

Gout management and outcomes during the COVID-19 pandemic: a cross-sectional internet survey

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Abstract

Aim: We aimed to assess the gout management during the COVID-19 pandemic. Methods: We assessed medication use, healthcare utilization, gout-specific health-related quality of life (HRQoL) on the Gout Impact Scale (GIS), psychological distress using the patient health questionnaire-4 (PHQ-4), and resilience in people with self-reported physiciandiagnosed gout during the COVID-19 pandemic in a cross-sectional Internet survey. Results: Among the 122 survey respondents with physician-diagnosed gout, 82% were prescribed urate-lowering therapy (ULT) and 66% were taking ULT daily; mean age was 54.2 years [standard deviation (SD), 13.8], 65% were male, and 79% were White. More regular use of gout medication was reported during the COVID-19 pandemic: allopurinol, 44%; colchicine, 37%; non-steroidal anti-inflammatory drugs, 36%. Gout flares were common: 63% had ≥1 gout flare monthly; 11% went to emergency room/urgent care; and 2% were hospitalized with gout flares. Between 41% and 56% of respondents reported more difficulty with gout management and related functional status related to COVID-19; 17-37% had difficulty with healthcare access for gout. HRQOL deficits were evident for gout concern overall, 79.4 (SD, 25); unmet gout treatment need, 64.5 (SD, 27.1); and gout concern during flare, 67.3 (SD, 27.1); but less so for gout medication side effects, 48.9 (SD, 27.4). Psychological distress was moderate in 19% and severe in 15% (mild, 22%; normal, 45%). Resilience score on Connor-Davidson Resilience Scale (CD-RISC2) was 5.6 (SD, 1.8; range 0-8). Compared with no/mild psychological distress, moderate-severe psychological distress during the COVID-19 pandemic was significantly associated with more difficulty getting gout medication filled (p = 0.02), flares treated (p = 0.005), and receiving gout education (p = 0.001).

Conclusion: Healthcare gaps, psychological distress, and HRQoL deficits were commonly reported by people with gout during the COVID-19 pandemic. Interventions to address these challenges for people with gout during the COVID-19 pandemic are needed.

Keywords: COVID-19, disease management, gout, internet, medication use, psychological distress, quality of life, resilience, survey

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Introduction

Gout is the most common inflammatory arthritis in adults, affecting 9.2 million Americans.¹ The use of urate-lowering therapy (ULT) for gout is associated with a reduction of gout flares and improved function,²⁻⁴ is recommended by gout

treatment guidelines,^{5,6} and helps achieve patient preferred goals in gout.^{7,8} The corona virus disease 2019 (COVID-19) has significantly impacted healthcare delivery in the U.S. Specifically, outpatient healthcare in the U.S. is currently a hybrid of in-person and telemedicine

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visits, compared with the conventional in-person visits only.9

A recent survey of people with rheumatic diseases found that disruptions in accessing rheumatic disease medications, including hydroxychloroquine, were among key patient concerns.¹⁰ However, a majority of these respondents had rheumatoid arthritis or osteoarthritis.¹⁰ To our knowledge, there are no studies of the impact of COVID-19 on people with gout.

Our objective was to assess the current patterns of gout care, including medication use and health-care access, health-related quality of life (HRQoL), psychological distress, and patient resilience, in people with gout in the midst of COVID-19. We aimed to explore these relationships in a cross-sectional survey study. We anticipated HRQoL deficits and moderate—high psychological distress in respondents, and an association of high psychological distress and lower resilience with poorer HRQoL, related to the COVID-19 pandemic.

Methods

We performed an online cross-sectional survey from April to June 2020 to examine the experiences of people with gout and the impact of the COVID-19 pandemic on gout care. We invited people visiting the website of the Gout Education Society (http://gouteducation.org), a U.S. non-profit organization of healthcare professionals dedicated to educating the public and healthcare community about gout, to participate in a brief anonymized Internet survey on a voluntary basis between April and June 2020. This study was approved by the human ethics committee at the University of Alabama at Birmingham (UAB).

In addition to the demographics, we collected information on the use of medications for gout including ULT (allopurinol, febuxostat, and probenecid) and the patterns of use, gout flares, gout-specific quality of life, psychological distress, resilience, medication adherence, and the impact of the COVID-19 pandemic on difficulty with gout care and healthcare access. Gout-specific quality of life was assessed by the gout-specific HRQoL assessed with the Gout Impact Scale (GIS) of the Gout Assessment Questionnaire. 11,12 It has 13 items that are

summed to provide the four subscales, namely, gout concern overall, unmet need, medication side effects, and concern during gout attack, each with a 0-100 score (higher score indicating more concern/need). The minimally clinical important difference (MCID) threshold on the four GIS subscales is 5-8 points. 12 We omitted the fifth GIS subscale of well-being during attack scale, since it consisted of 11 questions and our pragmatic decision was to keep the survey short and feasible for people visiting the gout website for information and education. To assess psychological distress we used the patient health questionnaire-4 (PHO-4), a brief validated measure of psychological distress (anxiety and depression) with scores in the range 0-12, higher scores indicating more psychological distress; scores were categorized to indicate normal (0-2), mild (3-5), moderate (6-8), and severe (9-12) psychological distress.¹³

We measured resilience, a stress coping ability, with a validated two-item Connor-Davidson Resilience Scale (CD-RISC2),¹⁴ scored from 0 to 8, higher scores corresponding with higher resilience, with a general population mean of 6.9.14 We categorized CD-RISC2 score of 7 or 8 as normal/high resilience since they are at par with the general population. Medication adherence was measured using the brief validated three-item measure by Voils et al., 15 scores ranging from 1 (perfect adherence) to 5 (perfect non-adherence). The overall score is an average of scores on three items. We used chisquare test for categorical or t-test for continuous variables. A p-value < 0.05 was considered statistically significant.

Results

Of the 228 visitors to the website who clicked on the survey, 122 survey respondents reported physician-diagnosed gout with a mean age of 54.2 years (SD, 13.8), 65% male, 79% White and 3% were Hispanic or Latino (Table 1). Among people with physician-diagnosed gout, 82% had been prescribed ULT by their provider; 30% had concomitant osteoarthritis, and 7% had concomitant pseudogout.

Gout flares were common in people during the COVID-19 pandemic (since 1 March 2020) with 63% reporting one or more gout flares monthly;

Table 1. Characteristics of the 122 study participants with doctor-diagnosed gout§.

	n (%)* N=122
Age in years, mean (standard deviation)	54.2 (13.8)
Male gender	79 (65%)
Race/ethnicity	
White	96 (79%)
Black or African American	7 (6%)
Asian	6 (10%)
American Indian or Alaskan Native	2 (2%)
Native Hawaiian or other Pacific Islander	4 (3%)
Other	3 (3%)
Hispanic ethnicity	4 (3%)
Urate-lowering therapy (ULT)¶ prescribed by doctor	100 (82%)
Concomitant additional doctor-diagnosed arthritic conditions§	
Osteoarthritis	37 (30%)
Calcium pyrophosphate deposition disease (CPPD)	9 (7%)
Number of gout flares per month since 1 March 2020 (the beginning of COVID-19 in U.S.)	 †
0	22 (18%)
1	31 (25%)
2	23 (19%)
3	10 (8%)
4 or more	14 (11%)
Visits to urgent care or emergency room per month with gout flare $\!\!\!^\ddagger$ since 1 March 2020	
0	78 (64%)
1	7 (6%)
2	5 (4%)
3 or more	1 (1%)
Hospitalized with gout flare since 1 March 2020	3 (2%)

^{*}n (%), unless specified otherwise.

[¶]ULT includes allopurinol, febuxostat or probenecid.

Has your doctor prescribed allopurinol (also called Zyloprim or Aloprim) or febuxostat (also called Uloric) or probenecid (also called benemid) for you? Yes No.

[§]Have you been told by a doctor that you have gout, calcium pyrophosphate disease (also called pseudogout) or osteoarthritis (wear and tear or cartilage loss or old-age arthritis)? Yes No.

Please check all of the diagnosis you have received from a healthcare provider (you can select more than one answer). Gout calcium pyrophosphate disease (also called pseudogout). Osteoarthritis (wear and tear or cartilage loss or old-age arthritis).

[†]Missing, n = 22 (18%).

[‡]Missing, n = 31 (25%).

11% went to the urgent care or emergency room for gout flares and 2% were hospitalized with gout flares (Table 1).

Gout medication use during COVID-19

A total of 66% of the survey respondents were taking their ULT daily and 6% were taking ULT intermittently (Supplementary Material Appendix 1 online). Regular or intermittent current use of anti-inflammatory drugs was reported commonly: colchicine, 45%; non-steroidal anti-inflammatory drugs (NSAIDs), 49%; and glucocorticoids, 27% (Supplementary Appendix 1).

Interestingly, 44% of respondents reported taking allopurinol more regularly, 15% were taking febux-ostat more regularly and 5% were taking probenecid more regularly since 1 March 2020 due to the coronavirus pandemic (Supplementary Appendix 1). A more regular intake of anti-inflammatory drugs was also reported commonly due to the coronavirus pandemic: colchicine, 37%; NSAIDs, 36%; and glucocorticoids, 15% (Supplementary Appendix 1).

Healthcare access during COVID-19

In total, 41% of survey respondents reported more difficulty with their gout overall and 41% reported more difficulty with the management of gout flares since the beginning of the COVID-19 epidemic in the U.S. (Supplementary Appendix 2). A similar proportion of patients reported difficulty with gout-related pain issues, performing activities at home, performing work and participating in social activities (Supplementary Appendix 2).

A total of 37% of the survey respondents reported difficulty in getting healthcare for gout in the outpatient clinic, and a smaller proportion reported difficulty in getting healthcare for gout in the emergency room (17%) or hospital (17%) (Supplementary Appendix 2). One in five patients reported difficulty in getting gout medication refills from the doctor and one in 10 of filling their gout medication prescription at the pharmacy. One in five patients reported difficulty in avoiding gout flares, avoiding complications of gout, getting information and education for self-management, and getting healthcare for gout flares.

Gout-specific quality of life, psychological distress, and resilience in people with gout during COVID-19

Mean GIS subscale scores in the pre-COVID-19 period were as follows: gout concern overall, 75.6 (SD, 30); unmet gout treatment need, 62.7 (SD, 29); gout medication side effects, 48.8 (SD, 30); and gout concern during flare, 64.8 (SD, 29) (Supplementary Appendix 3). Scores were a little higher (worse) numerically during the COVID-19 pandemic compared with the pre-COVID-19 period (Supplementary Appendix 3); these differences were not statistically significant. Mean scores on PHO-2 depression, PHO-2 anxiety, and PHQ-4 psychological distress scores were 1.9, 2.1, and 3.9, respectively (Supplementary Appendix 4). Psychological distress on PHQ-4 was normal in 45%, mild in 22%, moderate in 19%, and severe in 15% (Supplementary Appendix 4). Resilience score on CD-RISC2 scale was 5.6 (SD, 1.8) and 56% of the survey respondents had a CD-RISC2 score of 6 or higher.

During the COVID-19 pandemic, all four GIS subscales were significantly positively correlated with PHQ-2 depression, PHQ-2 anxiety and PHQ-4 psychological distress; in the pre-COVID-19 period, less consistent correlations were noted between GIS subscales and PHQ-2 depression and PHQ-4 psychological distress; none were noted with PHQ-2 anxiety (Supplementary Appendix 5).

Association of psychological distress with gout management during COVID-19

Moderate—severe psychological distress was significantly associated with more difficulty getting gout medication filled at the pharmacy, getting gout flares treated, and getting information and education to keep gout under control during this coronavirus epidemic (Table 2). People with moderate—severe psychological distress had more difficulty during this coronavirus epidemic with gout flares, chronic pain issues related to gout, and performing daily activities at home (Table 2).

COVID-19 infection and testing in people with gout

Eleven respondents reported a family member or friend testing positive for COVID-19. Six

Table 2. Association of psychological distress with gout and associated pain and function and access to healthcare for gout.

	No/mild psychological distress		Moderate/severe psychological distress		
	Agree	Not certain/ disagree	Agree	Not certain/ disagree	<i>p</i> -value
Due to the coronavirus epidemic, I have had more difficulty in.					
Getting healthcare for my gout in the clinic	34 (75.6%)	11 (24.4%)	15 (55.6%)	12 (44.4%)	0.08
Getting healthcare for my gout in the emergency room or urgent care	40 (71.4%)	16 (28.6%)	6 (50.0%)	6 (50.0%)	0.15
Getting healthcare for my gout in the hospital	41 (70.7%)	17 (29.3%)	6 (50.0%)	6 (50.0%)	0.16
Getting my gout medication refills from the doctor	40 (70.2%)	17 (29.8%)	6 (50.0%)	6 (50.0%)	0.18
Getting my gout medication filled at the pharmacy	46 (71.9%)	18 (28.1%)	2 (28.6%)	5 (71.4%)	0.02
Getting my gout flares treated	40 (75.5%)	13 (24.5%)	6 (37.5%)	10 (62.5%)	0.005
Avoiding my gout flares	36 (69.2%)	16 (30.8%)	8 (57.1%)	6 (42.9%)	0.39
Avoiding complications of my gout/arthritis	39 (75.0%)	13 (25.0%)	7 (50.0%)	7 (50.0%)	0.07
Getting information and education about how to keep gout under control	41 (77.4%)	12 (22.6%)	5 (33.3%)	10 (66.7%)	0.001
Compared with before the coronavirus epidemic, I have had m	nore difficulty du	ıring this epidem	nic with		
Gout overall	31 (73.8%)	11 (26.2%)	18 (60.0%)	12 (40.0%)	0.21
Gout flares	32 (78.0%)	9 (22.0%)	15 (51.7%)	14 (48.3%)	0.02
Chronic pain issues related to gout/arthritis	31 (83.8%)	6 (16.2%)	16 (48.5%)	17 (51.5%)	0.002
Performing my daily activities at home	30 (78.9%)	8 (21.1%)	17 (53.1%)	15 (46.9%)	0.02
Performing my work	26 (74.3%)	9 (25.7%)	20 (58.8%)	14 (41.2%)	0.17
Participating in social activities	24 (77.4%)	7 (22.6%)	22 (57.9%)	16 (42.1%)	0.09

respondents had been tested and all six were COVID-19 negative.

Discussion

In this Internet survey of 122 participants with physician-diagnosed gout, we assessed the impact of COVID-19 pandemic on gout care. Survey respondents reported taking allopurinol, colchicine or NSAIDs more regularly for gout during COVID-19. Gout flares were common and led to urgent care or emergency room visits in 11% and hospitalization in 2% of the survey respondents during the COVID-19 pandemic. Forty-one percent of the respondents reported more difficulty with their gout overall, including the management

of gout flares, gout-related pain, performing activities at home, performing work, and participating in social activities, during the COVID-19 pandemic. One-third of the respondents reported moderate or severe psychological distress; the CD-RISC2 score was 5.6. Several study findings merit further discussion.

A more regular intake of allopurinol in 44%, colchicine in 37% and NSAIDs in 36% was reported by the survey respondents during COVID-19, which might be due to increased patient self-management. This may be at least partially due to infrequent provider visits, a desire to avoid visits to healthcare facilities due to the fear of contracting COVID-19, and/or a higher patient confidence in

the effectiveness of gout medications in the absence of other options, due to limited availability of overthe-counter medications and/or natural supplements from the neighborhood pharmacy or the grocery store. Two-thirds of respondents were taking their ULT daily, higher than that reported previously. 16,17 Gout-specific HROoL assessed with GIS subscale scores was worse in our study during the COVID-19 pandemic compared with a community-based sample of people with gout in a previous study:11 gout concern overall, 79.4 (SD, 25) versus 63.1 (SD, 22); unmet gout treatment need, 64.5 (SD, 27.1) versus 38.2 (SD, 21); gout medication side effects, 48.9 (SD, 27.4) versus 48.3 (SD, 26); and gout concern during flare, 67.3 (SD, 27.1) versus 50.2 (SD, 24).11 Differences in three of the four GIS subscale scores (except medication side effects subscale) exceeded the MCID threshold of 5-8 points, 12 with a caveat that differences are between two patient populations rather than within a participant over time. Even larger differences were noted compared with a Dutch rheumatology clinic study in people with mean age of 67 years, 84% men, with respective GIS subscale scores of 53.8, 48.1, 45.2, and 44.7.18

The total PHQ-4 psychological distress score was 2.9 in Spanish speaking Hispanic people and 2.1 in English speaking Hispanic people¹⁹ in a community-based sample; the PHQ-4 score was reported to be 3.0 in college students.²⁰ In our study, the total PHQ-4 psychological distress score was 3.9, relatively higher than that noted in the previous studies. We cannot be sure whether this reflects COVID-19 pandemic-related stress or diseaserelated difference. An Internet study sample and differences in patient characteristics might be another reason for differences in adherence, HRQoL, and psychological distress. A moderate significant correlation was found between psychological distress and gout-specific HRQoL during the COVID-19 pandemic, an interesting finding in line with our expected study outcomes.

Previous studies of resilience showed that the mean CD-RISC2 scores in the 5-7 range, specifically, as follows: U.S. general population, 6.9; family medicine outpatients, 6.0; psychiatric outpatients, 6.1; patients with depression, 5.1; patients with generalized anxiety disorder, 5.0; and patients with post-traumatic stress disorder, 4.7. In our study, the mean CD-RISC2 score was 5.6, slightly lower than that noted in family medicine outpatient practice, and lower than the U.S. general population. Whether this lower

resilience is related to COVID-19, gout, or both cannot be determined from this study, given the lack of previous data on resilience in gout.

The association of psychological distress with more difficulty in managing gout and in getting healthcare access for gout is interesting. Due to the crosssectional nature of the study, we are unable to determine the direction of the association. This is similar to increased psychological distress noted in other cohorts of people with chronic diseases in the COVID-19 era.²¹ Interventions to address the healthcare access and/or psychological distress in people with gout may help improve gout management and outcomes during the COVID-19 pandemic. Peer-support, nurse-health worker support, and/or the use of technology to better connect patients with the provider teams all have the potential to reduce the effect of the COVID-19 pandemic on these important outcomes.

Our findings should be interpreted considering study limitations. We did not come across similar studies in other rheumatic diseases, so it is not possible to say whether these findings are goutspecific or not. Our cross-sectional survey study is at the risk of selection bias, since patients selfselected for participation, which makes our study findings generalizable only to gout patients who use the Internet and not to all gout patients. Those with more active gout or associated distress may have been more likely to visit the gout website and participate in our study. Nonresponder characteristics are not available, due to the nature of the study. We omitted one of the GIS subscales, well-being during the attack, for survey brevity and feasibility, which may have given us important data. Data regarding gout unmet treatment need should be interpreted with caution, given only a moderate test-retest reliability of 0.56-0.65.11,18 The validity of self-reported physician diagnosis of gout cannot be confirmed, although the question is based on various population-based surveys by the Centers for Disease Control and Prevention.²² The associations we noted could be in either direction, and therefore causation should not be interpreted.

Our study has several strengths as well. We focused on key questions related to gout management during the COVID-19 pandemic. We kept the survey brief to reduce responder burden. We made most questions non-mandatory to avoid patient frustration (all questions except the physician diagnosis of gout; prescription of allopurinol, Uloric, or

probenecid; current/past use of gout medications) and enhance a broader participation; this likely led to more data missingness for some questions, limiting the interpretation of those responses. We examined the association of psychological stress with patterns of gout management during the COVID-19 pandemic.

In conclusion, we performed a cross-sectional Internet survey of people with self-reported physician-diagnosed gout. We found that the COVID-19 pandemic impacted gout medication use and medication use patterns. Survey respondents reported more difficulty with their gout overall, the management of gout flares and other aspects of gout. None of the survey respondents were COVID-19 positive.

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Availability of data and materials

These data are available from the authors after permissions have been obtained from the University of Alabama at Birmingham Institutional Review Board and the Gout Education Society (GES).

Conflict of interest statement

There are no financial conflicts related directly to this study. JAS has received consultant fees from Crealta/Horizon, Medisys, Fidia, UBM LLC, Trio health, Medscape, WebMD, Clinical Care options, Clearview healthcare partners, Putnam associates, Focus forward, Navigant consulting, Spherix, Practice Point communications, the National Institutes of Health and the American College of Rheumatology and Charlotte Web Holdings. JAS owns stock options in Vaxart pharmaceuticals and Charlotte Web Holdings. JAS is on the speaker's bureau of Simply Speaking. JAS is a member of the executive of OMERACT, an organization that develops outcome measures in rheumatology and receives arms-length funding from 12 companies. JAS serves on the FDA Arthritis Advisory Committee. JAS is the chair of the Veterans Affairs Rheumatology Field Advisory Committee. JAS is the editor and the Director of the UAB Cochrane Musculoskeletal Group Satellite Center on Network Meta-analysis. IAS previously served as a member of the following committees: member, the American College of Rheumatology's (ACR) Annual Meeting Planning Committee (AMPC) and Quality of Care Committees, the Chair of the ACR Meet-the-Professor, Workshop and Study Group Subcommittee, and the co-chair of the ACR Criteria and Response Criteria subcommittee. NLE has received consultation fees from Takeda, Horizon, Shanton Pharmaceuticals, Aclaris Therapeutics, Atom Biosciences, and SKYBiopharma. NLE is Chair and CEO of the Gout Education Society.

Ethics/IRB approval and consent to participate

The University of Alabama at Birmingham's Institutional Review Board (IRB) approved this study and all investigations were conducted in conformity with ethical principles of research (UAB X120207004). The IRB waived the need for a signed informed consent for this anonymized study.

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Supplemental material

Supplemental material for this article is available online.

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