



Perceptions and behaviours related to COVID-19 in patients with rheumatoid arthritis: a cross-sectional study

Takahiro Itaya¹ · Mie Torii² · Motomu Hashimoto³ · Kazuaki Jindai¹ · Wataru Yamamoto^{3,4} · Kyosuke Tanigawa² · Yuki Urai² · Ayae Kinoshita² · Kazuko Nin² · Ryu Watanabe³ · Koichi Murata^{3,5} · Kosaku Murakami⁶ · Masao Tanaka³ · Hiromu Ito^{3,5} · Shuichi Matsuda⁵ · Akio Morinobu⁶

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Abstract

Objectives To study the perceptions and behavioural changes related to the coronavirus disease 2019 (COVID-19) in patients with rheumatoid arthritis (RA) and determine their associations with patient characteristics, such as health literacy.

Methods This cross-sectional study was conducted from September to November of 2020 and included 400 outpatients with RA aged 18 and above. We measured self-reported perceptions as outcomes, such as awareness, knowledge and behaviours related to COVID-19. Health literacy and other characteristics as exposures were investigated using self-report questionnaires and electronic health records. To analyse the association between patient factors and the outcomes, multivariable linear and logistic regression models were performed.

Results In total, 365 patients completed the survey. More than half (51%) of patients reported that they were ‘very worried’ about possible infection with COVID-19, whereas over 80% believed the possibility of getting COVID-19 was low. In the multivariable analyses, patients with low health literacy had limited knowledge about COVID-19 and did not change daily routines and perform preventive measures.

Conclusions In this pandemic, healthcare providers may need to be aware of more vulnerable individuals and share COVID-19 related information promptly and effectively with their patients.

Key Points

- This cross-sectional study aimed to investigate the perceptions and behavioural changes related to COVID-19 in patients with RA.
- All patients were aware of COVID-19 and most of them worried about getting infected.
- Health literacy, age, sex, disease activity and rheumatic drugs were associated with perceptions and behaviours related to COVID-19.

Keywords COVID-19 · Health knowledge · attitudes · practice · Health literacy · KURAMA cohort · Rheumatoid arthritis

✉ Motomu Hashimoto
mohashim@kuhp.kyoto-u.ac.jp

¹ Department of Healthcare Epidemiology, Graduate School of Medicine and Public Health, Kyoto University, Kyoto, Japan

² Department of Human Health Sciences, Graduate School of Medicine, Kyoto University, Kyoto, Japan

³ Department of Advanced Medicine for Rheumatic Diseases, Graduate School of Medicine, Kyoto University, Kyoto, Japan

⁴ Department of Health Information Management, Kurashiki Sweet Hospital, Kurashiki, Japan

⁵ Department of Orthopaedic Surgery, Graduate School of Medicine, Kyoto University, Kyoto, Japan

⁶ Department of Rheumatology and Clinical Immunology, Graduate School of Medicine, Kyoto University, Kyoto, Japan

Introduction

During the early pandemic phase of the coronavirus disease 2019 (COVID-19), more severe outcomes and higher hospitalisation were reported in patients with rheumatoid arthritis (RA) [1, 2]. Additionally, there have been many clinical studies and news coverage regarding inconsistent effects of rheumatic drugs on COVID-19 treatment [3, 4]. Generally, rheumatic patients are known to be at greater risk of infection due to their immune dysregulation, immunosuppressive therapy and older age [5]. Therefore, during this highly uncertain time, patients with RA may pose as a risk to themselves and their communities compared to general population or people with common chronic diseases such as diabetes and hypertension. Particularly, people with RA with high disease activity or using biological agents may have a strong fear or concern about COVID-19. Several previous studies have investigated the perceptions of COVID-19, included awareness and concern, knowledge, behaviour and preparedness, in the general population and in patients with these common chronic diseases and found significant associations with health literacy and race [6, 7], but a study on patients with RA has not yet been conducted. By investigating the perception, it is possible to identify which patients with RA are vulnerable to COVID-19 and to identify patient characteristics that healthcare providers should be aware of in their practice. The objective of this study was to clarify the perceptions related to COVID-19—such as awareness, knowledge and actions—amongst patients with RA. Furthermore, we examined the relationship between patient characteristics, especially health literacy and their perceptions.

Materials and methods

Study design and population

This cross-sectional study was conducted from 10 September 2020 to 2 November 2020 in Japan and utilised the Kyoto University Rheumatoid Arthritis Management Alliance (KURAMA) cohort, which has enrolled outpatients with RA since 2011 [8]. The eligibility criteria for inclusion were as follows: (1) consecutive outpatients with RA aged ≥ 18 years, and (2) without cognitive impairment. RA was defined by the classification criteria used by the 2010 American College of Rheumatology and European League Against Rheumatism [9, 10]. All participants provided informed consent and the Ethical Review Board at Kyoto University Graduate School and Faculty of Medicine Kyoto University Hospital Ethics Committee, Kyoto,

Japan, approved the study (approval number: R0357). This research was conducted according to the principles of the declaration of Helsinki and ethical guidelines for medical and health research involving human subjects by the Japanese Ministry of Health, Labour and Welfare.

Survey items of COVID-19 perceptions

We applied a modified version of a questionnaire used in previous studies (Table 1) [6, 11], and patients were asked to complete the questionnaire individually at the end of their outpatient visit. If they needed assistance due to hand contractures, the nurses helped them complete the form and assured them no answers were affected.

Variables

Health literacy—a primary exposure of interest—was assessed using the 14-item Health Literacy Scale (HLS-14) [12]. The total HLS-14 scores were divided into four groups by quartile points for analysis. We collected patient information using electronic health records (age, sex, disease duration years, disease activity score in 28 joints using erythrocyte sedimentation rate [DAS28-ESR], Health Assessment Questionnaire [HAQ] scores, rheumatic drugs such as biologic agents, methotrexate and glucocorticoids, and the number of comorbidities other than RA), and the questionnaire (working status). Age was categorised into three groups: < 60 years, 60–69 years and > 70 years. DAS28-ESR was categorised as a binary variable according to remission scores of < 2.6.

Statistical analysis

A complete-case analysis was performed and showcased all patient characteristics and survey responses as means with standard deviations for continuous variables and as counts and percentages for categorical variables. We used the items of the questionnaire as outcomes, and only the item of the seriousness of threat was used as a continuous variable while the other items were used as binary variables (e.g. ‘not worried’ was defined as the answers ‘a little worried’ or ‘not worried at all’ to the question of coronavirus concern), with reference to a previous study [6]. Multivariable linear regression models were used to estimate least-squares means and 95% confidence intervals for the continuous outcome. Multivariable logistic regression models were used to estimate odds ratios and 95% confidence intervals for the binary outcomes. All models included the following explanatory variables: age, sex, working status, health literacy, remission and rheumatic drugs. All statistical analyses were performed using STATA version 16.1 (Stata Corp., College Station,

Table 1 Perceptions and behaviours towards COVID-19 ($n=365$)

Survey item	Summary value
COVID-19 awareness and concern	
Mean response (SD) to ‘On a scale of 1 to 10, how serious of a public health threat do you think the coronavirus is or might become? (1 being no threat at all, 10 being a very serious public health threat)’	7.6 (2.0)
How worried are you about getting the coronavirus?	
Very worried	50.7
Somewhat worried	34.3
A little worried	14.0
Not worried at all	1.1
How worried are you about getting the flu?	
Very worried	18.9
Somewhat worried	46.9
A little worried	27.1
Not worried at all	7.1
Did you get a flu shot this past year?	
Yes	57.8
No	42.2
I do not know	0.0
Do you think you will get sick from the coronavirus?	
I definitely will	2.2
I probably will	16.2
It is possible	76.7
Not at all	4.9
How likely do you think it is that you or someone you know may get sick from the coronavirus this year?	
Very likely	2.5
Somewhat likely	16.2
Not that likely	76.2
Not at all likely	5.2
COVID-19 knowledge	
Mean response (SD) to ‘What percentage of people who get the coronavirus do you think will have severe symptoms?’	24.3 (21.8)
Mean response (SD) to ‘What percentage of people who get the coronavirus do you think will have only mild symptoms?’	58.8 (23.1)
Mean response (SD) to ‘What percentage of patients with RA who get the coronavirus do you think will have severe symptoms?’	45.8 (28.8)
Mean response (SD) to ‘What percentage of patients with RA who get the coronavirus do you think will have only mild symptoms?’	40.3 (23.9)
Correctly identified two symptoms of the coronavirus	
Yes	76.7
No	23.3
Correctly identified two prevention methods of the coronavirus	
Yes	71.5
No	28.5
Related behaviours	
How much has the coronavirus changed your daily routine?	
A lot	25.2
Some	39.2
A little	30.4
Not at all	5.2
How much has the coronavirus changed your frequency of taking more preventive measures, such as hand washing or mask-wearing?	
A lot	68.5
Some	21.6

Table 1 (continued)

Survey item	Summary value
A little	7.7
Not at all	2.2
Preparedness for COVID-19 pandemic	
How confident are you that the government of Japan can prevent a nationwide outbreak of the coronavirus?	
Very confident	1.9
Somewhat confident	41.9
Not very confident	47.1
Not confident at all	9.0
How prepared do you think you are if there were to be a widespread coronavirus outbreak?	
Very prepared	12.1
Somewhat prepared	48.2
A little prepared	38.1
Not prepared at all	1.6

COVID-19, coronavirus disease 2019; SD, standard deviation; RA, rheumatoid arthritis. The italicized entries specified the major components of the survey

TX, USA). Two-tailed *P* values < than 0.05 were considered statistically significant.

Results

Patient characteristics

In total, 400 patients were enrolled in this study, but only 365 patients answered the questionnaire completely. Most patients were over the age of 60, and 82% were female. The mean total score of health literacy was 52.1 points. The mean DAS28-ESR score was 2.7, and approximately 30% of the patients were in remission of RA. About half of the patients were using biological drugs, and 63% used methotrexate. Half of the patients had no comorbidities other than RA. More detailed characteristics are summarised in Table 2.

Awareness and concern of COVID-19

Most patients thought the public health threat of COVID-19 was high. Additionally, more than half of them answered that they were ‘very worried’ about getting COVID-19, whereas only 18.9% were ‘very worried’ about getting the influenza virus. Less than a fifth of participants believed that they would definitely or probably be infected with COVID-19. In the multivariable analyses, older patients and patients with high health literacy rated the COVID-19 threat with greater severity; conversely, patients using methotrexate felt that it was less serious than those without methotrexate (Table 3). Older individuals and women were statistically associated with greater worry regarding COVID-19 infection. However, the projection of getting sick from COVID-19 was not associated with any patient characteristics.

Table 2 Patient characteristics

Variable	Total (n = 365)	
Socio-demographic status		
Age years, mean (SD)	64.2	(11.4)
Age group, n (%)		
< 60 years	121	(33)
60–69 years	94	(26)
≥ 70 years	150	(41)
Female sex, n (%)	299	(82)
Employment status, n (%)		
Working full time or part time	167	(54)
Not working	198	(46)
Health literacy scores, mean (SD)		
Total score	52.1	(7.2)
Functional health literacy	20.8	(3.7)
Communicative health literacy	18.3	(3.5)
Critical health literacy	13.0	(3.0)
Clinical status		
Disease duration, mean (SD)	11.3	(9.9)
DAS28-ESR, mean (SD)	2.7	(1.0)
< 2.6 (remission), n (%)	118	(32)
HAQ, mean (SD)	0.42	(0.58)
Biological agent used, n (%)	178	(49)
Methotrexate used, n (%)	231	(63)
Glucocorticoid used, n (%)	86	(24)
Number of comorbidities without RA, n (%)		
None	182	(50)
1–2	155	(42)
≥ 3	28	(7.7)

SD, standard deviation; HL, health literacy; DAS28-ESR, disease activity score in 28 joints using erythrocyte sedimentation rate; HAQ, Health Assessment Questionnaire; RA, rheumatoid arthritis. Health literacy was measured by the 14-item health literacy scale (HLS-14)

Table 3 Multivariable models to investigate patient characteristics and perceptions of COVID-1

Variable	Awareness and concern			Knowledge		Related behaviours		Preparedness	
	Seriousness of threat (scale of 1 to 10)	Not worried	Not likely to get sick	Symptoms	Prevention	Changed daily routine	Took more preventions	Confidence in government	Not prepared
	LSM (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)
Age									
< 60 years	7.04 (6.65–7.43)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)
60–69 years	8.09 (7.69–8.48)§	0.62 (0.28–1.37)	0.80 (0.39–1.64)	1.21 (0.55–2.65)	0.65 (0.30–1.38)	0.81 (0.41–1.58)	1.51 (0.77–2.98)	1.27 (0.70–2.29)	0.79 (0.44–1.42)
≥ 70 years	7.78 (7.43–8.13)†	0.40 (0.17–0.97)†	0.56 (0.25–1.22)	0.63 (0.30–1.31)	0.35 (0.17–0.74)‡	0.98 (0.49–1.97)	1.07 (0.55–2.10)	1.46 (0.79–2.70)	0.68 (0.37–1.26)
Sex									
Female	7.69 (7.47–7.91)	0.43 (0.20–0.93)†	0.54 (0.26–1.11)	1.19 (0.59–2.39)	2.64 (1.38–5.05)‡	1.37 (0.67–2.80)	1.55 (0.82–2.92)	1.05 (0.58–1.91)	0.95 (0.52–1.73)
Male	7.26 (6.77–7.76)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)
Health literacy									
1st quartile (the lowest)	7.20 (6.80–7.59)	1.65 (0.68–4.05)	0.55 (0.24–1.22)	0.47 (0.22–0.98)†	0.33 (0.16–0.70)‡	0.44 (0.21–0.90)†	0.22 (0.11–0.44)§	1.08 (0.58–2.00)	0.93 (0.50–1.72)
2nd quartile	7.72 (7.31–8.14)	0.86 (0.33–2.23)	0.69 (0.32–1.49)	0.87 (0.38–1.97)	0.45 (0.21–1.00)†	0.76 (0.38–1.51)	0.64 (0.30–1.33)	1.12 (0.59–2.10)	0.90 (0.48–1.69)
3rd quartile	7.82 (7.43–8.21)†	1.40 (0.60–3.27)	0.78 (0.38–1.61)	0.70 (0.32–1.52)	0.62 (0.28–1.36)	0.84 (0.44–1.63)	0.76 (0.37–1.56)	1.49 (0.81–2.73)	0.67 (0.37–1.24)
4th quartile (the highest)	7.77 (7.35–8.18)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)
Remission									
Yes	7.74 (7.39–8.10)	0.66 (0.34–1.29)	0.95 (0.53–1.71)	0.74 (0.42–1.30)	1.09 (0.62–1.91)	0.54 (0.31–0.95)†	0.89 (0.53–1.50)	1.08 (0.68–1.73)	0.92 (0.58–1.47)
No	7.55 (7.31–7.79)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)
Biological agent									
Yes	7.66 (7.38–7.95)	0.75 (0.41–1.38)	0.83 (0.48–1.44)	0.95 (0.57–1.59)	0.93 (0.56–1.53)	0.85 (0.52–1.39)	0.87 (0.54–1.39)	0.98 (0.64–1.51)	1.02 (0.66–1.56)
No	7.57 (7.29–7.85)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)
Methotrexate									
Yes	7.44 (7.58–8.25)†	1.61 (0.82–3.19)	1.11 (0.61–2.02)	1.07 (0.62–1.84)	0.91 (0.53–1.54)	0.72 (0.43–1.21)	0.80 (0.49–1.33)	0.99 (0.63–1.56)	1.01 (0.64–1.60)
No	7.92 (7.19–7.69)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)
Glucocorticoid									
Yes	7.60 (7.39–7.85)	0.71 (0.32–1.57)	0.57 (0.27–1.21)	0.59 (0.33–1.05)	0.74 (0.41–1.31)	0.52 (0.27–0.98)†	0.74 (0.43–1.30)	1.68 (1.00–2.80)	0.60 (0.36–0.99)†
No	7.62 (7.18–8.02)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)	1.00 (reference)

‘Seriousness of threat’ was measured as a scale of 1 to 10, how serious of a public health threat do you think the coronavirus is or might become? (1, being no threat at all; 10, being a very serious public health threat). COVID-19, coronavirus disease 2019; LSM, least-squares mean; OR, odds ratio; CI, confidence interval. Remission was defined as the disease activity score in 28 joints using erythrocyte sedimentation rate < 2.6. †P < 0.05. ‡P < 0.01. §P < 0.001

The italicized entries specified the major components of the survey

Knowledge of COVID-19

Approximately 24.3% participants considered that people infected with COVID-19 will have severe symptoms, and 58.8% thought infected people will have only mild symptoms. Conversely, 45.8% and 40.3% of the participants thought that patients with RA would have severe and mild symptoms, respectively. Most patients correctly identified the two symptoms (76.7%) and two preventive measures (71.5%) of COVID-19 from the list. After adjustment, low health literacy was associated with low percentages of correct answers for both symptoms and prevention. Furthermore, in terms of prevention, older patients were more likely to give incorrect answers, while women were more likely to give correct answers.

Related behaviours

Most patients changed their daily routine and habits with the onset of COVID-19; in particular, 68.5% reported that they began taking more preventive measures for the disease. However, when asked about reduced visits to doctors, only half answered ‘some’ or ‘a little’. In the regression analyses, low health literacy was associated with less change in daily routines and fewer preventive methods. Patients in RA remission had fewer changes to their daily routines, and the frequency of visits to the doctor appeared to remain the same. In addition, patients using glucocorticoids were less likely to have a change in lifestyle.

Preparedness for COVID-19 pandemic

Respondents were divided on trusting and distrusting the government’s measures to prevent the outbreak. About 12% reported that they were ‘very prepared’ for the COVID-19 outbreak. In the multivariable analyses, there was no factor associated with confidence in government. Regarding preparedness, glucocorticoid users were more prepared for the pandemic compared to non-users.

Discussion

We found that all participants were aware about COVID-19, and most were worried about getting it. Health literacy was associated with three-quarters of the survey domains. In particular, those with lower health literacy scores had less preventive knowledge of COVID-19 and were less likely to take preventive measures. Previous studies with different target populations have shown similar results [6, 7]. Low health literacy is a barrier to gaining knowledge about health and enacting behaviour changes such

as wearing masks or hand washing. It is difficult to identify patients with low health literacy in clinical practice, but rheumatologists estimated that around 25% of their patients had low health literacy [13]. Health professionals would do well to provide patients with up-to-date COVID-19 information and to observe infection-related behavioural changes.

In terms of socio-demographics, older patients were more likely to believe that the pandemic was serious and were more worried about infection, compared to patients under 60 years. However, older patients had less knowledge about COVID-19. Older people understand that their age is a risk factor for the disease [14, 15], but they are not properly informed about it. Therefore, clinicians should share information effectively with older patients given their knowledge gap.

Clinically, patients with low RA disease activity did not change their daily routine or their number of health-care visits, given the pandemic; possibly, they consider themselves healthier than patients with high disease activity. Additionally, methotrexate users were less fearful of COVID-19 than non-users. This may be attributed to the fact that using methotrexate indicates that their disease is relatively well-controlled, and they assume that they are healthier than patients without methotrexate. Furthermore, glucocorticoid users were better prepared for the pandemic than non-users, but no lifestyle changes were found. This may be explained by the fact that, regardless of the pandemic, they are more likely to take preventive action against the everyday risk of infection.

Owing to the dynamic COVID-19 situation, this study has several limitations. First, examining the causal relationships between patient characteristics and perceptions of COVID-19 was limited due to the cross-sectional design. Although our findings are similar to previous research findings, future studies are needed to clarify these relationships. Second, the questionnaire we used could not check the validity of measuring perceptions and behaviours related to COVID-19. However, previous studies have used a similar format, making it easier to compare results [6, 7, 11]. Finally, although our recruited sample with RA was large, these findings have limited generalisability because this study was based on a university hospital in Japan and was conducted during the summer and autumn of 2020. Therefore, the results should be interpreted cautiously as the situation is dynamic, and future trends in the spread of infection may differ.

In conclusion, healthcare providers may need to be aware of more vulnerable individuals during the pandemic and share COVID-19 related information promptly and effectively with their patients. Especially, patients with lower health literacy faced disparities in knowledge and behaviour change towards COVID-19.

Author contribution TI, MTo, KJ and MH contributed to the conceptualisation and the study design. TI, MTo WY, KT, YU and MH were responsible for data acquisition. TI performed the analyses and wrote the first draft of the manuscript. All authors were responsible for data interpretation and drafting, revising and approving the final, submitted manuscript.

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Data availability Data are available upon reasonable request by contacting the corresponding author.

Declarations

Ethics approval The Ethical Review Board at Kyoto University Graduate School and Faculty of Medicine Kyoto University Hospital Ethics Committee, Kyoto, Japan, approved the study (approval number: R0357).

Consent for participation and publication All participants provided informed consent.

Competing interests Department of Advanced Medicine for Rheumatic Diseases is supported by Nagahama City, Shiga, Japan, Toyooka City, Hyogo, Japan and five pharmaceutical companies (Mitsubishi Tanabe Pharma Co., Chugai Pharmaceutical Co. Ltd, UCB Japan Co. Ltd, AYUMI Pharmaceutical Co. and Asahi Kasei Pharma Corp.). MH received a research grant and/or speaker fee from Bristol-Myers, Eisai, Eli Lilly and Mitsubishi Tanabe Pharma. RW received speaker's fee from Mitsubishi Tanabe Pharma, Pfizer, Sanofi, AbbVie, Asahi Kasei, Eisai, Eli Lilly, Bristol-Myers Squibb and Janssen. KMurat received speaker fees from Eisai Co., Ltd. MTa received research grants and/or speaker fees from AbbVie GK, Asahi Kasei Pharma Corp., Astellas Pharma Inc., Ayumi Pharmaceutical Corp., Bristol-Myers Squibb, Chugai Pharmaceutical Co., Ltd., Eisai Co., Ltd., Eli Lilly Japan K.K., Pfizer Inc., UCB Japan Co., Ltd., Janssen Pharmaceutical K.K., Mitsubishi Tanabe Pharma Corp., Novartis Pharma K.K., Taisho Pharma Co., Ltd., Takeda Pharmaceutical Co., Ltd. HI received research grants and/or speaker fees from BMS, Kyocera, Asahi-Kasei, Eisai, Mochida and Toyama. SM received research grants and/or speaker fees from AYUMI Pharmaceutical Co., Pfizer Inc., Eli Lilly Japan K.K., Mitsubishi Tanabe Pharma Corp., Kyocera, Chugai Pharmaceutical Co. Ltd., Mochida and Taisho Pharma Co., Ltd. AM received speaking fees and/or research grants from Eli Lilly Japan K.K., Ono Pharmaceutical Co., Pfizer Inc., UCB Japan, AbbVie G.K., Asahi Kasei Pharma and Chugai Pharmaceutical Co. Ltd. TI, MTo, WY, KT, YU, AK, KN, KJ and KMurak have declared no conflicts of interest.

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