



# Impact of COVID-19 outbreak on rheumatic patients' perceptions and behaviors: A cross-sectional study

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## Abstract

**Aim:** The dynamics of coronavirus disease 2019 (COVID-19) pandemic has become of special concern to the rheumatology community. Rheumatic patients are required to engage in effective health management but their behavior is often influenced by intrinsic and extrinsic factors. This cross-sectional study aims to examine patients' experiences during the current pandemic and its implication on their health perception and behavior.

**Method:** A patient-centered electronic survey was used, randomly sampling rheumatic patients in Saudi Arabia during March and April 2020. Questions included patients' socio-demographics, diseases, medications, COVID-19 knowledge, source of information, fear level, disease activity perception, health care utilization, medication accessibility, and therapeutic compliance (measured using a modified version of Medication Adherence Reporting Scale). Correlation and regression coefficients were used to evaluate associations among the aforementioned variables.

**Results:** A total of 637 respondents were included. The majority were rheumatoid arthritis patients (42.7%). Patients' knowledge about COVID-19 was correlated with social media use ( $P = .012$ ). Fear of COVID-19 infection correlated with healthcare facility for follow-up visits ( $P = .024$ ) and fear of disease deterioration if contracting the infection correlated with patients' levels of knowledge ( $P = .035$ ). Both types of fear did not correlate with patients' perceptions of disease activity. However, patients' perceptions of worsened disease activity were correlated with unplanned healthcare visits ( $P < .001$ ), medication non-adherence, and difficulty accessing medication ( $P = .010$  and  $.006$ , respectively).

**Conclusion:** The COVID-19 pandemic and surrounding public health measures could affect rheumatic patients' health management which might contribute to disease flare-up and subsequently taxing healthcare systems even further.

## KEYWORDS

COVID-19 outbreak, disease activity perception, health care utilization, medication adherence, self-management



## 1 | INTRODUCTION

The pervasiveness of coronavirus disease 2019 (COVID-19) pandemic has caused mayhem to public health worldwide. As chronic diseases continue to challenge advanced healthcare systems,<sup>1</sup> COVID-19 comes to exacerbate public health problems as if that were not enough.

Current data indicate that the majority of severe cases of coronavirus infection are among elderly adults and those with pre-existing chronic illnesses.<sup>2,3</sup> As more data emerge on the clinical characteristics of infected patients, case reports are claiming resemblance with rheumatic diseases,<sup>4-6</sup> although, it is still unclear whether these cases are viral in nature or linked to host susceptibility.<sup>7</sup>

Nevertheless, the dynamics of COVID-19 outbreak became of special concern to the rheumatology community,<sup>8</sup> as it could potentially put many of its patients at a greater susceptibility of infectious morbidity and mortality associated with immune dysfunction, underlying comorbidities and immunosuppressive therapy.<sup>9,10</sup> However, evidence of epidemiological implication of this outbreak on these vulnerable populations is limited.<sup>11</sup>

In face of this public health emergency, many countries have enforced local measures to flatten infection curves and curb death rates, all in hopes of delaying the spread of the virus until a vaccine is developed.<sup>12</sup> Although these measures aim to alleviate the burden on health service demand, rheumatologists are left to face an extraordinary challenge in monitoring the health of their patients remotely within their own context amid health resources scarcity.<sup>13,14</sup>

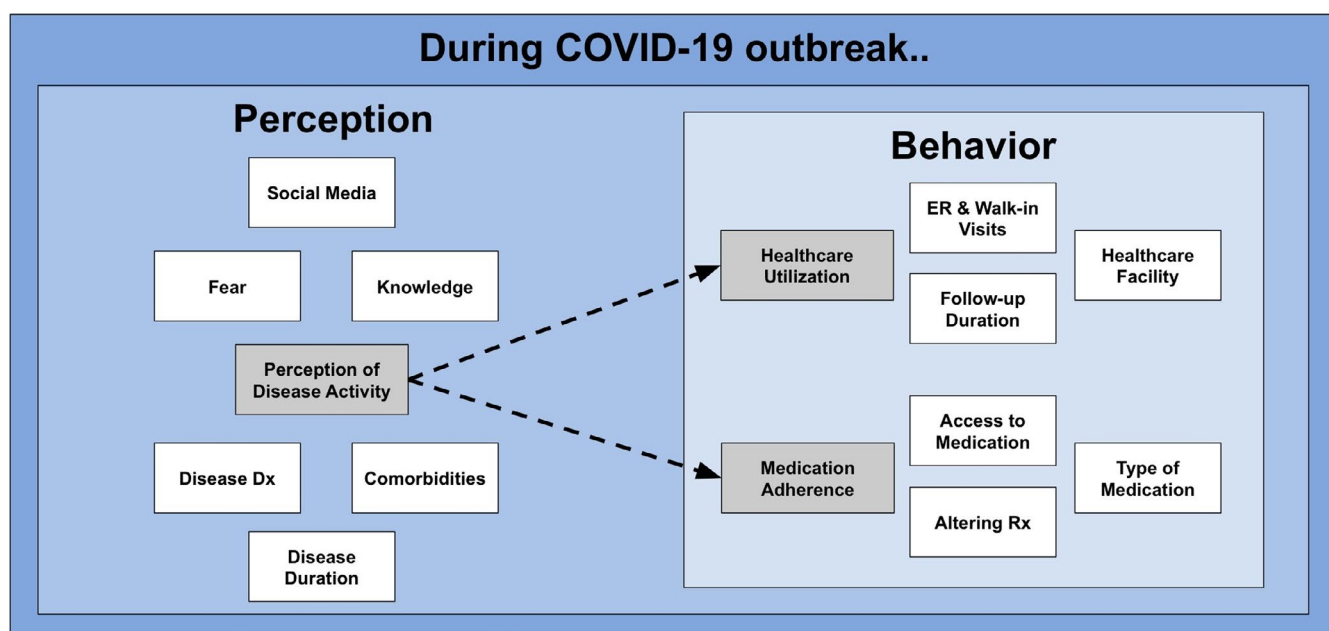
Rheumatic disease is a burdensome chronic illness that requires patient-centric management strategies.<sup>15</sup> A patient's ability to engage in effective coping health behavior is dependent on intrinsic

(ie, patient-related) and extrinsic (ie, healthcare-related) factors<sup>16</sup> (Figure 1). Because of the COVID-19 outbreak, the extent of the problem has increased, placing a huge burden on rheumatic patients to retrieve and understand health-related information considering the numeracy, literacy, and ambiguity around the topic of COVID-19,<sup>17</sup> then utilize it to evaluate the risk faced against the backdrop of their own disease experience, and make healthy decisions to maintain their disorder outcomes.<sup>18</sup>

Many researchers have shown associations between misperception and aversive outcomes<sup>19,20</sup> and reports from inflammatory bowel disease (IBD) studies are one case in point. Higher rates of voluntary infertility reported among many childbearing women diagnosed with IBD were associated with misconception of the risk of pregnancy, medication teratogenicity and other adverse reproductive outcomes with IBD.<sup>21,22</sup>

Given the importance of perception in managing individual health behaviors, it is crucial to address how it may indirectly influence public health measures during a pandemic.<sup>23,24</sup> A great illustration of this relationship was provided by Renner and Reuter's study conducted during the 2009 influenza A virus H1N1 outbreak. Their study examined the effect of general and personal perceptions on the success of government response in the context of swine flu vaccinations. Results showed that vaccine uptake was not directly impacted by infection preventative intention; rather it was facilitated by reducing the fear associated with personal perception toward vaccine side-effects.<sup>25</sup>

Thus, we aim in this study to investigate the implication of COVID-19 outbreak on rheumatic patients in Saudi Arabia (SA). We look to further understand the factors affecting patient perception and evaluate its relation to engagement in health behaviors. To this purpose, we set a patient-centered electronic survey to cross-examine demographic characteristics, COVID-19 knowledge, level of fear,



**FIGURE 1** Proposed relationship between perception and behavior related variables



disease activity perception, healthcare utilization, and medication adherence during the pandemic. The findings of this study may improve individual and public responses to COVID-19 outbreak.

## 2 | METHODS

### 2.1 | Study design

This report is concerned with the first stage of cross-sectional time series (administered at 3 time points: at the beginning of the outbreak, at the beginning of easing public health measures, and after the outbreak crisis is over) that examine the impact of COVID-19 outbreak on rheumatology patients. This report focused on factors related to perception and behavior of rheumatic patients during the current pandemic. The study report was guided by Strengthen the Reporting of Observational Studies in Epidemiology checklist (STROBE Statement).

### 2.2 | Ethics

Research ethical approval was obtained from the Institutional Review Board (IRB) of King Saud University (KSU) in Riyadh, SA (IRB approval no. E-20-4787). This study was carried out in accordance with the principles of the Declaration of Helsinki (World Medical Association).

### 2.3 | Setting

Participants were recruited from the database of the Charitable Association for Rheumatic Diseases, Saudi Inflammatory Disease Patients Support Group, and the Specialized Rheumatology Clinic at King Khalid University Hospital in KSU registries during March and April 2020. Phone numbers of all registered patients (total of 3000 patients) were accessed by database governors to send text message invitation with a link to complete our study survey. Patient identifiers remained concealed for the duration of the study. Informed consents were obtained electronically prior to enrolment according to IRB of KSU guidelines. Response rate for our survey was tabulated using Research Response Rate Calculator version 4.0 (American Association for Public Opinion).

### 2.4 | Participants

All individuals aged  $\geq 18$  years, diagnosed with any rheumatic disease, free of COVID-19 infection, and residing in SA at the time of the survey were considered eligible for inclusion. Rheumatic patients with overlapping health conditions, including those with comorbidities and treated psychiatric disorders, were also included in the study. All rheumatologic therapies prescribed for each patient during the study were allowed. Sample weighting was not done given the lack of accurate estimates of rheumatic disease

prevalence in SA. However, to ensure that the rheumatic diseases population was properly sampled, baseline characteristics were compared to results of COVID-19 Global Rheumatology Alliance.<sup>26</sup>

### 2.5 | Variables

#### 2.5.1 | Exposure

Primary exposure was COVID-19 knowledge and fear. Confounding variables accounted for included patient-related factors such as primary rheumatic disease, status and duration of disease, current medications, and concomitant diseases (including comorbidities and treated psychiatric disorders) and healthcare-related factors such type of healthcare facility, follow-up duration and residency region). Other factors were also considered such as source of COVID-19 information, accessibility to medication, and alteration of prescribed medication dosage.

#### 2.5.2 | Outcomes

Primary outcome was perception of disease activity and factors associated with it. Secondary outcomes were utilization of health services and adherence to rheumatologic medications during the pandemic.

### 2.6 | Instruments

The electronic survey, constructed using Google Forms, consisted of a series of questionnaires (in Arabic and English) that focused on socio-demographic information, health condition characteristics, currently prescribed medications, COVID-19 knowledge, fear (ie, fear of the coronavirus infection and fear of disease deterioration if infected), disease activity perception and health behaviors during the current pandemic. Healthcare utilization was assessed using questions related to clinic and emergency visits, in which unplanned or emergency visits were considered indicators of increase healthcare utilization. Also, medication adherence and psychosocial effects of COVID-19 were assessed using modified versions of Medication Adherence Rating Scale (MARS) and Patient-Reported Outcome Measurement Information System (PROMIS), respectively. For the purpose of this study, data from MARS were only reported in the results section of this manuscript. As for the findings of PROMIS, they will be addressed separately in our next paper. All captured data were collected onto Google Sheets and securely maintained in Google Drive until further analysis. See Appendix S1 for questionnaires and reliability analyses.

### 2.7 | Statistical analysis

Descriptive statistics of confounding variables were expressed as median (interquartile range [IQR]) or mean (standard deviation [SD])



for numerical data, while nominal data were expressed as prevalence (frequency and percentage). Student's *t* test (for continuous variables) and Pearson's Chi-square test (for categorical variables) were used to show presence of correlation between variables. Univariate and multivariate logistic regression models were used to examine the association between exposure and outcome variables after adjustment of potential confounders. Correlation coefficients were then evaluated to measure strength of association between variables. Distribution analyses used a 5% two-sided significance level and regression equations were expressed with 95% confidence intervals for the estimates of slope and intercepts. The *P* values of less than or equal to .05 were considered statistically significant. All analyses were performed using R Software version 4.0 (R Core Team) and SPSS® Statistics version 25.0 (IBM SPSS Inc).

### 3 | RESULTS

We had a total of 637 respondents with a response rate of (21.2%). Table 1 shows the demographic characteristics of these participants. The median (IQR) age was 35 (29-41) years. The majority of the participants were female (87.3%), many of whom were Saudi (84.8%) living in central provinces including Riyadh, Qassim, and Ha'il (48.8%) and the western region (24.4%). About half of them were married (50.7%) and a little over 60.0% attained some form of a college education.

As for their health conditions, 91.5% of the participants had not smoked previously and almost all (98.9%) never consumed alcohol. Rheumatoid arthritis (RA) (42.7%) and systemic lupus erythematosus (SLE) (31.9%) were more prevalent diagnoses than other inflammatory diseases (including Behçet's, Sjögren's, and spondyloarthritis) which amounted to 25% among all participants. The median (IQR) for primary rheumatic disease duration was 6 (3-11) years. Further, 34.7% of patients had reported having comorbidities. Common conditions included hypertension (7.4%), hypothyroidism (3.8), diabetes (3.6%), renal involvement (3.3%), immunodeficiency (2.5%), cardiovascular disease (2.5%), lung disease (1.9%).

Regarding the COVID-19 knowledge questionnaire, the vast majority of our study population (92.0%) had an acceptable level of COVID-19 knowledge, although 62.2% of them obtained their information from social media platforms, while the remaining 35.0% of them got their information from official sources such as World Health Organization, Ministry of Health, and their healthcare providers. Patients' knowledge significantly correlated with the use of social media ( $P = .012$ ).

Results from fear-related questions showed that only 33.4% of patients were fearful of contracting COVID-19 infection compared to 51.8% who feared their disease would deteriorate if they contracted the infection. Both types of fear correlated significantly with social media use as a source of COVID-19 information ( $P = .032$  and  $.007$ , respectively). Furthermore, results revealed that patients' knowledge was significantly associated with fear of disease deterioration ( $P = .035$ ) rather than the infection itself ( $P$

**TABLE 1** Participant characteristics (demographic information and health condition)

Participant characteristics	Descriptive statistics (N = 637)
Age, y	
Mean (SD)	35.7 ( $\pm$ 9.6)
Median (IQR)	35 (29-41)
Gender	
Female, n (%)	556 (87.3%)
Male, n (%)	81 (12.7%)
Nationality	
Saudi, n (%)	540 (84.8%)
Non-Saudi, n (%)	96 (15.1%)
Residency region	
Central region, n (%)	311 (48.8%)
Western region, n (%)	154 (24.2%)
Eastern region, n (%)	70 (11.0%)
Southern region, n (%)	67 (10.5%)
Northern region, n (%)	24 (3.8%)
Outside SA, n (%)	5 (0.8%)
Educational level	
College, n (%)	416 (65.3%)
Secondary, n (%)	187 (29.4%)
Elementary, n (%)	27 (4.2%)
No education, n (%)	7 (1.1%)
Health condition	
Smoking	
Current smoker, n (%)	37 (5.8%)
Previous smoker, n (%)	17 (2.7%)
Drinking	
Previous drinker, n (%)	6 (0.9%)
Current drinker, n (%)	1 (0.2%)
Rheumatic disease diagnosis	
Primary	
Rheumatoid arthritis, n (%)	272 (42.7%)
Systemic lupus erythematosus, n (%)	203 (31.9%)
Other inflammatory diseases, <sup>a</sup> n (%)	62 (9.7%)
Behçet's syndrome, n (%)	17 (2.7%)
Sjögren's syndrome, n (%)	11 (1.7%)
Spondyloarthritis, n (%)	10 (1.6%)
Secondary	
Overlap syndrome, <sup>b</sup> n (%)	37 (5.8%)
Disease duration, y	
Mean (SD)	7.9 ( $\pm$ 6.9)
Median (IQR)	6 (3-11)
Disease status at the time of last visit	
Not active, n (%)	275 (43.2%)

(Continues)



TABLE 1 (Continued)

Participant characteristics	Descriptive statistics (N = 637)
Active, n (%)	192 (30.1%)
Unknown, n (%)	170 (26.7%)
Concomitant diseases	
Comorbidities, <sup>c</sup> n (%)	221 (34.7%)
Psychological disorders, <sup>c</sup> n (%)	65 (1.0%)
Healthcare facility for rheumatologist visits	
University hospital, n (%)	150 (23.5%)
Ministry of Health hospital, n (%)	142 (22.3%)
Private hospital, n (%)	79 (12.4%)
Specialist hospital and research center, n (%)	49 (7.7%)
Armed forces hospital, n (%)	46 (7.2%)
National guards hospital, n (%)	38 (6.0%)
Security forces hospital, n (%)	12 (1.9%)
Follow-up duration, d	
Mean (SD)	128.8 ( $\pm$ 213.0)
Median (IQR)	82 (49-128)
Currently prescribed medications	
Monotherapy	
Conventional immunosuppressant DMARD, n (%)	96 (15.1%)
Conventional non-immunosuppressant DMARD, n (%)	86 (13.5%)
Targeted biologic DMARD, n (%)	56 (8.8%)
NSAID, n (%)	9 (1.4%)
Steroid, n (%)	8 (1.3%)
Targeted synthetic DMARD, n (%)	3 (0.5%)
Combitherapy	
Combination, <sup>d</sup> n (%)	333 (52.3%)

Abbreviations: DMARD, disease-modifying antirheumatic drug; IQR, interquartile range; n, number of patients; NSAID, nonsteroidal anti-inflammatory drugs; SA, Saudi Arabia; SD, standard deviation.

<sup>a</sup>Diseases included anti-phospholipid antibody syndrome, autoinflammatory syndrome, connective tissue disease, dermatomyositis, fibromyalgia, gout, inflammatory myopathy, polymyalgia rheumatica, psoriasis, Raynaud's disease, rheumatic heart disease, sarcoidosis, scleroderma, Takayasu disease, Wegener's granulomatosis and other inflammations related to cartilage, eye, lung, and skin.

<sup>b</sup>Patients could have more than 1 primary rheumatic disease diagnosis (all within  $n < 5$ ).

<sup>d</sup>Combination of 2 or more of current prescribed medications (all within  $n < 3$ ).

<sup>c</sup>Patients could have more than 1 disease (all within  $n < 4$ ).

= .302). Also, fear of infection was found to be associated with the type of healthcare facility the patient visits for a rheumatologist follow-up ( $P = .024$ ). The 3 most reported clinics belong to university hospitals (23.5%), followed by Ministry of Health hospitals (22.3%), then private hospitals (12.4%). Neither fear of COVID-19

infection nor fear of disease deterioration as a result of infection were correlated with patient perception of disease activity ( $P = .728$  and  $.573$ , respectively).

The majority of patients (93.9%) had visited their rheumatologists within 1 year. The mean (SD) for follow-up duration was 128.8 ( $\pm$  213.0) days. Disease status at the last follow-up visit was reported as inactive in 43.2%, active in 30.1%, and unknown in 26.7% of patients. However, results from patients' perceptions of disease activity during COVID-19 outbreak revealed that as many as 40.8% had perceived no change, followed by 23.7% who claimed that it had improved, 17.1% had worsened, and 14.6% did not even know the status of their disease activity. Patients' perceptions of disease activity correlated significantly with disease status at last rheumatologists visit ( $P < .001$ ).

Regression analysis of disease activity perception was found to be associated with health behaviors after adjustment of confounding variables (Table 2). Of main interest, disease activity was significantly correlated ( $P < .001$ ) with healthcare utilization, such that worsening disease activity perception is associated with unplanned healthcare visits (Table 2). Among the 637 included patients, 10.7% of patients sought unscheduled doctor visits (walk-ins) including emergency care during COVID-19 outbreak, 31.9% of them reported that they were not able to go to the hospital because of local restrictions, and the remaining patients (57.4%) stated that they did not need healthcare.

Additionally, the association between disease activity perception and medication adherence was significantly correlated ( $P = .010$ ), such that worsening disease activity perception was associated with poor medication adherence after adjustment of other confounding factors (Table 2). All rheumatologic medications were considered and categorized under respective drug classes (See Appendix S1: Data S10). In our study population of 637 patients, there were a total of 591 (92.8%) who reported taking rheumatologic medication(s) prescribed for their rheumatic disease. Out of those 591 patients, 507 (85.8%) were adherent and 84 (14.2%) were not adherent to their medication(s). Among the patients treated with monotherapy (258 [43.7%]), 218 (84.5%) were adherent and 40 (15.5%) were not adherent to their medication. Among the patients treated with combined therapy (333 [56.3%]), 289 (86.8%) were adherent and 44 (13.3%) were not adherent to their medications. There was no significant difference in adherence among patients treated with monotherapy or combination therapy ( $P = .429$ ).

It is worth noting that nearly half of all patients (47.9%) experienced difficulty in obtaining their medication during COVID-19 outbreak. Difficulty to access medication was significantly associated ( $P = .006$ ) with worsening disease activity perception (Table 2). Also, medication accessibility was mainly associated with conventional immunosuppressive disease-modifying antirheumatic drugs (DMARDs) ( $P = .043$ ), non-suppressive DMARDs ( $P = .014$ ) and steroidal drugs ( $P = .023$ ). In addition, 29.5% of them altered their prescribed medication(s) either by decreasing, increasing, or interrupting the dosage. Thus medication non-adherence correlated



significantly with medication self-alteration ( $P < .001$ ). See Appendix S1: Figure S1 for a summary of study associations.

## 4 | DISCUSSION

The focus of the present study on rheumatic disease management is congruent with the problem faced by rheumatology communities these days. The findings of our study offer new and eclectic insight into perception and engagement in health behavior among rheumatic patients during the COVID-19 outbreak. Despite little literature evidence on the topic, the high response rate (21.2%) not only strengthened our data but also indicated the importance of these concerns to our population. For practicing rheumatologists during the pandemic, understanding the current state of disease activity in patients is crucial especially with all the restrictions applied locally.

The majority of patients in our study population were considered knowledgeable of COVID-19 very early on in the outbreak. Mass and internet media use has, undoubtedly, played a role in putting a wealth

of information about the hazardous nature of this phenomenon at everyone's fingertips.<sup>27</sup> With the rapid dissemination of information, particularly on social media platforms, came a wave of egregious "infomedics" that made it hard to navigate reliable sources.<sup>28</sup>

Analyzing individual knowledge scores was not only reflective of a patient's level of COVID-related health literacy, but also predictive to some extent regarding one's personal experience during the pandemic. As suggested by Reyna and colleagues (2009), the higher score rate could be that a patient more likely had deciphered credible information and adopted it into their health beliefs, while a lower score might be suggestive of a patient's susceptibility to biases and potentially contributing to fear and anxiety.<sup>18</sup> In fact, patients' generally reported high levels of knowledge did not correlate with fear of contracting COVID-19 infection itself; rather the fear was of disease deterioration as a result of an infection. This finding was not entirely unexpected, as it is well documented that patients tend to be poor judges of their personal health risk in the face of the general threat,<sup>25</sup> and those with lower health literacy make even poorer judgments than those with higher in literacy.<sup>29,30</sup>

**TABLE 2** Univariate and multivariate logistic regression output of worsening disease activity perception (dependent variable) and various outcomes (independent variable)

Outcomes	Univariate analysis			Multivariate analysis (N = 580)		
	OR (95% CI)	B (SE)	P value	OR (95% CI)	B (SE)	P value
Health care utilization <sup>a</sup> (n = 607)	2.119 (1.391-3.229)	0.751 (0.215)	<0.001*	1.880 (1.202-2.940)	0.631 (0.228)	0.006*
Medication adherence <sup>b</sup> (n = 606)	0.509 (0.304-0.853)	-0.676 (0.264)	0.010*	0.561 (0.322-0.975)	-0.579 (0.282)	0.040*
Access to medication <sup>c</sup> (n = 609)	1.806 (1.185-2.751)	0.591 (0.215)	0.006*	1.716 (1.091-2.697)	0.540 (0.231)	0.019*
Fear Q1 <sup>d</sup> (n = 607)	0.913 (0.548-1.521)	-0.091 (0.261)	0.727	0.845 (0.431-1.656)	-0.169 (0.343)	0.623
Fear Q2 <sup>e</sup> (n = 607)	0.860 (0.511-1.447)	-0.151 (0.266)	0.569	0.961 (0.476-1.937)	-0.040 (0.358)	0.911
Follow-up duration <sup>f</sup> (n = 598)	1.000 (0.999-1.001)	0.000 (0.000)	0.885	1.000 (0.999-1.001)	0.000 (0.001)	0.857
Residency region <sup>g</sup> (n = 580)	-----	-----	-----	-----	-----	-----
Central	-----	-----	-----	0.655 (0.402-1.067)	-0.423 (0.249)	0.089
Western	-----	-----	-----	0.716 (1.265-0.290)	-0.334 (0.290)	0.250
Eastern	-----	-----	-----	0.625 (0.302-1.294)	-0.470 (0.371)	0.206
Southern	-----	-----	-----	1.656 (0.901-3.044)	0.504 (0.311)	0.104
Northern	-----	-----	-----	0.810 (0.315-2.084)	-0.211 (0.482)	0.662
Outside SA	-----	-----	-----	0.754 (0.106-5.363)	-0.282 (1.001)	0.778

Abbreviations: B, coefficient; CI, confidence interval; OR, odds ratio; P, probability; SA, Saudi Arabia; SE, standard error.

<sup>a</sup>Patient use of emergency care and unscheduled doctor visits.

<sup>b</sup>Patient non-adherence to prescribed medications.

<sup>c</sup>Patient experience of difficulty in obtaining medication(s).

<sup>d</sup>Patients fearful of COVID-19 infection.

<sup>e</sup>Patients fearful of disease deterioration if contracted COVID-19 infection.

<sup>f</sup>Follow-up duration since last rheumatologist visit (in d).

<sup>g</sup>Patient region of residency (listed in table).

\*Significant correlation ( $P < .050$ ).



Disease activity perception might serve as a surrogate marker of activity when physical assessment is not feasible, especially when combined with function and pain from Routine Assessment of Patients Index 3 (RAPID3).<sup>31</sup> However, patient-reported outcomes might be influenced by factors other than their disease activity such as pre-existing fibromyalgia and mood.<sup>32</sup> To examine these issues, we investigated whether diagnosis of fibromyalgia (either as a primary, secondary rheumatic disease or comorbidity) or feeling fearful of COVID-19 might have influenced patients' perceptions of disease activity. Because of the low prevalence of reported fibromyalgia among patients (1.4%) and the no correlational evidence between fear and patients' perceptions of disease activity, we were unable to discern this interaction even after adjusting for confounding variables.

Nevertheless, understanding the underlying drivers of perception is important not only to understand how people perceive and confront risk but also to predict acceptance of preventative strategies of public health measures.<sup>33</sup> In fact, several studies have already confirmed cases of fear about the threat of COVID-19 infection and infected individuals that impeded efforts to provide necessary ministrations,<sup>34,35</sup> and in one reported case, it led to suicide.<sup>36</sup> Thus, timely identification of risk-related fear is crucial to understand factors influencing patient perception and ultimately behaviors during the pandemic.

Rheumatic patients typically have higher use of healthcare services (ie, visits and hospitalization) than patients with other chronic conditions.<sup>37,38</sup> However, because of local measures over the outbreak, many patients' scheduled appointments have transformed into telemedicine in various hospitals across SA.<sup>39</sup> Therefore, 40.5% of patients in our study were found to not need healthcare service perhaps because they had visited their rheumatologists prior to COVID-19 outbreak or clinical services were already delivered to them over telemedicine.

A good portion of patients managed to utilize emergency care and walk-ins to obtain needed health services despite the restrictions, and patients with aggregate health conditions (2 or more comorbidities) were found to be more likely to seek healthcare services compared to others. Likewise, correlational evidence of this interaction coincided with needs-related factors in elderly patients with RA.<sup>40</sup> On the other hand, patients who claimed they could not go to the hospital were found to be presumably fearful of contracting the coronavirus from the healthcare facility they usually visit, especially the university and Ministry of Health hospitals. This concern of theirs is legitimate because many of these hospitals are at the forefront of the fight against COVID-19.<sup>41</sup>

Furthermore, we found that rheumatic patients' motives to seek healthcare services were positively correlated to their perception of disease activity. Patients who perceived their disease activity had worsened were more likely to use healthcare services. Meanwhile, patients who perceived their disease activity had improved were more likely to delay their visits. Many researchers have suggested that patient's behavior in healthcare-seeking is driven by perception of illness experience (eg, symptoms,

diagnosis, and severity),<sup>42,43</sup> which might be triggered by physiological or psychological etiologies.<sup>44</sup> However, the fact of the matter is that increased demand for healthcare services during the current pandemic could subsequently threaten to overwhelm the healthcare system.

Our findings also demonstrated a significant negative correlation between a patient's perception of disease activity and medication adherence. As such patients who perceived that their disease activity had worsened since the COVID-19 outbreak were more likely to be not adherent to their medications compared to those with a positive perception. Studies suggested that patients who have poor health perception might adhere less because of disbelief and maladaptive behavior.<sup>45,46</sup> Medication non-adherence could lead to increased morbidity, mortality, and healthcare costs.<sup>47,48</sup> However, patients who have misperceptions might be more likely to adhere to their medication if they experienced disease acceptance, therapeutic benefits, or fear of adverse outcomes.<sup>48-50</sup>

Another intriguing finding pertaining to misperception of disease activity was found to be related to medication accessibility. A good number of patients reported experiencing difficulty accessing certain medications needed to manage their disease, notably methotrexate, hydroxychloroquine, and prednisone. As a result, some patients were likely to alter medication dosage particularly steroids without a doctor's consultation. After further examination, we found that 15.8% of these patients thought changing their medication dosage would possibly prevent them from contracting COVID-19 infection while 44.8% of patients thought changing their medication dosage would possibly prevent their health condition from deteriorating as a result of an infection. Such findings not only raised a concern regarding medication supply and accessibility which may contribute indirectly to adverse disease outcomes because of medication non-compliance but also raised the question of whether patients employed self-efficacy to cope with unprecedented situations brought about by COVID-19 outbreak. Further investigation to examine the extent of this issue is warranted.

#### 4.1 | Limitations

Despite the relatively large population-based sample, it is not without limitations. First, our data is self-reported and no additional methods were used to confirm the participants' responses. Second, the complexity of rheumatic disease and self-management strategies employed by patients may have been generalized. Third, including patients with psychological disorders may have impacted our results and perhaps requires repeated measures to account for temporal changes over time. Fourth, socioeconomic status factors were not determined due the unavailability of an instrument to measure household income or complex family structures in SA. Finally, the scope of fear was limited in our study, thus requiring further investigation.



## 5 | CONCLUSION

This study shows that COVID-19 outbreak has the potential to impact rheumatic patients' behaviors. The perception of active disease per se has been found to be significantly associated with poor self-management. Findings of unplanned healthcare visits and interrupted medication access may have implications of long-term morbidity and mortality. Effective physician-patient communication should be established to address misperceptions and minimize disease activity assessment discrepancies. Identifying the underlying drivers of fear to understand how high-risk rheumatic groups perceive and confront the current health threat is an important direction of our future research. At any rate, there is still a lot to be learned about the extent of effect this phenomenon has on rheumatic disease. Multidisciplinary studies on this topic may serve as a basis for reforming current healthcare programs to predict and respond better in the face of pandemics.

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### CONFLICT OF INTEREST

Mohammed A. Omair sits as a member of the Charitable Association for Rheumatic Diseases. Otherwise, no potential conflicts of interest relevant to this article were reported.

### AUTHOR CONTRIBUTIONS

Lena M. Hassen and Ibrahim A. Almaghlouth equally contributed as primary authors. Mohammed A. Omair provided database access to Charitable Association for Rheumatic Diseases. Lena M. Hassen and Amal A. Almohisen performed statistical analysis. Ikhlass M. Hassen, Maha H. Daghestani, Eman M. Alqurtas, Abdulaziz Alkhalaf, Mohammed K. Bedaiwi, Mohammed A. Omair, Sultan M. Almogairen, Hussein F. Alarfaj, Abdulrahman S. Alarfaj critically appraised the manuscript.

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### REFERENCES

- Bauer UE, Briss PA, Goodman RA, Bowman BA. Prevention of chronic disease in the 21st century: elimination of the leading preventable causes of premature death and disability in the USA. *Lancet*. 2014;384(9937):45-52.
- Huang C, Wang Y, Li X, et al. Clinical features of patients infected with 2019 novel coronavirus in Wuhan, China [published correction appears in *Lancet*. 2020 Jan 30]. *Lancet*. 2020;395(10223):497-506.
- Grasselli G, Zangrillo A, Zanella A, et al. Baseline characteristics and outcomes of 1591 patients infected with SARS-CoV-2 admitted to ICUs of the Lombardy region, Italy [published online ahead of print, 2020 Apr 6]. *JAMA*. 2020;323(16):1574-1581.
- Cheng C, Li C, Zhao T, et al. COVID-19 with rheumatic diseases: a report of 5 cases. *Clin Rheumatol*. 2020;39(7):2025-2029.
- Jones VG, Mills M, Suarez D, et al. COVID-19 and kawasaki disease: novel virus and novel case. *Hosp Pediatr*. 2020;10(6):537-540.
- Zhang Y, Xiao M, Zhang S, et al. Coagulopathy and antiphospholipid antibodies in patients with Covid-19. *N Engl J Med*. 2020;382(17):e38.
- Misra DP, Agarwal V, Gasparyan AY, Zimba O. Rheumatologists' perspective on coronavirus disease 19 (COVID-19) and potential therapeutic targets. *Clin Rheumatol*. 2020;39(7):2055-2062.
- Calabrese C. COVID-19 and your rheumatology patients. *Cleve Clinic J Med*. 2020;87a(27):1-2.
- Chen Y, Li T, Ye Y, Chen Y, Pan J. Impact of Fundamental Diseases on Patients With COVID-1. *Disaster Med Public Health Prep*. 2020;14(4):1-6.
- Meroni PL, Zavaglia D, Girmenia C. Vaccinations in adults with rheumatoid arthritis in an era of new disease-modifying anti-rheumatic drugs. *Clin Exp Rheumatol*. 2018;36(2):317-328.
- Rothan HA, Byrareddy SN. The epidemiology and pathogenesis of coronavirus disease (COVID-19) outbreak. *J Autoimmun*. 2020;109:102433.
- Cowling BJ, Aiello AE. Public health measures to slow community spread of coronavirus disease 2019. *J Infect Dis*. 2020;221(11):1749-1751.
- Bodini G, Demarzo MG, Casagrande E, et al. Concerns related to COVID-19 pandemic among patients with inflammatory bowel disease and its influence on patient management. *Eur J Clin Invest*. 2020;50(5):e13233.
- Ferro F, Elefante E, Puxeddu I, et al. COVID-19: the new challenge for rheumatologists. *Clin Exp Rheumatol*. 2020;38(3):373-382.
- Grady PA, Gough LL. Self-management: a comprehensive approach to management of chronic conditions. *Am J Public Health*. 2014;104(8):e25-e31.
- Disler RT, Gallagher RD, Davidson PM. Factors influencing self-management in chronic obstructive pulmonary disease: an integrative review. *Int J Nurs Stud*. 2012;49(2):230-242.
- Paakkari L, Okan O. COVID-19: health literacy is an underestimated problem. *Lancet Public Health*. 2020;5(5):e249-e250.
- Reyna VF, Nelson WL, Han PK, Dieckmann NF. How numeracy influences risk comprehension and medical decision making. *Psychol Bull*. 2009;135(6):943-973.
- Jopson NM, Moss-Morris R. The role of illness severity and illness representations in adjusting to multiple sclerosis. *J Psychosom Res*. 2003;54(6):503-514.
- Rochelle TL, Fidler H. The importance of illness perceptions, quality of life and psychological status in patients with ulcerative colitis and Crohn's disease. *J Health Psychol*. 2013;18(7):972-983.
- Mountifield R, Bampton P, Prosser R, Muller K, Andrews JM. Fear and fertility in inflammatory bowel disease: a mismatch of perception and reality affects family planning decisions. *Inflamm Bowel Dis*. 2009;15(5):720-725.
- Selinger CP, Eaden J, Selby W, et al. Inflammatory bowel disease and pregnancy: lack of knowledge is associated with negative views. *J Crohns Colitis*. 2013;7(6):e206-e213.
- Cori L, Bianchi F, Cadum E, Anthonj C. Risk perception and COVID-19. *Int J Environ Res Public Health*. 2020;17(9):3114.
- Wise T, Zbozinek TD, Michelini G, Hagan CC. Changes in risk perception and protective behavior during the first week of the COVID-19 pandemic in the United States [Online]. *PsyArXiv Preprints*. 2020. <https://doi.org/10.31234/osf.io/dz428>





25. Renner B, Reuter T. Predicting vaccination using numerical and affective risk perceptions: the case of A/H1N1 influenza. *Vaccine*. 2012;30(49):7019-7026.
26. Gianfrancesco MA, Hyrich KL, Gossec L, et al. Rheumatic disease and COVID-19: initial data from the COVID-19 Global Rheumatology Alliance provider registries. *Lancet Rheumatol*. 2020;2(5):e250-e253.
27. Motta Zanin G, Gentile E, Parisi A, Spasiano D. A Preliminary evaluation of the public risk perception related to the COVID-19 health emergency in Italy. *Int J Environ Res Public Health*. 2020;17(9):3024.
28. Orso D, Federici N, Copetti R, Vetrugno L, Bove T. Infodemic and the spread of fake news in the COVID-19-era. *Eur J Emerg Med*. 2020;27(5):327-328.
29. Black WC, Nease RF Jr, Tosteson AN. Perceptions of breast cancer risk and screening effectiveness in women younger than 50 years of age. *J Natl Cancer Inst*. 1995;87(10):720-731.
30. Rutherford EJ, Kelly J, Lehane EA, et al. Health literacy and the perception of risk in a breast cancer family history clinic. *Surgeon*. 2018;16(2):82-88.
31. Khawaja MN, Bergman MJ, Yourish J, Pei J, Reiss W, Keystone E. Routine Assessment of Patient Index Data 3 and the American College of Rheumatology/European League Against Rheumatism Provisional Remission Definitions as Predictors of Radiographic Outcome in a Rheumatoid Arthritis Clinical Trial With Tocilizumab. *Arthritis Care Res (Hoboken)*. 2017;69(5):609-615.
32. Challa DNV, Crowson CS, Davis JM III. The Patient Global Assessment of Disease Activity in Rheumatoid Arthritis: Identification of Underlying Latent Factors. *Rheumatol Ther*. 2017;4(1):201-208.
33. Reintjes R, Das E, Klemm C, Richardus JH, Keßler V, Ahmad A. "Pandemic Public Health Paradox": Time Series Analysis of the 2009/10 Influenza A / H1N1 Epidemiology, Media Attention, Risk Perception and Public Reactions in 5 European Countries. *PLoS One*. 2016;11(3):e0151258.
34. Dong L, Bouey J. Public mental health crisis during COVID-19 Pandemic, China. *Emerg Infect Dis*. 2020;26(7):1616-1618.
35. Lin CY. Social reaction toward the 2019 novel coronavirus (COVID-19). *Social Health and Behavior*. 2020;3(1):1.
36. Goyal K, Chauhan P, Chhikara K, Gupta P, Singh MP. Fear of COVID 2019: First suicidal case in India!. *Asian J Psychiatr*. 2020;49:101989.
37. Mars NJ, Kerola AM, Kauppi MJ, Pirinen M, Elonheimo O, Sokka-Isler T. Patients with rheumatic diseases share similar patterns of health-care resource utilization. *Scand J Rheumatol*. 2019;48(4):300-307.
38. Verbrugge LM, Patrick DL. Seven chronic conditions: their impact on US adults' activity levels and use of medical services. *Am J Public Health*. 1995;85(2):173-182.
39. Hassan R. Telemedicine on the rise in Saudi Arabia amid pandemic. 2020. Saudi Arabia: Arab News. Available from <https://www.arabnews.com/node/1666576/saudi-arabia>. Accessed 21 May 2020.
40. Jacobi CE, Triemstra M, Rupp I, Dinant HJ, Van Den Bos GA. Health care utilization among rheumatoid arthritis patients referred to a rheumatology center: unequal needs, unequal care? *Arthritis Rheum*. 2001;45(4):324-330.
41. Kingdom of Saudi Arabia Ministry of Health. MOH: Over 1,400 Respiratory Isolation Rooms Prepared. Ministry of Health: MOH News. 2020. Available from: <https://www.moh.gov.sa/en/Ministry/MediaCenter/News/Pages/default.aspx>. Accessed 10 May 2020.
42. Sawyer AT, Harris SL, Koenig HG. Illness perception and high readmission health outcomes [Online]. *Health Psychol Open*. 2019;6(1):1-11.
43. Vervoort VM, Vriesekolk JE, Olde Hartman TC, et al. Cost of illness and illness perceptions in patients with fibromyalgia. *Clin Exp Rheumatol*. 2016;34(2 Suppl 96):S74-S82.
44. Leventhal H, Weinman J, Leventhal EA, Phillips LA. Health psychology: the search for pathways between behavior and health. *Annu Rev Psychol*. 2008;59:477-505.
45. Krauskopf K, Federman AD, Kale MS, et al. Chronic Obstructive Pulmonary disease illness and medication beliefs are associated with medication adherence. *COPD*. 2015;12(2):151-164.
46. Ruksakulpiwat S, Liu Z, Yue S, Fan Y. The Association Among Medication Beliefs, Perception of Illness and Medication Adherence in Ischemic Stroke Patients: A Cross-Sectional Study in China. *Patient Prefer Adherence*. 2020;14:235-247.
47. Chisholm-Burns MA, Spivey CA. The 'cost' of medication nonadherence: consequences we cannot afford to accept. *J Am Pharm Assoc*. 2012;52(6):823-826.
48. Gao X, Nau DP, Rosenbluth SA, Scott V, Woodward C. The relationship of disease severity, health beliefs and medication adherence among HIV patients. *AIDS Care*. 2000;12(4):387-398.
49. Chen LC, Chen TC, Huang YB, Chang CS. Disease acceptance and adherence to imatinib in Taiwanese chronic myeloid leukaemia outpatients. *Int J Clin Pharm*. 2014;36(1):120-127.
50. Levesque A, Li HZ, Pahal JS. Factors related to patients' adherence to medication and lifestyle change recommendations: Data from Canada. *Int J Psychol Stud*. 2012;4(2):42.

## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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