes the need to inform patients of the risks of RA and the benefits of achieving a reduction of disease activity, in addition to clearly communicating the benefits and risks of proposed therapies. It is crucial that communication flows both ways during the process, and decisions about both the therapeutic target and management plan are made jointly. The SDM process is incomplete without support for patient preferences. Patients need reassurance and support during the entire process. At the same time, when offering patients an option to participate in their medical decisionmaking, it is important to consider that a percentage of patients will prefer a paternalistic model, in which the physician has a dominant attitude over the patient (Counlter, 2007; Coulter, Parsons, & Askham, 2008; Friedrichs, Spies, Harter, & Buchholz, 2006).

Many recent studies indicate that patients in the United States prefer to be involved in decisions concerning their treatment, resulting in improved compliance with the treatment regimen and improved clinical outcomes for patients (Alden & Akashi, 2012; Chan & Ahmad, 2012; Degner & Venkatesh, 1997; Flynn, Smith, & Vanness, 1982; Giordano et al., 2008; O'Donnell & Hunskaar, 2007b). Studies in Europe have demonstrated similar results (Baars, Markus, Kuipers, & van der Woude, 2010; O'Donnell & Hunskaar, 2007a; Shields et al., 2004). There is less available evidence on patient preference for SDM and the associated effects on health outcomes among Japanese patients, although some evidence suggests that Japanese patients prefer to remain outside the decision-making process when a life-threatening condition is involved, including cancer (Narumi et al., 1998; Singh et al., 2016).

An early study conducted in Japan in 1996 found that Japanese patients play a passive role during consultations. This study showed that older patients (≥65 years of age) trusted their doctors to make treatment decisions (Narumi et al., 1998). Another study in the Japanese context confirmed that young patients favored patient-centered care for less serious disease conditions (Alden & Akashi, 2012). A recent study in 2004 in Kyoto examined 134 diabetic subjects at a single outpatient clinic who were randomly assigned to vignettes consisting of pneumonia, gangrene, or cancer (Sakimoto et al., 2004). The majority of study subjects across all sets were likely to prefer a collaborative role (71%), followed by a passive role (17%) or an active role (12%). This study suggested a split between age groups, with younger patients more likely to favor patient-centered care for less serious disease conditions, and older patients (65 years or older) more likely to trust their doctor to make important medical decisions. Those individuals who participated in the cancer vignette were less likely to prefer an active role, but were also more likely to want their family to participate in the decision-making process. This study demonstrated a tendency toward collaborative decision-making in patients who may have previously preferred a more paternalistic approach.



Another more recent study in 2010 focused on SDM preferences in Japanese RA patients. This study found a preference for a collaborative role among Japanese RA patients. The study results showed that the passive role was preferred by 38.4% of patients, while 61.6% expressed preference for a collaborative role. Interestingly, none of the patients who participated in the study preferred an active role in which the ultimate treatment decision would be made by the patient. Multivariate analysis demonstrated that younger age and not-housewife status were associated with high preferences for SDM (Aoki et al., 2013).

While Japanese medical patients have traditionally allowed their physician to have authority over their treatment (Alden & Akashi, 2012), there has been an apparent shift noted in recent studies that suggests a trend towards increasing preference for autonomous, active, or collaborative participation; compared to previous studies that suggested Japanese patients preferred a more passive role in their medical treatment decisions (Tariman, Berry, Cochrane, Doorenbos, & Schepp, 2010). The apparent change in patient preference among Japanese patients, favoring a more active decision-making role, should be examined closely.

With the availability of many new treatment options, particularly in the field of biologics, patient preferences are important, in light of evidence that suggests patient participation in treatment decision-making is linked to greater compliance, which in turn leads to better clinical outcomes. Basically, two medical treatment strategies are available in treatment of RA. Conventional disease-modifying anti-rheumatic drugs (DMARDs) such as methotrexate (MTX), sulfasalazine (SSZ), lefluno-mide (LEF), or tacrolimus (TAC) which are generically available and inexpensive. Alternatively, biologic DMARDs have been available since the late 1990s, and effectively delay or even prevent the clinical disease progression of RA (Smolen et al., 2010). Also, treatment with biologics can improve productivity and help people to stay in employment (Furuya et al., 2013). However, treatment costs of biologics are more than 20 times higher. The use of biologics for treatment of rheumatoid arthritis more than doubled in Japan between 2011 and 2014 (Mahlich & Sruamsiri, 2016a).

Moreover, with information readily available on the Internet, and with generational shifts and other social and cultural changes over the past decade, it is important to reassess the preferences of Japanese RA patients in relation to SDM in order to optimize patient satisfaction and clinical outcomes. Against this backdrop, our study objective is to determine the preferred role in the medical decision-making process among Japanese patients with rheumatoid arthritis and to determine what factors influence any differences in patient preferences.

2. Methods

2.1. Patient selection

The study identified 1000 Japanese patients with rheumatoid arthritis by a nationwide online survey in July and August of 2016. Five hundred patients who responded met the study eligibility criteria of (1) diagnosis of rheumatoid arthritis for at least one year and (2) currently receiving at least one medication for treatment of rheumatoid arthritis.

2.2. Variables

Patients were asked to identify basic clinical characteristics, socioeconomic status, and medical history. Clinical characteristics considered included (1) age, (2) gender, and (3) diagnosis. Socioeconomic characteristics considered included (1) marital status, (2) household income, (3) educational level, and (4) work status. Medical history characteristics were recorded, including (1) time since diagnosis, (2) surgical history, and (3) comorbidity. Treatment details included (1) current treatment, (2) type of hospital, and (3) frequency of visits.



Current treatment was classified into conventional disease-modifying anti-rheumatic drugs (DMRADs) such as methotrexate, sulfasalazine, leflunomide, or hydroxychloroquine; biologic agents (biologics) which are classified according to molecules they target such as tumor necrosis factor inhibitors or, more recently, Janus kinase inhibitors, interleukin-6, interleukin-1, B-cell and T-cell costimulation inhibitors; and a combination of both classes (DMARDs + biologics) (Mahlich & Sruamsiri, 2016b).

Disease severity was measured using the J-HAQ (Japanese-Health Assessment Questionnaire), a validated Japanese version of the Stanford Health Assessment Questionnaire used to measure the severity of disease in patients with RA (Matsuda et al., 2003). This questionnaire assesses relevant function in 8 categories, including: dressing and grooming, arising, eating, walking, hygiene, reach, grip, and activities.

A Japanese language version of the PHQ-9 (Patient Health Questionnaire-9) scale was used as a clinical measurement of depression. This scale has been validated for screening for depression in Japanese hospitals (Suzuki, Kumei, Ohhira, Nozu, & Okumura, 2015). Cut-off scores used to measure depression were: minimal (0-4); mild (5-9); and moderate to severe (≥10).

Patients were questioned regarding their preference for SDM using a questionnaire originally developed by Baars et al. (2010). This questionnaire, used to measure preference for SDM in Dutch patients, was translated independently by two native Japanese speakers. Validation of the quality and essence capture of the original questionnaire was performed by reconciliation of the two translations into a single questionnaire, which was then translated back into English by a native English speaker.

2.3. Outcomes

The questionnaire asked patients to answer questions about the importance of involvement in SDM with their physician, using a 4-point Likert scale with the following responses: (1) very important; (2) quite important; (3) quite unimportant; and (4) totally unimportant. In order to increase the statistical power of the study and to get a more balanced distribution, the categories were further refined to three dimensions: important (1); quite important (2); and unimportant (3 and 4).

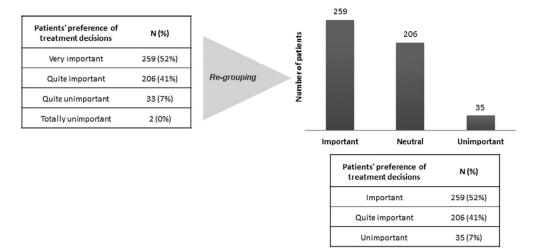
2.4. Statistical analysis

Descriptive statistics were used to determine the differences in the level of importance of SDM between the three groups. We then explored the association between decision-making preference and patient characteristics using univariable ordinal logistic regression. Following the approach of a recent study on treatment satisfaction in patients with inflammatory bowel diseases (Mahlich, Matsuoka, & Sruamsiri, 2017), variables with significant differences at the 0.2 level or better were selected to be included as explanatory variables in a full multivariable ordered logistic regression model with SDM as the dependent categorical variable. In our specification, the answer "important" received the highest code (3) and "unimportant" the lowest (1). Therefore, the resulting coefficients can be interpreted as the log odds of preferring a more active decision-making style

The Stata® statistics package (College Station, TX, USA) was used for analysis of the results. A value of p < 0.05 was defined as significant in the final model.



Figure 1. Distribution of the patients' preference for shared decision-making.



3. Results

A total of 500 Japanese patients with rheumatoid arthritis participated in the survey. The majority (52%) considered SDM in treatment decisions "very important" while only two respondents valued SDM totally unimportant (Figure 1).

Table 1 reports the patient characteristics of the sample. The survey population was majority female with a mean age of 54 years across all groups. Mean time since diagnosis was 10.67 years with an average HAQ score of 0.40. Those patients with longer time since diagnosis and/or higher disease severity had a non-significant trend towards higher preference for SDM. The most common comorbid condition among respondents was hypertension (16%). The primary treatment for 66% of patients surveyed was a DMARD.

Results from the descriptive statistics suggest significant differences at the 0.05 level with regard to gender. Female patients have a stronger preference for SDM compared to male patients. Also, significant differences were found with regard to the HAQ score: the higher the HAQ score, the more a patient wants to be involved. Recall that a higher HAQ score indicates poorer functioning. We also found that those patients who are treated with a biologic have a greater preference for SDM compared with those patients that are on a conventional DMARD.

The results of both the univariable and multivariable ordered logistic regression are reported in Table 2. In the final model, female gender was a strong predictor of a higher preference for SDM (OR 1.74, CI 1.09 - 2.77). It was further confirmed that patients treated with a biologic agent were most likely to prefer collaborative medical decision-making (OR 2.00, CI 1.09 - 3.69). A negative impact on preference for SDM was found for patients who have a comorbidity of moderate to severe depression (OR 0.54, CI 0.30 - 0.99), and for those working only part time (OR 0.50, CI 0.28 - 0.89).



Table 1. Patient characteristics by patients' preference (3 levels)	itients' preference (3 level	ls)			
Characteristics	Overall	Unimportant	Quite important	Important	p-value
Patients, N (%)	500	35 (7)	206 (41)	259 (52)	
Age (mean ± SD)	54.28 ± 10.02	54.60±11.80	53.29 ± 9.18	55.01 ± 10.36	0.062
<50 years, N (%)	178	12 (7)	77 (43)	89 (50)	
51-60 years, N (%)	196	10 (6)	89 (45)	97 (49)	
>60 years, N (%)	126	13 (10)	40 (32)	73 (58)	
Gender					0.017
Male, N (%)	163	19 (12)	(40)	79 (48)	
Female, N (%)	337	16 (5)	141 (42)	180 (53)	
Marriage status					0.307
Single, N (%)	76	10 (10)	41 (42)	46 (48)	
Married, N (%)	403	25 (6)	165 (41)	213 (53)	
Highest education					0.726
High school or less, N (%)	180	16 (9)	76 (42)	88 (49)	
College, N (%)	120	7 (6)	50 (42)	63 (52)	
Bachelor's degree or higher, N (%)	200	12 (6)	80 (40)	108 (54)	
Occupation					0.125
Fulltime, N (%)	164	11 (7)	70 (43)	83 (50)	
Part-time, N (%)	78	(8) 9	41 (52)	31 (40)	
Self-employed, N (%)	37	4 (11)	10 (27)	23 (62)	
House wife, N (%)	141	(4) 9	57 (40)	78 (56)	
Retired, N (%)	20	2 (10)	3 (15)	15 (75)	
Unemployed, N (%)	57	6 (10)	33 (58)	28 (32)	
Others, N (%)	3	0 (0)	2 (67)	1 (33)	
Region					
Hokkaido, N (%)	26	3 (11)	9 (35)	14 (54)	0.572
Tohoku, N (%)	23	1 (4)	11 (48)	11 (48)	0.751
Kanto, N (%)	230	17 (7)	99 (43)	114 (50)	0.652
Chubu, N (%)	63	2 (3)	24 (38)	37 (59)	0.310
Kansai, N (%)	95	6 (7)	39 (41)	50 (52)	0.954
Chugoku, N (%)	21	3 (14)	10 (48)	8 (38)	0.262
Shikoku, N (%)	11	1 (9)	2 (18)	8 (73)	0.291



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	58			18 (31)		39) 68		

anti-rheumatic drugs.

*One-way ANOVA for annual household income: p = 0.736.

 $^{\circ}$ One-way ANOVA for annual individual income: p=0.425.



Characteristics	Univariate analysis		Multivariate analysis	
	ORs (95% CI)	p-value	ORs (95% CI)	p-value
Age (Reference: ≤50 years)	· · ·	'		<u> </u>
51-60 years	1.01 (0.68 – 1.50)	0.095	0.93 (0.62 – 1.41)	0.745
> 60 years	1.25 (0.79 – 1.97)	0.333	1.05 (0.62 – 1.79)	0.845
Gender (reference: male)				
Female	1.36 (0.94 – 1.96)	0.102	1.74 (1.09 – 2.77)	0.020
Marital status (reference: single)				
Married	1.31 (0.85 – 2.01)	0.223		
Highest education (reference: high school or less)				
College	1.20 (0.77 - 1.88)	0.424		
Bachelor's degree or higher	1.26 (0.85 – 1.87)	0.243		
Occupation (reference: full-time)				
Part-time	0.68 (0.41 - 1.14)	0.144	0.50 (0.28 – 0.89)	0.020
Self employed	1.43 (0.69 – 2.98)	0.333	1.37 (0.64 – 2.94)	0.420
House wife	1.23 (0.80 - 1.91)	0.347	0.77 (0.44 - 1.32)	0.339
Retired	2.62 (0.90 – 7.59)	0.076	2.48 (0.78 – 7.92)	0.124
Unemployed	0.88 (0.49 – 1.59)	0.675	0.70 (0.36 - 1.34)	0.282
Others	0.65 (0.08 – 5.22)	0.688	0.77 (0.09 - 6.85)	0.815
Region				
Hokkaido	0.99 (0.45 – 2.17)	0.976		
Tohoku	0.91 (0.41 - 2.02)	0.820		
Kanto	0.85 (0.60 – 1.20)	0.362		
Chubu	1.44 (0.85 – 2.42)	0.175	1.40 (0.80 - 2.44)	0.232
Kansai	1.05 (0.68 - 1.63)	0.816		
Chugoku	0.52 (0.22 – 1.22)	0.135	0.44 (0.18 - 1.08)	0.073
Shikoku	2.31 (0.60 – 8.88)	0.223		
Kyushu	1.13 (0.56 – 2.32)	0.729		
Annual individual income (reference: <3.7 M Yen)				
3.7–7.7 M Yen	1.09 (0.71 – 1.69)	0.840		
>7.7 M Yen	0.76 (0.41 – 1.40)	0.247		
Time since diagnose (reference: ≤5 years)				
6-10 years	1.12 (0.73 – 1.72)	0.599	0.99 (0.63 – 1.56)	0.978
>0 years	1.73 (1.15 – 2.62)	0.009	1.39 (0.88 – 2.19)	0.158
HAQ score	1.21 (0.97 – 1.52)	0.092	1.10 (0.84 - 1.43)	0.481
Comorbidity				
Hypertension	0.73 (0.46 - 1.15)	0.231		
High cholesterol	0.94 (0.51 - 1.71)	0.831		
Diabetes	1.45 (0.65 - 3.24)	0.369		
Migraines	0.77 (0.24 - 2.43)	0.415		
Depression	0.71 (0.32 - 1.60)	0.652		
Heart condition	1.37 (0.32 – 5.86)	0.674		

(Continued)



Table 2. (Continued)					
Characteristics	Univariate analysis		Multivariate analysis		
	ORs (95% CI)	p-value	ORs (95% CI)	p-value	
Anxiety	0.84 (0.21 – 3.34)	0.806			
Current medication					
Pain killer (NSAIDs/oral pain med)	1.13 (0.71 – 1.82)	0.601			
Steroid	1.49 (0.97 – 2.29)	0.065	1.40 (0.88 – 2.22)	0.151	
Depression condition (reference: no depression)					
Mild depression	0.63 (042 – 0.94)	0.025	0.62 (0.40 – 0.97)	0.034	
Moderate to severe depression	0.60 (0.35 – 1.04)	0.068	0.54 (0.30 – 0.99)	0.040	
RA-related medication (reference: DMARDs)					
DMARDs + biologic agent	1.88 (1.22 – 2.90)	0.004	1.69 (1.05 – 2.71)	0.030	
Biologic agent	2.50 (1.40 – 4.48)	0.002	2.00 (1.09 – 3.69)	0.024	

Notes: ORs: odds ratio, CI: confidence interval, NSAIDs: nonsteroidal anti-inflammatory drugs, M: million, HAQ: health assessment questionnaire DMARDs: disease-modifying anti-rheumatic drugs, Bold values indicate significance of 20% or better in the univariate analysis and of 5% or better in the multivariate analysis.

4. Discussion

SDM in medicine has become increasingly common in the United States and Europe. In the past, Japanese patients have demonstrated a preference for a more passive role in the medical decision-making process, by which the physician makes treatment decisions. However, some studies have suggested a temporal shift towards a greater preference for collaboration among Japanese patients. (Morishige, Nakajima, Yoshizawa, Mahlich, & Sruamsiri, 2016). Our results support this notion. In our sample, 93% of the RA patients found SDM either very or quite important, which reflects an ongoing cultural change in patient-physician interaction in Japan.

When it comes to the factors that are associated with a stronger preference for SDM, we found trend towards patients with a greater disease burden (as indicated by the HAQ score) being more likely to have a strong preference for SDM. A recent study on Japanese patients with prostate cancer also concluded that patients who are in a more severe condition prefer SDM (Schaede et al., 2017).

Our results demonstrate that SDM plays an important role in the treatment of female patients, which echoes results from other countries outside Japan (Mandelblatt, Kreling, Figeuriedo, & Feng, 2006; O'Donnell & Hunskaar, 2007a). The results also suggest a greater preference for treatment involvement among patients treated with biologics, although the reasons for this are not clear. The increased preference for SDM in patients treated with biologics may be due in some part to the significant increase in patient cost associated with use of biologics compared to conventional disease-modifying anti-rheumatic drugs (DMARDs). Patients in Japan may pay up to 30% co-payment for treatment, making the decision to use a biologic a potential financial burden that may trigger a desire for increased participation in treatment decisions. Further study to establish the relationship of patient cost and preference for collaborative decision-making in patients may result in useful innovations in treatment involvement and compliance.

The study did not find a significant difference between preferences among married patients and unmarried patients, although there was a clear tendency in the univariable regression for married patients to prefer SDM. Previous studies have demonstrated a significant preference for SDM among married patients compared to those who are not married (Gattellari & Ward, 2005).



There was no significant difference in patient preference for SDM by age groups. This was in contrast to earlier studies of patients in Western countries, which demonstrated a significant difference between age groups, with a clear patient preference for active participation among younger patients (Baars et al., 2010; Flynn et al., 1982). There did not appear to be a difference in preference due to level of education or occupation, in contrast to previous studies that found patients with lower skills were likely to prefer to delegate medical decisions (Gattellari & Ward, 2005; O'Donnell & Hunskaar, 2007a, 2007b; Shields et al., 2004).

Limitations of this study include its cross-sectional design, which captured patient perceptions at the time of the study. These perceptions may be fluid over time. A further area of study suggested by this research would be determination of the change in patient preferences for SDM over time and the factors that influence these changes. This was also an online survey which might not be representative of the overall Japanese population. Usually volunteers that are more familiar with the Internet take part in online surveys. This subpopulation might be more prone to collecting health-related information online and might express a stronger desire for SDM than the overall population.

5. Conclusion

Our study reveals a preference in the majority of Japanese patients with rheumatoid arthritis for collaborative decision-making with their physician. SDM allows for a collaborative process between patients and their physicians, by which clinical evidence is considered in light of patient preferences and values. SDM provides a framework for exploration of patient goals and imperatives, so that treatment decisions take into account the factors that are most important to the individual.

Compliance with ethical guidelines

The results of this article are drawn from a web-based survey. This study does not involve any interventions conducted on human subjects by any of the authors. Informed consent was obtained from all patients in order to collect their personal information, with the exception of individual-specific information capable of identifying individuals, which was not collected.

The corresponding author had final editorial responsibility. The findings and conclusions in this report do not necessarily reflect the views of Janssen Pharmaceutical KK. No further approval was required as this was a questionnaire-based study only, involving no experimental treatment.

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Competing Interests

The authors declare no competing interest.

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