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Challenges faced by Patients in Gout treatment: A Qualitative Study

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Introduction

Gout is the commonest inflammatory arthritis in adults associated with negative effect on patient's quality of life, worker productivity and health care utilization^{1,2}. Despite the availability of effective and affordable treatments for lowering serum urate, i.e. urate-lowering therapy (ULT), to prevent chronic joint damage and frequent gout flares, quality care gaps characterized by under use and inadequate dosing of ULT are widely prevalent^{3,4}. Recent qualitative studies have assessed the patient's knowledge of gout treatments. In semi-structured interviews, patients (n=26; 80% male) reported discontinuing ULT since it triggered acute gout flares and cited concern for side effects, forgetfulness, and financial problems as reasons for non-adherence to ULT⁵. In a UK study, patients (n=20; 75% male) cited concern for side effects, lack of perception to take it long-term and their perception that they needed treatment only for acute attacks as the reasons to not take their ULT regularly⁶. These studies provided data from a primarily Caucasian men, i.e., women and African-Americans with gout are understudied. It is not known that these findings regarding barriers are generalizable to African-Americans and women with gout. Our objective was to assess barriers to gout treatments by performing a qualitative study in patients with gout including African-Americans and women.

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Patients and Methods

Outpatients seen at a community-based clinic with a diagnostic code for gout (274.xx) during 2011–2012 were invited for participation in our study that used nominal group technique (NGT), a variant of focus group methods. NGT aims at developing an inclusive list of issues related to a specific question, then soliciting feedback on the relative importance of these lists through rank-ordering procedures^{7–9}. NGT allows an even participation from all group members with an equal weighting of their input, which makes the results representative of the groups' implicit views. Our Institutional Review Board approved the study. We conducted three nominal groups, purposely oversampling for African-Americans and women, under-represented in gout research studies. Patients were asked to address a single question “In your opinion, what is most challenging about your gout treatment?” According to the NGT methodology, patients recorded all their responses independently on a worksheet, nominated each of these responses that were recorded on a flip chart, discussed, elaborated and consolidated responses. They then provided individual priority scores from 1 to 5 to the top five challenges (5=most important). The scores from all patients within each nominal group were aggregated into an overall score and ranked based on highest to lowest priority scores.

Results

Seventeen patients participated in three nominal groups. Mean age was 64.7 (standard deviation, 9.9), 8 were men, 9 were women, 5 Caucasian and 12 African-Americans. The top three themes in each of the three groups were: (1) Group 1: Recognizing attack had started and start taking medicine; side effects of Colcrys (colchicine); balance between managing gout and other conditions; (2) Group 2: Eating the right food and taking enough fluids; concern about medication side effects; and trouble taking gout medication due to kidney problem; and (3) Group 3: Knowing when and what to take during a gout attack; concern about interaction with other medications patients are taking; and allergic reaction or side effect to gout medication (Table 1).

Several patient quotes within these key themes illustrated patient concerns. Patients were worried about medication interactions and side effects: “How much do pharmacists and doctors know about medication interactions?” “Side effects are horrible and affect life”. Patients weren't sure which gout medication to take everyday and which during the attack: “Do we take or not take allopurinol during gout attack?” “...need to know what each medication is supposed to do and how and when to take it?” Patients had difficulty remembering to take gout medications regularly: “Have to discipline yourself”, “Remembering to take medication, don't want to take too much”.

Discussion

This is the first qualitative study in gout patients that describes the treatment challenges faced by a group of patients that included both African-Americans and women with gout. Our study findings add to the growing knowledge in this area. Study findings must be interpreted considering its limitations. Our sample size was small, but similar to other

previous qualitative studies^{5,6}; and our objective was not to do a wide survey, but gain in-depth insight into this issue/question. Generalizability to other populations for a single site study may be challenging, despite our attempt to include African-Americans and women with gout. We included women and African-Americans, since most previous qualitative studies have not included African-Americans and women with gout, limiting their generalizability. One limitation of our study is that we are unable to analyze differences by age, sex etc. We plan to explore differences by these factors in our future study. Several findings deserve further discussion.

We purposefully asked the question about gout treatment and not a specific group of medications. To our surprise, all patient nominal groups identified themes related to diet and dietary modification among their top ranked concerns, signifying that gout patients considered dietary modification an integral part of their treatment. This is an important finding and very encouraging, since diet and lifestyle modification are key to gout management and have been recommended by major gout guidelines. In conjunction with finding from other studies that patients have misinformation about the types of food to avoid and take^{5,6,10}, our study findings imply that patients need and may likely benefit from their gout providers' advice about diet.

All three nominal groups identified concern with gout medication among their top 3 concerns, including side effects, long-term effects on vital organs and interactions with their other medications. When we further explored, patients were also worried about effect of their other medications on gout medications, indicating that the concern is bi-directional. Patients were concerned about taking their gout medications in presence of kidney problems. While this concern may be valid for medications such as colchicine and NSAIDs, ULTs such as allopurinol and febuxostat, can be used safely in patients with renal failure. Although the risk of allopurinol hypersensitivity syndrome increases with higher dosing in renal failure, this side effect is rare. Both patients and physicians have unfounded fears about ULT dosing in renal failure^{5,6,10}, a knowledge gap that leads to under-dosing of allopurinol and needs to be addressed, if adherence to ULT is to be improved. Concerns about medication side effects is a general concern, not specific to gout, and has been reported in studies of other chronic diseases.^{11,12}

In summary, in this study of gout patients that included African-Americans and women, we found that patients consider diet management integral to the treatment of gout and had significant concerns about medication side effects/interactions. Concerns about medication side effects, dietary modifications and concern about what to do during a gout flare were universal and a bit surprising given the low rate of side effects of gout treatments. Although it is important and necessary for providers to address patients' focus on diet, experience indicates that many patients (and even providers) focus more on dietary factors while not realizing that ULT is the key in treating the vast majority of gout patients. Future studies are needed to confirm these findings in other populations.

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Table 1

Nominal group themes, quotes and group rank order based on summative priority score

In your opinion, what is most challenging about your gout treatment?	Priority score	Group Rank order
Nominal group 1 (68WM, 68AAF, 78AAM, 66AAM, 65WF, 60AAF, 61AAF, 60AAM; n=8)		
Recognizing attack had started and start taking medicine	31	1
Side effects of Colcrlys (colchicine)	24	2
Balance between gout and other conditions (pseudogout, high blood pressure)	17	3
We need cure, treatments are not enough	11	
Discipline taking medications all the time	9	
Interaction of gout medications with my other medications	9	
Pain is severe (even after medications)	7	
Being on a diet	7	
Doing what you doctor asks you (is not easy)	5	
Nominal group 2 [72AAM, 38AAF, 77AAF, 53WM; n=4)		
Eating right food and taking enough fluids	14	1
Most medications that I take have side-effects on vital organs	14	2
Medication I can't take due to kidney problem	10	3
Finding something to help swelling	8	
Problem putting Ice/Heat-Packs on the foot	7	
Trouble with sleep	4	
Wearing the right type of shoe	2	
Managing/taking medication every day	1	
Nominal group 3 [75AAF, 60AAF, 64WM, 75WF, 60AAM; n=5)		
Knowing when and what to take if I am having a gout attack	12	1
Concern about interaction of other medication with gout medications	11	2
Allergic Reaction/side effect to gout medication	9	3
What to eat?	9	3
Trusting my doctor during flare-ups	9	3
No specific meal time or bedtime, so forget taking medication sometimes	9	3
Some days get tired of "taking pills everyday"	6	
Quality of life is affected (by treatments)	5	
Medication fill and adherence are challenging	5	

AA, African-American; C, Caucasian; M, male; F, female; top three ranked concerns **in bold**; In group 3, four concerns tied for the third place