Patient Information about Gout: An International Review of Existing Educational Resources

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ABSTRACT. ***Objective.*** Inadequate patient information about gout may contribute to poor disease outcomes. We reviewed existing educational resources for gout to identify strengths and weaknesses and compare resources cross-nationally.

Methods. Content, readability, and dietary recommendations were reviewed using a sample of 30 resources (print and Web-based) from 6 countries.

Results. More than half of the resources were written at a highly complex level. Some content areas were lacking coverage, including comorbidity risks, uric acid target levels, and continuing allopurinol during acute attacks.

Conclusion. Our findings suggest significant room for improvement in gout patient educational resources, particularly regarding self-management. (First Release April 1 2015; J Rheumatol 2015;42:975–8; doi:10.3899/jrheum.141442)

Key Indexing Terms:
GOUT DISEASE MANAGEMENT DIET LIFESTYLE ALLOPURINOL URIC ACID

Inadequate patient education about self-management may contribute to poor outcomes for gout[1]. Patient education resources need to be easy to read and should provide clear and consistent messages regarding lifestyle, diet, and treatment recommendations for patients with gout to implement[2]. There is surprisingly little research into the content of existing educational resources for patients with gout[1,2]. Determining the coverage of core treatment recommendations in educational resources is a necessary first step in optimizing resources to then test effectiveness.

The prevalence of gout has increased dramatically and it is now one of the most common forms of inflammatory arthritis[3,4]. Certain ethnic groups, such as the indigenous Māori of Aotearoa/New Zealand, have a greater predisposition to gout than others[5]. Gout is caused by deposition of monosodium urate crystals within joint tissue, resulting in acute gout attacks[6]. Individuals with gout are 6 times more likely to develop diabetes and 4 times more likely to develop cardiovascular disease than individuals without gout[7], indicating that the management of gout necessarily includes the prevention and management of associated comorbid diseases.

Allopurinol is the most common urate-lowering therapy for gout[8]. Some research indicates that diet and lifestyle may also influence levels of serum uric acid (SUA)[9]. Modifications to diet and lifestyle may thus lower the risk of gout attacks and also lower the risk of comorbid diabetes and cardiovascular disease. Unfortunately, despite effective pharmacotherapy and modifiable lifestyle contributors, gout has low patient adherence rates compared to other rheumatic diseases[10] and chronic illnesses more broadly[11].

It is speculated that poor clinical outcomes in gout are in part due to inadequate patient education about the condition and the aims and modalities of treatment[2]. Patients who report greater understanding of their illness also report greater adherence to urate-lowering therapy[12], and the inclusion of patient education in gout care leads to high success rates in reaching target SUA levels[13]. Currently, however, few patients receive clear explanations of gout or appropriate lifestyle advice[14], resulting in patients holding inaccurate beliefs about gout and having unanswered questions about the etiology and management of gout[15]. Previous research on gout educational resources indicates low levels of readability and omission of important content[16].

In chronic illnesses such as gout, patients and their families must learn proactive self-management of the condition[17,18]. This knowledge can be used to monitor symptoms and raise awareness of when to take action to address risk factors and promote health[17,18]. While patient self-management of other chronic conditions such as rheumatoid arthritis and diabetes have received more attention[17,18], little focus has been placed on educational resources to help patients with gout self-manage their

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condition, despite the potential for highly effective control of gout if patients adhere to medication, diet, and lifestyle recommendations[9,10]. We reviewed a subset of existing patient education resources for content that would aid in gout self-management. We also investigated the ease of reading the materials, an additional factor influencing patients' abilities to use information to self-manage their health.

MATERIALS AND METHODS

Sample of resources. Thirty patient educational resources for gout (18 printed, 12 Websites) were identified. They came from Aotearoa/New Zealand (4 printed, 6 Websites), Australia (2 printed), Canada (1 printed), Ireland (1 printed), the United Kingdom (5 printed, 2 Websites), and the United States (5 printed, 3 Websites). There was also 1 international Website (Wikipedia). The print items included resources provided by health professionals and patient support organizations. Ten Websites were chosen based on a Google.co.nz search for "Gout", of which the first 10 were included in the sample (excluding links to PDF versions of print items already included in sample). This selection matches the typical first page of results that would be presented to a patient. Two additional online resources were included based on a specific Internet search for self-management resources for gout: an interactive tutorial, and a Web forum that provides educational resources and tools as well as discussion forums and a support blog.

Measures. Readability was assessed with an online test tool (http://readable.com) that assigns text a Flesch-Kincaid Grade Level score based on the number of words per sentence and syllables per word [0.39 × (words/sentences) + 11.8 × (syllables/words) – 15.59]. Grade scores indicate level of reading equivalent to the school grade system in the United States (e.g., Grade 1 = age 5–6 yrs, Grade 12 = age 17–18 yrs). Content of the resources was assessed based on coverage of key topics (Table 1). One specific content area, dietary recommendations, was explored in further detail.

Statistical analyses. The print and Web resources were compared using independent samples t tests. One-way ANOVA and chi-square tests were used to compare the resources from different countries with at least 2 resources.

RESULTS

Readability. Grade level scores ranged from 6 to 12 (mean = 8.7, SD = 1.82). Grade level did not differ between print (mean = 8.83) and Web resources [mean = 8.50; $t(28) = 0.48$, $p = 0.63$]. No significant differences in readability existed across the 3 countries with at least 2 resources (Aotearoa/New Zealand, United Kingdom, United States), based on grade level scores [$F(2,22) = 0.28$, $p = 0.76$].

Content. Table 1 presents the percent of resources covering each topic related to gout and its management. These are presented for the overall sample as well as by countries with 2 or more resources. All resources discussed the role of uric acid in gout and all but 1 mentioned the formation of crystals within joint tissue. All resources discussed body weight, alcohol, and the role of diet, as well as specific foods to avoid in relation to gout. Topics that were covered with less consistency included target SUA and having this checked. Only 46.7% of resources provided a target level for SUA (usually < 0.36 mmol/l or < 6 mg/dl); 40.0% suggested having SUA levels checked but only 30.0% recommended monitoring after diagnosis. Although 90.0% of resources mentioned the importance of longterm urate-lowering therapy, only 33.3% of resources specifically stated that such therapies should not be stopped during acute attacks of gout. The comorbidities of gout were also mentioned infrequently. Although potential kidney problems (e.g., kidney stones, kidney damage, kidney disease) were pointed out by 90.0% of resources, it was less likely for the risk of comorbid heart disease (60.0%) and diabetes (43.3%) to be stated.

The only significant difference across countries was that Aotearoa/New Zealand resources (50%) were more likely than UK resources (0%) to recommend not stopping

Table 1. Percent of resources covering each topic, in decreasing order of coverage.

Content	All Resources, n = 30	Aotearoa/New Zealand, n = 10	USA, n = 8	UK, n = 7
Role of uric acid	100.0	100.0	100.0	100.0
Uric acid is crystal	96.7	90.0	100.0	100.0
Longterm treatment	90.0	100.0	87.5	71.4
Acute treatment	93.3	100.0	100.0	71.4
Uric acid < 0.36 mmol/l	46.7	70.0	50.0	85.7
Check uric acid	40.0	40.0	37.5	42.9
Non-drug treatments	80.0	70.0	87.5	71.4
Not to stop medication	33.3	50.0*	25.0	0.0*
Heart disease	60.0	70.0	62.5	42.9
Diabetes	43.3	40.0	50.0	28.6
Kidney problems	90.0	90.0	100.0	71.4
Weight	100.0	100.0	100.0	100.0
General diet	100.0	100.0	100.0	100.0
Foods to avoid	100.0	100.0	100.0	100.0
Alcohol	100.0	100.0	100.0	100.0
Add low-fat dairy	60.0	70.0	50.0	42.9

* Significant difference between countries at $p < 0.05$.

urate-lowering medications during acute attacks of gout [chi-square(1) = 4.96, p = 0.04].

Dietary recommendations. Within the 30 resources, 126 food and drink items were mentioned. Table 2 presents the foods most frequently recommended to avoid. Inconsistent messages were given about certain foods, particularly with regards to plant-based proteins such as lentils, peas, and beans. Twenty percent of resources recommended avoidance of legumes based on high purine content, 10% recommended eating in moderation, and another 20% recommended increasing legume consumption based on high protein content. The resources also differed in their emphasis on diet in managing gout. While some resources indicated diet was as important as medication for managing gout, others pointed out that there is little scientific proof that avoiding high-purine foods can successfully reduce gout attacks or lower urate. ANOVA and chi-square tests indicated no significant differences between countries in the recommendations presented in Table 2.

DISCUSSION

Our findings suggest significant room for improvement in gout patient education resources, particularly regarding self-management. These results are consistent with previous research into the readability and content of gout education resources[16]. The majority of adults read between the eighth and ninth grade level[19]; however, 16 of the 30 resources we reviewed scored above Grade 9 in reading difficulty. Further, certain topics were not covered consistently within resources. For example, we believe that informing patients with gout of their increased risk of heart disease and diabetes is important for encouraging screening as well as modifying diet and lifestyle factors to manage risk. Providing patients with a target level for SUA may also prove important for tracking progress and maintaining motivation to take urate-lowering therapy during intercritical periods of gout. Research is now required to test whether gout health outcomes can be improved through educational intervention. One study demonstrated that patients with greater knowledge about gout were more likely to have normal SUA levels than patients with less knowledge, and further, that participation in intensive patient education sessions (including verbal instruction, videos, pamphlets, and visual aids) predicted lowered SUA levels in patients 2 years later, as compared to patients receiving only basic information about gout[20].

Further studies are needed of the links among educational resources, patient knowledge, and disease self-management, and health outcomes such as levels of SUA. Additionally, our review of resource content was not comprehensive, and other components of gout education (e.g., around antiinflammatory prophylaxis) may also prove useful for improving compliance.

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Table 2. Dietary items most frequently recommended to avoid. Data are percentages.

Item to Avoid	All Resources, n = 30	Aotearoa/New Zealand, n = 10	USA, n = 8	UK, n = 7
Meat	100.0	100.0	100.0	100.0
Offal	73.3	70.0	75.0	85.7
Red meat	56.7	60.0	25.0	71.4
Seafood	100.0	100.0	100.0	100.0
Shellfish	60.0	60.0	75.0	42.9
Oily fish	56.7	60.0	62.5	57.1
Beer	100.0	100.0	100.0	100.0
Sugar-sweetened beverages	80.0	90.0	62.5	71.4
Yeast extract	43.3	60.0	12.5	57.1
Plant-based protein	20.0	30.0	37.5	0.0

Red meat: beef, lamb; offal: brains, liver, kidneys, heart, tripe, tongue, sweetbread; oily fish: anchovies, herring, mackerel, sardines; shellfish: scallops, mussels, shrimps, crab, lobster, abalone, pipi (*Paphies australis*), clams.

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