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Original article

Implication of nurse intervention on engagement with urate-lowering drugs: A qualitative study of participants in a RCT of nurse led care



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ABSTRACT

Objectives: To explore patient perception of the role of a nurse-led complex package of care in facilitating engagement with urate-lowering therapies (ULTs) in the management of gout.

Methods: Thirty people who had participated in a randomised controlled trial investigating the effect of a nurse-led complex package of care for gout, were purposively sampled and interviewed between 18–26 months after the end of the trial. Interviews were recorded, transcribed and analysed using a modified grounded-theory approach. Data were managed using Nvivo. STATA v15 was used to describe summary statistics.

Results: Participants described their views and experiences of engaging with a nurse-led intervention designed to provide holistic assessment, individualised patient education, and involvement in shared decision-making for the long-term management of gout. The analysis revealed key themes in how nurse-led intervention facilitated engagement with ULT, namely by proving improved knowledge and understanding of gout and its treatment, involvement of patients in decision-making about treatment, and increased confidence about benefits from treatment. However, some treatment uncertainty and concern remained and one participant free of gout flares discontinued ULT, while another halved the dose after the end of the trial.

Conclusions: This study reports data on patient experience of engaging with ULT to manage gout after receiving nurse-led care. It demonstrates that shared decision-making and the joint efforts of fully informed practitioners and patients persuades patients to engage with ULTs, and that experiencing the benefits of curative treatment motivates them to maintain adherence.

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1. Introduction

Gout is the most common inflammatory arthritis worldwide. Between 3.7–3.9% of adults in France and the USA self-report physician diagnosed gout, while 2.5% of UK adults have gout according to their primary care healthcare records [1–3]. The incidence and prevalence of this condition are rising mainly due to an ageing population, and the obesity epidemic [4]. Gout is also the only rheumatic disease whose aetiopathogenesis is well understood, and which can potentially be cured by removal of the pathogenic agents (urate crystals) [5]. Current guidelines recommend the use of urate-lowering therapies (ULTs) for people with recurrent flares

or with complications such as tophi, renal stones, joint damage or impaired renal function [6–8]. Up-titration of ULT to reduce and maintain serum urate (SU) levels below 360 $\mu\text{mol/L}$ is the key to achieving long-term control of gout [6–8].

The uptake of ULTs is an important factor in its long-term management. Despite the availability of effective pharmacologic therapies, management of the condition remains suboptimal [9,10]: only 30%–40% of patients with gout are ever prescribed ULTs [1,11,12] and there is frequent absence of regular monitoring and dose up-titration against a target SU level [13–16]. Treatment adherence remains low: 70% of patients prescribed ULTs have gaps in their use, mostly during the first year of treatment [17]. The decision to initiate, persist on, and comply with a treatment is influenced by a combination of physician and patient factors [18].

Evidence from a previous proof-of-concept study from Nottingham, UK, demonstrated that people with gout who are fully informed about the disease and are involved in decisions about

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their treatment wish to receive ULT and subsequently persist with it [19]. Nurses manage many chronic conditions in the community and provide personalised support and care [20]. Indeed, data from the recent two-year randomised controlled trial (RCT) comparing nurse-led complex package of care for gout versus usual GP care demonstrates that a nurse-led package of care combining individualised patient education and engagement, lifestyle advice, and ULT using a treat-to-target approach improves drug persistence, reduces flare frequency and tophi, and improves quality of life [21]. The aim of this study was to qualitatively explore patients' perceptions of the role of nurse-led care in this RCT in facilitating their engagement with ULT.

2. Methods

2.1. Study design

Semi-structured qualitative interview study using elements of grounded-theory methodology including open and axial coding, constant comparison, and theoretical sampling [22]. Applying elements of grounded theory allows the study findings to be rooted in participants' experiences, highlighting what is important to them.

2.2. Ethical approval

Research ethics committee approval was obtained from the University of Nottingham, Medical School Research Ethics committee (reference No.: D16012017). All participants gave written informed consent before data collection.

2.3. Sampling

Two hundred and fifty-five participants randomised to the nurse-led care arm of the RCT were mailed a questionnaire about gout and its current treatment after the end of the study. The first 100 participants who were contacted with the survey were also approached to participate in an interview study. Of these, 52 people showed an interest in participating in the interview study, and 30 people (58%) were sampled to reflect differences across gender, age, ethnicity disease duration and type of ULT (i.e. allopurinol, febuxostat or benzbromarone) and were purposively recruited. The theoretical sampling approach requires researchers to begin with an open-ended sampling strategy, use opportunistic interviews and then, through an iterative process of data collection and analysis, refine the sampling strategy to be increasingly focused until theoretical saturation is reached [22]. ZL and AA met regularly to discuss the process of refining the sampling strategy to reach saturation.

2.4. Data collection

ZL designed a semi-structured interview guide in discussion with AA and MD. The agreed-upon questions focused on patients' perceptions of management of gout before, during and after the nurse-led intervention and covered areas such as their beliefs about the causes and consequences of gout, their symptoms (frequency and severity), the impact of their condition on their daily life and psychological and emotional wellbeing, medical management of their condition, their perception of ULT, previous contact with healthcare professionals and advice and information they had received, their treatment history and preferences, and their level of adherence to healthcare-professional advice about treatment. ZL piloted the interview schedule with a few participants and no revisions were required. WJ, a research nurse, contacted participants by telephone to arrange an interview with ZL. Interviews lasted twenty to ninety minutes. Twenty-two participants opted to

Table 1
Index of Multiple Deprivation (IMD) score for study participants.

	Median (interquartile range)
Overall IMD	5 (2–7)
IMD domains	
Income deprivation	4 (3–6)
Employment deprivation	4 (3–6)
Education, skills and training Deprivation	4 (2–6)
Health deprivation and disability	4.5 (2–6)
Crime	5 (3–7)
Barriers to housing and services	7 (5–9)
Living environment deprivation	5 (4–7)

be interviewed in the City Hospital Nottingham, in a private room located in Academic Rheumatology and the remaining eight were interviewed by telephone. Interviews were audio recorded and transcribed verbatim by an independent transcription company. Member checking was done throughout the interviews.

Data for the Index of Multiple Deprivation (IMD), the official measure of relative deprivation for small areas in England was obtained from Ministry of Housing Communities & Local Government, <http://imd-by-postcode.opendatacommunities.org>. The IMD ranks every post-code in England from most deprived to least deprived, and categorises the ranks into deciles. It combines information from seven domains, namely income deprivation; employment deprivation; education, skills and training deprivation; health deprivation and disability; crime; barriers to housing and services; and living environment deprivation to produce an overall relative measure of deprivation.

2.5. Data analysis

The data were analysed in parallel with the data-collection process, and initial results informed subsequent sampling and data collection. Analysis began with open coding to identify concepts and generate codes. Conceptual codes were grouped into major categories. Analysis proceeded with axial coding exploring relationships between major categories. The constant comparison method was used, allowing the data to be compared and contrasted within and between interviews, concepts and major categories [22]. Memos were also written to capture impressions of the data and to record emerging concepts and categories. ZL used NVivo version 11 software [23] to facilitate coding of all transcripts and a subset was blind-coded by GN. The coders discussed and resolved any discrepancies – a summary of preliminary findings was also presented to AA and MD who did not highlight any inconsistencies.

STATA version 14 was used for quantitative data analysis.

3. Results

3.1. Participants

Thirty participants (26 men) were interviewed between April and July 2017. This was between 18 and 26 months after the end of the RCT: the median post-intervention interval was 22 months (IQR: 19–21 months). Participants were aged between 36 and 85 years with a mean age of 65.17 (SD 11.51) years and came from white ($n=28$), Chinese ($n=1$) and East-African Asian ($n=1$) backgrounds. Their median (IQR) decile for IMD overall was 5 (2–7), and the median decile for each domain of IMD is summarized in Table 1. The mean disease duration was 14.9 (SD 11.12) years. Twenty-four participants received allopurinol, and the other six received either febuxostat ($n=5$) or benzbromarone ($n=1$). Their disease and demographic characteristics were similar to the participants in the main study. SU levels and tophi data before and on completion of the RCT in these 30 participants are summarised in Table 2. SU

Table 2

SUA levels and tophi data, before and on completion of the RCT.

	SUA ($\mu\text{mol/L}$) (mean \pm SD)	Participants with tophi n (%)
Baseline	439.77 \pm 81.06	2 (6.7%)
At 24 months	232.27 \pm 44.37	1 (3.3%)

Box 1: Illustrative quotes for themes 1 and 2

Theme 1: Improved understanding of gout and its treatment

..it [long-term ULT use] gets rid of the crystals altogether, which is obviously the problem lies with the crystals that form.

feel good that I understand what was happening and what caused it [gout] and why they've done it whereas other people I know that are just under the doctor, they have no real clue,

It's easy you just take the medication [ULT] and the gout is gone. I can't be bothered with my diet.

[After speaking with the nurse] I know things like, for instance, like this thing called purines, which obviously anything that's high in purines can cause the uric acid to build up.

I imagine it [gout] can damage the joints and I imagine [cause] some kind of kidney disease.

It's just I don't know if you'll ever come off the pills [ULT] (. . .) if your body produces too much uric acid, you're stuck with that aren't you.

Theme 2: Increased confidence

But mostly it's the talks [with the nurse] that were helpful because dealing with people who specifically have this condition as an expertise, it's good to be able to do that, whilst the GP, he had a knowledge of it but it wasn't sufficient to get the situation under control.

Fine, it was absolutely great, she [nurse] explained what would happen, the targets [optimum uric acid level] that we were aiming to get.

learned the right level of uric acid into the blood, yes, had to be below a certain limit, always take the pills, don't forget and I can remember the side-effects, negative ones.

I took these little tablets [colchicine] in case I got a bout of gout again, to take those as well [as the ULTs], and [the nurse] explained what they were for and what these were for and, as I say, I was on [both] tablets when I was on the study.

levels were not considered in the data analysis process. Analysis of the participants' account of their experiences of managing gout led to the identification of six core themes relating to the role of nurse-led care in facilitating engagement with ULT. Twenty-nine of the thirty participants were on ULT at the time of the interview study. These themes are discussed below and supported with illustrative quotations in Boxes 1–3.

3.2. Theme 1: improved knowledge and understanding of gout and its treatment

Participants reported that nurse-led care helped to improve their understanding of the nature of gout and the role of pharmacologic treatment in the long-term management of the condition (Box 1). Participants while reflecting on their experiences, frequently stated that primary-care practitioners had provided little information about the role of ULT in the management of gout. Post-intervention, most participants indicated that increased knowledge of the causes and long-term effects of gout fostered their engagement with ULT. Participants accepted that elevated SU levels and the resulting urate crystal accumulation in the body caused gout. Most understood that urate crystal accumulation would continue until the process was treated effectively with ULT. They explained that they primarily sought to engage with ULT to help lower urate levels, eliminate the crystals and thus prevent further flares.

While participants understood the role of pharmacologic interventions in the long-term management of gout, many were unaware of the importance of simultaneously making lifestyle adjustments: they preferred to rely on medication alone. However, many indicated that the provision of dietary information addressed

Box 2: Illustrative quotes for themes 3 and 4

Theme 3: Encouraged persistence

Well the gout study's a lot more thorough and it's more individualized – they adjust the dose and treatment to you, as well, you're on a personal basis. It's hands on and that's why you engage in it better and get good results. My flares were coming down, the nurse was doing a wonderful job [up titrating ULT] but then I went on holiday while I was on the study, forgot to take my tablets [ULTs] with me, and I had a flare. I thought, 'I must remember them.'

The nurse came to do my blood test, she said to me that it [SUA level] was high. She phoned me straight away, and said, I should increase my dose.

They [nurses] were good, they used to obviously give me a running tally on my urate level periodically when I used to go in, have a meeting and check my blood and that. So, it was a lot more in depth and a lot more, you know, managed.

The doctors, with all due respect to them, I'm a number in a vast amount of numbers for them. They give you 10 minutes and, you know, I'm not knocking the doctors at all, but you can't get the right dose [ULT dose] in 10 minutes.

Theme 4: Involved patients in decision-making about treatment

It's actually talking and being able to talk to the nurses involved in the study and getting encouragement from them, the fact that we're working together, it's not just me on my own, seeing the GP.

my brother-in-law had got gout and he was already on the Allopurinol and it was him that I discussed about, he was saying how good the drug was but again, he was saying, but once you start on it, you have to continue it. The nurse said the same.

I was put on it [allopurinol] by the research [intervention] and because it worked for a bit and then afterwards, it [SUA level] kept going back up again, it wasn't working for me, so I discussed it with the nurse, I was put on this Febuxostat and well, it just brought it [SUA levels] right down.

The first tablet [ULT] they [nurse] put me on, I came out in a rash and so I felt that it didn't suit me, she said, 'It can't suit you', and she talked it over with me and then put me onto the other tablet [ULT].

Box 3: Illustrative quotes for theme 5

Theme 5: Enhanced long-term adherence

And, the medicine [ULT] works for me. I haven't had a flare since coming out of the study. I never fail to take it, because I know what will happen to me if I don't, I think about it, oh did I take my tablet [ULT], so it's, religiously I take that tablet [ULT].

It's an arthritic condition but I don't understand, I don't know if it's coincidence, taking the Allopurinol does seem to help with the arthritis so that would seem to suggest there is some kind of connection somewhere.

misperceptions about the role of diet in the management of gout. Participants were also worried about the effect of progressive urate crystal deposition on their joints and the risk of irreversible joint damage. For most, knowledge of the long-term consequences of gout together with a desire to prevent further flares became a driver for engagement with treatment.

3.3. Theme 2: increased confidence in ULT

Participants indicated that nurse-led care addressed individual concerns about using ULT, and this helped them to overcome their resistance to taking medication (Box 1). Some participants had previously been prescribed fixed, low-dose ULT by primary-care practitioners which had failed to prevent flares. These participants were reluctant to re-engage with ULT until the nurse told them that the dosage needed to be optimised in order to prevent further flares. When they discovered that this could be determined by monitoring SU levels and up-titrating ULT against a specific target level, below the saturation point for crystal formation, they were persuaded to re-engage with ULT. Those with no previous experience of ULT use also benefitted from information about the up-titrating process. In both cases, awareness of the goal of up-titration increased patients' confidence in the potential efficacy of ULT, encouraging

them to begin therapy and engage with the up-titration process. All participants were advised that they could experience gout flares during up-titration and were prescribed pharmacologic treatment to manage flares. This reassured individuals that the nurse-led intervention gave equal weight to the management of both acute and long-term gout.

3.4. Theme 3: encouragement to persist with ULT during the trial

After initiating ULT, participants believed that periodic contact with the nurse provided them with the impetus to persist with their medication (Box 2). Many participants observed a progressive reduction in the frequency and severity of flares during the up-titration process and they attributed this to receiving individualised treatment. On observing the results of the new regimen, participants were determined to continue taking ULT in order to prevent recurring flares. Some participants did not experience any flares during the up-titration process and were motivated to continue with ULT because they understood that gout could flare up again. Those with previous experience of up-titration under a primary-care practitioner explained that they had not received information about the process, found it slow and were demotivated when they experienced flares as they had expected the treatment to prevent flares at a much earlier stage.

Participants valued the long-term monitoring and review of their condition and treatment – frequently suggesting that ongoing dialogue with a healthcare professional, especially while establishing a new regime, encouraged them to persevere with ULT. Most suggested that the availability of information on current and target SU levels provided the psychological motivation to continue with ULT while determining the optimum dose during an up-titration process. Participants were impressed by the consistent and timely access they had to a supportive healthcare professional, and the speed at which the target SU and optimum ULT dose was achieved. Both of these meant they suffered minimal inconvenience.

3.5. Theme 4: involved patients in decision-making about treatment

Individuals indicated that nurse-led intervention involved them in decision-making about treatment (Box 2). They were able to explore the risks and benefits of the treatment options available and make an informed decision about treatment in discussion with their healthcare professional. Most explained that they shared their preferences, goals and values, and the healthcare professional communicated information about the condition and treatment options. Some participants had researched treatment options and dietary restrictions, and bought this knowledge to discussions, as well as the relevant past experiences of family/friends. Patients with other medical conditions raised concerns about contraindications of ULT and interactions with other prescriptions. They were reassured when nurses provided information about potential side effects and prescribed the best suited ULT, feeling that their patient-specific risk factors were being addressed.

3.6. Theme 5: enhanced long-term treatment adherence after end of trial

Participants explained that engaging with nurse-led care helped to prevent further flares of gout which motivated their adherence to ULT (Box 3). None had experienced a flare since completing the trial, and all felt there had been improvements in their physical, psychological and emotional wellbeing as well as their quality of life. Some also perceived an improvement in overall joint function and joint-related symptoms, such as the stiffness and pain occasionally associated with other rheumatic conditions. They attributed

Box 4: Illustrative quotes for treatment uncertainty during and after the study end

Theme 6: Treatment uncertainty and concern

Allopurinol has quite a lot of side effects and I wonder if I'm on it long term how that will affect my health and the other medications I'm taking.

Well, I read in, it's one of the side effects. It [ULT] potentially can raise your white blood cells, I'm getting no symptoms of gout, I took a chance and halved it [ULT dose].

I was taking eight paracetamol codeine tablets. I was taking these 14 tablets a day, that was a lot so I stopped it [ULT]

I'm not sure anybody is monitoring it [uric acid levels] now. Because of my kidney issues, I get told to have a blood test, if I go to the doctor but I've not had one for gout.

improvements to a treatment approach which prioritised long-term management of gout rather than focusing just on the flares in the way primary-care practitioners had often done in their earlier consultations. Individuals feared flares and the prospect of pain prompted adherence.

3.7. Theme 6: treatment uncertainty and concern

Although most participants reported adhering to ULT, some raised concerns about long-term use related to prescription costs, polypharmacy, relative contraindications, overuse, dependency, long-term impact on health, and side effects (Box 4). Apprehension about long-term use of medication led to one participant halting ULT, and another self-adjusting the dose to a lower, personally acceptable level. Post-intervention, participants were concerned that there was no long-term monitoring or discussion of ULT use – although at the end of the study primary-care practitioners were advised to monitor SU levels annually, very few did.

4. Discussion

This qualitative study explores the role of nurse-led care designed to improve uptake of ULTs in the control of gout. Patients found that nurse-led care, unlike general-practitioner care, improved their knowledge and understanding of gout and the function of ULTs in its long-term management. Dialogue with a healthcare professional corrected any misperceptions about gout, alleviated any concerns about ULT use and allowed patients to start treatment with increased confidence. Information about up-titrated ULT and regular monitoring and review of SU levels reassured patients, encouraging them to persist with ULTs. It is likely that a reduction in the SU level was perceived as a therapeutic effect of persevering with the medicine, and further promoted drug adherence in a positive biofeedback loop. Additionally, education about the discordance between achieving a therapeutic SU level relatively early in the course of up-titrated ULT, and, the continued occurrence of gout flares enabled study participants to interpret their SU results correctly. This is of major importance in drug adherence and engagement with ULT. Discussing the risks and benefits of treatment options allowed patients to make informed decisions about their healthcare. Adherence to ULTs was promoted by effective control of gout which improved quality of life. Similarly, acknowledging the side effects of ULT, discussing it, and changing the treatment when required, would further improve persistence on treatment. Although a few patients reported an improvement in non-gout-related joint symptoms, it is not clear from the present study whether this is attributable to ULTs.

A previous qualitative study exploring factors influencing the uptake of ULT indicated that patients want to be involved in decision-making about their treatment, and value a healthcare approach which involves 'joint effort over time' [18]. Our study has

demonstrated that shared decision-making and such joint efforts as outlined above persuade patients to initiate ULT, and observing a reduction in the frequency of flares encourages them to persist with the therapy. Our findings suggest that knowledge about gout and understanding of its consequences and treatment enhances patient receptiveness to ULT and this is supported by other studies which have noted that increased patient understanding can improve willingness to take ULTs [18,24–26]. Once ULT has been initiated, qualitative findings have indicated that patient behaviour and their perception of the effectiveness of ULT can determine whether they continue with treatment [18]. In this respect, our findings reveal that regular monitoring can mitigate negative behavioural changes. Findings from a questionnaire-based study investigating long-term adherence to ULT among patients with gout who had received full information on gout and been monitored by a nurse for one year suggest that 91% respondents were using ULTs five years after initiation [19]. This present qualitative exploration shows that when patients experience the benefits of ULTs, they are motivated to adhere to long-term gout treatment. Our qualitative study has shown that nurse led care which provides holistic assessment, individualised patient education and engagement facilitates ULT uptake and subsequent persistence.

Participants in this study were interviewed at least 18 months after their last study visit. Several reported concerns about the lack of monitoring of SU levels, and absence of any ongoing discussion with their GP about the need for continuing ULT. This highlights the importance of regular monitoring of gout, and, suggests that any long-term package of care for gout should include regular review (for example, annually) involving discussion about gout status, measurement of SU, and assessment of adverse lifestyle factors and comorbidities.

Using a qualitative approach enabled exploration of how nurse-led intervention facilitates initiation, persistence, and long-term adherence to ULT from the perspective of patients. The sample was designed to include participants who had diverse experiences of engagement with ULT during the previous RCT, and we included participants who fit the ‘typical’ gout profile and those who did not [18]. The most significant limitation of this study is that the sample consisted of patients who were predominately white and of an older age and who were all living in the East Midlands. For cultural and regional reasons, other populations may express different views about the interplay between this type of nurse-led intervention and engagement with ULT to manage gout. Furthermore, participants in the RCT volunteered to take part and had experienced at least one flare in the twelve months before commencement of the RCT. It is not clear whether people with less frequent flares are willing to engage with ULTs. Finally, participants were interviewed 18–26 months (median: 22 months) after completing the RCT. This could influence their ability to accurately recall experience in the nurse-led care intervention and is a limitation of the study. Moreover, we did not collect information about educational attainment, employment status and income level from each participant in this study. However, their post-code based IMD data shows that their education, employment and income deprivation characteristics was below average for the UK, with a median score of 4th decile. Additionally, we did not measure their SU level at the time of the interview visit, and are unable to triangulate this with the results.

5.

In conclusion, we have established from the perspectives of patients that a nurse-led package of care designed to improve patient outcomes enables engagement with ULTs for the long-term management of gout. However, the findings have also highlighted

that people with gout are concerned about the implications of long-term medication use and this could prevent adherence. Furthermore, they lack understanding of the complimentary role of ULT and lifestyle adjustment in controlling gout. Previous qualitative research has suggested that people with gout associate ULTs with less requirement for dietary restriction and that this perception encourages ULT use [26]. Further studies are required to:

- develop and test interventions which communicate the risks and benefits of long-term ULT use in order to address patient-specific concerns;
- to assess methods which communicate how lifestyle adjustments can be used in combination with pharmacologic interventions in the control of gout.

Such interventions are long overdue in a society with rising prevalence and incidence of gout but continued suboptimal management of the condition.

Contributors

Conception: AA, MD and ZL. Data collection: ZL and WJ. Analysis: ZL and GN. Manuscript draft and approval: all.

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Disclosure of interest

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The other authors declare that they have no competing interest.

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