EJR European Journal of Rheumatology

DOI: 10.5152/eujrheum.2022.21133

Original Article

Early impacts of the COVID-19 pandemic on children with pediatric rheumatic diseases

Jonathan S. Hausmann[1,2], Kevin Kennedy[3], Salman Surangiwala[4], Maggie J. Larché[5], Rashmi Sinha[6], Karen Durrant[7], Gary Foster[3], Mitchell Levine[3], Lehana Thabane[3], Wendy Costello[8], Philip C. Robinson[9], Jean W. Liew[10], Jinoos Yazdany[11], Emily Sirotich[3,12], on behalf of COVID-19 Global Rheumatology Alliance

ORCID iDs of the authors:
J.S.H. 0000-0003-0786-8788;
K.K. 0000-0001-8230-091X;
S.S. 0000-0002-5606-1852;
M.J.L. 0000-0002-9506-1249;
R.S. 0000-0003-3045-3329;
K.D. 0000-0002-3200-5477;
G.F. 0000-0003-4716-3539;
M.L. 0000-0002-9010-0886;
L.T. 0000-0003-0355-9734;
W.C. 0000-0002-3662-1728;
P.C.R. 0000-0002-3156-3418;
J.W.L. 0000-0002-8104-2450;
J.Y. 0000-0002-3508-4094;
E.S. 0000-0002-7087-8543.

Cite this article as: Hausmann JS, Kennedy K, Surangiwala S, et al. Early impacts of the COVID-19 pandemic on children with pediatric rheumatic diseases. *Eur J Rheumatol.* 2022; 10.5152/eujrheum.2022.21133 [Epub Ahead of Print].

[1] Program in Rheumatology, Division of Immunology, Boston Children's Hospital, Boston, MA, USA
[2] Division of Rheumatology and Clinical Immunology, Beth Israel Deaconess Medical Center, Boston, MA, USA
[3] Department of Health Research Methods, Evidence, and Impact, McMaster University, Hamilton, ON, Canada
[4] Queen's University School of Medicine, Kingston, ON, Canada
[5] Divisions of Rheumatology/Clinical Immunology and Allergy, Department of Medicine, McMaster University, Hamilton, ON, Canada
[6] Systemic JIA Foundation, Cincinnati, OH, USA
[7] Autoinflammatory Alliance, San Francisco, CA, USA
[8] Irish Children's Arthritis Network (iCAN), Tipperary, Ireland
[9] University of Queensland Faculty of Medicine, Brisbane, Australia
[10] Section of Rheumatology, Department of Medicine, Boston University School of Medicine, Boston, MA, USA
[11] Division of Rheumatology, Department of Medicine, University of California San Francisco, San Francisco, CA, USA
[12] Canadian Arthritis Patient Alliance, Toronto, ON, Canada

Address for Correspondence: Jonathan S. Hausmann; Program in Rheumatology, Division of Immunology, Boston Childrenã s Hospital, Boston, MA, USA

E-mail: jonathan.hausmann@childrens.harvard.edu

Abstract

Objectives: The experiences of children with pediatric rheumatic diseases (PRD) during the initial phase of the COVID-19 pandemic have not been well-documented. We sought to determine the effects of the COVID-19 pandemic on protective behaviors, healthcare access, medication management, and education among an international cross-sectional parental survey of children with PRDs.

Methods: The COVID-19 Global Rheumatology Alliance Patient Experience Survey was distributed online, and parents of children with parental-reported PRD, with or without COVID-19 infection, were eligible to enroll. Respondents described their child's demographics, adoptions of protective behaviors, healthcare access, changes to immunosuppression, and disruptions in schooling.

Results: A total of 427 children were included in the analyses. The most common rheumatic disease was juvenile idiopathic arthritis (40.7%), and most children were taking conventional synthetic disease-modifying antirheumatic drugs (DMARDs) (54.6%) and/or biologic DMARDs (51.8%). A diagnosis of COVID-19 was reported in five children (1.2%), none of whom required hospitalization. Seventeen children (4.0%) had stopped or delayed their drugs due to concern for immunosuppression, most commonly glucocorticoids. Almost all families adopted behaviors to protect their children from COVID-19, including quarantining, reported by 96.0% of participants. In addition, 98.3% of full-time students experienced disruptions in their education, including cancelations of classes and transitions to virtual classrooms.

Conclusion: Despite the low numbers of children with PRDs who developed COVID-19 in this cohort, most experienced significant disruptions in their daily lives, including quarantining and interruptions in their education. The drastic changes to these children's environments on their future mental and physical health and development remain unknown.

Keywords: COVID-19, epidemiology, juvenile idiopathic arthritis, infections, patient-reported outcomes, pediatrics

Introduction

Children with pediatric rheumatic diseases (PRD) and their families faced unknown risks during the early phase of the coronavirus disease 2019 (COVID-19) pandemic. Although it was recognized that healthy children were not at particularly high risk for severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) adverse sequelae, the risk to children with PRDs or those immunosuppressed was less certain. Children with PRDs are at increased risk of infection due to their underlying condition and the medications used to treat them.[1,2] Early in the pandemic, there was disagreement among rheumatologists whether reducing immunosuppression was necessary among children with rheumatic diseases.[3] The pandemic also caused significant disruptions to healthcare delivery, including cancelations of clinic visits, postponement of initiation of immunosuppression, and delays in receiving rheumatology services,[4] making it more difficult for parents to discuss their concerns with their child's rheumatologist. Without a clear understanding of potential harm, parents may also have chosen to delay or defer the use of immunosuppression in their children to mitigate the risk of infection. In addition to the physical health concerns, school closures may also have generated significant mental health problems for children.[5]

Under this uncertainty, parents thus faced challenges in deciding how to adjust their families' behaviors to reduce their child's risk of infection. These decisions may have impacted a child's disease activity and

Submitted: June 22, 2021
Accepted: September 29, 2021
Available Online Date: January 24, 2022

Main Points

- Children with pediatric rheumatic diseases largely continued their immunosuppressive drugs in the early phase of the pandemic.
- Almost all families adopted protective behaviors to prevent potential COVID-19 exposure, including quarantining, social distancing, and using masks or gloves.
- Educational disruptions were widespread, including cancelations of in-person classes for most children.

their mental and physical health. The objectives of this study are to describe the impacts of the COVID-19 pandemic on protective health behaviors, healthcare access, and disruptions to education among children with PRDs by utilizing real-world data from an international parental survey of children with PRDs.

Methods

We report data from the COVID-19 Global Rheumatology Alliance (C19-GRA) Patient Experience Survey, an international cross-sectional study of adults and parents of children with PRDs (Supplementary Data S1). Details of the survey have been previously published.[6,7] Physicians, researchers, patient partners, and patient organization representatives developed a survey to answer questions most relevant to the rheumatology patient community and those caring for them. The survey was translated into nine languages and distributed online through patient support organizations and social media; it was hosted on a Qualtrics server. Parents of children with parental-reported PRD, with or without COVID-19, were eligible to complete the survey and did so on behalf of their children. Parents reported their child's rheumatic disease diagnosis, use of immunosuppressive drugs and how these were managed during the pandemic (continued, stopped, or delayed), the COVID-19 status of their child, and how the COVID-19 diagnosis was made (by the parent based on symptoms, by a healthcare provider based on symptoms, or through laboratory testing). For those reporting COVID-19, we assessed COVID-19 risk factors, disease symptoms, length of illness, and disease severity (categorized as no difficulties with activities of daily living [ADLs], some difficulties with ADLs, hospitalized with or without oxygen, or need for ventilatory support).

Medications were categorized as conventional synthetic disease-modifying antirheumatic drugs (csDMARDs): antimalarials (hydroxychloroquine, chloroquine), azathioprine, cyclophosphamide, cyclosporine, leflunomide, methotrexate, mycophenolate mofetil/mycophenolic acid, sulfasalazine, and tacrolimus. Biologic DMARDs (bDMARDs) included: abatacept, belimumab, CD-20 inhibitors, IL-1 inhibitors, IL-6 inhibitors, IL-12/IL-23 inhibitors, IL-17 inhibitors, and antitumor necrosis factor (TNF). Targeted synthetic DMARDs (tsDMARD) included: Janus Kinase inhibitors. "Other" medications included intravenous immunoglobulin (IVIG), apremilast, and thalidomide.

Parents reported whether they contacted their rheumatologist, adopted protective behaviors for their child, and engaged in activities that could increase their child's risk of exposure to COVID-19. Modes of communicating with their rheumatologist included phone call, email/patient portal, telemedicine/videoconference, office visit, unable to communicate, and unnecessary to communicate. The protective behaviors included social distancing (avoiding crowds and large groups of people), quarantining (staying home and avoiding others as much as possible), using gloves and/or masks during social interactions, or none. Those reporting quarantining also specified whether it was self-imposed or imposed by their government. We also asked about travel to an area with many COVID-19 cases, close contact with a person with confirmed or probable COVID-19, and presence in a healthcare facility where COVID-19 is managed. Parents noted how children enrolled in school participated in classes at the time of survey completion (in the classroom, virtually on the computer, classes were canceled, or other).

We report on data for all children under 18 years of age collected from April 3 to May 8, 2020. Subjects were included if the parent completed information regarding their child's medications, rheumatic disease diagnosis, gender, age, ethnicity, and country of residence. Data were described with counts and percentages. Data were cleaned, descriptive tables were generated, and statistical comparisons were performed with R Statistical Software 4.0.2. (R Foundation for Statistical Computing, Vienna, Austria).[8] The study was deemed exempt by the Institutional Review Board of Boston Children's Hospital.

Results

Clinical characteristics

A total of 427 children were included in the analyses (Table 1). Most participants resided in the Americas (277/427, 64.9%) and were white (313/427, 73.3%), female (269/427, 63.0%), and between the ages of 5 and 14 years (277/427, 64.9%). The most common rheumatic disease was juvenile idiopathic arthritis (JIA) (174/427, 40.7%), and most children were taking conventional synthetic disease-modifying antirheumatic drugs (csDMARDs) (233/427, 54.6%) and/or biologic DMARDs (bDMARDs) (221/427, 51.8%). Five children (1.2%) were reported to have COVID-19, three with a parental diagnosis due to symptoms (3/5, 60%), and two diagnosed by a healthcare provider based on symptoms (2/5, 40%); none of the children were hospitalized (Supplemental Table 1).

Medication management

A total of seventeen children (17/427, 4.0%) had their medications stopped or delayed

Table 1. Demographic and Clinical Characteristics of Children in the C19-GRA Patient Experience Survey (n = 427)

	N	%
Gender		
Female	269	63
Male	154	36.1
Nonbinary	2	0.5
Prefer not to answer	2	0.5
Race/Ethnicity		
White	313	73.3
Other	51	11.9
Latin American	47	11
Black	8	1.9
Asian	7	1.6
Native American / Aboriginal / First Nations	1	0.2
Age		
0-4	56	13.1
5-9	134	31.4
10-14	143	33.5
15-17	94	22
WHO Region		
Region of the Americas	277	64.9
European Region	125	29.3
African Region	14	3.3
Western Pacific Region	7	1.6
South-East Asia Region	3	0.7
Eastern Mediterranean Region	1	0.2
Rheumatic disease diagnosis*		
Juvenile idiopathic arthritis (JIA)	174	40.7
Systemic JIA	115	26.9
Autoinflammatory disease	74	17.3
Systemic lupus erythematosus	50	11.7
Inflammatory myopathy	16	3.7
Inflammatory eye disease	16	3.7
Chronic recurrent multifocal osteomyelitis	13	3
Vasculitis	10	2.3
Behcet's syndrome	8	1.9
Antiphospholipid syndrome	7	1.6
Mixed connective tissue disease	7	1.6
Undifferentiated connective tissue disease	5	1.2
Systemic sclerosis	4	0.9
Sjogren's syndrome	1	0.2
Comorbidities		
Asthma	56	13.1
Immunodeficiency	46	10.8
Other lung diseases	24	5.6
Pain syndromes	18	4.2
Inflammatory bowel disease	16	3.7
Other	55	12.9
Medications*		
NSAIDs	198	46.4
Glucocorticoids	113	26.5
csDMARDs	233	54.6
Biologic DMARDs	221	51.8
tsDMARDs	8	1.9
Other	16	3.7
COVID-19 Status, Diagnosis Method, and Severity	427	
Yes	5	1.2
Diagnosis by the parent based on symptoms	3	60
Diagnosis by a healthcare provider based on symptoms	2	40
Not hospitalized, no limitations in ADLs	2	40
Not hospitalized, some limitation in ADLs	3	60

bDMARD, biologic DMARD; csDMARD, conventional synthetic DMARD; tsDMARD, targeted synthetic DMARD; DMARD, disease-modifying antirheumatic drug; NSAID, nonsteroidal anti-inflammatory drug; TNF, tumor necrosis factor; ADL, activities of daily living such as bathing, eating, dressing.

csDMARD medications included: Antimalarials (hydroxychloroquine, chloroquine), azathioprine, cyclophosphamide, cyclosporine, leflunomide, methotrexate, mycophenolate mofetil/mycophenolic acid, sulfasalazine, tacrolimus.

bDMARD included: Abatacept, belimumab, CD-20 inhibitors, IL-1 inhibitors, IL-6 inhibitors, IL-12/IL-23 inhibitors, IL-17 inhibitors, and anti-TNF.

tsDMARD included: Janus Kinase inhibitors.

Other included: IVIG, apremilast, thalidomide.

*Participants may have more than one condition and take more than one type of medication.

due to concern for immunosuppression, most frequently glucocorticoids in nine children (9/102, or 8.8% of children who were taking glucocorticoids; Figure 1). In 14 of the 17 children who stopped medications (14/17, 82.4%), the decision was made by the rheumatologist, whereas, in the other 3 cases (3/17, 17.6%), the decision was made by the family. Difficulties obtaining prescription medications in the pharmacy were rare but often occurred with glucocorticoids (5/102, 4.9%).

Engagement in protective and risky behaviors

Almost all families (425/427, 99.5%) observed at least some protective behavior, including quarantining (410/427, 96.0%), social distancing (277/427, 64.9%), or using masks and/or gloves (157/427, 36.8%) (Table 2). A third of families (131/427, 30.7%) observed all protective behaviors. At the same time, most families (313/420, 74.5%) avoided engaging in risky behaviors that could increase their child's risk of becoming infected. The most common potential exposure was presence in a healthcare facility where COVID-19 cases were being managed, reported by 12.4% (52/420) of families.

Communication with rheumatologist

Families communicated with their rheumatologists most commonly through the telephone (36.8%, 157/427) or email/patient portal (33.3%, 142/427). Only 4.7% (20/427) were unable to contact their rheumatologist during this time.

Impact on education

Most children (82.2%, 351/427) were full-time students prior to the pandemic. At the time of the survey, the majority of students (67.2%, 236/351) had switched to virtual classes, 21.4% (75/351) had their classes canceled, 1.7% (6/351) continued attending classes in the classroom, and 9.7% (34/351) reported other changes, such as being homeschooled.

Discussion

From this international cross-sectional survey of parents of children with parental-reported PRD with frequent immunosuppression use in the early phase of the pandemic, we report the widespread impacts of the COVID-19 pandemic on education, behaviors, healthcare access, and medication usage. There were significant disruptions to children's education related to the COVID-19 pandemic. Of the 351 children attending school full-time prior to the pandemic, the great majority had their classes converted to virtual classrooms or canceled. While school closures quickly affected most children worldwide, evidence grew that showed a school's low risk for COVID-19 transmission and the potential for school closures to cause harm.[5,9] Estimates suggest that every

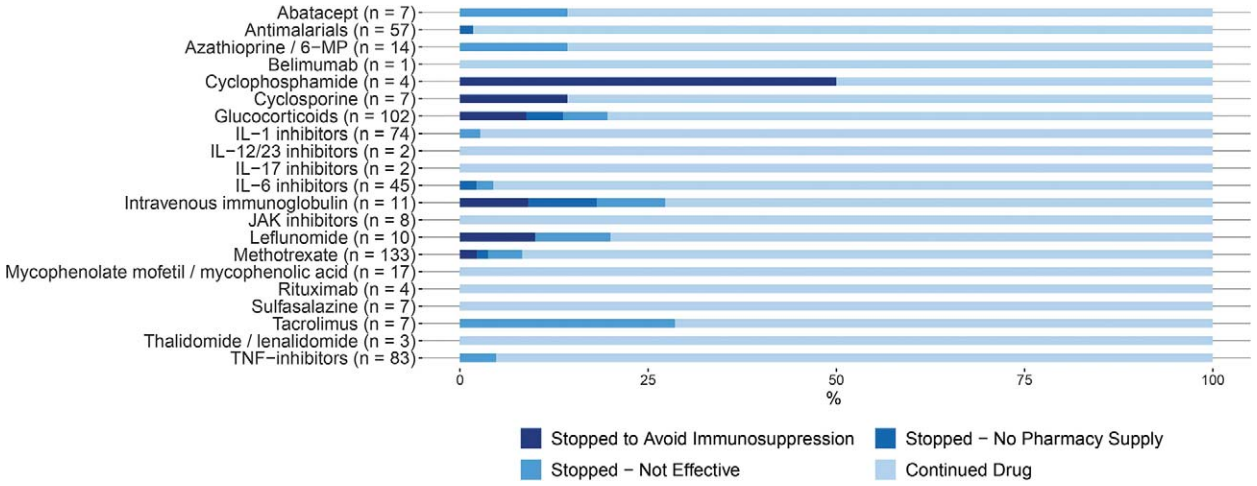

Figure 1. Medication changes during the pandemic. Parents reported whether their child's drug was continued, stopped due to inefficacy, stopped to avoid immunosuppression, or stopped because there was a lack of pharmacy supply.

Table 2. Protective and Risky Behaviors and Methods of Communication with a Rheumatologist During the Early Phase of the COVID-19 Pandemic

	N	%
Protective behaviors*	427	
Quarantining	410	96.0
Government imposed	217	52.9
Social distancing	277	64.9
Using masks and/or gloves	157	36.8
None	2	0.5
All protective behaviors (quarantining, social distancing, and using gloves/masks)	131	30.7
Risky behaviors*	420	
Presence in healthcare facility	52	12.4
Close contact with confirmed/probable case of COVID-19	10	2.4
Travel to an area of high COVID-19 prevalence	16	3.8
Other	17	4.0
None	313	74.5
Don't know	32	7.6
Any risky behavior	75	17.6
1 risky behavior	58	13.8
2 risky behaviors	14	3.3
3+ risky behaviors	3	0.7
Communication with rheumatologist*	427	
Telephone	157	36.8
Email/patient portal	142	33.3
Office visit	42	9.8
Telemedicine	39	9.1
Other (social media/texting)	25	5.8
Not needed to communicate	97	22.7
Unable to communicate	20	4.7

*Participants may indicate more than one method of communication with a rheumatologist, protective behavior, and risky behavior.

year of additional schooling adds 10% to future salary earnings[10] thus, a loss of a school year can have significant, long-term impacts. These findings are especially concerning for children with PRD, who, studies have shown, may have higher rates of unemployment as compared to their peers once they become adults[11,12]

Almost all families reported adopting protective behaviors to avoid COVID-19 exposure and most avoided activities that could increase their child's risk of infection. The high uptake of protective behaviors among this cohort of children with PRDs suggests families' increased perceived risk of COVID-19 infection. Studies of adults with rheumatic diseases have shown that they are more likely to quarantine than healthy controls[13] and that those taking bDMARDs are more likely to quarantine than those taking other DMARDs.[14] It is also interesting to note that the rates of quarantining among the children

of this cohort were higher than those of adult patients with rheumatic diseases from the same survey (96.0% vs 85.5%), despite a child's lower risk of adverse outcomes.[7] This could reflect increased parental concern for their child's health compared to their own, not unlike other protective health behaviors, such as the use of sunscreen.[15,16]

At the same time, parents continued their child's immunosuppression in most cases. It is possible that the high frequency of communication between families and their rheumatologists during this time of uncertainty successfully discouraged families from discontinuing immunosuppression. Although previous studies found that pediatric rheumatologists were likely to "reduce the use/dosage/frequency of biologics" in their patients,[3] we show real-world data that this did not appear to be happening at scale. Even during the early phase of the pandemic, rheumatologists worldwide shared their experiences in caring for children with PRDs on social media[17] and through networks such as the COVID-19 Global Rheumatology Alliance.[18] These efforts may have been crucial to disseminating information to physicians about the safety of continuing immunosuppression in children with PRD, even before professional organizations released their guidance statements with similar recommendations.[19]

These results also underscore the importance of communication between families and their healthcare providers, especially during times of crisis. As the COVID-19 pandemic progressed and continued to disrupt in-person visits, telemedicine encounters became essential within pediatric rheumatology and allowed for the continuation of care of children with PRDs with their rheumatologists.[20] While not without its shortcomings, options for telemedicine should remain available for children with PRDs in a post-pandemic world, especially given the shortage of rheumatologists.[21]

Compared to adults with rheumatic diseases who answered the same survey, COVID-19 was less frequently reported among these children, all of whom had favorable outcomes. Other research studies do not appear to show increased incidences of COVID-19 among children or adults with rheumatic diseases treated with antirheumatic drugs.[22–25] Further, studies of adults with rheumatic disease who develop COVID-19 showed that conventional, biologic, or targeted synthetic DMARDs do not appear to increase the risk of hospitalization due to COVID-19, whereas glucocorticoid use in doses $\geq$10 mg daily do appear to increase that risk.[26] In our study, it is interesting to note that glucocorticoids were the drugs stopped in the largest number of children, perhaps because there may be more flexibility in their use, as compared to DMARDs. At the time of this survey, the increased risk of hospitalization with higher doses of glucocorticoids was not yet known. It is also reassuring that of the 57 children taking antimalarials, the great majority did not face medication shortages in the pharmacy, which many adult patients experienced as hydroxychloroquine was repurposed for the treatment of COVID-19.[27]

This study's limitations include a convenience sample of parents of children with PRDs engaged via patient organizations and social media and willing to participate in a research study, which does not represent the pediatric rheumatology population. Most respondents were white and from the Americas. The poor representation of racial and ethnic minorities in this study is likely related to multiple factors, including distrust of the medical system[28] and poor representation of minorities within patient support groups.[29] There is an overrepresentation of children with more rare PRDs, perhaps related to the increased presence of these parents online to find information and receive support from other families managing children with similar diseases.[30] All data, including diagnosis of PRD, were self-reported and could not be verified, and none of the children had confirmation of COVID-19 through laboratory testing. Hospitalized children with COVID-19 may be underrepresented, although studies of pediatric rheumatology units, even in areas significantly affected by COVID-19, do not report significant numbers of children with rheumatic disease with adverse outcomes.[31]

In conclusion, even though only a handful of children with PRD developed COVID-19 in this cohort, we show the extent to which the pandemic affected children's daily lives. Almost all families quarantined to decrease the risk of infection in their children. For the most part, they continued their child's immunosuppression and were able to communicate with their child's rheumatologist remotely. Educational disruptions were widespread. The long-term impacts of these changes on the physical and mental well-being of children with PRD remain to be seen.

Ethics Committee Approval: The study was deemed exempt by the Institutional Review Board of Boston Children's Hospital.

Peer-review: Externally peer-reviewed.

Author Contributions: Concept - J.S.H., E.S.; Design - J.S.H., K.K., E.S.; Data collection and/or analysis: J.S.H., K.K., S.S., M.J.L., R.S., K.D., G.F., M.L., L.T., W.C., P.C.R., J.W.L., J.Y., E.S.; Writing - J.S.H., K.K., J.W.L., E.S.; Critical reviews - J.S.H., K.K., S.S., M.J.L., R.S., K.D., G.F., M.L., L.T., W.C., P.C.R., J.W.L., J.Y., E.S.

Acknowledgments: The authors would like to thank our patient partner organizations and their members for their continued support and guidance, and without whom the development of the COVID-19 Rheumatology Patient Experience Survey would not have been possible.

Conflict of Interest: J.S.H.: Grants from the Rheumatology Research Foundation, Childhood Arthritis and Rheumatology Research Alliance (CARRA), and consulting from Novartis, Pfizer, and Biogen, all not related to this work.

M.J.L.: Grants/consultancy/honoraria from AbbVie, Amgen, Boehringer-Ingelheim, BMS, Celgene, Janssen, Mallinckrodt, Novartis, Pfizer, Roche, Sandoz, UCB, all not related to this work.

R.S.: Grant from the Chan Zuckerberg Foundation, not related to this work.

P.C.R.: Consultancy to Abbvie, Eli Lilly, Janssen, Gilead, Novartis, Pfizer, Roche, UCB. In-kind support from BMS. Research funding from Novartis, Janssen, and UCB.

J.W.L.: Research grant from Pfizer not related to this work.

J.Y.: Consultancy to AstraZeneca and Eli Lilly, not related to this work. NIH/NIAMS P30, AR070155, and K24AR074534.

E.S.: Board Member of the Canadian Arthritis Patient Alliance, a patient-run, volunteer-based organization whose activities are primarily supported by independent grants from pharmaceutical companies.

K.K., S.S., K.D., G.F., M.L., L.T., and W.C. have no COI to declare.

Financial Disclosure: This work was supported by The COVID-19 Global Rheumatology Alliance, which is funded by the American College of Rheumatology and EULAR. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

Disclaimer: 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, the European League Against Rheumatism (EULAR), or any other organization.

REFERENCES

1. Beukelman T, Xie F, Chen L, et al. Rates of hospitalized bacterial infection associated with juvenile idiopathic arthritis and its treatment.

Arthritis Rheum. 2012;64:2773-2780. [CrossRef]
2. Becker I, Horneff G. Risk of serious infection in juvenile idiopathic arthritis patients associated with tumor necrosis factor inhibitors and disease activity in the German Biologics in Pediatric Rheumatology Registry. *Arthritis Care Res*. 2017;69:552-560. [CrossRef]
3. Mehta B, Jannat-Khah D, Mancuso CA, et al. Geographical variations in COVID-19 perceptions and patient management: A national survey of rheumatologists. *Semin Arthritis Rheum*. 2020;50:1049-1054. [CrossRef]
4. Dejaco C, Alunno A, Bijlsma JW, et al. Influence of COVID-19 pandemic on decisions for the management of people with inflammatory rheumatic and musculoskeletal diseases: A survey among EULAR countries. *Ann Rheum Dis*. 2021;80:518-526. [CrossRef]
5. Golberstein E, Wen H, Miller BF. Coronavirus disease 2019 (COVID-19) and mental health for children and adolescents. *JAMA Pediatr*. 2020;174:819-820. [CrossRef]
6. Sirotich E, Dillingham S, Grainger R, et al. Capturing patient-reported outcomes during the COVID-19 pandemic: Development of the COVID-19 global rheumatology alliance patient experience survey. *Arthritis Care Res*. 2020;72:871-873. [CrossRef]
7. Hausmann JS, Kennedy K, Simard JF, et al. Immediate effect of the COVID-19 pandemic on patient health, health-care use, and behaviours: Results from an international survey of people with rheumatic diseases. *Lancet Rheumatol*. 2021;3(10):e707-e714. [CrossRef]
8. R Core Team. R: A Language and Environment for Statistical Computing. https://www.R-project.org/. Accessed November 11, 2021.
9. Buonsenso D, Roland D, Rose CD, et al. Schools closures during the COVID-19 pandemic: A catastrophic global situation. *Pediatr Infect Dis J*. 2021;40: E 146-e150. [CrossRef]
10. Psacharopoulos G, Patrinos HA. Returns to investment in education: A decennial review of the global literature. *Educ Econ*. 2018;26:1-14.
11. Foster HE, Marshall N, Myers A, Dunkley P, Griffiths ID. Outcome in adults with juvenile idiopathic arthritis: A quality of life study. *Arthritis Rheum*. 2003;48:767-775. [CrossRef]
12. Packham JC, Hall MA. Long-term follow-up of 246 adults with juvenile idiopathic arthritis: Social function, relationships and sexual activity. *Rheumatology*. 2002;41:1440-1443. [CrossRef]
13. Hooijberg F, Boekel L, Vogelzang EH, et al. Patients with rheumatic diseases adhere to COVID-19 isolation measures more strictly than the general population. *Lancet Rheumatol*. 2020;2:e583-e585. [CrossRef]
14. Yates M, Mahil S, Langan S, et al. Risk mitigating behavior in people with rheumatic diseases or psoriasis during the COVID-19 pandemic differ by immunosuppressant treatment type: A patient survey study [abstract]. *Arthritis Rheumatol*. 2020;72(suppl 10). https://acrabstracts.org/abstract/risk-mitigating-behavior-in-people-with-rheumatic-diseases-or-psoriasis-during-the-covid-19-pandemic-differ-by-immunosuppressant-treatment-type-a-patient-survey-study/. Accessed September 21, 2021.
15. Scerri L, Aquilina S, Gauci AA, Dalmas M. Sun awareness and sun protection practices in Malta. *J Eur Acad Dermatol Venerol*. 2002;16:47-52. [CrossRef]
16. Weinstein JM, Yarnold PR, Hornung RL. Parental knowledge and practice of primary skin cancer prevention: Gaps and solutions. *Pediatr Dermatol*. 2001;18:473-477. [CrossRef]
17. Hausmann JS, Sufka P, Bhana S, et al. Conducting research in a pandemic: The power of social media. *Eur J Rheumatol*. 2020;7:S85-S88. [CrossRef]
18. Wallace ZS, Bhana S, Hausmann JS, et al. The rheumatology community responds to the COVID-19 pandemic: The establishment of the COVID-19 global rheumatology alliance. *Rheumatol Oxf Engl*. 2020;59:1204-1206. [CrossRef]
19. Wahezi DM, Lo MS, Rubinstein TB, et al. American college of rheumatology guidance for the management of children with pediatric rheumatic disease during the COVID-19 pandemic: Version 1. *Arthritis Rheumatol*. 2020;72:1809-1819. [CrossRef]
20. Goh YI, Bullock DR, Taylor J, et al. Exploring pediatric Tele-Rheumatology practices during COVID-19: A survey of the PRCOIN network. *Front Pediatr*. 2021;9:642460. [CrossRef]
21. Correll CK, Ditmyer MM, Mehta J, et al. American College of Rheumatology workforce study and demand projections of pediatric rheumatology workforce, 2015-2030. *Arthritis Care Res*. 2020. DOI: 10.1002/acr.24497.
22. Michelena X, Borrell H, López-Corbeto M, et al. Incidence of COVID-19 in a cohort of adult and paediatric patients with rheumatic diseases treated with targeted biologic and synthetic disease-modifying anti-rheumatic drugs. *Semin Arthritis Rheum*. 2020;50:564-570. [CrossRef]
23. Gianfrancesco M, Yazdany J, Robinson PC. Epidemiology and outcomes of novel coronavirus 2019 in patients with immune-mediated inflammatory diseases. *Curr Opin Rheumatol*. 2020;32:434-440. [CrossRef]
24. Haslak F, Yildiz M, Adrovic A, et al. Management of childhood-onset autoinflammatory diseases during the COVID-19 pandemic. *Rheumatol Int*. 2020;40:1423-1431. [CrossRef]
25. Yildiz M, Haslak F, Adrovic A, Sahin S, Barut K, Kasapcopur O. The frequency and clinical course of COVID-19 infection in children with juvenile idiopathic arthritis. *Clin Exp Rheumatol*. 2020;38(6):1271-1272.
26. Gianfrancesco M, Hyrich KL, Al-Adely S, et al. Characteristics associated with hospitalisation for COVID-19 in people with rheumatic disease: Data from the COVID-19 global rheumatology alliance physician-reported registry. *Ann Rheum Dis*. 2020;79:859-866. [CrossRef]
27. Mendel A, Bernatsky S, Askanase A, et al. Hydroxychloroquine shortages among patients with systemic lupus erythematosus during the COVID-19 pandemic: Experience of the systemic lupus international collaborating clinics. *Ann Rheum Dis*. 2021;80:1-2. [CrossRef]
28. Sirotich E, Hausmann JS. Removing barriers and disparities in health: Lessons from the COVID-19 pandemic. *Nat Rev Rheumatol*. 2021;17:125-122. [CrossRef]
29. Mandell DS, Salzer MS. Who joins support groups among parents of children with autism? *Autism*. 2007;11:111-122. [CrossRef]
30. Hausmann JS, Vizcaino-Riveros J, Marin A, et al. Feasibility and efficacy of online strategies to recruit parents of children with rheumatic diseases for research. *ACR Open Rheumatol*. 2021 (accepted manuscript).
31. Costi S, Caporali R, Cimaz R. Dealing with COVID-19 in a pediatric rheumatology unit in Italy. *Pediatr Drugs*. 2020;22:263-264. [CrossRef]

Supplementary Table 1. Characteristics of Children Reported to Have COVID-19 (N = 5)

	n	%
Rheumatic diagnosis		
Juvenile idiopathic arthritis (JIA)	2	40
Autoinflammatory disease	2	40
Systemic JIA	1	20
COVID-19 symptoms		
Malaise	4	80
Fever	3	60
Headache	3	60
Sore throat	3	60
Arthralgias	3	60
Chest pain	2	40
Abdominal pain	2	40
Cough	2	40
Myalgias	1	20
Vomiting	1	20
Anosmia	1	20
Rhinorrhea	1	20
Irritability/confusion	1	20
How COVID-19 diagnosis was made		
Self-diagnosis	3	60
Physician diagnosis based on symptoms	2	40
Length of illness		
Days 5 or less	2	40
20+ days	2	40
Unresolved at time of survey (13+ days)	1	20
COVID-19 Severity		
Not hospitalized, some limitations in ADLs	3	60
Not hospitalized, no limitation in ADLs	2	40
Potential COVID-19 exposures		
Close contact with COVID-19	1	20
Healthcare facility contact	1	20
None/don't know	3	60
Rheumatic disease control at the time of COVID-19 diagnosis		
Mean disease activity score	2.4 (range: 0-7)	
Rheumatic medications at the time of COVID-19 diagnosis		
NSAIDs	3	60
Methotrexate	1	20
None	1	20

ADL, activities of daily living.
Disease activity score is a visual analog scale from 0 = very well to 10 = very poor.