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Patients and providers view gout differently: a qualitative study

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Abstract

Objective—We sought to examine patients' and providers' views on the treatment of gout to better understand why management is suboptimal.

Methods—In-depth telephone interviews were conducted with gout patients (n=26) who initiated treatment with a urate-lowering drug (ULD) in the prior 6 months and with providers who care for gout patients (n=15). The interviews were audiotaped and transcribed verbatim. Using qualitative methods, results were analyzed and themes were identified. Interviews focused on the acute management, chronic management, and prevention and improvement strategies.

Results—Providers viewed the majority of patients as having excellent relief with nonsteroidal anti-inflammatories, colchicine and glucocorticoids while some patients felt these medications were ineffective. Providers felt most patients had a good understanding of the rationale for ULD therapy and that patients responded well. Some patients felt ULDs triggered, worsened or had no impact on their disease. Most providers thought medication adherence was relatively good. Some patients reported discontinuing medications. Discontinuations were largely purposeful and due to clinical or financial concerns. Most providers thought their skills adequate to teach disease self-management behaviors. Patients requested more information and longer visit times.

Conclusions—Providers view gout as easily managed while patients report challenges and purposeful nonadherence.

Keywords

medication use; gout treatment; medication adherence; qualitative

Introduction

Gout is a common form of arthritis and the incidence is rising. [1–3] Acute attacks are treated with colchicine, nonsteroidal anti-inflammatory medications (NSAIDs), and glucocorticoids. For patients who have recurrent gout attacks and/or tophaceous deposits, current clinical guidelines suggest sustained treatment with urate-lowering drugs (ULDs). [4–6] In addition, dietary changes have been recommended for gout prevention. [6]

Previous studies have demonstrated it is challenging to manage gout. [7] Chronic use of ULDs has been shown to reduce the frequency of gout flares, to have a low incidence of

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adverse effects and to be relatively inexpensive; however, the majority of patients do not use ULDs regularly. [7–11] A recent study comparing medication nonadherence across 7 common chronic conditions such as hypertension, osteoporosis and diabetes mellitus found adherence was lowest with gout. [12]

Deficits in the quality of care provided to gout patients have been documented as well, both for the acute and chronic management.[13,14] Using evidence-based quality of care indicators for gout management, suboptimal adherence to these indicators was demonstrated both in the United States and the United Kingdom.[15,16] In fact, Neogi et al. found that seeking care from a physician for an acute gouty flare was a risk factor for mismanagement. [14] Lastly, inadequate patient education about disease management including lifestyle recommendations and the role of medications has been reported.[17,18]

To our knowledge, there have been no studies to date directly asking patients or providers about the barriers to and facilitators of effective gout management. In particular, since medication treatment of gout with ULDs can trigger gouty flares, we felt that we could not extrapolate from other chronic conditions in which investigators have examined patient and provider views on disease management. Given the scarcity of data in this area, qualitative methods are a helpful first step in gaining a better understanding of why deficits in gout care occur and in developing hypotheses for further investigation. In this exploratory study, we conducted in-depth interviews to explore the knowledge, beliefs and experiences of patients who are newly prescribed ULDs as well as providers who prescribe ULDs for their gout patients.

Methods

Study population

This study used a cross-sectional design and involved in-depth telephone interviews to assess the barriers to, and facilitators of effective disease management. In order to ground the interviews, providers were asked about the treatment strategies they employed and patients were asked about the treatments they received. Eligible patients were identified based on enrollment in the Fallon Community Health Plan (FCHP), a mixed-model HMO located in Central and Eastern Massachusetts, United States. The patient study population included only members of the group-model component of the plan who received care from the Fallon Clinic, a multispecialty group practice. The computerized information system of the health plan contains records on utilization of all health care services, including medical diagnoses and prescription drug data. A total of 191,000 individuals were enrolled in the health plan in 2006. Potential provider participants were identified based on employment by the Fallon Clinic. The study was approved by institutional review boards at FCHP, Fallon Clinic and the University of Massachusetts Medical School.

Participants

Potential patient participants included those aged 18 years or older with a diagnosis code for gout (ICD-9 code 274.XX) in the prior 5 years, continuously enrolled in the health plan, new users of a ULD within the last 6 months (180 days) and who had no prior use. Primary care providers of the patients were sent letters explaining the purpose of the study and the providers were asked to notify the research team if there were patients who were unsuitable for the study. There were 70 eligible patients who were sent a letter that provided them with an opportunity to decline participation. Those patients who did not opt out of the study were then contacted to invite participation.

Adult primary care physicians, rheumatologists, podiatrists, nurse practitioners and physician assistants who saw patients at the Fallon Clinic at least one day a week were

identified. While these providers may have cared for the patient participants, we did not specifically match providers to the patient participants. The providers were sent a letter notifying them of the study purpose and contact information in order to opt out of the study. Only one provider opted out of the study. The remaining providers were sent an email to invite participation.

Interviews

An initial draft of both the provider and patient interview guide was developed by the authors and pilot tested with 2 providers (one rheumatologist and one internist) and 2 patients. The guide included questions in each of the following topic areas: 1) clinical experiences, 2) treatment, 3) knowledge and beliefs, 4) self-management, 5) barriers to management, 6) facilitators of gout management, and 7) suggestions to improve care. Follow-up questions were used to elicit more detail based on responses. The telephone interviews were conducted by interviewers after training (SV for patient interviews and LRH for provider interviews). The interviews occurred from July, 2008 through October, 2008. Those patients contacted who consented to the study participated in individual in-depth interviews lasting approximately 30 to 60 minutes and were compensated $25. Providers who consented to the study participated in individual semi-structured interviews lasting 20 to 30 minutes and were compensated $100, which is the standard amount for interviews with Fallon Clinic providers. The interviews were audio taped and transcribed verbatim. Recruitment for both the patient and provider interviews was terminated once we achieved saturation on themes.

Analysis

Qualitative analysis of the transcripts was done using an iterative process. One investigator read several transcripts and generated an initial list of themes and coding categories based on the interview guide. A second investigator read 5 additional transcripts and suggested modifications. We repeated this process with successive readings of the transcripts. Two additional investigators read 4 to 6 transcripts each to assess completeness of the coding categories. This process continued until all investigators agreed that the listing captured all major issues raised by the interviewees. We coded interviewee responses through application of the coding categories with modifications suggested and discussed.

After coding, we sorted all interviewee responses by question and response code and reviewed them for additional themes or subthemes. Any questions or discrepancies which were not easily resolved were brought to the full team for resolution. Two investigators reread the entire set of transcripts to ensure that no relevant themes had been missed. The major thematic categories identified included education and knowledge regarding gout, treatment strategies and response to treatment for both the acute and chronic management of gout. In addition, issues surrounding gout prevention recommendations and follow through on the recommendations were explored. Lastly we identified suggestions for strategies to improve gout management. We present these major themes contrasting the providers' views with the patients'.

Results

Characteristics of the participants

Of the 15 providers who participated, 8 were female, and all but 2 were aged 40–59 (Table 1). Thirteen were Caucasian, 1 Asian and 1 Southeast Asian. Eleven were primary care providers with 2 podiatrists and 2 rheumatologists. Thirteen providers were physicians; 2 were nurse practitioners. Most providers cared for 5 or fewer patients with acute gouty flares in a typical month.

There were 26 patients with gout who were interviewed, of whom 20 were men (Table 2). The mean age was 73 (±11). Most rated their overall health as good or very good and most were married. They were all Caucasian. Twenty-four of the 26 patients reported that their diagnosis of gout was made based on the clinical presentation and serum uric acid result. Only two patients reported that they had had a joint aspiration confirming gout through visualization of monosodium urate crystals. Fifteen reported rare gout attacks with the rest having attacks weekly to every few months. Only a few patients reported receiving prophylaxis with colchicine or NSAIDs prior to initiation of a ULD. Almost all patients had vivid recollections of their first episode of gout with symptoms of pain, swelling and discoloration. Most were limited in terms of daily activities or ambulation when they had a gout flare.

Acute gout management

Most providers thought patients understood how to manage acute gouty flares (Table 3). Only a few thought patients had a difficult time grasping the behaviors necessary to prevent an attack. In fact most patients did have a regimen that they followed when they had an acute attack. Some patients had to contact their doctor in order to get medical treatment. Physicians reported prescribing NSAIDs, colchicine, and prednisone. Most patients did take these medications. In addition, several patients reported using other techniques including ice packs on affected areas as well as drinking cherry juice or eating cherries. The prevailing view of the providers was that treatment of acute gout was satisfying as the vast majority of patients will respond to treatment. Several patients reported inadequate symptom relief with the medication regimen prescribed for acute flares. As one patient said “I still haven’t gotten any relief from the pain.”

Chronic gout management

The two podiatrists referred patients to the primary care provider for chronic management. Most primary care providers as well as the 2 rheumatologists stated that their patients had a good understanding on the cause of gout and the need for chronic medications (Table 3). In fact, many patients understood that allopurinol was prescribed to reduce serum uric acid and prevent gout attacks; however, several patients reported that their provider did not provide details on what causes gout. Patient comments included “I get very little information on this from doctors”, “they don’t tell you what the pills are for,” “if I call there with some problems, sometimes she makes me feel bad” and “I sometimes wonder why the heck I even go to the doctors…he just wants to get rid of you.”

Providers cited frequent attacks or tophi as reasons for ULD initiation. They all prescribed allopurinol with starting daily doses ranging from 100 to 300 mg, and adjusting doses based on clinical symptoms, serum uric acid levels or renal function. The most commonly prescribed ULD was allopurinol. Some of the primary care providers and both rheumatologists gave prophylaxis with colchicine or NSAIDs when initiating allopurinol. Several patients reported either increasing or decreasing the dose of allopurinol during an acute attack. Many patients were unsure of the planned duration of allopurinol therapy.

In terms of response to therapy, provider comments included “it’s one of the easiest [diseases to treat] actually,” “I find it very satisfying. We can actually fix it…there are very few things in medicine that you can actually say that [about],” and “it’s pretty easy.” Many patients thought gout was a chronic condition that they would have to adapt to while only a few patients thought it was a condition that could be controlled with medications and lifestyle changes. Several patients thought allopurinol triggered or worsened their gout and thus discontinued the medication. One reported “the one big toe had no signs of pain or

anything else up until I took the medicine…I'm glad to get rid of this [allopurinol] because it didn't help. It caused a problem."

Prevention: recommendations and adherence

Most providers suggested dietary changes to their patients; the most common recommendation was reduction in alcohol intake (Table 3). Indeed most patients recalled being told to reduce their intake of beer, rich or fatty foods, shellfish, high protein foods, and other forms of alcohol. Most patients had identified triggers that they then avoided or behaviors that they believed reduced gout symptoms including avoiding beer, shellfish and other food triggers as well as eating cherries or cherry juice and drinking lots of water.

The majority of providers felt that adherence to chronic gout medications was not a problem, but that adherence to the dietary recommendations was more challenging. However, both rheumatologists in the study cited medication nonadherence as a substantial problem. Factors quoted by providers as influencing medication adherence included the number of concurrent medications, possible side effects related to the medication, family support, and cognitive functioning of the patient. Several cited the pain of a gout attack as a strong motivating factor for adherence. One provider stated "I think gout is an interesting disease because there is a strong negative reinforcement for messing up" meaning being noncompliant with dietary and medication recommendations. Another stated that if patients get recurrent attacks he finds "adherence is essentially never a problem." Several suggested that the personality of the patient was related to medication adherence. A few providers mentioned less active disease, male gender and excessive alcohol consumption as being related to reduced adherence.

Some patients reported nonadherence with allopurinol. A few expressed difficulties due to not remembering to take the medication. Most cited pill boxes or a routine which often included taking other medications as a prompt to ensure medication adherence. Many patients were motivated by the desire to avoid the pain of another gout attack to be adherent to the medications. A few stated that their reason for taking allopurinol was because their provider told them to. Financial concerns were a motivation for skipping or discontinuing medications in a few patients. Several patients discontinued allopurinol as they thought it triggered or worsened their gout and several more were thinking about stopping it in the future. Side effects or concern about side effects of chronic gout medications was voiced by several patients. One patient stated "I read the paperwork [that you get with your medications] … that's so scary."

Strategies to improve gout management

Virtually all providers mentioned that patient education was vital for ensuring optimal care (Table 3). All but a few thought they were sufficiently trained and able to provide the necessary education. The competing priorities of patient volume and patient education were mentioned by one primary care provider. He stated that he had taken "a huge financial hit" in order to spend "a huge amount of time per patient" for clinical care including patient education. Other strategies proposed included involving patients and their families in the decision making process, providing advice on how to incorporate medications into their routine, giving educational handouts and describing the risks associated with nonadherence.

Suggestions from patients on how to improve care included providing more information (both orally and through written materials), more time for patient-provider interactions and follow-up after initiating treatment. One patient suggested that providers should tailor their messages based on the specific needs of the patient. Additional comments from patients included "wait until a patient experiences symptoms before giving allopurinol," "be aware

of alternative methods such as cherry juice" and "tell the patient if they are taking a medication than can cause gout." Several patients, when asked what recommendations they would make to other patients afflicted with gout, suggested seeing a rheumatologist rather than the primary care physician.

Discussion

The providers and patients who participated in this study expressed conflicting opinions regarding gout management. The providers saw gout as a treatable condition in which the majority of patients understood disease management and prevention, and did well with both acute and chronic disease therapies. Providers overwhelming thought they had the training and skills necessary to provide the patient education necessary to teach disease self-management behaviors. In contrast the patients had a wide range of knowledge, beliefs and experiences regarding gout. Some patients felt the medications for acute gout symptoms were ineffective. Many patients were unsure of the duration of chronic therapy with ULDs. Some felt these medications triggered or worsened their disease as they were unaware of the risk of gouty flares with ULD initiation. Most nonadherence by patients was purposeful and due to clinical factors and financial concerns. Patients felt they would benefit from more information, more time for interactions with their providers and greater awareness on the part of providers on the use of natural remedies.

The majority of providers were unaware of the difficulties patients have with gout treatment. There are several possible explanations for these findings. There has not been much research comparing medication adherence across multiple chronic conditions, thus providers are likely unaware that adherence to chronic gout medications is worse than for other conditions.[12] Another possible explanation is that much of the work documenting deficits in care of gout have been published in subspecialty journals which may not be read by a general primary care audience.[5,6,16,19,20] Also, until recently there has not been much published on the implications of gout in terms of morbidity and mortality as well as associated health care utilization and costs.[21–24]

While the patients were not matched to the participating providers, patient and provider miscommunication is likely a contributing factor to suboptimal gout management. The providers thought they had the skills necessary for patient education, while patients had unanswered questions about the etiology and management of gout. One possible explanation is inadequate health literacy, which is increasingly being recognized as a large problem that impedes patient education, following instructions from a physician and taking medication properly.[25] While providers had very few suggestions regarding how to improve care, it is likely more creative ways to educate and counsel patients are needed. These might include sending educational materials prior to appointments in order to facilitate a more effective dialogue, use of support staff for following up with patients, as well as motivational interviewing.[26, 27]

The purpose of this study was to identify potential hypotheses to be explored further to explain suboptimal management of chronic gout. Of interest is the finding that nonadherence to ULDs in most part was intentional. This was related to gout flares with ULD initiation. The lack of prophylaxis with colchicine or NSAIDs and lack of patient education on the short-term effects of ULDs greatly contributed to this. We are currently developing a patient questionnaire to explore the issue of gout flares with ULD initiation in a larger patient population.

An important strength of this study is that it is the first to identify both patients who were new users of ULDs and providers. This allowed us to better identify facilitators of, and

barriers to effective management. This study does have several limitations. First, we performed a relatively small number of interviews with gout patients and providers and this may limit the generalizability of the results. However, this approach should be sufficient to learn about the range of ideas patients and providers hold about the condition in preparation for quantitative studies in the future. Also the patients who were interviewed may or may not have been cared for by the providers who participated. Given the small number of providers interviewed, we are unable to make comparisons across specialties. Because this study was conducted in the context of a managed care health plan, the findings may not be generalizable to patients with other types of insurance or who are uninsured. Furthermore, all the patients were Caucasian, so we do not know if members of other racial or ethnic groups would have responded similarly. Additionally, as in any qualitative interview study, the interviewers may have inadvertently influenced the subject's responses.

This work identifies patient and provider barriers to the optimal management of gout. In follow-up to these in-depth interviews, further questioning of providers regarding their knowledge of treatment guidelines and literature documenting deficits in care is necessary. This is essential as a few patients reported unusual treatment practices including being told by their provider to change the ULD dose during acute gouty attacks. In the meantime, these findings suggest changes in current clinical practice may be warranted. Providers should routinely offer prophylaxis at the time of ULD initiation and inform patients of the risk of a gout flare with ULD initiation. In addition, information regarding the short-term and long-term effects of ULDs may need to be reinforced to patients in multiple modes (i.e. orally and in print) as well as at multiple time points. Follow-up telephone calls or face-to-face encounters after ULD initiation may be useful to review the goals of therapy, troubleshoot problems and answer any questions that have arise. Patients should be encouraged to practice self-management of gout. In summary, these findings are an important first step in understanding patient and provider views regarding gout management.

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Table 1

Characteristics of the providers who participated in the study

	N	(%)
Gender		
Female	8	(53)
Age group		
30–39	2	(13)
40–49	6	(40)
50–59	7	(47)
Specialty		
Internal medicine	7	(47)
Family practice	4	(27)
Podiatry	2	(13)
Rheumatology	2	(13)
Training		
Physician	13	(87)
Nurse practitioner	2	(13)

Table 2

Characteristics of the patients who participated in the study.

	N	(% or SD)
Gender		
Male	20	(77)
Age		
Mean (years)	73	(11)
Marital status		
Married	20	(77)
Single	1	(4)
Widowed	2	(8)
Divorced	3	(12)
Education		
< 4 years of high school	4	(15)
High school graduate	8	(31)
Some college	7	(27)
4 year college degree	4	(15)
> 4 year college degree	3	(12)
Work status		
Retired	21	(81)
Disabled	1	(4)
Working	4	(15)

Table 3

Responses from the patient and provider in-depth interviews.

Themes	Provider's responses	Patients' responses
Acute management		
Education and knowledge	Patients have a good understanding regarding the management of gout.	They were aware of a regimen to take for acute attacks
Treatments	NSAIDs*, colchicine or steroids were prescribed.	NSAIDs*, colchicine, steroids and natural remedies were used.
Response to treatment	The vast majority of patients have an excellent response to therapy.	Several reported inadequate pain relief with the prescribed treatments.
Chronic medication management		
Education and knowledge	Patients have a good understanding regarding the need for long-term medication use.	They were aware that allopurinol reduces serum uric acid levels, but had unanswered questions regarding gout etiology
Treatments	Allopurinol was prescribed; the dose was adjusted based on symptoms, serum uric acid level and renal function.	Several changed doses during attacks; many patients were unclear of the duration of therapy with allopurinol.
Response to treatment	Patients respond well to therapy.	Several believed allopurinol triggered or worsened their gout.
Prevention and adherence		
Recommendations	Dietary changes were recommended to most patients.	Most reported receiving recommendations on dietary changes to prevent gout.
Follow through on recommendations	Medication adherence is not a problem as the pain of a gout attack is a strong motivator; lifestyle changes more challenging for patients to adhere to.	Most reported incorporating the recommended lifestyle changes; medication nonadherence was due to clinical and financial factors.
Strategies to improve management		
Educational	Education of patients using handouts was recommended.	They requested more information (both oral and print).
Specific areas to focus on	Providers suggested including patients and family members in the decision-making process, discussing risks of nonadherence, and providing advice on incorporating medications into their routine.	They requested more time for encounters and suggested follow-up after initiating treatment. They wanted providers to be aware of potential natural remedies. They felt providers should tell them if prescribed medications were triggering gout. Lastly they suggested providers tailor their messages to the specific needs of the patient.

* NSAIDs = nonsteroidal anti-inflammatories