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Shared decision making in gout treatment: A national study of Rheumatology provider opinion and practice

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Abstract

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Declarations:

Ethics/IRB approval and consent to participate: This was a QI initiative that only assessed opinions of healthcare providers and therefore an Institutional Review Board (IRB) approval was not required.

Consent for publication: No individual person's data were presented in any form in this study and therefore no consent to publish is required.

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Objective: To assess rheumatologists' views and practices related to shared decision making (SDM) in gout treatment.

Methods: We performed a cross-sectional electronic survey of rheumatologists at U.S. Veterans Affairs (VA) medical centers, assessing views and practices related to SDM in gout.

Results: Of the 154 VA rheumatology providers eligible, 90 responded (response rate, 58%). Fifty-eight percent were female, the mean age was 51 years (standard deviation, 9.6), 42% had >20 years of experience in medical practice. Rheumatologists reported routinely offering a choice to their patients for: (1) starting urate-lowering therapy (ULT) for gout vs. doing nothing (70%); (2) choosing NSAIDs, corticosteroids, or colchicine for the treatment of acute flares (67%); and (3) choosing NSAIDs, corticosteroids, or colchicine for anti-inflammatory prophylaxis when starting ULT (51%). Very few rheumatologists offered choice regarding: (4) choosing allopurinol vs. febuxostat as the first ULT (16%); and (5) taking daily ULT long-term vs. intermittently (15%). Rheumatologists perceived that a large proportion of patients were often or sometimes unsure of the best choice for these five decisions, 34%, 76%, 76%, 52%, and 54%, respectively. Similar proportions of rheumatologists felt that patients were uninformed about both medication benefits and risks, unclear about the personal importance of the benefits and risks, and unsupported in decision-making. For the five decisions respectively, rheumatologists supported SDM with patients in 76%, 56%, 58%, 27%, and 25%.

Conclusions: The majority of VA rheumatologists incorporated SDM in several gout treatment decisions. Rheumatologists also recognized that patients need better support to participate in SDM in gout.

Keywords

Gout; Shared decision-making; management; survey; rheumatologists; urate-lowering therapy; allopurinol; febuxostat; NSAIDs; colchicine

Introduction

Patients with gout have low medication adherence rates to urate-lowering therapy (ULT) (1–3). Long-term ULT is key to the achievement of target serum urate of less than 6 mg/dl in gout, which is associated with better outcomes (4–6). Therefore, long-term ULT is a cornerstone of gout treatment, and recommended by treatment guidelines (7).

Patients' attitudes and beliefs affect outcomes in gout. Negative views about gout were associated with poorly controlled disease, lower ULT adherence, and progression of musculoskeletal disability (8). Patient knowledge deficits about dietary triggers and medications to treat gout are common (9). Patient and primary care physicians' perceptions of patient self-management of gout were discordant (10). While most providers reported adequate skills to teach self-management, patients requested more information on gout (10).

Shared decision making (SDM) between patients and their healthcare providers increases patients' knowledge, feeling of being informed, and allows them to play a more active role in decision-making across diseases (11). The identification of decision-making needs is one of the first steps in understanding and improving SDM.

The Veterans Affairs (VA) healthcare system is the largest integrated healthcare system in the U.S. with 1,255 facilities that provide care to more than 9 million veterans annually (12). Our objective was to conduct a national survey of VA rheumatologists to understand providers' perceptions, and practices related to decisional needs and SDM for patients with gout.

Methods

We conducted an electronic survey among VA rheumatologists about gout care in the U.S. as a quality improvement (QI) initiative using SurveyMonkey™. The rheumatologists were identified from the VA Rheumatology Consortium, volunteer work group. Non-responders received two reminders to complete the survey in the two-weeks after the initial email invitation. This was a QI initiative that only assessed opinions of healthcare providers and therefore an Institutional Review Board approval was not required.

The needs assessment questionnaire was developed by three experts with expertise in patient decision aid development and SDM (K.T., J.B., J.S.), and the care of patients with gout (J.B., J.S.). Modifications were made after pilot testing with two providers for clarity of the questions, the sequence of the questions, the total survey length, and matching the needs assessment questions to key dilemmas in gout treatment decision-making. Our needs assessment questionnaire was based on the needs assessment workbook provided at the University of Ottawa Patient Decision Aids website (13), and used the Ottawa Decision Support Framework, which have face and content validity (14, 15). Many studies previously have used this needs assessment survey (16–20).

In addition to assessing provider demographics, the survey included questions on the following topics: (1) offering patients a choice about five distinct treatment decisions: starting ULT, choosing the type of treatment for acute flares (non-steroidal anti-inflammatory drugs (NSAIDs), corticosteroids or colchicine), choosing prophylaxis treatment when starting ULT (NSAIDs, corticosteroids or colchicine), choosing between allopurinol and febuxostat as the first ULT, and choosing whether or not to take ULT continuously; (2) assessment of provider perception of patient difficulty with each of these 5 decisions in 4 domains: being supported in decision-making, having clarity of the personal importance of benefits/risks, knowing both benefits/risks, and being sure about the best choice for them; (3) provider role in decisions: provider made decision alone, provider participated in SDM with patient, or patient decided alone; and (4) barriers and facilitators to SDM.

Summary statistics, including means or proportions, were calculated. Associations were also assessed by provider age-group, sex and years of practice, using proportions and chi-square test, as relevant. IBM® SPSS v25 (Armonk, NY, USA) was used to conduct analyses. A p-value <0.05 was considered statistically significant.

Results

Of the 154 VA rheumatologists surveyed, 10 opted out and 90 responded (79 complete and 11 partial). The survey response rate was 58%. The mean time to complete the survey was

7.1 minutes (SD, 5.4). Fifty-eight percent were female, and the mean age was 51 years (SD, 9.6; see Table 1 for provider characteristics).

More than 2/3rds of the rheumatologists reported they offered a choice regarding starting ULT vs. doing nothing and regarding the choice of treatment of acute flares (Appendix 1); a much higher percent of those with 10 year practice duration provided this choice to their patients compared to providers with longer practice duration (95% vs. 67%; $p=0.015$; Appendix 1). Only half of the rheumatologists offered a choice of between anti-inflammatory drugs to patients for prophylaxis when starting ULTs.

Most rheumatologists (>80%) did not offer a choice between allopurinol vs. febuxostat as a first ULT or whether to take ULT continuously vs. intermittently (Appendix 1). We noted no other differences for providing a choice for other gout treatment decisions were noted by years of practice (Appendix 1).

For all five decisions, rheumatologists reported that one-third to two-thirds of the patients were often or sometimes unsure of the best choice for them (Table 2). The rheumatologists reported that 44–64% of the patients were uninformed about both benefits and risks, 52–73% were unclear about the importance of the benefits and risks, and 36–52% were unsupported in decision-making (Table 2).

With the exception of two decisions (choosing between allopurinol vs. febuxostat as a first ULT or whether to take their ULT continuously vs. intermittently), 56%–76% rheumatologists supported shared decisions with their patients and an additional 5–11% provided support for patients making their own decisions (Appendix 2). No differences were noted by years of practice for type of support for shared decisions, except for choosing allopurinol vs. febuxostat as the first ULT, where a lower percent of those with 10 year practice duration shared this decision with their patients (10% vs. 31%; $p=0.02$; Appendix 2).

Barriers, included the lack of patient knowledge, misinformation about gout medications comorbidities poly-pharmacy, patient cost/time issues, barriers to technology-based education, patient reluctance to take any medication for gout, historical non-adherence to medications, sequencing of ULTs in most cases (allopurinol and probenecid before febuxostat) and suboptimal education of primary care providers. (Appendix 3).

Facilitators to SDM included provider recognition of the value of SDM in gout, the provision or the use of a patient decision support tool including patient handout/pamphlet, availability of nurse or pharmacist, face-to-face discussion with the patient (including ACR gout pamphlet), using evidence to share facts with the patient, positive impact of SDM on medication adherence and discussing drug costs, were also considered facilitators (Appendix 3).

Other feedback from rheumatologists included challenges with offering a choice between allopurinol and febuxostat due to the VA policy of allopurinol as the first line.

Discussion

In this national cross-sectional survey of VA rheumatologists, the majority reported that they provide patients a choice with respect to three key gout treatment decisions. Age/sex/years of practice characteristics are similar to a previously reported national sample of rheumatologists (21). They engage in SDM with patients for the following decisions: starting ULT; choice of therapy for acute flares and prophylaxis when starting ULT. A SDM approach to selection of ULT to optimize serum urate and the use of anti-inflammatory drugs to prevent and/or treat acute flares, is key to the successful management of gout.

We queried VA rheumatologists about intermittent use of ULT for the treatment of gout, a frequently noted quality gap in gout care (1–3). Appropriately, more than 80% of responding rheumatologists did not offer a choice whether to take ULT continuously vs. intermittently. As expected, more than two thirds of the rheumatologists made this decision for their patients and counseled them regarding the appropriate continuous ULT use, since intermittent use is associated with a higher rate of gout flares (22) and therefore not evidence-based practice.

Most rheumatologists also did not report that they offer their patients a choice between allopurinol vs. febuxostat as the first ULT with allopurinol as the preferred drug, consistent with the current American College of Rheumatology gout treatment guidelines (7). Allopurinol is the preferred ULT at the VA and febuxostat requires prior authorization for use as a second-line agent. This approach may differ from the non-VA settings, where febuxostat may be more readily available. The availability of patient decision aids may help reduce these practice variations. A detailed discussion with the patient with regard to relative benefits and risks related to allopurinol vs. febuxostat is needed to facilitate SDM at the VA and elsewhere.

Rheumatologists reported that for each of the five gout treatment decisions, patients often had difficulty making choices. This clearly points to the need for a SDM tool such as a patient decision aid for gout treatment. In the absence of any previously published studies of provider practices and perceptions of SDM in gout, we are unable to compare our findings to those of others.

The recognition of several barriers and facilitators to SDM in gout treatment is important. Key barriers included the perceived lack of patient knowledge comorbidities and contraindications to treatments, poly-pharmacy, patient reluctance to take any medication for gout, non-adherence to medications, and the need to sequence ULTs due to cost and VA formulary guidelines at some hospitals. Key perceived facilitators to SDM in gout treatment decisions included a patient handout/pamphlet, a nurse or pharmacist to provide education and the relative out-of-pocket cost, a face-to-face discussion with the patient related to diagnosis, medications, and the impact of other comorbidities on gout.

The study findings must be interpreted considering limitations. We had a 58% response rate, comparable to the mean 61% response rate for physician surveys (23). The imperfect response rate and missing data for some respondents on SDM questions both limit the generalizability of the findings to the entire U.S. VA health care system. We did not specify

the time-frame for SDM practices in our questions, therefore it is possible that some participants are thinking of the most immediate periods and others of the longer periods of time. Recall bias is another study limitation, which should be considered when interpreting findings. We did not have characteristics of non-responders. therefore, we cannot determine the non-response bias. Our findings may not be generalizable to other healthcare systems that report different rates of SDM with gout patients. In order to keep the survey short and feasible, we were unable to address many other important aspects of gout management such as treat-to-target urate threshold, and behavioral interventions needed for optimal gout management (weight loss, exercise, alcohol use, diet).

In conclusion, the majority of VA rheumatologists surveyed reported engaging in SDM for three of the five decisions with gout patients. Rheumatologists also reported that a majority of patients still need more support in making choices for gout treatment. Development of patient-directed tools for SDM was proposed as one such solution, as recommended in the 2020 ACR gout treatment guidelines (7).

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Availability of Data and materials:

These data are available from the authors after appropriate approvals have been obtained from the authorities at the University of Alabama at Birmingham, and after meeting all privacy policies and regulations.

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Key Messages

1. Rheumatologists offered shared decision-making to gout patients for 3 key treatment decisions.
2. Rheumatologists perceived that many patients were unsure of the best choice for these decisions.
3. Rheumatologists felt that patients were uninformed about medication benefits/risks, and unsupported in decision-making.

Table 1.

Characteristics of survey respondents (n=90 providers)

	N (%) unless specified otherwise *
Female Sex	45 (58%)
Age in years, mean (standard deviation)	51 (9.6)
Age group	
50 years	34 (47%)
>50 to 65 years	34 (47%)
>65 years	4 (6%)
U.S. region	
Northeast	18 (27%)
West	15 (22%)
Midwest	12 (18%)
South	68 (34%)
Years in Practice	
0–5 years	6 (11%)
6–10 years	12 (16%)
11–20 years	23 (31%)
21–30 years	23 (31%)
>30 years	9 (12%)

* Missing: Sex, n=13; age, n=18; Region, n=22; years in practice, n=15

Table 2.

Provider view of patient difficulties and their role in shared decision-making (SDM) process in gout

	Often	Sometimes	Rarely	Never	Don't know
Q1. How common is it for your patients to have difficulty starting urate-lowering therapy vs. doing nothing....					
a. Unsure about the best choice for them?	11 (14%)	41 (51%)	25 (31%)	2 (2%)	1 (1%)
b. Uninformed about both benefits and risks?	28 (36%)	23 (29%)	22 (28%)	5 (6%)	0 (0%)
c. Unclear about the personal importance of the benefits and risks?	32 (58%)	26 (33%)	16 (20%)	4 (5%)	1 (1%)
d. Unsupported in decision-making?	8 (10%)	29 (37%)	25 (32%)	11 (14%)	5 (6%)
Q2. How common is it for your patients to have difficulty choosing between non-steroidal anti-inflammatory drugs (NSAIDs), steroids or colchicine for the treatment of acute flares...					
a. Unsure about the best choice for them?	20 (26%)	35 (45%)	23 (18%)	9 (6%)	4 (5%)
b. Uninformed about both benefits and risks?	22 (28%)	28 (36%)	18 (23%)	7 (9%)	3 (4%)
c. Unclear about the personal importance of the benefits and risks?	22 (28%)	33 (42%)	12 (15%)	7 (9%)	4 (5%)
d. Unsupported in decision-making?	10 (13%)	27 (35%)	19 (25%)	12 (16%)	8 (10%)
Q3. How common is it for your patients to have difficulty choosing between NSAIDs, steroids, or colchicine for prophylaxis when starting ULTs...					
a. Unsure about the best choice for them?	22 (28%)	32 (42%)	13 (17%)	5 (7%)	4 (5%)
b. Uninformed about both benefits and risks?	25 (33%)	22 (29%)	16 (21%)	9 (12%)	4 (5%)
c. Unclear about the personal importance of the benefits and risks?	26 (35%)	23 (32%)	14 (19%)	7 (9%)	4 (5%)
d. Unsupported in decision-making?	11 (14%)	29 (38%)	17 (22%)	12 (16%)	8 (10%)
Q4. How common is it for your patients to have difficulty choosing between allopurinol vs. febuxostat as a first urate-lowering therapy (ULT)....					
a. Unsure about the best choice for them?	15 (20%)	12 (16%)	24 (32%)	12 (16%)	13 (16%)
b. Uninformed about both benefits and risks?	17 (23%)	16 (21%)	17 (23%)	12 (16%)	13 (17%)
c. Unclear about the personal importance of the benefits and risks?	19 (25%)	21 (28%)	11 (15%)	14 (13%)	14 (19%)
d. Unsupported in decision-making?	9 (12%)	18 (24%)	17 (23%)	17 (23%)	14 (19%)
Q5. How common is it for your patients to have difficulty choosing whether to take daily ULT and continue taking it long-term vs. intermittently.....					
a. Unsure about the best choice for them?	18 (24%)	16 (21%)	22 (29%)	13 (17%)	8 (10%)
b. Uninformed about both benefits and risks?	19 (25%)	19 (25%)	19 (25%)	11 (15%)	8 (10%)

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	Often	Sometimes	Rarely	Never	Don't know
c. Unclear about the personal importance of the benefits and risks?	20 (26%)	20 (26%)	18 (24%)	11 (14%)	8 (10%)
d. Unsupported in decision-making?	12 (16%)	18 (24%)	20 (26%)	15 (20%)	11 (14%)

Missing data: Q1, n=10; Q4, n=15; Q5, n=13; Q2, n=12; Q3, n=13