

## REVIEW ARTICLE

# Determinants of Self-Management Behavior in Gout: A Scoping Review

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**Objective.** This study aimed to identify modifiable determinants of self-management behavior in patients with gout.

**Methods.** Four databases (Medline, Embase, PsycINFO, and CINAHL) were searched using terms related to gout, self-management, and determinants of behavior as described in the Theoretical Domains Framework (TDF). Two reviewers independently selected relevant studies via screening of title/abstract and full text. Thematic synthesis was performed for qualitative data; quantitative data were summarized using cross-tabulation displaying the investigated associations of determinants with self-management behavior. The TDF facilitated identification and grouping of determinants.

**Results.** From 2,087 unique articles found, 56 studies were included in this review, of which there were 27 qualitative and 29 quantitative studies. Eight themes were identified: knowledge and skills for self-management, acceptance of disease, beliefs about necessity of self-management to improve gout-related health, resistance and reluctance for medication adherence and dietary alteration/changes, negative emotions influencing self-management, social support and interactions, environmental context, and self-regulation of behavior. Quantitative determinants associated with self-management behavior, predominantly medication adherence, were mapped to 12 of the 14 domains of the TDF. No determinants regarding skills and goals have been identified in quantitative research.

**Conclusion.** Intervention targets for self-management behavior in patients with gout mainly included determinants related to knowledge, implicit and explicit beliefs and attitudes, the environmental context and resources, and (social) support and reinforcement.

## INTRODUCTION

Gout is a chronic disease caused by deposition of monosodium urate crystals in joints and soft tissue, which can occur in a state of hyperuricemia. These crystals trigger an immune response that results in painful arthritis. Despite available and effective management options, gout treatment is often suboptimal, with cited ranges of approximately 20% to 36% of all patients with gout treated in primary care being under the target serum uric acid (sUA) levels of  $\leq 36$  mmol/L, therefore causing patients to continue experiencing flares.<sup>1–3</sup> This poor result has various causes, such as insufficient knowledge about the disease and its management among patients and health professionals and nonadherence to (non)pharmacological interventions.<sup>4–6</sup> Inadequate treatment and subsequent flares decrease quality of life and functioning, increasing burden on patients, the health care

system, and society through higher health care resource use and work productivity losses.<sup>7–9</sup>

Given the suboptimal treatment and expected rise of patients with gout without a proportionate rise in health care resources and personnel, stimulating self-management is a promising solution to improve care.<sup>8,10–14</sup> Self-management concerns an individual's ability to manage symptoms, treatment, physical and psychological consequences, and lifestyle changes inherent to living with a chronic illness.<sup>14</sup> Self-management in patients with gout is important because it enables individuals to effectively treat flares and adhere to long-term medication and lifestyle adjustments. However, several studies indicate suboptimal self-management behavior, such as a lack of lifestyle changes and treatment adherence.<sup>4–6,15–17</sup>

Previous research has investigated nurse-guided self-management programs in patients with gout, demonstrating increased adherence to long-term medication and improved

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### SIGNIFICANCE & INNOVATIONS

- Modifiable determinants were identified for almost all domains of the Theoretical Domains Framework, which can act as targets for interventions.
- Most studies on determinants of self-management behavior in patients with gout assess medication adherence as self-management outcome.
- Results on determinants of self-management behavior concerning lifestyle and care-seeking behavior are scarce.

clinical outcomes.<sup>2,18,19</sup> However, being labor intensive, these types of interventions will not be feasible in the future due to staff shortages.<sup>11,20</sup> eHealth-based interventions delivered through applications (apps) or websites may provide an efficient solution to promote self-management, for example by providing education and support in an automated manner. These interventions, efficient in terms of labor, look promising in stimulating self-management to a certain extent, but effects on clinical outcomes, if any, remain small.<sup>21–23</sup> Studies, also efficient in terms of labor, have shown improved adherence behavior and clinical outcomes when patients self-monitor sUA levels and use interactive voice-response systems.<sup>24,25</sup> However, evidence on large and persistence of adherence behavior effects induced by (digital) interventions, taking into account labor efficiency, remains scarce.

According to the Capability, Opportunity, Motivation, and Behavior (COM-B) model, behavior will only be performed when patients have the capability, opportunity, and motivation to do so. The aforementioned interventions may enhance knowledge and opportunities but might not foster the necessary skills and motivation for desired behavior. It's crucial to target interventions at the right determinants to ensure patients have all influencing factors, increasing the likelihood of behavioral change and improved treatment outcomes. Finding out what factors affect self-management is an important first step, and many studies have looked into this.<sup>4,5,16</sup> However, no studies to date have created a comprehensive overview of determinants associated with gout self-management behavior, which can consequently be used to inform evidence-based interventions. Therefore, this scoping review aimed to identify and describe determinants associated with self-management behavior in patients with gout.

## MATERIALS AND METHODS

The protocol of this review was registered in Open Science Framework at the January 25, 2023 (doi:[10.17605/OSF.IO/4PQFX](https://doi.org/10.17605/OSF.IO/4PQFX)). This study used the five-step scoping review methodology described by Levac et al.<sup>26</sup> The Preferred Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews guideline was used to ensure quality and transparency of reporting (Supplementary S1).<sup>27</sup> Due to the nature of this work being a

scoping review, ethical approval from an institutional review board or ethics committee was not required.

**Step 1: identify the research question.** The research question was defined by the research team as, “What are determinants associated with self-management behavior in gout?”

**Step 2: identifying relevant studies.** A literature search was performed in four databases: Medline (PubMed), Embase (Ovid), PsycINFO (Ovid), and CINAHL. The searches were performed on November 16, 2022. The Sample, Phenomenon of Interest, Design, Evaluation and Research type (SPIDER) tool was used to specify the inclusion criteria for literature and guide the search strategy development (Table 1).<sup>28</sup> The search strategy included the use of mapped subject headings and key terms, using wildcards/truncations when applicable (ie, various spellings and verb forms). The search strategies combined terms related to (1) gout, (2) self-management behavior, and (3) determinants of behavior based on the Theoretical Domains Framework (TDF; Supplementary Material 2).<sup>14,29</sup> The TDF, a more detailed version of the COM-B model, was used to identify and categorize modifiable determinants that can be targeted using behavior change interventions.<sup>30</sup> We operationalized self-management behavior for gout by translating the definition by Barlow et al<sup>14</sup> to the context of gout (care) as following: (1) adherence to medication (urate-lowering therapy [ULT] and medication to treat

**Table 1.** Study inclusion and exclusion criteria based on the SPIDER tool\*

Criterion	Justification
Sample	Adult patients with a diagnosis of gout Not studies related to cells/animals/models or healthy individuals, health care providers, etc
Phenomenon of interest	Determinants based on the TDF domains and constructs (Supplementary Material 2)
Design	Cross-sectional, longitudinal, observational and intervention studies, questionnaires, RCT Interviews, focus group (discussion or nominal group technique) Not case reports, literature reviews, editorials, commentaries
Evaluation	The association of determinants with self-management behavior defined as: <ul style="list-style-type: none"> <li>• adherence to receiving medication (ULT and medication to treat acute gout flares)</li> <li>• adherence to diet recommendations (eg, alcohol restriction, purine low diet, and staying hydrated)</li> <li>• adherence to recommendations for physical activity, exercise, and losing weight (training programs)</li> <li>• care-seeking behavior</li> <li>• self-monitoring of disease status</li> </ul>
Research type	Quantitative, qualitative, and mixed methods; peer-reviewed original research articles; conference abstracts 2020 to 2022; published in English

\* RCT, randomized controlled trial; SPIDER, Sample, Phenomenon of Interest, Design, Evaluation and Research type; TDF, Theoretical Domains Framework; ULT, urate-lowering therapy.

acute gout flares); (2) adherence to diet recommendations (eg, alcohol restriction, purine low diet, and staying hydrated); (3) adherence to recommendations for physical activity, exercise, and losing weight (training programs); (4) care-seeking behavior; and (5) self-monitoring of disease status. Search terms for each database are shown in Supplementary Material 3.

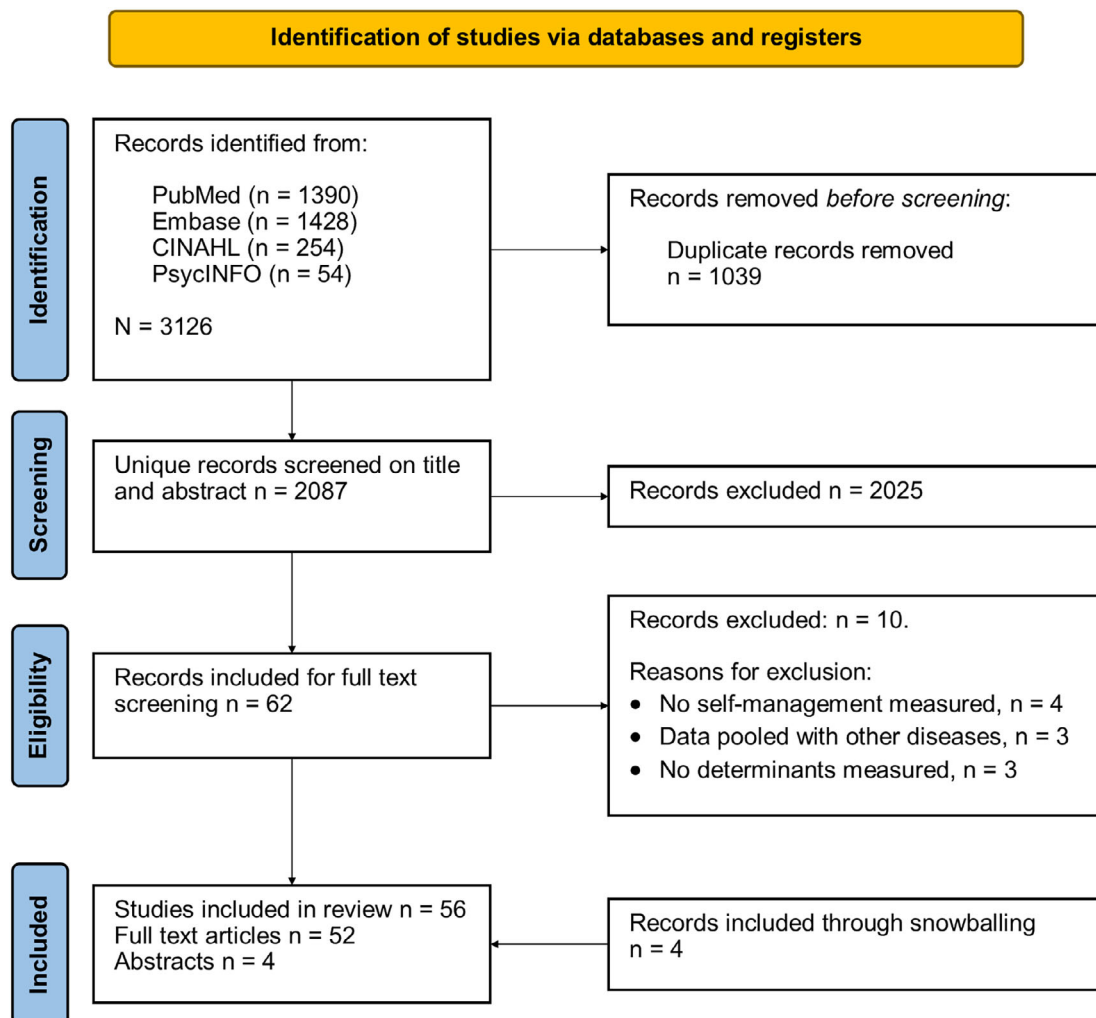
**Step 3: selecting studies.** First, duplicate articles were removed. Studies were screened by title and abstract for relevance independently by two authors (JvdV and LMV), and disagreements were discussed until consensus was reached over inclusion or exclusion. This approach was repeated after full-text screening. From the included articles, references were screened for potential relevance, as well as the articles that cited the included articles (snowballing).

**Step 4: charting the data.** Relevant data, using a predefined extraction format developed by the research team, were retrieved from the included articles by JvdV and verified by LMV through comparison with full-text articles.

**Step 5: collating, summarizing, and reporting the results.** To analyze and report the findings from included qualitative studies, a thematic synthesis was performed using Atlas.ti (version 23).<sup>31</sup> One author (JvdV) performed the steps of analysis, which were discussed with two other authors (BJFvdB and LMV). Statistical associations reported between determinants, and different types of self-management behavior were mapped in a cross-table and categorized according to the 14 TDF constructs and the domains of the COM-B model, which represents a simplified version of the TDF.<sup>30</sup> Associations that were only reported descriptively were narratively reported.

## RESULTS

The search strategy yielded 2,087 unique articles, of which 62 articles were included for full-text screening. In total, 56 studies (52 full-text articles and 4 conference abstracts) were included in our scoping review (Figure 1).



**Figure 1.** Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) flow diagram of the scoping review.

**Overview.** The characteristics (first author, year of publication, country, setting, study aims, sample size, and study design/methods) of all included studies are reported in Supplementary Material 4. The studies were published between 2008 and 2023 in 16 different countries and spread over all continents except South America and Africa. Studies were performed in many settings but mostly in secondary care ( $n = 28$ ; 50%). Of 29 quantitative studies, 20 were observational studies (18 cross-sectional and 2 longitudinal), 8 were interventional studies, and 1 involved a secondary data analysis from the GOSPEL cohort.<sup>32</sup> The median sample size for quantitative studies was 298 (interquartile range [IQR] 77–1,352). A total of 27 qualitative studies (interviews and focus groups) were included, with a median sample size of 24 (IQR 17–43).

**Thematic synthesis of qualitative studies.** The thematic analysis yielded eight themes describing determinants related to self-management behavior, but mainly adherence to medication and dietary recommendations, and are described below. Supporting quotes can be found in Table 2.

*Knowledge and skills for self-management.* Patients adhered to gout-specific medication when they gained knowledge about the causes of gout, the consequences of having gout, the goals of ULT treatment, and knowing that flares can occur more frequently during the up-titration of ULT.<sup>33–37</sup> Likewise, not knowing or receiving a warning for this initial increase in flares was reported as a barrier for ULT adherence.<sup>36,37</sup> Also, nonadherence to ULT was attributed to a lack of awareness regarding the necessary ULT regimen and its significance in treating gout.<sup>37–39</sup> Some patients thought they should only take ULT when having a flare and used medication accordingly.<sup>40,41</sup> Furthermore, patient skills were reported as a barrier for self-management. Patients

experienced issues with getting medication refills,<sup>37</sup> planning their medication regimen ahead when traveling, or had trouble reading labels.<sup>42</sup> Finally, patients accidentally forgot to take medication,<sup>37–39,43–45</sup> for example when traveling or due to having too many pills and forgetting to collect prescriptions.<sup>40,42</sup> In terms of diet, gaining more knowledge led to avoidance of trigger foods and alcohol.<sup>39,46</sup>

*Acceptance of disease.* Patients reported that acceptance of having gout led to improved medication adherence and lifestyle modification.<sup>35,41,47,48</sup> In contrast, not accepting the disease led to resistance to ULT.<sup>36–38</sup> Finally, masculinity caused reluctance to seek medical attention because men wanted to avoid the embarrassment of admitting severe pain in a small body part.<sup>49</sup>

*Beliefs about necessity of self-management to improve gout-related health.* Patients adhered to ULT when they felt the need to prevent or reduce disease symptoms (eg, to prevent flares and associated pain).<sup>33,34,37,38,42,43,45,47,50</sup> Other reasons to adhere to ULT included the prevention of disease progression; disability; surgery; avoiding additional hospital visits; improving quality of life, mobility, and daily functioning; and being able to care for others and not having to change their diet.<sup>34,35,37,38,42,48,51</sup> For the latter, some patients elaborated that lifestyle modification was difficult to adhere to in the long run.<sup>48</sup> On the contrary, the identification of dietary triggers for gout and the subsequent belief that gout could be prevented through diet acted as a barrier to receiving ULT.<sup>37,48,51</sup> Additional barriers to receiving ULT included preferences for alternative medicine, perception that other medication is more effective,<sup>42</sup> and only receiving ULT when SUA levels increase.<sup>48</sup> Some patients preferred to treat flares only receiving short-term treatment instead of long-term ULT<sup>35–37</sup> if flare frequency was acceptable to them. After quitting, patients were motivated to restart receiving ULT when recently experiencing a

**Table 2.** Quotes supporting each of the themes described\*

Theme	Quote
Knowledge and skills for self-management	“For one participant, forgetting seemed to be connected to lacking knowledge, with the belief that ULT is: ‘built up after, you know, a week of taking it straight, missing it one day is probably not going to be detrimental, right?’” <sup>38</sup>
Acceptance of disease	“Just my eating, my drinking, and I guess the attitude that I had to realize that I had this problem and I just have to deal with it and had to change my whole routine, way of thinking.” <sup>47</sup>
Beliefs about necessity of self-management to improve gout-related health	“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].” <sup>33</sup>
Resistance and reluctance for medication adherence and dietary alteration/changes	“So I know gout’s never going to kill me, right. So I don’t want to be taking—I don’t want to be rattling around full of tablets all the time.” <sup>36</sup>
Negative emotions influencing self-management	“Fear. Because ... when I get an attack, it’s debilitating ... before I was on the allopurinol. You know, I would call it a great preventer.” <sup>37</sup>
Social support and interactions	“I was really well looked after. It depends on familiarity, on how used to being in contact with it [gout] they [family or friends] are. It is all relative, if they know you and you have persisted in having to stick to a diet, then they are more on your side.” <sup>48</sup>
Environmental context	“Copay was \$20—I have to ration the pills; I go with the pill I need the most, when I do that.” <sup>42</sup>
Self-regulation of behavior	“Make sure that you take your meds on time. Get in a regimen of taking certain meds at a certain time. If you are a military person, you know how to discipline yourself. So, get in that regimen, watch what you eat, make sure you take your meds on time.” <sup>47</sup>

\* ULT, urate-lowering therapy.

recurrent flare.<sup>37</sup> Regarding lifestyle, patients adjusted their diet by either consuming foods they believed to be beneficial or avoiding foods believed to be detrimental to alleviate symptoms and reduce (the frequency of) flares.<sup>35,43,47,51,52</sup> Patients generally believed that changing dietary habits and being physically active were necessary to reduce sUA levels.<sup>41,46–48</sup> Limitations in daily activities and the desire to accomplish life plans were also motivators for lifestyle modification.<sup>35,46</sup>

*Resistance and reluctance for medication adherence and dietary alteration/changes.* Patients resisted receiving ULT when they were not convinced of its necessity,<sup>38,45</sup> mostly due to absence of pain or frequent flares,<sup>42,47</sup> sometimes believing their gout was cured<sup>49</sup> and disliking the long-term commitment.<sup>33,35–37,39,52</sup> Patients reported experimenting with diet and medication during an asymptomatic period.<sup>34,37,38,45,46,49</sup> Many patients experienced initial flares when starting ULT, leading to feelings of negative experiences and subsequent nonadherence.<sup>34,37,38,42,43</sup> Other factors contributing to nonadherence to receiving ULT included side effects<sup>42,44,46</sup> and lack of symptom improvements.<sup>43,53</sup> Patients felt they were receiving too many pills,<sup>33,42,45,54</sup> which for some, felt detrimental to their body or led to feelings of frustration.<sup>42,53</sup> Other negative attitudes toward receiving medication included a feeling of being dependent,<sup>37</sup> disliking receiving multiple medications, resistance due to side effects,<sup>41</sup> and general resistance toward medication,<sup>36,51</sup> even though some did not have specific concerns receiving ULT.<sup>35</sup> Patients were resistant toward making dietary changes because of the restrictiveness of diet and long-term commitment,<sup>39,48,51</sup> but poor dietary compliance could also originate as part of a “resistance to authority” reaction to the feeling being forced into lifestyle adaptations by the health care professional (HCP).<sup>46</sup> Diet modification was also perceived to be unrealistic, unmanageable, and irrelevant.<sup>51</sup> Some patients were reluctant to seek care,<sup>46,49,55,56</sup> although they were in severe pain.<sup>45</sup> Sometimes, gout was not considered severe enough to seek care,<sup>39</sup> whereas others were reluctant to seek care due to their belief that gout was not curable and seeking care was therefore not helpful.<sup>46</sup>

*Negative emotions influencing self-management.* Feelings of insecurity (eg, with receiving a [generic] substitution),<sup>45</sup> impatience for treatment effectiveness<sup>36</sup> and concerns and fear for (long-term) side effects of receiving ULT negatively impacted adherence to ULT.<sup>33,37,41,46,49,50</sup> Fear of a gout flare and associated pain led to adherence to ULT<sup>35</sup> and lifestyle modification.<sup>46,47,51</sup> Feelings of shame or embarrassment led patients to avoid seeking help from a general practitioner (GP) because they perceived gout as self-inflicted.<sup>35</sup> Finally, feelings of depression or desperation negatively impacted self-management.<sup>35,47</sup>

*Social support and interactions.* Support from others could facilitate self-management behavior.<sup>46</sup> Family members reminded patients to take medication<sup>37,45</sup> and to maintain a diet or stop

drinking alcohol.<sup>46–48</sup> Patients were motivated to change their self-management behavior to unburden their family.<sup>42,46</sup> Positive experiences shared by other patients prompted patients to modify their lifestyle or medication regimen.<sup>37,44,51</sup> On the other hand, negative stories from others led to nonadherence to ULT.<sup>56</sup> Social occasions made it difficult for patients to adhere to restrictions regarding alcohol and diet,<sup>41,46</sup> impacting their social lives.<sup>51</sup> Engagement and regular contact with an HCP improved adherence to ULT<sup>33</sup> and trust in the HCP and their recommendations.<sup>34,37,42,48</sup> Many patients were adherent to ULT or stopped drinking alcohol because the doctor told them to or told them about the importance and consequences.<sup>42,43,47,52</sup> A lack of guidance and attention were barriers to ULT adherence or seeking care.<sup>37,46</sup> A lack of confidence in the GP caused patients to prefer seeking treatment in a hospital over treatment by a GP.<sup>6</sup>

*Environmental context.* Patients experienced problems with pill size and picking up prescriptions, which acted as barriers for ULT adherence.<sup>42</sup> Patients reported limited access to HCPs and long wait times, delaying care seeking.<sup>55,56</sup> Financial constraints delayed care seeking<sup>55,56</sup> and hindered ULT adherence.<sup>42,43,52</sup> Receiving incorrect, conflicting, or unclear advice regarding food and medication<sup>35,57</sup> led to patients not modifying their diet and resulted in nonadherence to ULT.<sup>37,45,51</sup> However, receiving digital lifestyle advice was considered an important digital feature that motivated patients to lose weight.<sup>58</sup> Patients described strategies, tools, and interventions to improve self-management behavior. These included stocking on ULT, placing it in a convenient location,<sup>45</sup> and including ULT in a regimen with other medicines.<sup>37,42,47</sup> Patients found (digital) reminders or calendars helpful for remembering to take their medications,<sup>37,44,58</sup> pick up prescribed medications,<sup>40</sup> and stick to their exercise routine.<sup>37,44</sup> Pill boxes also supported medication adherence.<sup>42,43,47</sup> An app facilitating communication with HCPs could help to seek care from a rheumatologist, according to patients.<sup>44</sup> Finally, patients mentioned that an individual treatment approach can overcome medication resistance by adjusting the medication dose and addressing individual needs and concerns.<sup>33,44</sup>

*Self-regulation of behavior.* Patients described that establishing habits and routines for receiving medication or lifestyle adjustments positively influenced adherence to medication and lifestyle recommendations.<sup>34,37,38,42,45,46,48,51,52</sup> Likewise, lack or interruption of routine decreased adherence to ULT.<sup>34,37,42</sup> Patients believed that self-discipline was necessary for good adherence to ULT and dietary recommendations.<sup>34,37,44,47</sup> Patients made self-directed decisions such as adjusting physical activity<sup>38</sup> and altering ULT doses,<sup>52,56</sup> sometimes based on how they were feeling.<sup>37,42,46</sup> Additionally, patients used opioids to cope with pain,<sup>52</sup> self-increased doses of colchicine,<sup>54</sup> and adjusted diet instead of taking medication<sup>51</sup> to gain a sense of control. Insight into sUA levels served as motivator for patients to adjust their diet and adhere to medication<sup>33,37,58</sup>; it allowed them to assess the effectiveness of ULT and informed lifestyle modifications by identifying dietary triggers.<sup>37</sup> In



**Table 3.** Associations between determinants and adherence to medication\*

Determinants	Association (reference)
<i>Psychological capability</i>	
Knowledge	
• Awareness of gout management strategies	+ <sup>15</sup>
• Understanding/Knowledge about the disease	+ <sup>65,66</sup>
Behavioral regulation	
• Patience	+ <sup>67</sup>
• Compliance with diet advice	+ <sup>67</sup>
• Compliance with exercise advice	+ <sup>67</sup>
Memory, attention and decision making	
• Preferring ULT vs lifestyle modification only, both ULT and lifestyle modification and others	+ <sup>15</sup>
• Performing dietary modification	ns <sup>15</sup>
<i>Social opportunity</i>	
Social influences	
• Perceived social support	ns <sup>68</sup>
• Relationship with hospital doctors	ns <sup>68</sup>
<i>Physical opportunity</i>	
Environmental context and resource	
• No provider visits for gout before ULT initiation vs 3 or more visits <sup>a</sup>	– <sup>69a</sup>
• Initiation of ULT in a hospital setting vs GP and private rheumatologist	– <sup>70</sup>
• Number of hospitalizations before ULT initiation	ns <sup>69</sup>
• Number of physician visits prior to ULT initiation	ns <sup>69</sup>
• Prescriber specialty rheumatologist vs non-rheumatologist prescriber	+ <sup>71,72</sup>
• Prescriber specialty non-rheumatologist/nephrologist vs rheumatologist or nephrologist	– <sup>73</sup>
• Digital education and monitoring flares, logging information using an app vs regular care	ns <sup>21</sup>
• Education using story telling with DVD's in culturally matching language vs regular care	ns <sup>74</sup>
• Care in community-based outpatient clinic and other type clinic vs veterans affairs medical center <sup>b</sup>	+ <sup>72b</sup>
• Care in a combination of community-based clinic/veterans affair medical center vs veterans affairs medical center <sup>b</sup>	– <sup>72b</sup>
• Rural residence vs urban residence	+ <sup>72</sup>
• Performing regular measurements of sUA	+ <sup>67</sup>
• Receiving information on lifestyle changes	+ <sup>67</sup>
• Low vs average socio-economic status <sup>c</sup>	– <sup>75c</sup>
• Higher/unknown socio-economic status vs average socio-economic status <sup>c</sup>	+ <sup>75c</sup>
<i>Reflective motivation</i>	
Role and identity	– <sup>65</sup>
• Experiencing symptoms believed to be related to illness (Identity)	
Beliefs capabilities	
• Self-efficacy	ns <sup>79</sup>
• Confidence to keep serum urate under control	+ <sup>66</sup>
• Confidence to have blood tests at recommended frequency	+ <sup>66</sup>
• Confidence to take gout medications regularly	+ <sup>66</sup>
• Personal control (over disease)	ns <sup>65</sup>
Optimism	
• Good perception of one's illness	ns <sup>68</sup> , – <sup>67</sup>
• Satisfaction with long-term treatment	+ <sup>67</sup>
• Optimistic status	– <sup>80</sup>
• Perceived susceptibility	+ <sup>79</sup>
• Satisfaction with effectiveness of ULT	+ <sup>66</sup>
• Global satisfaction	+ <sup>66</sup>
Beliefs consequences	
• Positive beliefs about medication	+ <sup>68</sup>
• Higher consequences of the disease	– <sup>65</sup>
• Timeline (how long will symptoms continue)	ns <sup>65</sup>
• Higher perceived severity of disease	+ <sup>79</sup>
• Treatment control (helpfulness of treatment)	ns <sup>65</sup>
• Higher perceived benefits ULT	+ <sup>79</sup>
• Low perceived barriers to ULT	+ <sup>79</sup>

(Continued)

Table 3. (Cont'd)

Determinants	Association (reference)
Intentions	
• Obedience	+ <sup>67</sup>
<i>Automatic motivation</i>	
Reinforcement	
• Interactive voice-response system to assess adherence, alert pending prescriptions and provide encouragement vs regular care	+ <sup>25</sup>
• Digital education and reminders vs regular care	+ <sup>22</sup>
• Self-monitoring sUA using a PoCT device vs regular care	+ <sup>24</sup>
Emotions	
• Emotional response	- <sup>65</sup>
• Concerns	ns <sup>65</sup>
• Mental status	+ <sup>66</sup>
• Depression	ns <sup>66</sup>

\* Determinants are mapped to the corresponding theoretical domains framework construct, specified in bold, which were in turn mapped to the capability, opportunity, motivation and behaviour model domains, specified in italic, in the outer left column. Statistically significant associations between determinants and adherence to medication are reported as a plus sign (+) when positively associated, and as a minus sign (-) when negatively associated. Ns indicates no significant association was found. Between brackets are the studies in which a finding was reported. For associations between determinants and other self-management behaviours, see Supplementary Table S1.

<sup>a</sup> (69) = The variable provider visits before ULT initiation consisted of 4 categories; 0 visits, 1 visit, 2 visits and 3 or more visits. 3 or more visits was the reference category, 1 visit or 2 visits were not associated with adherence compared to 3 or more visits.

<sup>b</sup> (72) = The outpatient clinic type variable consisted of four categories, “Veterans Affairs Medical Center” as the reference category, “community-based outpatient clinic”, A combination of the first two categories and “Other” clinic type.

<sup>c</sup> (75) = The variable of socioeconomic status consisted of 6 categories; < 8, 9-11, 12-13 (reference category), 14-16, 17-20, unknown. We named <8 as lower SES than average (the reference category) and 14-16, 17-20 and unknown as higher than average. The latter 3 categories were all significantly associated with the reference category. Only 9-11 was not associated with the reference category.

terms of possibly self-monitoring sUA levels, patients preferred to own and use a point-of-care device for gout to prevent blood tests.<sup>37</sup> Laziness caused nonadherence to medication, not getting refills in time, and delaying care seeking.<sup>38,39,42</sup> Finally, patients believed in the need for an active role in treatment,<sup>37</sup> such as knowing when to take colchicine,<sup>38,54</sup> changing diet,<sup>48</sup> and proactively seeking care.<sup>38,44</sup> However, self-diagnosis and treatment led to delay in care seeking.<sup>55</sup>

**Descriptive determinants of self-management of quantitative research.** A subset (n = 6) of quantitative studies provided descriptive reports on determinants of self-management. Reasons for discontinuing ULT included patients feeling it was no longer required or becoming fed up with the medication.<sup>59</sup> In a cross-sectional observational study, intentional nonadherence was driven by desires for a normal life, perceiving oneself as healthy, and testing the necessity of treatment. Medication-related concerns encompassed dislike for side effects, worry about dependence, belief in decreasing efficacy, perceived harshness on the body, high doses, and doubts about treatment efficacy.<sup>60</sup> An eight-year retrospective study revealed ULT discontinuation in 46.8% of 282 patients, with determinants including poor health literacy, perceived inefficacy, and adverse events.<sup>61</sup> Other patient-reported nonadherence reasons included remission, concerns about side effects, inadequate education, receiving alternative medicine, forgetting to receive medication, and inconvenience in obtaining medication.<sup>62</sup> Improved patient understanding of the disease and treatment seemed to increase

adherence.<sup>63</sup> Finally, physicians can influence patients’ dietary behavior by addressing and proposing lifestyle interventions.<sup>64</sup>

**Associations of determinants with self-management behavior of quantitative research.** The majority of statistical associations reported between TDF determinants and self-management behavior related to adherence to medication (19 of 23 studies), shown in Table 3. For adherence to dietary recommendations, physical activity recommendations, and care-seeking behavior, five, three, and two studies were found, respectively, which can be found in Supplementary Table 1<sup>21,22,76,77,78,81,82</sup>. No studies were found investigating determinants of self-monitoring of disease status.

DISCUSSION

In this comprehensive scoping review, we included studies investigating modifiable factors of self-management behavior using the TDF to guide our search. A thematic synthesis of 27 qualitative studies resulted in eight themes: knowledge and skills for self-management, acceptance of disease, beliefs about necessity of self-management to improve gout-related health, resistance and reluctance to medication adherence and dietary alteration/changes, negative emotions influencing self-management, social support and interactions, environmental context, and self-regulation of behavior. Most studies addressed medication adherence. Several studies described lifestyle and care seeking, and one study described self-monitoring of disease. Both quantitative and qualitative findings support the importance

of knowledge, skills, preference for receiving ULT as opposed to other self-management options, and positive beliefs about medication in influencing adherence to receiving ULT. Contradicting results were found regarding acceptance of the disease in association with adherence to ULT in quantitative and qualitative findings.

The results of this review provide practical, evidence-based targets for systematically developing interventions to stimulate self-management behavior. Although the results described in this study are related specifically to patients with gout, many of the determinants of medication adherence are also found in patients with other chronic diseases (eg, diabetes or hypertension). The similarities include, for example, the stimulating effect of social support and positive beliefs, whereas hindering effects were found for limited care access, information and communication problems, problems experienced with medication, and negative beliefs.<sup>83</sup> Thus, our findings regarding medication adherence align with other chronic diseases, which supports validity of our results and suggests that the findings may be transferable to other chronic diseases.

To develop successful interventions, a thorough understanding of the target behavior and its underlying determinants is required. We have used the TDF to identify behavior determinants. An important question remains: What should effective interventions entail? The Behaviour Change Wheel (BCW) offers various intervention functions targeting TDF constructs and COM-B domains. The latter presents a simplified version of behavioral factors in which three interacting domains—capability, opportunity, and motivation—determine whether a behavior is performed or not.<sup>30</sup> Additionally, interventions should target determinants with highest impact potential, with an additional potential for spillover effects to other COM-B domains. To illustrate, education targeting psychological capability may be important for medication adherence but may not create additionally motivation opportunity to actually perform the behavior. Therefore, the *Education* and *Persuasion* intervention functions could aim to increase motivation by cultivating appropriate beliefs and creating positive expectations within the motivation domain regarding medication adherence behavior, which were determinants identified in this study. To directly provide more opportunities for correct medication use, an *Enablement* intervention function can facilitate (digital) reinforcement and access to appropriate care and increase (social) support. The EULAR self-management recommendations also suggest a role for (social) support, and previous research stresses the importance of reinforcing patients.<sup>2,12,24</sup> Finally, interventions could focus on fostering habitual behavior, which is more likely to persist over time.<sup>84</sup>

Regarding mode of delivery, eHealth can play an important role because it facilitates delivery of intervention functions in a cost-efficient manner. A combination of eHealth supported by HCP guidance could be most optimal due to promised efficiency

of the former and proven effectiveness of the latter.<sup>2,18</sup> The use of eHealth is supported by the 2021 EULAR recommendations for implementing self-management in patients with inflammatory arthritis because eHealth can allow patients to acquire a more active role in their health as well as facilitate use of relevant patient-reported outcome domains.<sup>12</sup> Guidance on development of eHealth apps for rheumatic diseases is described in the EULAR points to consider for the development, evaluation, and implementation of mobile health.<sup>85</sup> An important factor to bear in mind when implementing eHealth for patients with rheumatic diseases is that it should complement care rather than serve as a replacement.<sup>86,87</sup>

The use of the scoping review methodology approach allowed us to capture both qualitative and quantitative data relevant to the research question, providing a comprehensive and detailed overview of determinants that influence self-management. Also, mapping of determinants to the TDF and COM-B model allows for identification of suitable interventions to positively influence self-management behavior. A few limitations may be acknowledged. Quality appraisal of included studies was considered not feasible due to the large number of studies and heterogeneity in study type and design. Due to this, biased results from studies with lower methodologic rigor could have impacted our findings. For example, of the eight included interventional studies, six were randomized controlled trials (RCTs), one was a prepost study, and another one was quasi-experimental. Arising from their design, the latter two studies have a higher risk of bias compared to the RCTs. In general, the RCTs were considered of good quality. However, in two studies, blinding was not possible due to the nature of the intervention, possibly leading to performance and/or detection bias.<sup>24,25</sup> Additionally, we cannot provide conclusions on the strength and causality of the associations that were reported.

This study identified determinants for self-management behavior in gout and provides targets for researchers and policy makers to select and develop evidence- and theory-based interventions targeting patients with gout and their context. Subsequently, implementing these interventions is expected to increase self-management behavior and thereby improve clinical outcomes. This study also reveals the complexity and the quantity of determinants that could be targeted to improve and support self-management. Although a complex intervention targeting the specific barriers for self-management of individuals may be most effective, a general intervention could target the COM-B domains by using the *Education*, *Persuasion*, and *Enablement* intervention functions according to the BCW.<sup>30</sup> More information on determinants of self-management behavior other than adherence to receiving ULT, such as lifestyle modifications, care-seeking behavior, and self-monitoring of disease status in gout, are needed to get a complete picture of determinants associated with self-management behavior. To, conclude, we identified various modifiable determinants of self-management behavior in patients with gout, which can



function as targets for interventions aiming to improve gout care through increased self-management.

## AUTHOR CONTRIBUTIONS

All authors contributed to at least one of the following manuscript preparation roles: conceptualization AND/OR methodology, software, investigation, formal analysis, data curation, visualization, and validation AND drafting or reviewing/editing the final draft. As corresponding author, Mr van der Ven confirms that all authors have provided the final approval of the version to be published, and takes responsibility for the affirmations regarding article submission (eg, not under consideration by another journal), the integrity of the data presented, and the statements regarding compliance with institutional review board/Declaration of Helsinki requirements.

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