Factors Related to Knowledge, Perception, and Practices Towards COVID-19 Among Patients with Autoimmune Diseases: A Multicenter Online Survey

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ABSTRAK

Latar belakang: penyintas autoimun lebih rentan untuk mengalami infeksi. Pengetahuan yang cukup, persepsi dan perilaku yang baik sehubungan dengan COVID-19 penting untuk penyintas autoimun selama pandemi. Studi ini bertujuan untuk mengetahui tingkat pengetahuan, persepsi dan perilaku penyintas autoimun terkait pandemi COVID-19. Metode: studi potong lintang menggunakan survei daring dilakukan dari April sampai Mei 2020. Penyintas autoimun ditanyakan mengenai karakteristik demografi, diagnosis, riwayat pengobatan, pengetahuan, persepsi dan perilaku terkait COVID-19. Hasil: total responden sebanyak 685 orang. Mayoritas adalah perempuan, memiliki diagnosis lupus eritematosus sistemik, dengan median usia 37 tahun. Hampir semua responden memiliki pengetahuan yang baik terkait penularan COVID-19 dan melakukan perilaku yang tepat. Kecukupan informasi dan penggunaan steroid atau mofetil mikofenolat/asam mikofenolat (MMF/MPA) berhubungan dengan persepsi bahwa pandemi memengaruhi kesehatan mereka. Kunjungan ke klinik swasta dan penggunaan hidroksiklorokuin/klorokuin atau sulfasalazin berhubungan dengan persepsi penyakit autoimun dapat menyebabkan penyintas autoimun lebih rentan terinfeksi COVID-19. Penyintas autoimun yang bekerja dari rumah berhubungan dengan

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persepsi bahwa ketika terinfeksi COVID-19, gejala yang timbul lebih berat. Berdomisili di daerah Sumatera dan mendapatkan hidroksiklorokuin/klorokuin sulfat atau MMF/MPA berhubungan dengan persepsi bahwa pengobatan autoimun dapat mengurangi risiko terinfeksi COVID-19. Kecukupan informasi, pendidikan universitas, kunjungan ke klinik swasta dan penggunaan hidroksiklorokuin/klorokuin sulfat berhubungan dengan persepsi bahwa pandemi COVID-19 akan menyebabkan penyintas semakin sulit mendapatkan obat. **Kesimpulan:** hampir semua responden memiliki pengetahuan yang baik dan melakukan kebiasaan yang tepat terkait COVID-19. Kecukupan informasi, jenis pengobatan autoimun, bekerja dari rumah, latar belakang pendidikan, domisili tempat tinggal, dan fasilitas kesehatan berhubungan dengan persepsi penyintas autoimun terkait pandemi COVID-19.

Kata kunci: pengetahuan, persepsi, perilaku, autoimun, COVID-19.

ABSTRACT

Background: autoimmune patients can be more susceptible to infection. Proper knowledge, perception, and practices towards COVID-19 are essential for these patients during pandemic. This study aimed to know their knowledge, perception, and practices regarding COVID-19. Methods: cross sectional study using online survey was conducted from April to May 2020. Patients with autoimmune disease were asked about demographic characteristics, diagnosis, history of treatment, knowledge, perception, and practice regarding COVID-19. **Results:** there were 685 respondents. Most of them were female and had systemic lupus erythematosus with median age of 37 years old. Almost all respondents had good knowledge regarding transmission of COVID-19 and did proper prevention practices. Adequacy of information and steroid or mycophenolate mofetil/mycophenolic acid (MMF/MPA) use were related to perception of the effect of pandemic to their own health. Visiting private clinic and receiving hydroxychloroquine/chloroquine sulfate or sulfasalazine were related to perception that autoimmune conditions would make them more prone to COVID-19. Work from home was related to perception that when contracting COVID-19, the symptoms would be more severe. Living in Sumatra region and getting hydroxychloroquine/ chloroquine sulfate or MMF/MPA were related to perception that autoimmune medications could reduce risk of getting COVID-19. Adequate information, university education, private clinic visit, and hydroxychloroquine/ chloroquine sulfate use were related to perception that COVID-19 pandemic would cause difficulties in getting medications. Conclusion: almost all respondents had good knowledge and practices regarding COVID-19. Adequacy of information, autoimmune treatment, work from home, educational background, area of living, and health care facilities contributed to perception regarding COVID-19 pandemic.

Keywords: knowledge, perception, practice, autoimmune, COVID-19.

INTRODUCTION

On March 11, World Health Organization declared COVID-19, an infection caused by severe acute respiratory coronavirus 2 (SARS-CoV-2), as a pandemic outbreak. The number of confirmed cases as of 25 June 2020 was more than eight million cases, while the number of deaths reached 479,133 cases.²

Pre-existing impaired immune response can likely contribute to the immunopathogenesis of COVID-19.³ Autoimmune disease occurs when immune system attacks the body own cells. To control the disease activity, some patients with autoimmune diseases need immunosuppressant. These conditions make them more susceptible to

infection. ^{4,5} Therefore, during this pandemic, there are concerns among patients with autoimmune diseases whether they will be more prone to get COVID-19 infection or not and the greater risk of presenting a severe form of COVID-19 infection. However, there is still not enough evidence to answer these questions.

Knowledge and perception towards COVID-19 pandemic are essential for patients with autoimmune diseases. In the absence of effective COVID-19 treatment, the implementation of protective measures will potentially prevent the people from getting infected by the disease and reduce disease dissemination. They should obtain accurate

information about COVID-19 and how to prevent the disease and practice the preventive measures properly. To improve the management of autoimmune patients in Indonesia during this COVID-19 pandemic, it is important to know about their knowledge, perception, and practices regarding COVID-19 pandemic.

METHODS

We conducted a cross-sectional study using online survey in Indonesian language from April to May 2020. Inclusion criterion was patients diagnosed with autoimmune disease, and the exclusion criterion was those who refused to participate. People that fulfilled the criteria would be included in the study. The required sample was the total sampling from the filled online survey. This study had been approved by Ethical Committee of Faculty of Medicine Universitas Indonesia (KET-443/UN2.F1/ETIK/PPM.00.02/2020).

Data Collection

We developed and published an online survey for patients with autoimmune diseases through foundations or patient support group. The survey was disseminated to 23 Whatsapp and Facebook groups which had 3588 members.

A patient can be a member of different groups. Respondents were given informed consent and if they agreed, then they filled out the survey. The questions were developed to get information about demographic characteristics of the respondents, diagnosis, history of treatment, and the respondents' knowledge, perception, and practices regarding COVID-19 pandemic and their health. Six hundred eighty-eight respondents joined the online survey. Three respondents were not included in analysis because did not give proper autoimmune diagnosis.

Statistical Analysis

Statistical analysis relied on Microsoft Excel and SPSS version 20.0. Bivariate analysis of two categorical data was conducted with Chi Square. Multivariate analysis was conducted with logistic regression.

RESULTS

A total of 685 patients with autoimmune diseases joined the online survey. Most of the respondents were female (637 subjects; 93%) with median age of 37 (IQR 29-45) years old. All but two respondents lived in Indonesia (**Figure 1**). Most respondents (84.5%) lived in Java Island.

INDONESIA

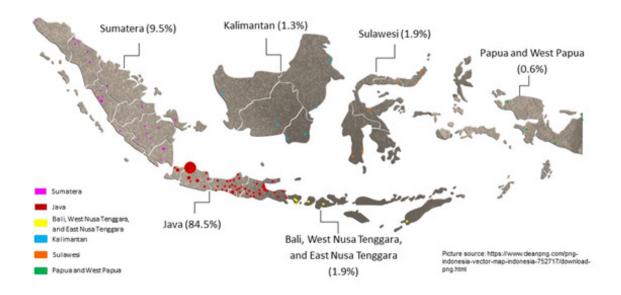


Figure 1. Distribution of respondent's residence location.

Table 1. Characteristics of study subjects

Characteristics (N=685)	Number (%)
Age group - <19 years old	14 (1.9)
- 19-60 years old	654 (95.7)
- >60 years old	17 (2.4)
Educational background	17 (2.4)
- Basic (elementary and junior high school)	16 (2.3)
- Intermediate (senior high school)	160 (23.4)
- High (university)	506 (73.9)
- No data	3 (0.4)
Occupation	3 (0.4)
- Health care worker	34 (5)
- Non-health care worker	416 (60.7)
- Not working	232 (33.9)
- No data	3 (0.4)
Health Funding	3 (0.4)
- National insurance program	447 (65.3)
- Other insurance	82 (12)
- Other funding	120 (17.5)
- Self-funding	288 (42)
Health care facilities	200 (42)
- Government hospital	373 (54.5)
- Private hospital	384 (56.1)
- Public Health Center (<i>Puskesmas</i>)	85 (12.4)
- Private clinic	109 (15.9)
Diagnosis of autoimmune diseases	109 (15.9)
- Systemic lupus erythematosus	277 (40.4)
	, ,
- Sjogren's syndrome	140 (20.4)
- Rheumatoid arthritis	131 (19.1)
- Psoriasis	86 (12.6)
- Autoimmune thyroid disease	44 (6.4)
- Antiphospholipid syndrome	36 (5.3)
- Vasculitis	31 (4.5)
- Inflammatory bowel disease	25 (3.6)
- Immune Thrombocytopenia Purpura	24 (3.5)
- Myositis	20 (2.9)
- Autoimmune hemolytic anemia	15 (2.2)
- Myasthenia gravis	13 (1.9)
- Multiple sclerosis	11 (1.6)
- Ankylosing spondylitis	8 (1.2)
- Systemic sclerosis	7 (1)
- Uveitis	4 (0.6)
- Chronic Inflammatory demyelinating polyneuropathy	4 (0.6)
 Other autoimmune neurology (Guillain barre syndrome, neuromyelitis optics, transverse myelitis, multifocal motor neuropathy) Other autoimmune diseases (type 1 diabetes, celiac disease, alopecia areata, rheumatic fever, 	9 (1.3)
interstitial lung disease, autoimmune hepatitis, Evan's syndrome, pemphigus vulgaris, sarcoidosis, primary biliary cirrhosis, adult onset still disease, mixed connective tissue disease, juvenile rheumatoid arthritis, vitiligo)	32 (4.7)
Comorbidities	
- Allergy	149 (21.8)
- Hypertension	59 (8.6)
- Asthma	56 (8.2)
- Diabetes mellitus	16 (2.3)
- Pulmonary tuberculosis	15 (2.2)
- Heart diseases	15 (2.2)
- Cerebrovascular disease	8 (1.2)
- Renal failure	5 (0.7)
- Malignancies	3 (0.4)
- No comorbidities	306 (44.7)

Table 1. Characteristics of study subjects

Characteristics (N=685)	Number (%)
Medications	
Steroid use	
- No steroid	293 (42.8)
- <7.5 mg per day equivalent prednisone	260 (38)
- 7.5 mg-30 mg per day equivalent prednisone	116 (16.9)
- >30 mg per day equivalent prednisone	13 (1.9)
- No information	3 (0.4)
Steroid sparing agent	
- Hydroxychloroquine/Chloroquine sulfate	181 (26.4)
- Mycophenolate mofetil/mycophenolic acid	153 (22.3)
- Methotrexate	90 (13.1)
- Azathioprine	50 (7.3)
- Sulfasalazine	36 (5.3)
- Cyclosporine	24 (3.5)
- Mesalamine	18 (2.6)
- Leflunomide	10 (1.5)
- Tacrolimus	7 (1)
- Cyclophosphamide	6 (0.9)
- Biologics	5 (0.7)
- Budesonide	2 (0.3)
- Acitretin	1 (0.1)

Table 1 shows other characteristics of study subjects. More than half of the subjects got treatment at government hospital and used national insurance program. Most respondents had high educational background, were diagnosed with systemic lupus erythematous, and had no comorbidities. Almost half of respondents did not get any steroid (42.8%). Mycophenolate mofetil or mycophenolic acid and hydroxychloroquine/chloroquine sulphate were steroid sparing agent that was used the most.

Source of Information Related to COVID-19 Pandemic

Figure 2a shows sources from where respondents got COVID-19 information. Television was the main source of information of COVID-19 (66%), followed by doctor/medical staff (43%). More than a quarter of respondents got information from social media: Whatsapp/Line/Telegram (38%) and Instagram (29%).

Ninety-one subjects (13.3%) said that they did not get enough information related

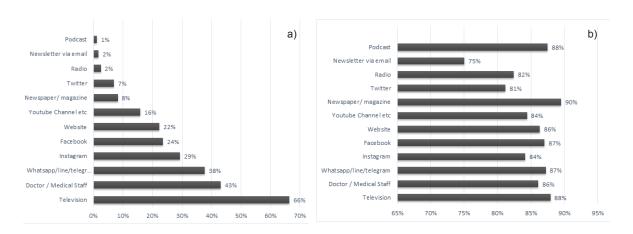


Figure 2. Sources of COVID-19 information (a) and respondent's satisfaction for each source of information (b).

to COVID-19 pandemic. Satisfaction for each resource of information is shown in **Figure 2b**. Information from newspaper or magazine was the most satisfying source (90%), higher than information from doctor or medical staff (86%).

Knowledge, Perception, and Practice of Study Subjects Related to COVID-19 Pandemic

About 670 respondents (97.8%) gave right answers on how COVID-19 infection could be transmitted (via droplet), seven respondents (1%) gave wrong answers and eight respondents (1.2%) answered that they did not know how it could be transmitted. No respondents who used podcast, newsletter, or radio as sources of information gave wrong answers (**Table 2**). The proportion of respondents giving right answer was similar according to adequacy of information and educational background.

Some questions were related to subject's perception on the effect of COVID-19 pandemic to their own health. Most of the respondents (79.7%) felt anxious but that did not affect their daily life. The others feel worried and that

affected their daily activities (15.3%), but others did not feel worried (5%). Most of respondents thought that they were more prone to COVID 19 infection (587 subjects, 85.7%) and would be more severe if getting COVID-19 infection (359 subjects; 52.4%). About 148 (21.6%) respondents thought that their medications could reduce their risk of getting COVID-19 infection. Half of the respondents (344 subjects; 50.2%) were afraid that the pandemic would cause difficulties in getting their medications.

We did analysis to know factors related to respondent's perceptions during COVID-19 pandemic. **Table 3** shows results of bivariate and multivariate analysis of patients' variable with perception. On perception of the effect of pandemic to their own health, adequate COVID-19 information and steroid use were related to lower risk of feeling worried which affected their daily activities (p=0.02; OR 0.09 95% CI 0.01-0.72 and p=0.01; OR 0.29 95% CI 0.11-0.76, respectively). Higher risk was seen in respondents who got MMF/MPA (p=0.01;

Table 2. Knowledge on COVID-19 transmission.

	COVID-19 t	transmission
Variables	Right answer 670 respondents (%)	Wrong answer/did not know the answer 15 respondents (%)
Source of information		
Doctor or other health professionals	286 (96.9)	9 (3.1)
Television	446 (98)	9 (2)
Whatsapp/Line/Telegram platform	256 (99.2)	2 (0.8)
Instagram	194 (96.5)	7 (3.5)
Facebook	160 (99.4)	1 (0.6)
Website	152 (99.3)	1 (0.7)
Youtube	107 (98.2)	2 (1.8)
Newspaper/magazine	56 (98.2)	1 (1.8)
Twitter	46 (95.8)	2 (4.2)
Radio	17 (100)	0 (0)
Newsletter	12 (100)	0 (0)
Podcast	8 (100)	0 (0)
Adequacy of information related to COVID-19		
Adequate	581 (97.8)	13 (2.2)
Not adequate	89 (97.8)	2 (2.2)
Educational background		
Elementary school & junior high school (16 respondents)	15 (93.8)	1 (6.2)
Senior high school & universities (666 respondents)	652 (97.9)	14 (2.1)
No information (3 respondents; 0.4%)	3 (100)	0 (0)

Table 3. Bivariate and multivariate analysis of patient's variable to perception related to COVID-19 pandemic

	How do	es this	COVID-1:	9 pande	How does this COVID-19 pandemic affect your health?	ct your	health?																	
Patient's variables	Worr	ied, affecting ities vs no wo (N=105 vs 34)	Worried, affecting daily activities vs no worries (N=105 vs 34)	illy es	Anxiot their da (us, but not aff aily life vs no v (N=546 vs 34)	Anxious, but not affecting their daily life vs no worries (N=546 vs 34)	ing rries	Autoii would i	mmune col make patie COVID-19 (N=685)	Autoimmune conditions would make patients more prone to COVID-19 infection (N=685)	ons nore ction	When c infect would b the aut	ontracting ion, the sy e more sev oimmune c	When contracting COVID-19 infection, the symptoms would be more severe due to the autoimmune conditions (n=390)	D-19 ms ue to ions	Autoirr could r risk of	immune medicat I reduce the pati of getting COVIC infection(N=546)	Autoimmune medications could reduce the patients' risk of getting COVID-19 infection(N=546)		COVID-19	pandemic s in getting (N=546)	COVID-19 pandemic would cause difficulties in getting medications (N=546)	l cause cations
•	Bivariate	ate	Multivariate	riate	Bivariate	ate	Multivariate	riate	Bivariate	ate	Multivariate	ıriate	Bivariate	ate	Multivariate	riate	Bivariate	ate	Multivariate	iate	Bivariate	ate	Multivariate	ariate
	OR (95%CI)	۵	OR (95%CI)	۵	OR (95%CI)	۵	OR (95%CI)	۵	OR (95%CI)	۵	OR (95%CI)	۵	OR (95%CI)	۵	OR (95%CI)	۵	OR (95%CI)	۵	OR (95%CI)	۵	OR (95%CI)	۵	OR (95%CI)	۵
Female	0.32	0.45			0.40	0.72			1.88 (0.92-	0.08	1.84 (0.87-	0.11	1.39	99.0			1.45	0.42			0.52	0.14	0.47	0.10
Adequate	(2.03)		0		3.04)		07		3.02)		3.00)		0.30)				3.04)				0.25		0.20	
inform. related to COVID-19	(0.01-	0.01	(0.01-	0.02	(0.03-	0.16	(0.02-	0.10	(0.67-2.22)	0.52			(0.22-2.56)	-			(0.51-	0.71			(0.13- 0.50)	<0.001	(0.10-0.44)	<0.001
University education	0.89 (0.36-2.20)	0.80			0.88 (0.39-	0.75			1.06 (0.65-1.73)	0.81			1.30 (0.59- 2.87)	0.51			0.86 (0.56- 1.33)	0.50			0.56 (0.37- 0.86)	0.01	0.60 (0.38-0.95)	0.03
National insurance program	0.92 (0.41-2.07)	0.85			1.05 (0.51- 2.16)	06.0			1.29 (0.83-2.00)	0.26			1.11 (0.52- 2.36)	0.78			1.22 (0.81- 1.82)	0.35			1.05 (0.72- 1.51)	0.81		
Other insurance	2.36 (0.28- 19.88)	0.68			5.17 (0.70- 38.4)	0.11		0.09	0.65 (0.36-1.18)	0.15	0.70 (0.38-1.32)	0.27	1.12 (0.38- 3.33)	-			1.17 (0.67-2.04)	0.59			0.98 (0.58- 1.67)	0.95		
Other funding	0.59 (0.22- 1.62)	0.30			0.85 (0.36-2.02)	0.72			1.01 (0.58-1.78)	96.0			0.50 (0.22-1.20)	0.13	0.65 (0.23- 1.88)	0.43	1.13 (0.69-1.87)	0.62			0.64 (0.40-1.01)	0.05	0.70 (0.42-1.18)	0.18
Self- funding	1.41 (0.64- 3.12)	0.39			1.14 (0.56- 2.33)	0.72	5.67 (0.76- 42.37)		0.92 (0.60-	0.69			1.30 (0.61- 2.80)	0.49			0.68 (0.46- 1.00)	0.02	0.62 (0.16- 2.39)	0.48	1.04 (0.73- 1.48)	0.82		
Govern- ment hospital	1.62 (0.74- 3.53)	0.22	2.37 (0.94- 5.99)	0.07	1.32 (0.66- 2.65)	0.43			1.42 (0.93-2.18)	0.12			1.63 (0.78- 3.40)	0.19	1.03 (0.38- 2.76)	0.95	0.97 (0.66-	98.0			1.40 (0.98- 1.99)	90.0	1.04 (0.67- 1.62)	0.87
Private hospital	0.64 (0.29-1.39)	0.26			0.95 (0.47-1.92)	0.88			0.82 (0.53-1.27)	0.37			0.65 (0.30-1.40)	0.27			1.08 (0.74-1.58)	0.68			0.65 (0.46- 0.93)	0.02	0.69 (0.47-1.01)	0.06

Table 3. Bivariate and multivariate analysis of patient's variable to perception related to COVID-19 pandemic

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	How do	es this	How does this COVID-19 pandemic affect your health?	9 pand	emic affe	ct you	r health	~																
Patient's variables	Worr	ried, aff rities vs (N=105	Worried, affecting daily activities vs no worries (N=105 vs 34)	aily ies	Anxiou their da (us, but not aff iily life vs no v (N=546 vs 34)	Anxious, but not affecting their daily life vs no worries (N=546 vs 34)	cting orries	Auto would prone t	immune co make patie to COVID-19 (N=685)	Autoimmune conditions would make patients more prone to COVID-19 infection (N=685)	ons nore ction	When c infect would due to cor	ontraction, the d be mα the au	When contracting COVID-19 infection, the symptoms would be more severe due to the autoimmune conditions (n=390)	D-19 ms re ne	Autoir could risk o	immune medicat I reduce the pati of getting COVII infection(N=546)	Autoimmune medications could reduce the patients' risk of getting COVID-19 infection(N=546)	ons nts' 19	COVID	0-19 pan difficult	COVID-19 pandemic would cause difficulties in getting medications (N=546)	ould ting
	Bivariate	iate	Multivariate	riate	Bivariate	ate	Multivariate	ariate	Bivariate	iate	Multivariate	ariate	Bivariate	ate	Multivariate	riate	Bivariate	ate	Multivariate	riate	Bivariate	iate	Multivariate	riate
	OR (95%CI)	۵	OR (95%CI)	۵	OR (95%CI)	۵	OR (95%CI)	<u>a</u>	OR (95%CI)	۵	OR (95%CI)	۵	OR (95%CI)	۵	OR (95%CI)	۵	OR (95%CI)	۵	OR (95%CI)	۵	OR (95%CI)	۵	OR (95%CI)	۵
Public health center	0.75 (0.24-2.30)	0.56			0.82 (0.31-2.20)	09.0			1.02 (0.53-1.95)	0.95			5.08 (0.68- 38.07)	0.10		-	0.67 (0.35-	0.22	0.28 (0.04-1.82)	0.18	1.54 (0.86-2.74)	0.14	1.43 (0.77-2.64)	0.26
Private clinic	0.84 (0.30-2.35)	0.74			0.88 (0.36-	0.79			0.43 (0.26-0.70)	0.001	0.45 (0.26-0.78)	0.005	0.90 (0.33-2.45)	0.79			1.45 (0.87-2.43)	0.16	1.79 (0.48- 6.63)	0.38	0.55 (0.34-0.90)	0.02	0.52 (0.31-	0.01
Sumatra vs other than Sumatra and Java	0.56 (0.08-3.80)	0.66			0.91 (0.16- 5.29)	~			0.59 (0.15- 2.39)	0.53			1.15 (0.18- 7.53)	-			2.83 (1.04- 7.71)	0.04	4.40 (1.29- 14.94)	0.02	0.86 (0.33- 2.25)	0.75		
Java vs other than Sumatra and Java	0.68 (0.14-3.31)	-			1.19 (0.27-5.24)	0.69			0.47 (0.14-1.56)	0.21	0.37 (0.12- 1.25)	0.11	1.32 (0.29- 6.01)	99.0			1.10 (0.46- 2.64)	0.82			0.70 (0.31-1.56)	0.38		
Work from home	0.70 (0.22-2.18)	0.54	ç c		0.99 (0.35- 2.79)	0.98	2		0.88 (0.49- 1.60)	0.68	7		2.57 (1.06- 6.26)	0.03	2.61 (1.06- 6.45)	0.0	0.99 (0.58-1.70)	0.97			0.81 (0.50-1.33)	0.40		
Steroid	0.46 (0.20- 1.05)	90.0	0.29 (0.11- 0.76)	0.01	0.56 (0.26- 1.19)	0.13	(0.20- 0.96)	0.04	1.55 (1.01- 2.38)	0.04	0.67- (0.87- 1.81)	0.71	1.24 (0.50- 2.60)	0.56			1.63 (1.06- 2.49)	0.02	0.43 (0.08- 2.24)	0.31	1.09 (0.76- 1.58)	0.63		
Hydroxychlo- roquine/ chloro-quine sulfate	1.12 (0.45-2.78)	0.80			1.13 (0.50- 2.56)	0.77			2.09 (1.17- 3.73)	0.01	1.85 (1.02- 3.36)	0.04	2.33 (0.79- 6.82)	0.12	2.11 (0.58- 7.63)	0.25	2.57 (1.73- 3.81)	0.001	7.22 (2.23- 23.38)	0.001	1.91 (1.29- 2.84)	0.001	1.99 (1.32- 3.01)	0.001
Azathioprine	0.63 (0.11- 3.62)	0.63			1.40 (0.32- 6.05)	~			1.24 (0.52-3)	0.63			0.91 (0.88- 0.94)	0.10		-	0.94 (0.48-1.82)	0.85			0.79 (0.44-1.43)	0.44		
Mycophenolate mofetil myco- phenolic acid	5.82 (1.31- 25.88)	0.01	15.68 (1.93- 127.31)	0.01	4.65 (1.10- 19.69)	0.02	6.69 (1.55- 28.80)	0.01	1.56 (0.88- 2.76)	0.12	1.45 (0.78-2.70)	0.24	0.96 (0.42-2.23)	0.93			1.46 (0.97- 2.19)	0.07	5.66 (1.86- 17.23)	0.002	1.53 (1.02- 2.29)	0.04	1.50 (0.98- 2.30)	0.06

Table 3. Bivariate and multivariate analysis of patient's variable to perception related to COVID-19 pandemic
How does this COVID-19 pandemic affect your health?

	How does	s this C	How does this COVID-19 pandemic affect your health?	demic an	ect yor	ır neamı																
Patient's variables	Worried activitik (N:	ied, affecting ities vs no wo (N=105 vs 34)	Worried, affecting daily activities vs no worries (N=105 vs 34)	Anxio their da	us, but ally life (N=546	Anxious, but not affecting their daily life vs no worries (N=546 vs 34)	ting	Autoi would prone tc	nmune co make patie COVID-19 (N=685)	Autoimmune conditions would make patients more prone to COVID-19 infection (N=685)	ns ore :tion	When contracting COVID-19 infection, the symptoms would be more severe due to the autoimmune conditions (n=390)	ntractii on, the be mo the au	then contracting COVID-1 infection, the symptoms would be more severe due to the autoimmune conditions (n=390)	D-19 ns e e	Autoirr could r risk of inf	mune educe getting fection(Autoimmune medications could reduce the patients' risk of getting COVID-19 infection(N=546)	COVID	-19 pan difficult dication	COVID-19 pandemic would cause difficulties in getting medications (N=546)	ould ting
	Bivariate		Multivariate	Bivariate	iate	Multivariate	riate	Bivariate	ate	Multivariate	riate	Bivariate	te	Multivariate	iate	Bivariate	ıte	Multivariate	Bivariate	iate	Multivariate	riate
	OR (95%CI)	<u>a</u>	OR P	OR (95%CI)	۵	OR (95%CI)	_	OR (95%CI)	۵	OR (95%CI)	۵	OR (95%CI)	۵	OR (95%CI)	۵	OR (95%CI)	•	OR P	OR (95%CI)	۵	OR (95%CI)	۵
	0.74			0.94				3.96		2.92		1.58				0.89		(in the second s	1.18			
Cyclosporine		0.19	-	(0.92-	0.62			(0.53-	0.23	(0.38-	0.31	(0.20-	—			(0.35-	0.81		(0.50-	0.70		
	0.82)			0.96)				29.63)		22.70)		12.28)				2.29)			2.82)			
	0.75			0.94				98.0				0.92				2.04			1.48			
Tacrolimus	-89.0)	_		(0.92-	~			(0.83-	09.0			-68.0)	←			(0.45-	0.40		(0.28-	~		
	0.83)			0.96)				0.88)				0.95)				9.22)			7.67)			
	0.54			0.57		0.73		1.58		1.71		92.0				0.91			0.93			
Methotrexate		0.26		(0.24-	0.19	(0.30-	0.48	-77-0)	0.21	(0.75-	0.20	(0.28-	0.58			(0.54-	0.73		(0.58-	0.77		
	1.50)			1.35)		1.77)		3.27)		3.90)		2.09)				1.54)			1.50)			
9	0.24			0:30				0.33		0.16		0.34				1.35			2.96			
cyclopinospila-		0.24	·	(0.04-	0:30			-90:0)	0.21	(0.02-	0.08	-40.0)	0.34			(0.24-	99.0		(0.34-	0.42		
D ====================================	0.32)			2.69)				1.82)		1.21)		3.12)				7.44)			25.56)			
	0.97			0.86				6.15		8.94		1.58				1.44			0.99			
Sulfasalazine	(0.19-	_		(0.20-	0.69			(0.83-	0.04	(1.07-	0.04	(0.20-	-			(0.70-	0.32		(0.49-	0.98		
	5.04)			3.79)				45.42)		74.87)		12.28)				2.97)			2.02)			
	0.75			0.94				2.89				1.22				0.57			0.51		0.36	
Mesalamine	(0.68-	_		(0.92-	-			(0.38-	0.49			(0.16-	_			(0.16-	0.58		(0.19-	0.17	(0.12-	90.0
	0.83)			0.96)				21.99)				9.58)				2.00)			1.34)		1.04)	
				0.94				98.0				0.92				0.73			0.63			
Budesonide	,	1		(0.92-	-			(0.83-	-			(0.89-	—			(0.69-	-		(0.59-	0.53		
				(ps.)				0.00)		o o		0.30)		0		(,,,)			0.07			
l effinomide				0.94	·			0.38	91	0.38	0.21	0.17	0 22	0.28	0.32	0.33	0.46		81.1	-		
				0.96)				1.50)	5	1.75)	! 5	1.91)		3.50)	1	2.68)	2		4.76)			
	0.75			0.94				0.25		0.40		0.08		0.08		0.73			0.19		0.49	
Biologics	-89.0)	_		(0.92-	~			(0.04-	0.15	-90.0)	0.33	-900.0)	0.15	(0.01-	0.08	-69.0)	0.58		(0.02-	0.15	(0.05-	0.54
	0.83)			0.96)				1.50)		2.53)		1.37)		1.34)		0.76)			1.87)		4.93)	
				0.94				0.86				0.92				0.73			0.63			
Acitretin	,	,		(0.92-	~			(0.83-	_			-68.0)	—			-69.0)	—		(0.59-	_		
				0.96)				0.88)				0.95)				0.77)			0.67)			

OR 15.68 95% CI 1.93-127.31). Use of steroid and MMF/MPA were also related to perception of anxious which did not affect daily activities (p=0.04; OR 0.44 95% CI 0.20-0.96 and p=0.01; OR 6.69 95% CI 1.55-28.80, respectively).

Respondents who went to private clinic were related to lower risk of having perception that autoimmune conditions would make them more prone to COVID-19 infection (p=0.005; OR 0.45 95% CI 0.26-0.78). On the other hand, hydroxychloroquine/chloroquine sulfate and sulfasalazine administration were related to perception (p=0.04; OR 1.85 95% CI 1.02-3.36 and p=0.04; OR 8.94 95% CI 1.07-74.87 respectively). Respondents who could work from home during COVID-19 pandemic were associated with higher risk of having perception that when contracting COVID-19 infection, the symptoms would be more severe due to the autoimmune conditions (p=0.04; OR 2.61 95% CI 1.06-6.45).

Respondents who lived in Sumatra region, got hydroxychloroquine/chloroquine sulfate, or got MMF/MPA showed higher risk of having perception that autoimmune medications could reduce their risk of getting COVID-19 infection (p=0.02; OR 4.40 95% CI 1.29-14.94, p=0.001; OR 7.22 95% CI 2.23-23.38; and p=0.002; OR 5.66 95% CI 1.86-17.23, respectively). Respondents with adequate COVID 19 information or university education or who visit private clinic had lower risk of having perception that COVID-19 pandemic would cause difficulties in getting medications (p<0.001, OR 0.22 95% CI 0.10-0.44; p=0.03, OR 0.60 95% CI 0.38-0.95; p=0.01 OR 0.52 (0.31-0.88) respectively). Respondents who got hydroxychloroquine/chloroquine sulfate showed higher risk of having that perception (p=0.001; OR 1.99 95% CI 1.32-3.01).

We also asked what respondents did as prevention to avoid contracting the infection as presented in **Table 4**. Washing hands, physical distancing, and wearing mask were the most common prevention practices. Interestingly, a small number of respondents said that they practiced spraying disinfectant to bodies, taking antibiotic, and using mouthwash to prevent COVID-19 infection. None of them used podcast

nor came from lower educational background (elementary school up to junior high school).

From bivariate analysis, there was no significant relation between educational background and adequacy of information with wrong practices related to COVID-19 (p=1 and p=0.21 for spraying disinfectant to bodies; p=1 and p=1 for taking antibiotics; and p=1 and p=0.76 for using mouthwash).

Table 4. Practices to avoid getting COVID-19 infection.

	Practices	Number (%)
Rig	ht practices	
-	Washing hands	661 (96.5)
-	Physical distancing	625 (91.2)
-	Using face mask	615 (89.8)
-	Staying at home	590 (86.1)
-	Not touching face	565 (82.5)
-	Consuming fruits or vegetables	490 (71.5)
-	Getting adequate sleep	488 (71.2)
-	Not using public transportation	442 (64.5)
-	Disinfecting properties	400 (58.4)
-	Taking supplements/multivitamins	351 (51.2)
-	Sunbathing	289 (42.2)
-	Exercising regularly	273 (39.9)
Wr	ong practices	
-	Using mouthwash	25 (3.6)
-	Spraying disinfectant to bodies	23 (3.4)
-	Taking antibiotics	13 (1.9)

DISCUSSION

This study involved 685 autoimmune patients across Indonesia with mostly female respondents, median age of 37 years old and Java as their place of residence. Predominant finding of female gender was in accordance to the fact that women had higher incidence and prevalence of some specific autoimmune diseases than men did.7 Most of our study participants were diagnosed with SLE (40.4%) and Sjogren's syndrome (20.4%) which were more commonly found among female. Most of our study participants (95.7%) were 19-60 years old. The onset age of autoimmune disease varied widely depending on the disease, but most commonly occurred between 15-55 years old.8 Most of our participants lived on Java island (84.9%), which caused unequal distribution of respondents. Several possibilities may explain this distribution, such as racial-genetic difference in Indonesian population and the difference of health care facilities capability across Indonesia for diagnosing autoimmune diseases. Financial barrier in some Indonesian regions may lead to underdiagnosis of autoimmune diseases. Moreover, in some regions autoimmune laboratory tests were not readily available. The unequal distribution of Indonesian doctors may further contribute to lack of access for presumably autoimmune patients, with more than 57% of Indonesian doctors concentrated in Java-Bali. 10.11

Most of our study participants were taking corticosteroid (57.2%) with low dosage (38%) to manage their autoimmune diseases. The use of low dose steroid might implicate that most of our participants were well controlled or had mild manifestation, therefore they could participate in our online survey.¹²

Individuals, organizations, and governments use social media to communicate with each other on a number of issues related to the COVID-19 pandemic.¹³ COVID-19-related information can be taken from the following sources: the Internet, friends, traditional media, formal lessons on COVID-19 (whether online or inperson), medical staff in health care settings, coworkers, and family members.14 The vast majority of the participants (86.7%) believed that they had enough information related to COVID-19 with leading main sources being television, doctor, and chatting application platforms. This finding might denote that television was the most accessible source of information for Indonesian citizens; therefore COVID-19 health campaign should be directed in television. Basch et al study¹⁵ demonstrated the potential role of entertainment television in saving lives. The implication is that in addition to holding regular press briefings covered by national news, public health officials may be able to achieve our collective goal of community mitigation by appearing on other television programs and communicating clearly about the specific behaviors that people must practice to protect themselves, their families, and their communities.

Our study also shows that social media platforms and internet have become other leading sources of information compared to more conventional media platforms, such as newspaper. This finding may be explained by the fact that over 107.2 million people were predicted as internet user in Indonesia in 2019 and the relative young median age of our study participants. ¹⁶ Therefore, Indonesian government should utilize the social media more as the alternative source for COVID-19 education platform. However, social media can also be a source of misinformation, therefore monitoring by government is needed.

Knowledge is expected to largely influence the degree of adherence to the personal protective measures and ultimately the clinical outcome.¹⁷ More than half of respondents had a good educational background, so that they were able to understand information better about COVID-19. Most of our survey participants answered correctly regarding the COVID-19 transmission mode and the right measures to avoid acquiring COVID-19 infection. This might be one reason why we did not see the difference in knowledge according to educational background or adequacy of information. Several studies conducted in other Asian countries also showed high level of COVID-19 information in general population.¹⁸ No respondents who used podcast gave wrong answers on COVID-19 transmission and preventive measures. This might be related to low proportion of respondents using this media.

Perception of disease has relevant role in individual's psychological adjustment. ¹⁹ WHO has also warned that the risks posed by COVID-19 may generate greater distress, anxiety, anger, and stress. ²⁰ Huang et al study²¹ found that 1/3 participants showed anxiety disorders. The possible reason for these mental problems might be related to the "hypochondriac concerns" (worry about being infected) and fear that the epidemic was hard to control.

Assessment regarding anxiety among our study participants showed that most of participants felt worried about their health during COVID-19 pandemic but it did not affect their daily routine life. The source of anxiety among

our study participants was the perceived higher susceptibility in contracting COVID-19, followed by the possibility of more severe COVID-19 course if they got infected and difficulties in their autoimmune drug access during pandemic. Adequate COVID-19 information was related to lower risk of feeling worried which affected daily activities and perception of difficulties in getting medications. Therefore, physicians and other health care providers should advise, give proper information, and comfort their patients, in order to manage their concern and anxiety during pandemic, as higher anxiety may give negative impact in their quality of life. ^{22,23}

Treatment with hydroxycholoroquine/ chloroquine sulphate was related to higher risk of perception that pandemic would cause difficulties in getting medications, and university education or visiting private clinic were related to lower risk of having that perception. Since the spread of news that hydroxychloroquine can be used to treat COVID-19, there was an increase in hydroxychloroquine demand which lead to its shortage. This condition could make the access of hydroxychloroquine more difficult for autoimmune patients. Before COVID-19 pandemic, the access of hydroxychloroquine had already been difficult due to its availability and price.24 Most of our respondents used national insurance program. It is important for the government to ensure the availability of medications that are essential for patients with chronic diseases.

Interestingly, treatment with hydroxychloroquine that was also being studied for COVID-19 treatment was related to higher perception of autoimmune medications being able to reduce risk of getting COVID-19 infection. This should be clearly clarified to our patients, so that it will not give sense of false security that loosens proven preventive measures. There is no benefit of hydroxychloroquine treatment for hospitalized patients with COVID-19 in term of 28 days mortality and hospital stay duration. ²⁵ Patients with lupus with or without hydroxychloroquine as baseline therapy have similar risk regarding probability or severity of COVID-19 infection. ²⁶

Our studies possessed some limitations

related to the method of this study. There is also a possibility of bias as some autoimmune patients may not have access to internet to participate in our online survey. The possibility of only autoimmune patients with milder condition that could participate in our online survey should also be considered. Self-reported online survey was affected by patient's honesty and recall memory.

CONCLUSION

Almost all respondents had good knowledge regarding transmission of COVID-19 and did proper practices to prevent COVID-19. Respondents preferred television, medical staff, Whatsapp/Line/Telegram, and Instagram as sources of information. Most of the respondents felt anxious but that did not affect their daily life. Adequacy of information, autoimmune treatment, work from home, educational background, area of living, and health care facilities contributed to perception regarding COVID-19 pandemic.

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