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Capturing patient-reported outcomes during the COVID-19 pandemic: Development of the COVID-19 Global Rheumatology Alliance Patient Experience Survey

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Disclosure:

The views expressed here are those of the authors and participating members of the COVID-19 Global Rheumatology Alliance and do not necessarily represent the views of the American College of Rheumatology or any other organization.

Conflict of Interests

ES is a Board Member of the Canadian Arthritis Patient Alliance, a patient run, volunteer-based organization whose activities are largely supported by independent grants from pharmaceutical companies.

SD is the founder of Women with Rheumatoid Disease, a patient support group, and she runs Grace & Able, a medical supply company.

RG reports personal and/or speaking fees from Abbvie, Janssen, Novartis, Pfizer, Cornerstones, and travel assistance from Pfizer (all < \$10,000), not related to this work.

JSH is supported by grants from the Rheumatology Research Foundation and the Childhood Arthritis and Rheumatology Research Alliance (CARRA). JSH has received consulting fees from Novartis (<\$10,000) not related to this work.

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Introduction

The coronavirus disease 2019 (COVID-19) Global Rheumatology Alliance (C19-GRA) was formed in March 2020 as a grassroots organization to coordinate the response of the international rheumatology community to the pandemic [1]. The C19-GRA launched an international, secure, de-identified physician registry of patients with rheumatic diseases infected with the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) to provide insights into the management and treatment of COVID-19 in this population.

However, patients with rheumatic diseases highlighted the limitations of a physician registry, in which patient-oriented outcomes are not sufficiently captured. Furthermore, the physician registry does not include data from patients with mild symptoms who do not seek medical care, nor does it capture the resulting behavioral changes of patients in response to the pandemic, which is likely to occur regardless of infection status.

Patient community members also had unique concerns related to their disease and its treatment. These included whether their rheumatic disease or immunosuppressive treatments increased their risk of COVID-19 infection, or of poor outcomes should they become infected, if changes to their medications were desirable, and if their ability to obtain their medications would be impaired, as rheumatic disease drugs were being used to treat COVID-19 [2-4]. In the first two weeks of the pandemic, almost half of patients in one US cohort described significant disruption to their rheumatology care, including disrupted or postponed appointments, and self-imposed or physician-directed changes to medications [5].

To answer these questions and expand upon the rheumatology community's understanding of the impact of the COVID-19 pandemic on people with rheumatic disease, the C19-GRA launched the Patient Experience Survey (www.rheum-covid.org/patient-survey). This international, anonymous, patient-facing survey is

intended for adults and parents of children with rheumatic diseases, whether or not they have contracted COVID-19. The purpose of this editorial is to provide a timely description of the rapid engagement of people with rheumatic disease, patient organizations, and rheumatologists to develop a unique survey running in parallel to the physician registry. This survey collects data *from* people with rheumatic diseases and explores how the pandemic is affecting their physical and mental health, behavior, and ability to manage their rheumatic disease. In this paper we define the data elements captured, address how we involved patient groups in all aspects of the survey development and dissemination, and explain the outputs that are expected from this work. In describing this process, we present a model that can be used when collaboration from multiple stakeholders is required to tackle a complex problem rapidly, to meet the care and emotional needs of our patients.

The Inception of the Patient Experience Survey

Patient experience surveys have been successfully used to complement measures of clinical outcomes [6]. The COVID-19 Patient Experience Survey was developed in cooperation between the C19-GRA Steering Committee, patient partners, and patient organization representatives. Patients were involved in all aspects of this research, including the generation of the research questions, study design, development of the measuring instruments, recruitment of patients to the study, contribution to manuscripts, and participation in the C19-GRA Steering Committee. Such extent of patient involvement has been found to improve the quality and relevance of research [7]. The collaboration was facilitated via Slack, an online team collaboration and messaging platform. The process of survey development used principles from “agile methodology,” in which continued patient community involvement occurred throughout the survey process [8]. This methodology enabled rapid iteration of the survey questions to ensure focus on outcomes most relevant to the patient community, as well as issues of importance to the rheumatologists caring for them. A Qualtrics version of the survey was then sent to physicians, patients, and patient groups for further review,

including for the use of appropriate language that was sensitive to diverse cultures and belief systems. Once finalized, bi- and multilingual patients and physicians translated the survey into other languages. The survey was reviewed by the Institutional Review Board at Boston Children's Hospital, and it was deemed exempt, as it was intentionally created to be anonymous by excluding any protected health information.

Collaborating with patient organizations

While many patient organizations wanted to develop their own surveys for their members, they also realized the potential benefits of distributing a single C19-GRA survey to the global patient community, with robustly developed data domains that paralleled the physician survey, secure data management, and IRB approval. At the same time, we realized the need for these organizations to understand better the experience of their members during the pandemic. As such, we offered to provide organizations with the aggregate results from their members when survey participants indicated that they had membership in an organization. For patient organizations that preferred to deploy their own survey, we made our questions open-access, available to any organization so they could incorporate some (or all) of our questions, with the goal of sharing data in the future (see Online Supplement 1). A final novel aspect of this initiative was that survey dissemination was led by patients, including a comprehensive and coordinated communications plan. As part of this plan, patient organizations were supplied with a social media kit, designed to appeal to patients. Recruitment via patient organizations that supported the C19-GRA increased the reach of the survey and boosted participation.

Data Elements Captured

The Patient Experience Survey provides an opportunity for all people with rheumatic disease to report their experiences during the COVID-19 pandemic, whether infected with the SARS-CoV-2 or not. Many data elements mirror the C19-GRA physician

survey, such as demographics, rheumatic disease diagnosis, medications, comorbidities, and details of COVID-19 diagnosis and its treatment, if relevant. These items were included so that the patient-reported data and physician-reported cases could be used in complementary ways. Research has shown that patient-reported studies lead to results similar to those conducted by physicians under clinical conditions [9].

We are especially interested in examining whether certain rheumatic diseases or immunomodulatory medications place patients at an increased or decreased risk of COVID-19 complications. For instance, much controversy has arisen regarding the potential benefit of hydroxychloroquine in the treatment or prevention of COVID-19 [2], and our study is poised to generate real-world data to examine this question.

Moreover, while patients on immunosuppressive medications are thought to be at higher risk of severe illness related to COVID-19 [10], drugs used to treat rheumatic diseases are also being employed to manage complications of COVID-19 [3,4], so the ultimate impact on patient risk is unclear. We will also assess whether the use of these medications as off-label treatments for COVID-19 has led to drug shortages that prevent patients from obtaining their prescribed medications.

We include questions about the impact of the COVID-19 pandemic on patients' behavior, employment, decision to continue immunosuppression, and ability to connect with their rheumatologists. Patient-reported Outcome Measurement Information Systems (PROMIS) measures were included to understand the impact of COVID-19 on the physical and mental well-being of patients with rheumatic disease. These validated patient-reported outcomes (PRO) measures allow for comparisons across a range of chronic conditions as well as in healthy controls [11].

Future Impact

As of April 16, 2020, two weeks after the release of the survey, the C19-GRA Patient Experience Survey has had 9,541 responses. The most common diagnoses in this group were rheumatoid arthritis (25%) and systemic lupus erythematosus (20%). Five percent of the cohort were children under the age of 18. In the entire cohort, 465 patients (4.9%) had diagnoses of COVID-19 based on symptoms or on physician diagnosis with positive laboratory tests. In comparison, the C19-GRA physician registry had 360 patients with diagnoses of COVID-19. While we expect the physician registry to provide more detailed data about the clinical course of COVID-19 in patients with rheumatic diseases, the Patient Experience Survey should complement that work and reveal how our patient community is managing during this pandemic.

The robust survey response also illustrates an often untapped resource--our patients--and the benefit they can provide to the research process and generation of data. The results of both the C19-GRA Physician-Registry and Patient Experience Survey will provide insight into the treatment strategies, disease activity, behavioral impacts, and experiences of patients with rheumatic disease with and without a COVID-19 diagnosis. Our ability to quickly engage all stakeholders in the rapid development and dissemination of this survey provides an exemplary model of patient-patient organization-physician collaboration, albeit triggered by an ugly pandemic.

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