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COMMENTARY

Rebranding Gout: Could a Name Change for Gout Improve Adherence to Urate-Lowering Therapy?

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Abstract

Gout is the most common form of inflammatory arthritis in men, yet both patients and the public often do not recognise gout as a form of arthritis. Instead, due to historical misconceptions, gout is typically seen as a lifestyle disease caused by poor diet. In reality, there are a number of risk factors that contribute to gout, including genetic factors. Views of gout as precipitated by lifestyle alone can lead to stigma, and maladaptive beliefs that it should be treated primarily through dietary changes. This is thought to contribute to poor uptake of, and adherence to, effective pharmaceutical treatments. Gout has some of the poorest medication adherence rates of any chronic disease, contributing to suboptimal health outcomes for patients. Recent research suggests that when gout is referred to as 'urate crystal arthritis' (a rarely used name for gout), the perception of the disease by members of the public was more accurate. It was viewed as being less under personal control (i.e. less appropriately managed by behaviours such as dietary intake), and more appropriately managed by long-term medical treatment. This finding raises the possibility that patients themselves might also benefit from gout being explicitly labelled as arthritis. Indeed, parallels can be drawn between this case and other diseases that have recently had their names changed to improve outcomes, namely primary biliary cirrhosis and schizophrenia. A movement away from the term gout may benefit those living with the disease by changing illness perceptions and increasing uptake of, and adherence to, guideline-recommended treatment(s).

Keywords Gout · Urate-lowering therapy · Allopurinol · Name change · Urate crystal arthritis · Treatment adherence

Gout is the most common form of inflammatory arthritis in men, with an estimated 1 to 4% prevalence in North America and Western Europe, rising to 10% in the Oceania region [1]. The disease preferentially affects men, though the risk of developing the disease increases for women post menopause [2]. Gout is caused by hyperuricaemia, with urate crystallising in the joints and causing periodic, but self-subsiding, inflammatory responses known as gout flares. Not only is the condition painful and debilitating, contributing to decreased productivity and quality of life [3], but gout is also associated with long-term problems, such as tophi (accumulation of urate deposits in tissues) as well as joint and tissue damage [4, 5]. This well-defined pathogenesis is treatable with established and effective urate-lowering medications, which have limited adverse effects [6]. Indeed, gout is the only form of arthritis for which a widely accessible, cheap treatment is available that can stop the debilitating episodes of pain to the extent where a person is effectively 'cured'. Despite this, studies indicate that the prescription of urate-lowering therapy (ULT) is poor, with one large study finding that only 38% of people with gout were being treated with ULT [7]. To further exacerbate this problem, gout also has some of the poorest treatment adherence rates of any chronic disease [8], with pooled results from studies indicating that only 46% of patients are adherent to ULT [9]. Why, then, is this widespread, well-understood, and manageable disease so poorly controlled?

A variety of interrelated patient-, practitioner-, and treatment-related factors contribute to poor uptake of, and adherence to, ULT. A common theme through both the

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patient- and practitioner-related factors is the perception of the disease. Gout has a long history, having been described as far back as 400 BC [10]. Over the years it gained the moniker 'disease of kings' due to its association with alcohol and rich foods. Such food and drinks, which typically have a high purine content (the metabolic precursor to uric acid), historically were only consistently accessible to the affluent, leading to gout being perceived as a product of a lavish lifestyle and excess [10, 11]. Whilst our current understanding of gout emphasises the role of genetics in predisposing individuals to develop hyperuricaemia and/or gout due to insufficient renal clearance [12], the perception of gout as a disease of poor lifestyle remains. As will be discussed below, correcting this perception would benefit patients by providing a more accurate understanding of the condition that better reflects its aetiology and pathophysiology.

In gout patients, these illness perceptions contribute to the mismanagement and poor medication adherence by stigmatisation and maladaptive beliefs about how gout should be managed. People with gout report a strong sense of denial and shame, with the disease being treated with ridicule and humour, the root cause of which being the view that the disease is self-inflicted and under their own personal control [13–16]. Unfortunately, this stigma contributes to delays in engaging with healthcare services, and, thus, receiving appropriate management [13, 17]. In addition, the perception of gout as a disease of poor lifestyle leads to a belief that lifestyle changes, such as not consuming certain foods and alcohol, will be sufficient to reduce urate concentrations and avoid future gout attacks [11]—an approach as yet not shown to be effective and harder to maintain than ULT [18]. Social support, a key factor in promoting adherence to medication [19], is also hampered by this misperception. Clearly, a change in the perception of gout is required to facilitate appropriate management.

Practitioners also often view gout as a self-inflicted disease and promote lifestyle changes to patients as a non-pharmacological treatment approach [20, 21]. This contributes to patients' misperception of the disease. Practitioners also report being unaware of the current guidelines for managing gout, often because gout is viewed as a lower priority compared to other conditions [13, 21]. This ignorance of guidelines affects gout management, with practitioners failing to up-titrate ULT to the dose required to sufficiently reduce urate concentrations to avoid further gout flares [13, 22]. A suboptimal ULT dose is likely to contribute to poor adherence, as patients would experience suboptimal therapeutic outcomes and eventually discontinue treatment. ULT also has the potential to induce gout flares for a period after initiation. Guidelines highlight the importance of informing patients of the potential for flares after commencing ULT and to prescribe prophylactic anti-inflammatory treatments such as colchicine, though this is often neglected in clinical practice [23]. Understandably, the occurrence of a gout flare after commencing treatment for gout would be detrimental to patients' perceived efficacy of the treatment, particularly if they are unaware of this potential when commencing therapy, leading to patients discontinuing therapy [16]. In this manner, whilst practitioners may have a better understanding of the condition than patients, lapses in guideline-appropriate management as well as an overemphasis on lifestyle changes contributes to suboptimal outcomes for patients. Initiatives drawing practitioners' attention to guidelines and the aetiology of gout are required to ensure patients receive appropriate information and optimal treatment.

Tackling all these factors in clinical practice has proven a challenge. Whilst a range of successful interventions have been employed to improve outcomes for people living with gout, these are typically carried out by specifically trained health professionals with an emphasis on patient education and appropriate prescribing of ULT [24, 25]. Thus far, however, such interventions have been ineffectively translated into practice. Given that evidence-based guidelines are already available, as well as the difficulty in implementing educational interventions into clinical practice, a wider shift in how the disease is perceived that draws attention to the disease and its management is required. An approach with this potential is a public health campaign, which, to our knowledge, has not been undertaken in gout outside a few charity initiatives. An effective educational campaign has the potential to draw public attention to gout and its treatment, improving patient knowledge, as well as reducing stigma towards the disease, thus improving social support and engagement with healthcare services. Such a campaign, however, would also need to draw practitioners' attention to the disease to ensure patients seeking treatment receive guideline-recommended management.

One such means of attracting attention to gout may be to change its name. Urate crystal arthritis is a seldom used name for gout [26]. Intriguingly, a recent study by Petrie et al. examining illness perceptions towards the names 'gout' and 'urate crystal arthritis' within the general populace found a substantial difference in the beliefs about the disease and its management dependent on which name was presented [27]. Gout was seen as more embarrassing, with a greater weight being placed on the lifestyle of those affected and the need for dietary and lifestyle change, whilst urate crystal arthritis was perceived as being a more serious, chronic condition beyond the control of those afflicted and best managed with long-term medical treatment. As the study participants had likely not encountered the term urate crystal arthritis before, these perceptions are likely based around the arthritic label of the disease. This suggests that there are stark differences between the illness perceptions of gout and other arthritic conditions within the general public. Diseases with the label arthritis are associated with more accurate perceptions and beliefs about management that more closely reflect guidelines. Importantly, many people with gout are also unaware of its arthritic classification [13].

Whilst the study by Petrie et al. was not conducted in a population with gout, it does raise the possibility that the patients themselves may also perceive their condition differently if it was explicitly labelled as arthritis. Such a ‘rebranding’ may overcome some of the barriers to the management of gout, notably the expectations of management with lifestyle changes and stigma towards those with the disease, by distancing the disease from current negative perceptions and bringing it closer to other arthritic conditions which are more accurately perceived and to which it taxonomically belongs. Coupled with an educational campaign drawing prescribers’ attention to guidelines alongside a name change, this rebranding may then benefit those living with the disease by increasing engagement with medical care and ultimately uptake of, and adherence to, guideline-recommended treatment. In this manner, changing the name of gout represents a novel method by which prescription and use of ULT may be improved.

One important point to consider is the feasibility of a change in nomenclature. Whilst uncommon, there is precedence for diseases to have their names changed. Typically, this occurs due to an increased understanding of disease causation, such as the shift from ‘consumption’ to tuberculosis. Seemingly appropriate names, however, have also been changed. One recent example is the hepatic disease primary biliary cirrhosis, now called primary biliary cholangitis [28]. This change occurred for several reasons, though a pertinent one was the negative connotations of the label cirrhosis [28, 29]. Those with primary biliary cholangitis, a genetic autoimmune disease, were faced with the stigma of alcohol abuse due to the association of the term cirrhosis with alcoholism. This situation has clear parallels to gout, although in the case of gout it is the perception of the illness itself, as opposed to an association with another condition. This experience also offers insight into the process behind a change in disease nomenclature in modern medicine [28]. The notion was discussed at international conferences and with patient representatives before surveys were conducted seeking support and consensus within professional associations. Finally, with the support from experts worldwide, the proposal was submitted to the World Health Organisation seeking revision to the International Classification of Diseases.

Given the prevalence of gout, not to mention its cultural ubiquity, changing its name would be a difficult undertaking. Indeed, the idea of expunging the name gout and starting anew with the disease is perhaps naïve. Nonetheless, there is a contemporary example of a change in nomenclature for a commonly known disorder. Over the last few decades there has been a growing movement to change the name of schizophrenia [30]. Those advocating this change primarily emphasise the stigmatising effect of the label within society and how this hinders treatment and recovery [31]. In 2002 Japan became the first country to change the name of schizophrenia to reduce stigma, re-classifying the condition as integration disorder [31, 32]. Promisingly, a follow-up study found that young adults had fewer negative stereotypes towards the new label, although it was still viewed more negatively than other mental health disorders such as depression [33]. Whilst there is some difficulty comparing stigma between psychiatric and medical conditions due to the distinct reasons for social stigma, the example of schizophrenia does suggest that a name change can alter perception and management of a condition. It is also interesting to note that only 41% of the sample in the follow-up study knew that both integration disorder and schizophrenia referred to the same disorder [33]. To date, however, the long-term effects of a name change (i.e. whether the new term is superseding the old term, or whether the general population are slowly learning that the two names refer to the same condition) are unknown. As such, the long-term benefits of such a name change are yet to be established, though further research examining this is required. Despite this, the outcomes to date from this change are promising. As such, even if completely removing the use of the name gout is not feasible, a movement towards this goal by emphasising gout as a form of arthritis through educational material and during diagnosis may still be a beneficial and more feasible outcome to change illness perceptions in gout for the better. Such a change may be reinforced by public health campaigns, reinforcing more accurate understanding of the disease to ensure long-term effectiveness as well as the use of guideline-recommended treatment in disease management.

In conclusion, the study by Petrie et al. raises an interesting notion: could outcomes for people living with gout be improved by changing its name? It is important to note that no research has examined how a change in nomenclature may influence illness perceptions in people with gout. Further, the long-term effects of such a change are currently unknown, highlighting the need for an educational campaign alongside the name change to ensure long-term effectiveness. Nonetheless, this study still puts forth a tantalising possibility that avoiding the term gout, a difficult task in and of itself, and instead emphasising that the disease is a form of arthritis, could potentially change perceptions of the disease and how it is managed. In particular, perceptions of gout might shift from one that places the blame upon the afflicted person, which is considered as manageable by dietary and lifestyle changes, to one that is not the fault of the person and is best controlled with medication. Certainly, with a greater emphasis on long-term medication as the appropriate means of treatment, this persistent and pernicious, yet eminently manageable, disease might finally be controlled.

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Compliance with Ethical Standards

Conflict of interest

No conflicts of interest.

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