Concerns, Healthcare Use, and Treatment Interruptions in Patients With Common Autoimmune Rheumatic Diseases During the COVID-19 Pandemic

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ABSTRACT. Objective. To assess concerns and healthcare-related behaviors of patients with autoimmune rheumatic diseases during the coronavirus disease 2019 (COVID-19) pandemic.

Methods. Adults from the United States with rheumatoid arthritis (RA), psoriatic arthritis (PsA), ankylosing spondylitis (AS), and systemic lupus erythematosus (SLE) from the ArthritisPower Patient-Powered Research Network and CreakyJoints patient community completed surveys. Concerns and behaviors were compared among patients with different autoimmune conditions, disease-modifying antirheumatic drug (DMARD) use, and geographic measures of urban status, income, education, and COVID-19 activity.

Results. Among 1517 participants (925 RA, 299 PsA, 185 AS, 108 SLE), mean age was 55.1 years, 88.3% were female, and 89.5% were White. COVID-19 concerns were similar across the country and were higher in biologic users (P < 0.001). Avoidance of doctor’s office visits (56.6%) or laboratory testing (42.3%) and use of telehealth (29.5%) were more common in urban areas. Among participants receiving a DMARD without COVID-19 or other respiratory illness, 14.9% stopped a DMARD, with 78.7% of DMARD interruptions not recommended by a physician. DMARD stopping was more common in participants with lower socioeconomic status (SES) and in participants who avoided an office visit (OR 1.46, 95% CI 1.04–2.04) or reported lack of telehealth availability OR 2.26 (95% CI 1.25–4.08).

Conclusion. In the early months of the COVID-19 pandemic, patients with RA, PsA, AS, and SLE frequently avoided office visits and laboratory testing. DMARD interruptions commonly occurred without the advice of a physician and were associated with SES, office visits, and telehealth availability, highlighting the need for adequate healthcare access and attention to vulnerable populations during the pandemic.

Key Indexing Terms: antirheumatic drugs, COVID-19, health behavior, rheumatoid arthritis, spondyloarthritis, systemic lupus erythematosus

Coronavirus 2019 (COVID-19), caused by SARS-CoV-2 (severe acute respiratory syndrome coronavirus 2)1,2, may be of particular concern to patients with autoimmune rheumatic diseases such as rheumatoid arthritis (RA), psoriatic arthritis

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(PsA), ankylosing spondylitis (AS), and systemic lupus erythematosus (SLE). These patients are at increased risk of infections, with immunosuppression and common comorbidities further affecting infection risk.3,4

To better understand how the COVID-19 pandemic has affected these patients, the ArthritisPower Patient-Powered Research Network (PPRN) registry (www.ArthritisPower.org)5 launched a study to capture patient experiences during the pandemic across the United States, hypothesizing that patients with autoimmune diseases would have high levels of concern about COVID-19 and frequent disruptions in office visits, routine monitoring, and disease-modifying antirheumatic drug (DMARD) use that would vary geographically.

MATERIALS AND METHODS

Study population. Adults aged > 18 years in the ArthritisPower PPRN or CreakyJoints patient community were sent email invitations. The ArthritisPower PPRN is a patient-led online registry of patients with inflammatory arthritis and other rheumatic conditions created as a joint venture of the patients and patient advocates of the Global Healthy Living Foundation, the CreakyJoints patient community, and researchers at the University of Alabama at Birmingham. Participants of partnering patient organizations were directed to a landing page (www.rheumcovid.com). Results are presented for surveys completed from March 29 to May 26, 2020, from participants in the US with a diagnosis of RA, PsA, SpA, or SLE. Participants provided consent and the protocol was approved by the Advarra Institutional Review Board (Protocol 00042873).

Data collection. Participants reported demographics, zip code, comorbidities, rheumatic conditions, and use of DMARD. For participants indicating multiple autoimmune conditions, a hierarchical approach was taken (SLE > PsA > AS > RA), similar to previous studies.6

Participants were asked about their concerns about COVID-19 (5-point Likert scale), respiratory illnesses within the previous 2 weeks, COVID-19 testing/diagnoses, avoidance of office visits or laboratory/diagnostic testing, and use and availability of telehealth (“telephone or telehealth visit”), and DMARD interruptions.

Geographic data. County rural versus urban status was defined using the National Center for Health Statistics classification.7 Tertiles of COVID-19 activity in the patient’s county relative to all other counties in the US on the survey date were defined using the cumulative cases per capita on that date, weighing counties by population.8 Zip code–based median household income and education from the American Community Survey 2014–2018, five-year estimates were also divided into tertiles.9

Statistical analysis. Median scores for concerns about COVID-19 were graphed among states/territories with ≥ 5 respondents. Kruskal-Wallis tests assessed for differences in concerns by geography (9 census divisions), autoimmune disease, biologic/Janus kinase (JAK) inhibitor use, urban versus rural geography, tertiles of zip code–based median household income, education, and county-based COVID-19 cases per capita.

The proportions of participants who had avoided an office visit, avoided testing, had a telehealth visit, or stopped medications were compared in the same subgroups of interest using univariate logistic regression to assess for statistical differences. DMARD stopping was assessed among participants reporting DMARD use, primarily evaluating patients without a respiratory illness or COVID-19 diagnosis to avoid participants who stopped DMARD because of illness.

RESULTS

Invitation emails were opened by 14,001 individuals, with 2895 clicking to access the study and 1935 completing the baseline survey as of May 26, 2020. Excluding 20 participants outside the US and 398 without an autoimmune condition of interest left 1517 participants representing all 50 states and Puerto Rico (Figure 1). The mean age was 55.1, 88.3% of participants were female, and 89.5% were White (Table 1).

A physician diagnosis of COVID-19 was reported by 11 participants (0.7%), with 243 (13.9%) reporting a respiratory illness without a diagnosis of COVID-19. Patients frequently wanted to be tested but were not, including 23.8% of patients who were not ill and 47.9% of patients reporting a respiratory illness. The most common barriers to testing were that the test was either not available (43.0%) or not offered/recommended (36.8%; Supplementary Table 1, available with the online version of this article).

Concerns about COVID-19. Overall, 698 (46.0%) participants were extremely concerned and 515 (34.0%) moderately concerned about COVID-19, and 803 (52.9%) and 414 (27.3%) noted that their autoimmune disease extremely or moderately affected their concerns about COVID-19, respectively.

Table 1. Participant demographic and clinical characteristics.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Value (n = 1517)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, yrs</td>
<td>55.1 ± 11.7</td>
</tr>
<tr>
<td>Female</td>
<td>1340 (88.3)</td>
</tr>
<tr>
<td>White</td>
<td>1358 (89.5)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>75 (4.9)</td>
</tr>
<tr>
<td>Rural</td>
<td>214/1454 (14.1)</td>
</tr>
<tr>
<td>Autoimmune conditions</td>
<td>RA 925 (61.0), PsA 299 (19.7), AS 185 (12.2), SLE 108 (7.1)</td>
</tr>
<tr>
<td>Medications</td>
<td>bDMARD 790 (52.1), JAK inhibitor 158 (10.4), Methotrexate 946 (62.4), Hydroxychloroquine 537 (35.4), Glucocorticoids 402 (26.5), NSAID 373 (24.6)</td>
</tr>
<tr>
<td>Comorbidities</td>
<td>Hypertension 621 (40.9), Lung disease 518 (34.2), DM 179 (11.8), Heart disease 121 (8.0), Kidney disease 80 (5.3), Malignancy 33 (2.2), Current smoking 141 (9.3)</td>
</tr>
<tr>
<td>PROMIS Anxiety, T-score</td>
<td>59.8 ± 8.5</td>
</tr>
</tbody>
</table>

Values are n (%) or mean ± SD. a Rural status shown among participants with available zip code. b PROMIS Anxiety short form with range of 1–100, US adult population (mean 50 ± SD 10). AS: ankylosing spondylitis; bDMARD: biologic disease-modifying antirheumatic drug; DM: diabetes mellitus; JAK: Janus kinase; NSAID: nonsteroidal antiinflammatory drug; PsA: psoriatic arthritis; PROMIS: Patient-Reported Outcomes Measurement Information System; RA: rheumatoid arthritis; SLE: systemic lupus erythematosus.
Levels of concern were high across the US (Figure 1, Supplementary Figure 2), with no significant difference by geography, urban versus rural, median household income, or education level. Concerns were higher in participants receiving biologics/JAK inhibitors ($P < 0.01$; Supplementary Figure 1).

**Effects on healthcare.** Avoidance of doctor’s office visits, laboratory testing, and other testing was reported by 56.6%, 42.3%, and 36.0% of participants, respectively, with higher rates in participants with SLE (all $P < 0.05$). Participants receiving a biologic/JAK inhibitor, those in urban or higher COVID-19 activity counties, and participants with greater COVID-19 concerns were more likely to avoid office visits or testing (Table 2; Supplementary Table 2, available with the online version of this article).

Telehealth visits were reported by 448 (29.5%) participants, more commonly by participants in urban locations (30.7% vs 22.4%, $P = 0.02$; Table 2). Overall, 951 (62.7%) participants reported that their doctor’s office offered telehealth, 474 (31.2%) did not know, and 92 (6.1%) reported that telehealth was not available.

**DMARD interruptions.** Among participants treated with DMARD who did not report a respiratory illness or COVID-19 diagnosis, 169/1132 (14.9%) stopped a DMARD. More frequent stopping was associated with biologic/JAK inhibitor use, lower education, lower or higher median household income, and greater COVID-19 concerns (Table 2; Supplementary Table 2, available with the online version of this article). Only 21.3% of these DMARD interruptions were recommended by a physician (Supplementary Table 3). Participants who avoided an office visit were more likely to stop DMARD [106/622 (17.0%) vs 63/510 (12.4%)], OR 1.46 (95% CI 1.04–2.04), $P = 0.03$.

Telehealth use was not associated with stopping a DMARD (OR 1.04, 95% CI 0.72–1.49), but DMARD stopping was more common among participants who reported that telehealth was not available [17/67 (25.4%)] versus those reporting telehealth availability [91/695 (13.1%)], OR 2.26 (95% CI 1.25–4.08), $P < 0.01$, with even stronger associations among patients who avoided office visits [OR 3.01 (95% CI 1.43–6.34), $P < 0.01$; Supplementary Table 4].

DMARD interruptions were reported by 48/172 (27.9%) and 7/11 (63.6%) patients reporting respiratory illness or COVID-19 diagnosis, respectively; 56.4% of these interruptions were recommended by a physician (Supplementary Table 3, available with the online version of this article).

**Sources of information.** The news media (84.4%) and government websites (67.4%) were the most common sources for information about COVID-19 (Supplementary Table 5, available with the online version of this article). Healthcare providers were more commonly a source of information among participants reporting a telehealth visit (63.4% vs 34.9%, $P < 0.001$).
DISCUSSION
This study of patients with common autoimmune rheumatic diseases across the US during the early months of the COVID-19 pandemic found that participants had high levels of concern about COVID-19 and frequently avoided office visits and testing. Of particular concern, approximately 15% had stopped one of their DMARD, especially patients who avoided office visits or reported that telehealth was not available.

Most medication interruptions in patients without illnesses occurred without a physician recommendation, similar to previous findings. Although there are limited data on how immunosuppression affects the risk of severe COVID-19, medication interruptions can risk disease flares and glucocorticoid increases, both associated with infection risk. The American College of Rheumatology recommends continuing DMARD unless patients are exposed or infected, but these recommendations may not reach patients or be accepted by them. In this study, participants most frequently had obtained information about COVID-19 from news sources or government websites, which may not include information specific to patients with autoimmune disease. Participants who had avoided office visits or who reported that telehealth was not available were the most likely to have stopped a DMARD. Higher rates of stopping a DMARD among participants with lower socioeconomic status are concerning and require further investigation.

Participants in urban areas more frequently avoided office visits or testing for their autoimmune condition, and these areas were also those with the most telehealth use. These observations could be due to increased concerns or restrictions around clinic office visits, greater availability of or access to healthcare providers, or greater availability of telehealth technology/infrastructure in these areas. Although socioeconomic status was not associated with telehealth use, participants tended to be of higher socioeconomic status and might be more likely to be telehealth users; continued assessment of inequities in access to care and the optimal use of telehealth are important as the pandemic continues.

Several limitations are important to note. Patients who...
are survey respondents and members of online communities or networks may have different concerns and behaviors than the general population. Respondents were primarily White, and results may differ in racial/ethnic minority populations. Participants self-reported autoimmune and COVID-19 diagnoses, although they were specifically asked about physician diagnoses. We could not evaluate whether medication interruptions contributed to disease flares.

In conclusion, participants with autoimmune rheumatic disease across the US were highly concerned about COVID-19 and frequently avoided office visits or tests. Participants often stopped medications without the advice of a physician, especially those who had missed office visits and did not have tele-health access. Physicians should ask patients about medication concerns and interruptions, proactively contact patients who have missed visits, and ensure patients are aware of available options for accessing care. Continued assessment of disruptions in care, with a particular focus on vulnerable populations, is of critical importance as the pandemic continues.

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ONLINE SUPPLEMENT
Supplementary material accompanies the online version of this article.

REFERENCES