



# Impact of the COVID-19 pandemic on patients with chronic rheumatic diseases: A study in 15 Arab countries

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## Abstract

**Aim:** To evaluate the impact of the coronavirus disease 2019 pandemic (COVID-19) on the access to rheumatology care for patients with chronic rheumatic diseases (CRD) in the Arab countries.

**Method:** A web-based cross-sectional survey was designed by the Arab Adult Arthritis Awareness group (AAAA) consisting of 16 rheumatologists representing countries from the Arab League of Associations for Rheumatology (ArLAR) and was validated by the ArLAR scientific committee. The survey was disseminated online through social media and patients' association channels between May 8 and May 22, 2020. The steering committee developed recommendations to improve the care of patients with CRD during the COVID-19 pandemic.

**Results:** A total of 2163 patients were included in the analysis; 72% were female; mean age was 40 years (SD 11.9). The Levant, the Gulf, and North Africa contributed almost equally to the sample. The pandemic had a significant negative impact on rheumatology visits in 82% of cases, access to hydroxychloroquine (47%), and chronic medication persistency (28%). The negative impact on rheumatology visits was associated with female gender, country, medication non-persistency, isolation due to COVID-19, and impact on mental health. Sixty-one patients (2.8%) stated that they had COVID-19, 5% said that a close contact was infected, and 47% were in isolation because of COVID-19.

**Conclusion:** The current study highlights the deleterious consequences of the COVID-19 pandemic on the continuity of rheumatology care. Therefore, an action plan, including establishing a telemedicine platform, securing drug availability, and promoting medication persistence through the appropriate communication channels, is strongly recommended.

## KEYWORDS

access to care, adherence, COVID-19, persistency



## 1 | INTRODUCTION

The coronavirus disease 2019 (COVID-19) emerged in December 2019 in Wuhan, China, and quickly became a global outbreak and a significant public health issue.<sup>1,2</sup> On January 30, 2020, the World Health Organization (WHO) declared COVID-19 a public health emergency of international concern,<sup>3</sup> and, on March 20, 2020, due to the devastating number of new cases reported globally, WHO declared it as a pandemic.<sup>4</sup> At the time of drafting this manuscript (June 5, 2020), the WHO reported more than 6.5 million COVID-19 cases and 387 155 deaths.<sup>5</sup>

COVID-19 is caused by a novel coronavirus, the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) that can cause illness ranging from the common cold to the SARS. To date, no antiviral treatment or vaccine has been explicitly recommended. Therefore, applying preventive measures to control the infection is the most critical intervention. In consequence, on top of its significant public health impact, the pandemic had a major influence on social interactions and global economies, as countries locked down and social distancing measures were imposed by governments worldwide.<sup>6</sup>

Patients living with chronic rheumatic diseases (CRD) require an additional consideration with regard to this pandemic. Many of these patients are immunocompromised and generally vulnerable to infection. Whether they have a higher risk of infection with SARS-CoV-2 is uncertain,<sup>7-12</sup> and although several recommendations were developed worldwide,<sup>13-17</sup> strong evidence is lacking to guide treatment decisions. Moreover, difficulty in accessing the rheumatology clinic drove some patients to self-modify their treatment,<sup>18</sup> which put them, along with the significant stress factor, at high risk of CRD flare. Furthermore, since some rheumatology drugs are thought to have potential activity against SARS-CoV-2, such as chloroquine, hydroxychloroquine (HCQ), anti-interleukin (IL)6 agents, anti-IL1 agents, and Janus kinase inhibitors, a drug shortage was witnessed in many countries, making these essential drugs inaccessible to the rheumatology patients who need them.<sup>19-21</sup>

In the Arab countries, a special interest group, the Arab Adult Arthritis Awareness group (AAAA), consisting of 16 rheumatologists representing 14 countries from the Arab League of Associations for Rheumatology (ArLAR)<sup>22</sup> was formed in 2019 with the mission to improve patient awareness about CRD. Since the beginning of the COVID-19 pandemic, the group has spread awareness and issued guidance to Arab patients with CRD, through its vast network of social media and connections with individuals and patients' associations. However, the impact of the COVID-19 pandemic on patients with CRD remains poorly understood. In this regard, the AAAA network offers a unique opportunity to investigate this impact, concerning access to rheumatology care, chronic medications as well as other significant components.

### 1.1 | Objectives

The primary objective of the study was to evaluate the impact of the COVID-19 pandemic on the access to rheumatology care for patients with CRD in Arab countries.

The secondary objectives were to assess the impact of the pandemic on mental health, on patients' infection with SARS-CoV-2, on patients' attitudes toward telemedicine, on sources of information about COVID-19, and to develop recommendations for an action plan for improving the rheumatic care of patients during the pandemic.

## 2 | METHODS

A steering committee, formed among the AAAA members, designed a 15-items web-based cross-sectional survey on Google form, in English. The survey was translated by the AAAA members to Arabic and French and validated in the 3 languages by the ArLAR scientific committee, who evaluated the readability, relevance, and acceptability. The survey design was conducted following the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) guidelines.<sup>23</sup>

The survey consisted of 15 closed-ended questions and covered 5 areas: demographic characteristics, impact of COVID-19 on rheumatology care (visits to the rheumatologist, self-interruption of chronic treatment [medication persistency], HCQ shortage, precautions used), direct impact on patients' personal lives (personal or close-contact infection with SARS-Cov2, isolation due to COVID-19, impact on mental health [self-reported] and income), attitude toward telemedicine and sources of information about COVID-19 (Data S1). The impact on the visits to the rheumatologists, the medication persistency, the access to HCQ were considered as surrogate measures of the access to rheumatology care.

A pilot test performed in the 3 languages, on 10 rheumatology patients in each language, evaluated clarity, acceptability, and timing. The survey was clearly understood, well accepted, and required 3 to 4 minutes to complete.

The survey instrument was made accessible through a shortened link. It was advertised to the Arab patients with CRD through the ArLAR social media platforms (Facebook, Twitter, Instagram) and the AAAA network, between May 8 and May 22, 2020. It was named "HANDLING" on social media (How Are the rheumatology patients Dealing with the COVID-19 pandemic).

After the analysis of the survey's results, the steering committee developed a set of recommendations for an action plan to improve the care of patients with CRD during the COVID-19 pandemic.

### 2.1 | Consent to participate and ethical considerations

The patients viewed the invitation to participate in social media. Clicking on the button "fill out the form" was considered an equivalent to consent to participate in the survey. Confidentiality of personal information was maintained throughout the study by making participants' information anonymous. The study was approved by



the Saint-Joseph University Ethics Committee (number CEHDF 1653).

## 2.2 | Statistical analysis

For the analysis, the countries of residence were grouped into 3 regions: Levant (Iraq, Jordan, Lebanon, Palestine, Syria), Gulf (Bahrain, Kuwait, Oman, Qatar, Kingdom of Saudi Arabia [KSA], Oman, United Arab Emirates [UAE]) and North Africa (Algeria, Egypt, Libya, Morocco, Sudan, Tunisia).

Continuous variables were expressed as mean and standard deviation and categorical variables as numbers and percentages. A comparison of the patients' characteristics and responses between the Arab countries was performed using the Pearson Chi-square or Fisher test for the categorical variables and the t test or analysis of variance for the continuous variables.

Univariate and multivariable logistic regression analyses were conducted to identify factors associated with the following dependent variables: access to the rheumatology clinic, mental impact of COVID-19 (both transformed into binary variables), and personal infection with SARS-CoV-2. All independent variables with a  $P$  value  $<0.1$  in the univariate analysis were taken into account in the multivariable logistic regression analysis;  $P$  values  $<.05$  were accepted as statistically significant. All statistical analyses were performed using SPSS v25.0 (IBM).

## 3 | RESULTS

### 3.1 | Descriptive analysis of the HANDLING study patients (Table 1)

The link to the survey in the 3 languages was clicked on 3749 times. A total of 2190 patients participated in the survey and completed the questionnaire, 1971 in Arabic, 175 in French, and 44 in English. Five responses with missing data and 22 responses from non-Arab countries were eliminated. In total, 2163 responses were analyzed (Figure 1: Flowchart of the study participants Table 1).

The mean age of participants was 40.0 years (SD 11.9). Seventy-two percent were female. Around half of the participants were unemployed (51.1%), and around a third were full-time employed. Thirty-four percent were from the Levant, 31% were from the Gulf, and 30% were from North Africa. Age and gender were similar across the 3 regions ( $P = .814$  and  $P = .863$ , respectively).

When asked about their attitude toward telemedicine, 98.8% said that they would accept a teleconsultation (50% through the internet and 48.8% through a telephone contact).

Also, to get information about COVID-19, the patients relied mostly on social media (73%), followed by television (51%). They used newspapers as a source of information in 8% and radio in 6% only. They relied on their healthcare provider (HCP) for information in 30% of cases and their friends and family in 20%.

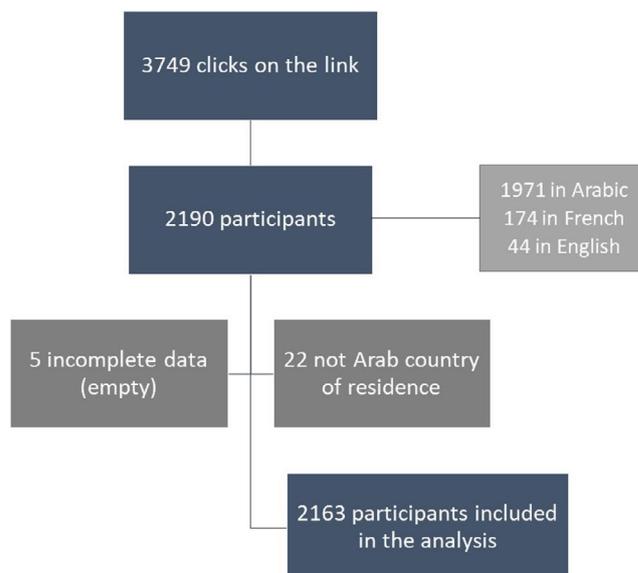


FIGURE 1 Flowchart of the study participants

### 3.2 | Impact of COVID-19 on patients and rheumatic diseases management (Table 2)

#### 3.2.1 | Impact on the rheumatology visits

The COVID-19 pandemic had a significant negative impact on rheumatology visits, on the access to HCQ, and chronic medication persistency (Table 2). In univariable analysis, the impact on rheumatology visits was associated with country of residence ( $P < .001$ ), region of residence ( $P < .001$ ), medication persistency ( $P < .001$ ), access to HCQ ( $P < .001$ ). It was also associated with use of precautions ( $P < .001$ ), use of a mask ( $P = .006$ ), personal infection with SARS-CoV-2 ( $P = .002$ ) or a close contact infection with SARS-CoV2 ( $P = .005$ ), isolation due to COVID-19 ( $P < .001$ ), impact on mental health  $P < .001$ , impact on income ( $P = .015$ ), and acceptance of teleconsultation ( $P = .009$ ). Other variables such as age, gender, and occupation were not associated with the impact on the rheumatology visit. In multivariable analysis (Table 3), gender (females had a higher negative impact,  $P = .008$ ), region (highest impact in the Gulf and North Africa, lowest in the Levant,  $P < .001$ ), medication non-persistency ( $P < .001$ ), acceptance of teleconsultation ( $P = .006$ ), isolation due to COVID-19 ( $P = .002$ ) and negative impact on mental health ( $P = .018$ ) remained associated with the negative impact on rheumatology visits.

#### 3.2.2 | Impact on mental health

The pandemic had an impact on mental health in 73% of the participants (minor in 48%, major in 25%). In univariable analysis, the impact on mental health was associated with region of residence (highest in North Africa,  $P < .001$ ), negative impact on rheumatology visits ( $P < .001$ ), medication non-persistency ( $P < .001$ ),

**TABLE 1** Characteristics of the 2163 participants in the survey

	All participants
Number	2163
Age, mean (SD)	40.0 (11.9)
Females, n (%)	1564 (72.3)
Occupation, n (%)	
Full-time employed	631 (29.2)
Part-time employed	178 (8.2)
Self-employed	187 (8.6)
At home	1105 (51.1)
Countries n (%)	
Iraq	539 (24.9)
KSA	480 (22.2)
Egypt	283 (13.1)
Morocco	155 (7.2)
Algeria	137 (6.3)
Kuwait	117 (5.4)
Lebanon	91 (4.2)
Jordan	78 (3.6)
Tunisia	60 (2.8)
UAE	34 (1.6)
Syria	12 (0.6)
Libya	11 (0.5)
Palestine	11 (0.5)
Oman	10 (0.5)
Qatar	6 (0.3)
Other	28 (1.3)
Regions, n (%)	
Levant	731 (33.8)
Gulf	671 (31.0)
North Africa	649 (30.0)

decreased access to HCQ ( $P < .001$ ), use of precautions ( $P < .001$ ), use of a mask ( $P < .001$ ), personal infection with SARS-CoV-2 ( $P = .024$ ) and contact infection with SARS-CoV-2 ( $P = .007$ ), isolation due to COVID-19 ( $P < .001$ ) and negative impact on income ( $P < .001$ ). In multivariable analysis (Table 4), all remained significantly associated, except for the close-contact infection with SARS-CoV-2.

### 3.2.3 | Personal infection with SARS-COV2

Sixty-one patients (2.8%) stated that they were infected with SARS-CoV-2, 5% reported that a close contact was infected, and 47% were in isolation because of COVID-19. The infection with SARS-CoV-2 was statistically correlated with the country of residence ( $P = .006$ ). Among the 61 cases, 28 were from Iraq, 12 from KSA, 9 from Morocco, 6 from Egypt, 2 from Algeria, and 1 from

UAE. The infection was also associated with precautions used during the visit to the rheumatologist ( $P = .011$ ), with close-contact infection ( $P < .0001$ ), personal isolation due to COVID-19 ( $P = .004$ ), impact on mental health ( $P = .024$ ) and on the visit to the rheumatologist ( $P = .005$ ). In multivariable analysis, country ( $P = .041$ ), close-contact infection with SARS-CoV-2 ( $P < .001$ ), and negative impact on mental health ( $P = .038$ ) remained associated with personal infection.

### 3.2.4 | Impact on other components

The impact on the patients' income was reported in 57% of the participants (slightly in 30%, significantly in 27%).

Regarding the precautions that the patients used when visiting the rheumatologist, 75.8% stated that they wore masks, and 48.2% wore gloves. However, 10% indicated that they took no precautions at all.

## 4 | DISCUSSION

The current study showed a significant negative impact of the COVID-19 pandemic on patients with CRD. The pandemic negatively influenced access to rheumatology care by affecting the visits to the rheumatologist, medication persistency, and access to HCQ. It also had a significant negative influence on mental health and income. All these substantial impacts suggest an indirect deleterious effect of the pandemic on the control and management of CRD, which may be more significant than the potential direct impact of the infection.<sup>24</sup> The concerns about the access to rheumatology care, to medication, and to proper education about drug persistency were raised in several expert opinion publications in the pre-COVID-19 era<sup>25,26</sup> but are most probably exaggerated because of the pandemic. The negative impact on the rheumatology visits was different according to the regions, which reflects a difference in healthcare systems and possible differences in the duration and strictness of the application of quarantine measures. In the early phases of the pandemic, the ArLAR issued a general guidance for patients with rheumatic diseases about maintaining chronic anti-rheumatic drugs and general measures social distancing, based on the WHO recommendations. However, the adherence to this guidance may differ from one country to another.<sup>27</sup> Also, the important association with non-persistency in medication (odds ratio = 3.9) highlights the importance of the contact with the rheumatologist to ensure a continuity of chronic treatment, which is a major factor for better disease outcomes. The absence of association with personal infection in the multivariable analysis may be due to the low number of COVID-29 cases, but may also reflect the lower impact of the direct SARS-CoV-2 infection compared to the indirect effects.

The young age of participants (40 years) reflected the profile of social media users, rather than the usual older age reported in studies on patients with CRD.<sup>10,28</sup> In fact, according to the Arab



Impact of COVID-19 pandemic	Type of impact	n	%
Impact on rheumatology visit	Not affected	371	17.2
	I can see my rheumatologist only in emergencies	511	23.6
	I can only have a remote contact with my rheumatologist	625	28.9
	It is impossible to see my rheumatologist	578	26.7
Impact on access to hydroxychloroquine (HCQ)	No impact	872	52.8
	Shortage of HCQ	297	18
	Difficulty to access HCQ	481	29.2
Impact on persistency in chronic medication	No impact	1495	69.1
	I stopped all medication because of the fear of infection	98	4.5
	I stopped some medication because of the fear of infection	177	8.2
	I stopped some medication because of drug shortage	317	14.7
Impact on mental health	No impact	511	23.6
	Minor effect	1044	48.3
	Major effect	540	25.0
Impact on income	Not affected	821	38.0
	Slightly affected	657	30.4
	Significantly affected	589	27.2
Personal infection with SARS-Cov-2	Yes	61	2.8
Contact infection with SARS-Cov-2	Yes	106	4.9
Personal isolation due to COVID-19	Yes	1009	46.6

**TABLE 2** Impact of COVID-19 pandemic on patients with chronic rheumatic diseases

Social Media Report,<sup>29</sup> 64.3% of social media users were aged less than 30 years. On the other hand, the gender of participants (72%

**TABLE 3** Factors associated with a negative impact of the COVID-19 pandemic on the patient's visit to the rheumatologist

	Odds ratio <sup>a</sup>	95% CI	P value
Female gender	1.53	1.12 2.09	.008
Region			
North Africa	1		<.001
Levant	1.66	1.13 2.43	
Gulf	0.77	0.51 1.18	
Medication non-persistence	3.90	2.08 7.30	<.001
Isolation due to COVID-19	1.57	1.17 2.13	.003
Mental impact of COVID-19	1.49	1.07 2.07	.018
Accepting a teleconsultation	0.27	0.08 0.93	.006

<sup>a</sup>After adjusting for: hydroxychloroquine difficulty, mask, precautions, personal COVID infection, contact COVID infection, impact on income, impact on mental health.

rather reflected the profile of patients with CRD.<sup>10,28</sup> The same report indicated that 32% of social media users were female, whereas the published cohorts of patients with CRD reported a female prevalence of 72%.<sup>10,30</sup>

Around 60% of our population were from 3 countries: Iraq, KSA, and Egypt. This high contribution reflects the large populations in these countries. They account for 173 million inhabitants among the 333 million inhabitants in the ArLAR countries (52%).

The percentage of patients infected with SARS-CoV-2 in our sample was low (2.8%). Although there was most probably a selection bias toward less severe cases, this low prevalence is in line with previous publications. In a cohort of 3591 CRD patients from Madrid, a city that was severely affected by the pandemic, 123 COVID-19 cases were reported (3.4%),<sup>30</sup> and hospital admissions related to COVID-19 occurred in 54 patients (1.36%).<sup>28</sup>

The most used source of information about COVID-19 was social media. This was most probably biased toward overestimation since the survey was conducted mainly on social media. However, it highlights the importance of this communication channel when there is a need to convey general guidance to patients. Facebook is the most used platform in the Arab countries, with 156 million users in 2017



(half of them based in Egypt, KSA, and Algeria), a mean penetration rate of 39%, and an estimation of 1 out of 5 users regularly checking their account. The most used language is Arabic, as was observed in our survey.<sup>29</sup>

Based on the survey's results, the steering committee developed recommendations for an action plan to improve the care of patients with CRD during the pandemic (Table 5). The committee highlighted the need for a reliable telemedicine platform to maintain the continuity of care for patients with CRD, as these patients will probably suffer more from the lack of proper follow-up than from the

SARS-CoV-2 infection itself. In this regard, medication persistence should also be strongly recommended, by raising awareness among patients, but also among other stakeholders, such as governments, who should work to avoid drug shortage. Also, the issue of mental health impact should not be neglected, as it may be a significant trigger for CRD flares, in addition to its direct effect on patients. Moreover, the precautions during the physical visits to the rheumatology clinic should be emphasized, since, for now, only these preventive measures are effective to halt the spreading of the pandemic. Finally, all communication channels should be used to disseminate general guidance to patients. In particular, social media constitutes an important channel due to its widespread availability, ease of use, and low cost. Nevertheless, efforts should be made to raise public awareness about information authenticity and the avoidance of fake news. Also, the establishment and registration of patients' associations should be encouraged for that purpose.

The study has some limitations. The questionnaire was developed de novo by the steering committee, based on the available literature. However, it was validated by an independent scientific committee and pilot-tested successfully for readability, acceptability, and timing.

Also, the study was cross-sectional, covering a period where the pandemic had already reached its peak in some countries, whereas it was still in the ascending part of the incidence curve in others. Therefore, the responses reflect the status in each country in a particular time frame of the pandemic. Of note, up to the end of the study period, 166 175 COVID-19 cases were reported.<sup>5</sup>

Further, the data presented in this study were self-reported and partly dependent on the participants' honesty and recall ability; thus, they may carry subjectivity and recall bias. Moreover, duplicate data, although very unlikely, cannot be ruled out. However, not collecting personal identification data was a choice that the authors had to make for the sake of anonymity.

Despite these limitations, the current study provides valuable information about the impact of COVID-19 on the care of patients with CRD. It has gathered significant information from 2163 patients

**TABLE 4** Factors associated with a negative mental impact of the COVID-19 pandemic on patients with chronic rheumatic diseases

	Odds ratio <sup>a</sup>	95% CI		P value
Region				
North Africa	1			<.001
Levant	2.42	1.65	3.56	
Gulf	1.73	1.16	2.56	
Positive personal infection with SARS-CoV-2	4.93	1.38	17.61	.014
Positive isolation due to COVID-19	2.45	1.86	3.25	<.001
More precautions during the rheumatology visit	2.19	1.15	4.20	.006
Less visits to the rheumatologist	1.97	1.29	2.99	.017
Difficulty of access to hydroxychloroquine	1.86	1.34	2.59	<.001
Negative impact on income	1.28	0.90	1.80	.014
Medication non-persistence	0.36	0.16	0.84	<.001

<sup>a</sup>After adjusting for: accept teleconsultation, mask, contact COVID infection.

**TABLE 5** Recommendations for an action plan to improve the care of patients with chronic rheumatic diseases

Concept	Suggestion
Telemedicine	Establish a reliable telemedicine platform to maintain the continuity of care for patients with rheumatic diseases
Drug persistence	Increase patient awareness about the need to maintain chronic treatment unless advised otherwise by the rheumatologist
Drug availability	Increase government awareness about the need to maintain chronic treatment and avoid drug shortage
Mental health	Acknowledge and address the significant mental impact and its possible association with disease flares
Precautions	Increase awareness about the necessity to use additional precautions during the visit to the rheumatologist (masks in public places are mandatory by law in most countries)
Communication	Use social media for disseminating general guidance to reach the maximum of patients Encourage the establishment and registration of patients' associations and groups



across 15 Arab countries within 15 days. It was disseminated in 3 languages, catching the broadest audience in the region. The sample was representative of the Arab countries, with a balanced contribution from the main regions, that is, the Levant, the Gulf, and North Africa.

## 5 | CONCLUSION

The HANDLING study highlights the deleterious consequences of the COVID-19 pandemic on the continuity of rheumatology care, the persistence on chronic medication, and patients' mental health, all key predictors of disease prognosis. Therefore, an action plan, including establishing a telemedicine platform, securing drug availability, and promoting medication persistence through the appropriate communication channels is strongly recommended.

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### CONFLICT OF INTEREST

The authors declare no conflict of interest related to this study.

### AUTHORS' CONTRIBUTIONS

NZ designed the study, contributed to patients' recruitment, to the social media campaign, conducted the analysis, drafted the manuscript. LK participated in the study design, contributed to patients' recruitment, managed the social media campaign, and critically reviewed the manuscript. IH participated in the study design, contributed to patients' recruitment, to the social media campaign, participated in the analysis, and critically reviewed the manuscript. NA, HH, WH, FA, MR, and BM contributed to patient recruitment, to social media campaign and critically reviewed the manuscript. All the authors contributed substantially to the work, revised the manuscript critically, approved the submitted version, and agree to be accountable for all aspects of the work.

### ETHICAL APPROVAL

The study complies with the Declaration of Helsinki. The Ethics Committee of Saint-Joseph University, Beirut has approved the research protocol (CEHDF 1653).

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## SUPPORTING INFORMATION

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

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