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A Patient-Centered Gout Information Value Chain: A Scoping Review

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Abstract

Objective—To examine and identify the scope of research addressing health information requirements for gout patients using value chain analysis.

Methods—Five electronic databases (PubMed, CINAHL, ERIC, PsycINFO, Embase, and Scopus) and grey literature (WorldCat) were searched in accordance with a published protocol. Only English language articles were included, with no limitations for date of publication. The findings of the 33 studies included for final analysis were subsequently divided into 6 groups according to the stages of the care delivery value chain their research most closely pertained to: screening/preventing (n=2), diagnosing (n=1), preparing (n=7), intervening (n=11), recovering/ **rehabilitating** (n=5), and monitoring/managing (n=13).

Results—The 33 studies focused on one or more of the following information phenotypes: 1) pathophysiology; 2) medical treatment; and 3) nonpharmaceutical interventions. Long term treatment adherence was a popular topic amongst studies that focused on gout patient education.

Conclusion—Based on the identified studies, gout patients are **being told what to do, but are not being adequately educated regarding why recommended interventions are important or how to accomplish them.**

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Practice Implications—This review provides a foundation to develop and evaluate personalized education materials using value chain analysis.

1. Introduction

1.1 Rationale

Chronic disease management makes delivering optimal patient education a vital, yet complex and challenging task. This is especially true for gout, the most common type of inflammatory arthritis which affects up to 6 million Americans [1]. Gout is characterized by deposition of monosodium urate crystals in joints and tissues which usually presents with intermittent painful attacks followed by periods of remission. The risk of developing gout increases with age. It is also associated with several common clinical (e.g., chronic kidney disease, low dose aspirin, hypertension, cardiovascular disease) and behavioral (e.g., consumption of alcohol, seafood, and beef) factors [2]. Further complicating matters, gout treatment requires two different treatment approaches, one for the acute symptoms (anti-inflammatory drugs) that arise when the disease is not properly managed and one for chronic disease management (urate-lowering therapy [ULT]) designed to prevent the deposition of monosodium urate crystals in joints and surrounding tissues [3].

Despite being considered the best understood of the joint diseases and the only chronic arthritis with the potential to be ‘curable’, gout still often goes undiagnosed and sub-optimally treated [4]. There are myriad reasons for this, many of which can be traced back to a lack of appropriate information needed for patient education. The complex nature of gout requires self-management for optimal treatment which typically includes medications and lifestyle changes. This makes identifying information values throughout the long-term care continuum critical to encourage patient engagement in self-care [5]. However, this endeavor is often unsuccessful because there is no established consensus among stakeholders as to the goals and means of patient education in the various stages of care [6].

Despite extensive research on patient education and counseling, there is relatively little attention given to understand how the chronic or acute gout management and its informational values are changed over the course of care management. Given the increasing availability of health information and its sources, an extensive review of the current literature seemed pertinent to identify relevant topics and key information for aiding in the management of gout.

1.1.1 Care Delivery Value Chain as a Theoretical Framework—The concept of a value chain was first introduced by Michael Porter as the set of activities that an industry specific firm uses to create value in the market [7]. Originally applied to a manufacturing context, Porter theorized the myriad activities that organizations must perform in order to transform inputs into outputs as primary or secondary activities. Primary activities are those considered essential for the creation of value and competitive advantage. Secondary activities are those undertaken to support and improve primary activities. Porter similarly objected to applying the value chain to subsets of a business. Segmenting and analyzing a firm according to lines such as products or geography would not be useful. Due to the interrelated nature of an organization’s subsets, it would not be possible to fully understand the value chain without the view provided by the firm-level value chain. Nevertheless, researchers have continued to do so, especially in the realm of health information.

1.1.2 Value of Information—

With the advent of the Internet, Rayport and Svlioka (1995) argued that every business must compete in both a physical and virtual world and that the processes for creating value in each are not the same. Porter's value chain views information in a supporting role and indeed managers often use data obtained from the primary activities to improve those processes. However, this does not account for cases where information explicitly adds value.

According to Coiera (2019), information only has value when it can be expected to lead to change, and he proposed an information value chain composed of five stages connecting the initial interaction with information to the ultimate outcomes of information use. From a health information perspective, the chain begins with an interaction where information is provided that can then be used to make decisions. The decisions made set the course of care and ultimately impact patient outcomes. Because changes in one stage of a value chain do not necessarily affect all subsequent stages, the information value provides a lens to focus on and evaluate each stage individually. Coiera (2019) hypothesized that events taking place in later stages of the value chain were often more valuable. Therefore, this study focuses on information that has the potential to impact stage 4: care processes altered. More specifically, we are interested in information that could impact the patient self-care process provided the patient receives and uses the information for decision-making.

1.1.3 Health Care Application from Patient Perspective—

A conventional approach to value chain analysis involves mapping the activities involved in delivering a **product** or service. Value activities are commonly identified and classed according to technologic and strategic distinction. In contrast, the complete value chain for healthcare products and services can span multiple industries and encompass numerous organizations and could potentially be considered a global value chain. The traditional business approach ignores the fact that, in healthcare, the patient is both the input and the output. Therefore, any value chain must begin and end with the healthcare consumer.

According to Kim, Farmer, and Porter [8], primary value is created by delivering care for specific medical conditions. Their care delivery value chain (CDVC) emphasizes the interrelated nature of healthcare and highlights the need for integrated care. From a patient perspective, lab tests by themselves have no value, though they still must pay for them. A test's value is in being able to connect the patient to needed treatment. Even treatment itself is not the ultimate goal, but patient well-being. Thus, to analyze value in healthcare delivery, the focus must shift from products and services provided to outcomes achieved via information received. In this manner, value for health outcomes cannot be attributed to a specific intervention at one point in time but must be redefined as the total outcomes achieved per costs over the total cycle of care. Patient education has been shown to improve disease outcomes [9]. Porter and Tiesburg [10] argue that in order to optimize value, patient education should be included at each stage of care, starting with prevention. Though not traditionally handled by clinical professionals, involvement in prevention and monitoring activities, such as prevention campaigns, can help raise awareness and serve as a type of marketing. Diagnosing aids in early disease detection, which often helps to reduce the impact of a disease. Successful treatment relies on a patient receiving the proper information in the preparing stage for their specific procedures and therapies. Intervening, whether with drugs or procedures, should be performed with the most suitable specialists and technologies. Patient needs analysis should be conducted to fine-tune medications and find the best recovering and rehabilitation regimen to avoid relapse. Finally, patient care must be monitored and managed to continually learn and improve, as well as follow-up on treatment compliance [11].

The CDVC highlights the complexities inherent in healthcare and demonstrates potential applications to successfully utilize information to address that complexity. From a patient information perspective, the CDVC provides a breakdown of care processes that could be altered with the goal of improving clinical outcomes.

1.2 Objective

Using value chain analysis as a theoretical framework, this review aimed to identify and examine the available research concerning or related to the information needs of gout patients with a focus on the six primary activities of the CDVC: screening and monitoring, diagnosing, preparing, intervening, recovering/**rehabilitating**, and monitoring and managing.

2. Methods

2.1. Protocol and Registration

This review was conducted using a scoping review protocol published by Khalil et al. [12]. The scoping review included using a three-step literature search process to identify and select relevant studies before tabulating and collating the results using value chain analysis to identify implications for patient care delivery. As the aim was not to evaluate the quality of the available literature, but rather the span of the subject knowledge and the extent of specific topic focus for a field that had not been widely reviewed, this seemed the ideal methodological approach to determine the current state of research and identify knowledge gaps [13].

2.2. Eligibility Criteria

In accordance with previously published methods for scoping reviews [14], the eligibility criteria for this review included any study where health information was specifically or tangentially mentioned concerning patients seeking or receiving information for the purpose of treating and managing gout. Due to gout being rare in children, the minimum age for patient inclusion was 18 years. Studies that did not clearly distinguish between patients and non-clinical health information consumers seeking to aid patients, such as family members, were also included.

Only lay consumers of health information were of interest to the study. Thus, studies that only investigated the role of professionals, such as healthcare or information providers, in the use of gout information were excluded. Only studies published in the English language were included, however, there were no restrictions based on geographic area or publication date.

2.3 Sources

The initial search utilized only two databases believed to be able to provide the broadest overview of results pertinent to the scoping review topic. PubMed was chosen for its range of biomedical literature and the Cumulative Index to Nursing and Allied Health Literature (CINAHL) was included for perspectives from the allied health professions.

A targeted search was then conducted on the basis of the preliminary search using five databases chosen to provide a complete picture of gout patient information requirements. Boolean operators and controlled vocabulary terms were used whenever possible. MeSH (Medical Subject Headings) terms found in PubMed formed the base for controlled vocabulary equivalencies found in the other electronic databases. CINAHL and their Major Headings (MH terms) were included in this search, as well. In addition, the Education Resources Information Center (ERIC) was searched using Descriptors (DE terms) for patient education research and PychINFO was searched using Index Terms for psychology-related literature. Scopus, which does not provide a controlled vocabulary search option, was included for a comprehensive review of available research literature.

A gray literature search was conducted through WorldCat using the keywords and phrases that had been mapped to the controlled vocabularies for the final search strategy. The resulting search strategy steps utilized on February 10, 2020 are detailed below.

2.4. Search

The scoping review was conducted by first performing a comprehensive search for relevant literature using online databases. The research team included a library and information science expert **who** was involved in the development and refinement of the search strategy. The strategy was designed to adhere closely to the previously mentioned approach [13].

The results of this search were used to modify the initial search terms for the purpose of expanding the range of relevant results. Additional terms identified in this manner were used to create the final search strategy: ("gout"[MeSH Terms] OR "gout"[All Fields]) AND ("patients"[MeSH Terms] OR "patients"[All Fields] OR "patient"[All Fields]) AND ("Information (Basel)"[Journal] OR "information"[All Fields]).

The reference lists of all literature that met the eligibility criteria were reviewed for any additional studies related to the topic. In turn, the references of each additional relevant article were reviewed until saturation was reached. All search results were imported into EndNote, where duplicates were removed before a two-step screening process was conducted to determine inclusion eligibility.

2.5 Selection of sources of evidence

During the first step of screening, only the titles and abstracts were read. Articles determined to be relevant on the basis of this screening were then read in full to assess their ultimate inclusion or exclusion.

2.6. Data charting process

Two reviewers evaluated the extracted articles to validate that the informational values extracted were relevant, comprehensive, and consistent according to the adopted value chain framework.

2.7. Data items

Per our scoping review protocol, the final included articles were examined and summarized in tabular format to include publication details (author surnames, publication date), research objectives, methods, key findings, and conclusions drawn for each study.

2.8. Data synthesis

The information involved in each study was also categorized according to the care delivery value chain to provide additional context in aid of the aims of this review.

2.8.1 Gout information value chains—The gout value chain analysis that we used as our analytic framework is divided into six categories of primary activities. The initial stage of the value chain (preventing/monitoring) contains information pertinent to the pre-diagnosis phase including critical signs and symptoms and risk factors for the disease. For gout, this stage is more accurately called screening. If such factors are present in a patient, this phase is followed by diagnosing, where diagnostics exams and tests are performed. In the case of a confirmatory diagnosis, a patient moves into the preparing stage where they are given information for treatment options. The chosen treatment is then administered in the intervening stage. For gout, there is no recovering/**rehabilitating** stage in the traditional sense. Instead, this phase is dedicated to fine-tuning therapies to minimize side effects while keeping gout symptoms in remission. Monitoring and managing acute gout attacks and other complications is continuous and constitutes the final stage of the value chain.

This study utilized both tabular and narrative approaches to integrate and synthesize data. The great variation in research design, focus, and quality between the included studies lent itself to the use of narrative integration for data synthesis. Thus, while tables were used to summarize the extracted data, narratives were used to evaluate the data and explain key findings.

3. Results

3.1. Selection of sources of evidence

Overall, 1100 records were retrieved using the outlined search strategy. More specifically for each of the five databases, Scopus yielded the most results (n=487), followed by PubMed (n=297), then CINAHL (n=122), with ERIC (n=1) and PsycINFO (n=11) both producing far fewer results. WorldCat produced an additional 182 results. The diagram for the exclusion process is presented in figure 1 below.

3.2. Characteristics of sources of evidence

All the included studies were published after the year 2000, with the vast majority having a publication date after 2010. Much of the literature were themselves literature reviews (n=13). The studies were predominantly qualitative (n=17) with many of the more quantitative studies also including and analyzing qualitative data. One study did not discuss methodology.

Well over half of the included studies **had** a focus on information pertaining to treatment, either alone or with other topics. Only the screening/preventing phase did not contain any articles regarding gout treatment information. In this category, Doherty et al. [4] and Richardson et al. [15] both focused solely on information regarding pathophysiology. Most of the studies included several types of information, with information about treatment appearing the most often by itself in studies (n=9), especially in articles classed in the intervening stage.

3.3. Results of individual sources of evidence

Included studies were subsequently divided into 6 groups according to the stage of the care delivery cycle their research most closely pertained to: screening/preventing (n=2), diagnosing (n=1), preparing (n=7), intervening (n=11), recovering/**rehabilitating** (n=5), and monitoring/managing (n=13). A study could be included in more than one group if it contained separate findings and conclusions relevant to more than one stage of care. The following six tables summarize some highlights of the review result.

3.3.1. Screening/Preventing—Although containing information pertinent to the pre-diagnosis phase of gout, neither study categorized in this stage of care specifically focused on screening. Table 1 shows the results for this stage. Richardson et al. [15] was a qualitative study of gout knowledge in female gout patients, while Doherty et al. [4] was a literature review searching Medline with general gout terms along with more specific phrases relating to the treatment and management of the disease. Both studies make it clear that patients have little knowledge of risk factors for the disease and the little information acquired prior to diagnosis often leads to misunderstandings about gout, which can hinder diagnosis.

3.3.2. Diagnosing—The sole article concerned with information pertaining to gout diagnosis was included in a journal supplement is displayed in Table 2 Perez-Ruiz [16] reads like material for gout education that is mainly concerned with treating and curing gout and contains no information about methodology. Any information related to other phases of care is included as a means of providing understanding and support for the targeted treatment recommendation. Patients need to understand the means of diagnosis to understand the need for long term therapy.

3.3.3. Preparing—The studies featured in this group (n=7) displayed the greatest variety in topics with all studies featuring <2 types of information as recorded in Table 3. Lack of information and knowledge relating to gout pathophysiology was highlighted in all studies concerning patient education. Zhang et al. [17] was the only quantitative study. While the qualitative studies were designed to elicit feedback from patients through interviews for the purpose of thematic analysis to aid understanding about gout perceptions and knowledge, Zhang et al. [17] aimed to create an instrument that could evaluate such knowledge. Harrold et al. [18] highlights that knowledge gaps are not due to a lack of desire for information on the part of the patient and Chandratre et al. [19] specifies that patients want more of this type of information from their healthcare providers. Patients also express a desire for more time with healthcare providers with Khanna et al. [20,21] specifying that patients want healthcare providers to spend more time explaining the disease progression in particular. There is also a general lack of knowledge concerning treatment options, especially urate-lowering therapy (ULT). Lindsay et al. [22] found a general perception among men that gout is a disease that must be simply endured. Similarly, Spencer et al. [23] found that patients are unaware of the existence of allopurinol, a urate-lowering drug (ULD) that can prevent acute gout attacks. Moreover, according to Perez-Ruiz [16] patients are unaware that ULTs commonly cause gout flares upon treatment initiation and have no knowledge of prophylactic therapy as an option to reduce this side effect. The findings in this category indicate that a targeted awareness campaign for the disease would be helpful and welcome.

3.3.4. Intervening—Studies included in this group (n= 11) understandably focused on information related to disease treatment, specifically pharmacological interventions. Information about these studies is included in Table 4. This phase of care featured the most quantitative studies and the only intervention studies. Rees et al. [24] featured an education intervention and tested SUA levels 12 months later. Two studies were follow-ups to previous education interventions with Mikuls et al. [25] being a randomized evaluation of a pharmacist-led intervention, while Abhishek et al. [26] featured a five year follow up questionnaire for a nurse-driven intervention. Sarawate et al. [27] was a retrospective claims analysis using logistic regression. Each of these studies also used SUA levels as outcome measures.

There were two systematic literature reviews included in this category. Galo et al. [28] focused exclusively on treatment, while Reach [27] discussed disease progression along with treatment information as a means to understand why side effects occur when commencing ULT. Dalbeth et al. [29] similarly concluded that patients with greater understanding of gout had higher adherence to ULTs. However, Robinson and Schumacher [30] found that this type of information was missing from the majority of patient education materials that they analyzed. Beyond long term pharmacological treatments, patients are only aware of very limited treatment options for symptom relief during acute attacks [22]. Likewise, only Singh [31] included information pertaining to lifestyle modifications, as diet was identified as a concern for their target population of African Americans and women with gout.

3.3.5. Recovering/Rehabilitating—As a chronic disease, articles included in this group (n=5) pertain to topics related to the fine-tuning of long-term therapies and continuous management of gout. All studies in Table 5 highlight a lack of understanding regarding short-term side effects, ultimate goals, and expectations of treatments leading to poor adherence to long-term medications and treatment plans. Most of the studies focus on ULDs, while several specifically mention allopurinol. Coburn et al. [32] has the most specific target population, focusing on a population of VA patients that have recently initiated allopurinol therapy. While all studies contain information pertaining to treatment, Becker and Chohan [6] offer an editorial review that contains the most variety with information relevant to pathophysiology, disease progression, and labs, as well. Doherty et al. [4] is the only literature review in this category and the only study that refers to lifestyle advice. The two qualitative studies have only treatment information for this category; however, Chandratre et al. [19] explores gout's impact on quality of life (QOL), while Harrold et al. [33] is more concerned with general perspectives on ULDs.

3.3.6. Monitoring/Managing—

As the largest group of articles (n=12), this phase reflects the long-term, slow build up which results in sudden acute attacks and other complications. This care phase has the most information concerning lifestyle modifications. As with all phases of care, an overall lack of education and understanding is highlighted by Table 6, with a particular emphasis on non-pharmacological interventions and managing comorbidities. In line with Perez-Ruiz’s [16] contention that knowledge of non-pharmacological approaches and lifestyle modifications is essential to gout management, only Ogdie et al. [34] does not include lifestyle advice, instead focusing on the long-term monitoring of SUA levels. The needs assessment conducted by Rifaat et al. [35] indicates that this type of information, specifically dietary guidelines, is the most sought after in this phase of care, at least by highly educated patients. Interestingly, the patients involved in Harrold et al. [33] did recall being told to avoid certain foods, but the patients involved in Harrold et al. [36] were largely unaware of dietary triggers of gout attacks. In contrast, Vaccher et al. [37] found that most patients do know some personal triggers for acute attacks, but do not recall receiving this information from their general practitioner and instead, sought it out online. However, Johnston et al. [38] found that all 30 of the patient education materials they reviewed contained lifestyle information, including diet, particularly foods to avoid. Other types of information were not included as consistently and Jimenez-Linan et al. [39], who analyzed similar resources, points to a distinct lack of emphasis on the importance of ULTs. This category also features the British Society for Rheumatology’s recommended guidelines for gout management [5] as it relates to health information, as well as EULAR’s patient education recommendations for inflammatory arthritis [40]. Both of these sources advocate for what Fields and Batterman call a multifaceted approach to gout patient education and management.

3.4 Synthesis of results

On the basis of this review, we developed a care delivery value chain for gout that highlights the information that patients need at each stage of care.

For screening, we identified information that could motivate patients to seek proper medical care, including the hallmark symptoms of gout, such as pain in the big toe, so that patients **could be motivated to seek proper medical care**. For diagnosing, a patient needs to know what to expect for testing and be aware that synovial fluid analysis is the gold standard for diagnosis. In the preparing stage, patients should be educated about their treatment options from either **paid (e.g., clinicians) or unpaid sources (e.g., community resources)**, so that they can make the best choice and increase chances of compliance. Once this choice has been made, the patient moves into the intervening stage, where attention should be given to information related to the ordering and administration of the chosen treatment plan. Recovering and **rehabilitating** continues focusing on interventions with an emphasis on adjusting medications and needed therapies. Monitoring and managing continues throughout life for gout patients. This stage focuses on keeping an eye on possible comorbidities and preventing the advancement of gout and future complications.

4. Discussion and Conclusion

4.1. Discussion

4.1.2 Summary of evidence—The results of this scoping review indicate that treatment and other interventions are the most popular topics for gout patient information related research. This is reflective of the confusing and complicated nature of gout treatment as both a chronic and acute condition. Moreover, several key findings highlight the interrelated nature of the various information types necessary to successfully manage gout.

A heavy focus on treatment for a health problem is to be expected, especially for a chronic painful condition like gout. However, the emphasis on treatment in research studies for a disease that has proven treatment protocols is indicative of a larger problem in the different care stages. Several studies highlighted that adherence to long term therapies is lacking in gout patients in the different care stages [23,41]. Patients often indicated that this is due to a lack of understanding of when and how to take both long- and short-term medications prescribed for gout. However, many studies found that lack of knowledge about the causes and progression of the disease was a contributing factor to misunderstandings regarding adherence to treatment strategies. Patient interventions personalized according to the stages of gout management should be advised.

Furthermore, the lack of understanding of gout pathophysiology leads to underdiagnosis. The research focus on this topic throughout the care cycle indicates that this issue is not remediated in later stages and continues to create barriers to effective disease management. As diagnostic procedures are more relevant to professional education, etiology to explain causality of gout pathology has not been reinforced in gout patient education nor management. This can perpetuate the stigmatization of gout as a disease patients bring on themselves and must endure. Recent research has found that genetic factors can play a larger role than diet patterns in not only having the disease, but also determining the effectiveness of allopurinol therapy (Dalbeth et al., 2017). Better understanding of the physiological underpinnings of gout has been shown to increase health outcomes (Lawrence et al., 2019). Therefore, when a rheumatologist initiates a gout therapeutic plan, it would be beneficial to restate what might cause gout, with an emphasis on the role of genetic factors, so that patients can adjust their behaviors as a part of therapeutic enforcement.

In addition, the variety of information types identified as being necessary for optimal gout management is reflective of the multifaceted nature of gout. Several of the articles highlighted multiple information types demonstrating that the categories work together to enhance understanding and aid the behavioral, cognitive, and emotional processes necessary for treatment compliance. Specifically, patients desire more information regarding natural remedies and lifestyle advice. However, the current literature does not address what is thought to be alternative information. There are gaps in the literature between what patients want and the current literature investigated for use in gout patient education and management. More reliable and authentic information could be validated through patient education of gout information studies.

Finally, because there are no agreed upon measures for the value of information, it is difficult to quantify the utility of each type of information presented in the value chain. Nor does the literature included concern itself with placing values on the information identified as necessary for patient understanding. However, we were able to identify four broad categories which might offer measurement possibilities for future studies. Clinical outcomes are the most obvious source of quantifying value of information with interventions included in our review primarily relying on changes in SUA levels as their outcome measure. Health-related quality of life was another measure used in the reviewed literature. Other than these professional measurements, many studies found that patients simply want more information indicating that quantity of information received could be explored as a measure of value. Moreover, patients preferred that information come from healthcare professionals. Future studies could examine the value of information from various sources.

4.1.2 Limitations—Despite the rich research findings provided by the relevant articles identified by the scoping review, the majority were only tangentially related to our aim of identifying the information required for improving the efficacy of treatment/management strategies. The existing literature is largely focused on identifying gaps in patient knowledge with conclusions drawn about needed information through inference from the results. More research needs to be done to explicitly identify the information that is required for more efficient education guidelines to avoid extraneous information that risks overwhelming the patient. Therefore, the primary information highlighted in our findings can be utilized as essential information to be highlighted to reduce information overload.

Despite the meticulous and robust methods utilized, the review still has limitations. First, in line with general scoping review protocol, the quality of the available research was not evaluated. As such, this review only identifies the existence of key findings and makes no judgement on the worth or potential benefits of said findings. Second, only articles published in the English language were included, meaning that articles relevant to the topic that could have further incites might have been excluded. Last, it is possible that some relevant studies were not retrieved using our search strategy. Though the search terms were chosen because they were believed to be sufficiently broad so as to encompass the majority of relevant research, it is possible that some authors expressed the concept of ‘gout patient information’ in an alternate way that would not be retrieved by our search strategy.

Furthermore, current research on gout information and education as identified by our search strategy is focused on physiological or biomedical information. **It is acknowledged that lifestyle modifications must occur to effectively manage gout, but little attention is paid to how to encourage behavioral factors that optimize disease self-management.** This study conceptualizes this type of information as related to primary activities of the value chain. However, other information that could be conceptualized as secondary activities, such as appointment scheduling or financial information including insurance, are important aspects of accessing care information and should be investigated in future research.

4.2. Conclusions

Our review findings reiterate that patients give up on medications and treatment options when side effects occur due to misunderstandings **(e.g., starting dose of urate lowering therapy too high, without prophylaxis)**, essentially leading them to skip the recovering/ **rehabilitating** phase in favor of treating only the symptoms of acute attacks. Our study highlighted the six education interventions with two being systematic literature reviews. All studies found the interventions to be successful for increasing treatment adherence, however, each study utilized different methods for implementing and measuring the outcomes of the chosen intervention. Limited research is available for interventions outside of the treatment stage.

Furthermore, studies have identified that, just as gout therapies need to be fine-tuned for the individual, education is best tailored and personalized to each patient. Future research could focus on exploration of what to do for improvement, rather than what is not being done. Future studies investigating the content of current patient education materials and their distribution of informational values over the different stages of gout management could be beneficial.

Additionally, several included studies emphasized the fact that it is not enough to simply provide information to patients, especially in written form. **While the current literature is clear that providing quality written materials to patients as a supplement to oral information and instructions can increase health literacy and is a necessary component of imparting disease-related knowledge, it does not always lead to increased adherence.** Gout patients want more time with healthcare professionals to discuss their disease and care. **This is in line with previous research that showed that knowledge alone is not enough to affect complex behavioral changes, such as those involved in lifestyle modifications. Clinicians need to understand the underlying beliefs, intentions, and self-efficacy to optimize behavior change** [48]. Future studies could work to differentiate the information best presented in text and that which patients need more personal interaction to clarify treatment plans. This could provide healthcare professionals with guidance on where best to focus their time with patients.

This review highlights the limited attention that has been paid to the information needs of gout patients. Though interest has grown in the last two decades, there is still an explicit need to explore the essential information requirements for optimal care and patient self-management. **While current research has well defined the biomedical aspects of pharmaceutical and lifestyle interventions for gout including goal SUA levels,** there is a need to determine what information is most beneficial at each stage of the value chain to increase adherence to prescribed interventions.

4.3. Practical Implications

This is the first scoping review conducted for this topic. The broad search strategy and inclusion criteria contributed to the breadth of evidence uncovered and provided a comprehensive overview of available research. In addition, these factors were essential to conducting a rigorous review in adherence with published scoping review protocols at each step of the screening, selection, and evaluation processes.

This scoping review is an initial attempt to grow the field of patient education research through the application of value chain analysis to identify areas that need further exploration by highlighting where value is currently being created and where gaps still occur. Continuation of this type of research can aid in recognizing the extensive health information needs of gout patients for the purpose of ensuring the receipt of adequate amounts of information at the time it is most beneficial. Such research can further be used to develop education interventions and other solutions to address issues in patient education.

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Highlights

- Only a small part of the included records focused on the health information needed for gout patients.
- Medical treatment was the main topic of studies that focused on gout patient information.
- There is a persistent dearth of relevant information provided to gout patients for adequate disease management.
- Multiple findings highlight the interrelated nature of the various information types necessary to successfully manage gout.
- Value chain analysis can be used to identify information required by gout patients to effectively engage in self-care management.

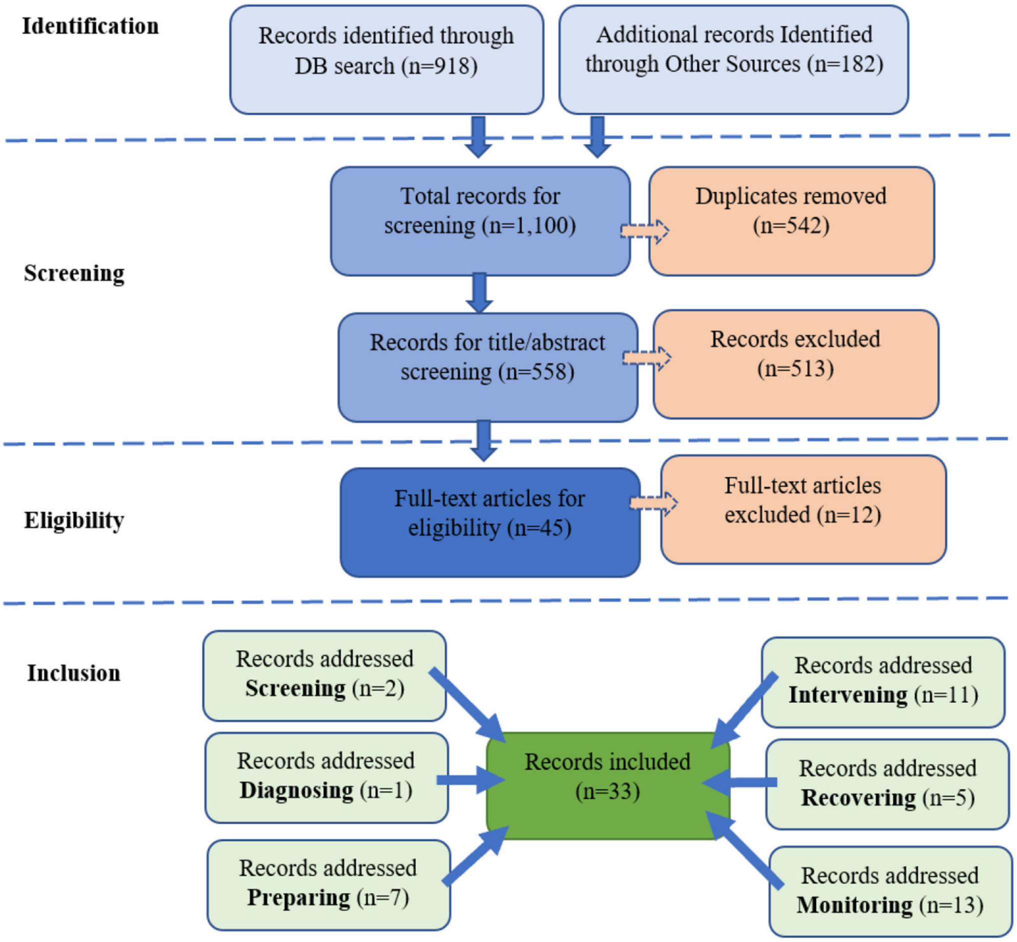

Figure 1.

Flow chart of study selection process

Table 1

Screening/Preventing stage literature review results.

Publication	Objective	Methods	Findings	Information Type	Conclusion
Doherty, et al. [4]	Identify and address why a 'curable' disease is so poorly managed.	Literature review searched the Medline database for articles published in English language using the search terms ‘gout’, ‘hyperuricaemia’, ‘hyperuricemia’, ‘tophi’ and ‘monosodium urate’ published after 1 January 1980, searched keywords 'therapy', 'management', 'cure', and 'treatment' alone and with the previous terms, other materials judged relevant.	Perception of gout as benign, humorous, self-inflicted disease.	pathophysiology	Patients need to understand the genetic and other risk factors of the disease.
Richardson, et al. [15]	Explore and better understand the experience women with gout.	Semi-structured interviews of female gout patients using a narrative approach	No knowledge of gout before diagnosis, inability to find information relevant to women.	pathophysiology	Diagnosis is likely to be missed due to lack of knowledge about gout in women and its perception as a man's disease.

Table 2

Diagnosing stage literature review results.

Publication	Objective	Methods	Findings	Information Type	Conclusion
Perez-Ruiz [16]	Review practices for long-term gout management w/emphasis on MSU crystals in pathogenesis and treating to target SUA level.	No explicit methodology.	Patients need to understand the role of MSU crystal observation for definitive diagnosis and the need for long term therapy to eradicate these crystals.	labs, pathophysiolog y, treatment	Patients need to be educated about diagnosis, the disease, and their contribution in long term treatment

Table 3

Preparing stage literature review results.

Publication	Objective	Methods	Findings	Information Type	Conclusion
Lindsay, et al. [22]	Explore the experience and attitudes of men with gout, especially those affecting outcomes w/emphasis on barriers to urate-lowering therapy.	Qualitative grounded theory interviews of 11 men with gout. Categorized by themes using NVivo.	Lack of understanding of pain severity, disease progression, disease mechanisms and causes of attacks (model of gout). Lack of knowledge about long term treatment. Perception of gout as something that must be endured.	disease progression, pathophysiology	Patients need a "pathophysiologic model of gout" that aids understanding and destigmatization.
Khanna, et al. [21,26]	Identify conceptual gaps for patients that lead to poorly controlled gout.	In-depth focus groups.	"1) Patients did not have a clear understanding of the natural history of gout; 2) patients did not realize that recurrent acute flares resulted in chronic joint damage; 3) there was lack of knowledge regarding treatment options and duration of therapy for acute and chronic gout; 4) patients felt that physicians did not spend enough time explaining the progression, i.e. natural history of the disease and its long-term effects; 5) patients did not grasp the need for chronic ULT to avoid complications and disability; and 6) patients were not aware of treatment goals for hyperuricemia, as evident by adherence to their gout medications."	pathophysiology, disease progression, treatment, labs	These are the key variables that need targeted in patient education resources.
Zhang, et al. [17]	Design and test a survey to evaluate patient gout-related knowledge and identify targets for patient education.	Survey of gout knowledge in 3 hospitals.	Most patients know about too much uric acid in the blood but are unaware of actual crystals in joints. Poor knowledge of optimum SUA levels and duration of use for SUA lowering drugs.	pathophysiology, disease progression, treatment, labs	Need to design more effective educational materials similar to those for diabetes.
Spencer, et al. [23]	Explore patient and provider perceptions of gout to improve management practices.	Semi-structured interviews of gout patients between age 30 and 100 analyzed using a grounded theory approach.	Patients do not understand that crystals continue to accumulate while symptom free. Unaware of existence of allopurinol which can prevent gout attacks.	disease progression, treatment, pathophysiology	"universal lack of knowledge and understanding about the cause and consequence of gout and the importance of making adequate lifestyle changes and adherence to lifelong ULT"
Perez-Ruiz [16]	Review practices for long-term gout management w/ emphasis on MSU crystals in pathogenesis and treating to target SUA level.	No explicit methodology.	Explain to patients that mobilization flares are 'price to pay' for cure and risk can by reduced through prophylactic therapy	pathophysiology, treatment	Patients need to understand the importance of therapy adherence to obtain sUA targets and eradicate crystals.
Harrold, et al. [24]	Explore patient and provider views of ULDs for gout management.	Qualitative in-depth phone interviews of gout patients	Lack of details about what causes gout. Perception of gout as condition that must be adapted to rather than one that can be controlled through lifestyle and medication.	pathophysiology, treatment	Patients want more information and more time from providers.

Publication	Objective	Methods	Findings	Information Type	Conclusion
Chandratre, et al. [19]	Explore patient perspectives on how gout impacts HRQOL.	Thematic analysis of focus group interviews about HRQOL.	Confusion concerning role of diet in cause and treatment, lack of 'trusted' sources of information, self-discovered sources considered overwhelming/frightening. Gout not viewed as disease.	pathophysiology, treatment	Patients concerned about quality of Internet sources found and desire more information from healthcare providers.

Table 4

Intervening stage literature review results.

Publication	Objective	Methods	Findings	Information Type	Conclusion
Lindsay, et al. [22]	Explore the experience and attitudes of men with gout, especially those affecting outcomes w/emphasis on barriers to urate-lowering therapy.	Qualitative grounded theory interviews of 11 men with gout. Categorized by themes using NVivo.	Patients learn treatment methods from other family members with gout. Lack of knowledge about long term treatment. Perception of gout as something that must be endured.	treatment	Patients only aware of anti-inflammatories and diet and exercise as symptom management options.
Abhishek, et al. [27]	Explore the effects of nurse-led intervention on ULT adherence.	Proof of concept study: 5 year follow up questionnaire to patients that had participated in a previous intervention.	Very high proportion of responders had excellent ULT adherence and EULAR target SUA level.	treatment	Personalized interactive education can have long term effects on ULT persistence.
Mikuls, et al. [35]	Examine the impact of pharmacist-driven intervention to optimize allopurinol therapy.	Randomized evaluation of pharmacist led intervention via telephone	Intervention patients showed increased adherence and met SUA goals.	treatment	Shows that simple interventions can be effective, but most patients still failed to reach the low SUA levels generally recommended.
Serawate, et al. [28]	Determine treatment patterns, specifically for allopurinol.	Retrospective claims analysis using multivariable logistic regression for factors associated with adherence to allopurinol therapy.	Previous diagnosis was positively associated with treatment compliance, while post index SUA flares indicated less compliance	treatment	Newly diagnosed and flare patients may require more education to promote therapy compliance.
Galo, et al. [29]	Identify and assess medication adherence intervention studies for rheumatic diseases.	Systematic literature review: "searched Medline (1946–June 2014), Embase (1974–June 2014) and International Pharmaceutical Abstracts (1970–June 2014). We used Medical Subject Headings for concepts underlying our search, 'medication adherence', 'intervention' and 'inflammatory arthritis' and applied keywords for concepts that did not map."	All interventions that had an effect on adherence included an education component and were tailored to the patient.	treatment	Patients need personalized education about therapies including proper administration and risks/benefits and
Dalbeth, et al [31]	Examine the relationship between illness perceptions of gout patients and disease outcomes, particularly medication adherence and musculoskeletal disability.	Questionnaire for patients with gout for under 10 years.	Patients with greater understanding of gout also reported a higher need for, less concern about, and stronger adherence to ULT.	treatment	Interventions to improve disease understanding may reduce concerns about ULT and increase adherence.
Robinson & Schumacher [36]	Examine characteristics, including readability,	Analysis of written patient information content.	"treating serum uric acid (SUA) to target and	treatment	Information content coverage is generally good, but the

Publication	Objective	Methods	Findings	Information Type	Conclusion
	content, and construction, of gout patient education materials from different countries and organizations.		prophylaxis against acute flare during urate-lowering therapy (ULT) initiation and titration" were absent in 60% of the studied resources.		most commonly missing information is important." Failure to understand that SUA needs to be below a certain threshold (the target) may prevent patients from returning to their doctor for assessment of their SUA and titration of their ULT. Being unaware of the importance of using anti-inflammatory prophylaxis against acute flares could reduce adherence during ULT initiation and titration. This lack of such prophylaxis would allow more flares and cause patients to stop ULT and/or lose confidence in their doctors.:
Rees, et al. [25]	Test effectiveness of nurse-led intervention based on 'best practices' delivered in a hospital-based gout clinic setting.	Proof of concept study: education intervention followed by measurement of SUA at 12 months.	Package of care' that includes patient education, individualized lifestyle advice and slow upward titration of ULT according to serial SUA levels achieved target levels in over 90% of patients.	pathophysiology including cause of gout, its risk factors and prognosis (including the risk of chronic joint damage), and available treatment strategies that can eliminate the crystals	Given proper education, knowledge of their therapeutic target, and regular contact with a nurse specialist,
Aung, et al. [33]	Review and discuss intervention strategies to improve ULT adherence and gout outcomes.	Review of treatment interventions	Patients are concerned about lack of information and understanding about treatment strategy.	Pathogenesis, treatment	Patients feel that healthcare visit time is too short to provide adequate information and discussion about gout, leading them to rely on Internet sources.
Reach [30]	Discuss reasons for gout treatment strategies and review literature on adherence.	Literature review	Patients often stop taking medications because they believe they are not working or bring on attacks when attacks occur early in therapy.	treatment, disease progression	Patients need to be informed about the reasons for increased attacks upon treatment initiation and understand that long term adherence decreases the risk of attacks.
Singh [32]	Assess barriers to treatment.	NGT study of African Americans and women with gout diagnosis code about gout treatment.	Patient worries about medication interactions and side effects. Not sure which medications for every day vs. during attacks. All groups indicated concerns about dietary modifications.	treatment, lifestyle	Patients need provider advice about diet. Medication concerns are common for chronic conditions and not specific to gout.

Table 5

Recovering/**Rehabilitating** stage literature review results.

Publication	Objective	Methods	Findings	Information Type	Conclusion
Harrold, et al. [24]	Explore patient and provider views of ULDs for gout management.	Qualitative in-depth phone interviews of gout patients.	Patients understand use of allopurinol for reducing serum uric acid and preventing gout attacks, not clear on planned duration of therapy. Belief that allopurinol triggers or worsens gout, concerns about side effects.	treatment	Patients unaware of potential for flares upon ULD initiation as short-term side effect.
Coburn, et al. [34]	Examine patient knowledge of gout, especially SUA goals including factors associated with that knowledge and the effects on health outcomes.	Survey of gout knowledge for VA patients over 19 that had started allopurinol in the previous 6 months.	Correct knowledge was high in patients for all topics except SU goal.	treatment, labs	SU goal knowledge was associated with more SU measurements during the first 2 years following ULT initiation.
Becker & Chohan [38]	Identify and discuss factors contributing to suboptimal gout management with emphasis on immediate opportunities for improvement.	Editorial Review	Education about the disease is key: "diagnosis and course, the distinctive therapeutic modalities employed, circumstances likely to promote or mark progression, the significance of comorbid associations, and means to monitor therapy and maximize adherence to therapeutic recommendations".	pathophysiology, disease progression, treatment, labs	Patient education is key to improving clinical outcomes.
Chandratre, et al. [19]	Explore patient perspectives on how gout impacts HRQOL.	Thematic analysis of focus group interviews about HRQOL.	Lack of information about acute attacks as side effect of allopurinol, interactions between medications for comorbidities. Incorrect advice to discontinue treatment.	treatment	Lack of knowledge about ULT benefits may lead to poor HRQOL.
Doherty, et al. [4]	Identify and address why a 'curable' disease is so poorly managed.	Literature review searched the Medline database for articles published in English language using the search terms ‘gout’, ‘hyperuricaemia’, ‘hyperuricemia’, ‘tophi’ and ‘monosodium urate’ published after 1 January 1980, searched keywords 'therapy', 'management', 'cure', and 'treatment' alone and with the previous terms, other materials judged relevant.	Belief that gout refers to the acute attacks.	Lifestyle, treatment	Patients underestimate the importance of long-term ULT.

Table 6

Monitoring/Managing stage literature review results.

Publication	Objective	Methods	Findings	Information Type	Conclusion
Roddy, Zhang, & Doherty [45]	Compare practices for chronic gout management in the UK to EULAR recommendations, including lifestyle advice and ULT therapy.	Questionnaire mailed to all patients over 30 in 2 general practices. Self-reported gout or acute arthritis attacks invited for clinical assessment.	Infrequent lifestyle modification advice.	lifestyle advice regarding weight loss, alcohol reduction, diet.	Advocates dissemination of EULAR recommendations for management.
Harrold, et al. [24]	Explore patient and provider views of ULDs for gout management.	Qualitative in-depth phone interviews of gout patients.	Patients recall being told to reduce certain foods, suggest follow up after initiating treatment.	lifestyle, treatment	Patients want more information about natural remedies.
Harrold, et al. [18]	Identify and understand patient gout knowledge, beliefs, and barriers to management.	Questionnaire about gout knowledge and beliefs.	Lack of knowledge regarding dietary triggers, ULT dosing during flares, risk of causing flares upon initiation. Deficit greater in those with active gout.	Lifestyle, treatment	Provide oral and written information regarding short- and long-term effects of ULTs and dietary factors throughout care.
Hui, et al. [43]	Revise and update recommendations for gout management in the UK.	The British Society for Rheumatology/ British Health Professionals in Rheumatology guideline for the management of gout	"All patients with gout should be given verbal and written information about the following: the causes and consequences of gout and hyperuricaemia; how to manage acute attacks; lifestyle advice about diet, alcohol consumption and obesity; and the rationale, aims and use of ULT to target urate levels. Management should be individualized and take into account comorbidities and concurrent medications. Illness perceptions and potential barriers to care should be discussed"	treatment, lifestyle	Updated recommendation due to better understanding of barriers to effective care
Ogdie, et al. [37]	Describe key points of intervention and propose educational improvements.	Review-no details	Patients need to understand that SUA levels under 6 mg/dl means unlikely to have gout and goal of therapy should be to maintain that level.	labs	Patient education may be most effective method to change physician behavior. Campaign with slogans to get patients to check their SUA levels.
Perez-Ruiz [16]	Review practices for long-term gout management w/emphasis on MSU crystals in pathogenesis and treating to target SUA level.	No explicit methodology.	The role of lifestyle changes and non-pharmacological approaches to gout management is essential information	lifestyle, treatment	These types of measures might only have a modest effect on sUA levels but are very beneficial for general health.
Johnston, et al. [41]	Review internationally available gout education resources to investigate content and ease of reading.	Analysis of written patient information content in 30 gout sources from several countries.	All sources noted role of uric acid, lifestyle factors such as weight, alcohol, and diet, including foods to avoid. Other topics not covered consistently.	Lifestyle, treatment, pathophysiology	"informing patients with gout of their increased risk of heart disease and diabetes is important for encouraging screening as well as modifying

Publication	Objective	Methods	Findings	Information Type	Conclusion
					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."
Vaccher, et al. [40]	Investigate gout understanding and explore barriers to optimum care.	Inductive thematic analysis of semi-structured interviews about understanding of gout management.	Most patients have basic knowledge of gout and know some personal triggers of attacks, but do not understand medications or the earliest signs of an attack.	Pathophysiology, lifestyle, disease progression, treatment	Most patients do not recall receiving information about gout from their GP, leading them to research gout themselves and expressed a desire for more informative sources.
Jimenez-Liñan, et al. [42]	Assess content, readability, and accuracy of free online patient education materials as related to current gout knowledge.	Review of 30 online gout education resources	education resources often contain no or inaccurate information about pathogenesis and fail to emphasize the importance of ULT.	pathophysiology, treatment	Not many web-based sources provide accurate and easy to read information about gout.
Zangi, et al. [44]	Develop patient education recommendations for those with inflammatory arthritis and identify areas for further research.	An extensive systematic literature search in Medline, Embase, PsycINFO, Cochrane Library and CINAHL from January 2003 up to September 2013 of publications in English, German, French or Spanish describing any kind of PE activities, was conducted	Trend toward emphasis of behavioral, cognitive, and emotional processes in patient education	lifestyle, pathophysiology, disease progression	Eight recommendations with the overarching principle that patient education should enable people to manage their life and optimize health and well-being
Rifaat, et al. [39]	Identify patient knowledge gaps and concerns for inclusion in education initiative.	Needs assessment given to highly educated patients being seen by rheumatologists	Information of most interest was diet guidelines.	lifestyle	Major gaps in knowledge essential to self-management.
Abhishek & Doherty [46]	Highlight common knowledge gaps, recommend core knowledge for education, and review non-pharmacological strategies for gout management.	Systematic literature review: searched PubMed from inception to 28 March 2017	Gout patients have significant knowledge gaps. Lack of time to provide individualized education is one of the many barriers to care of gout.	pathophysiology, disease progression, treatment, lifestyle	"People with gout should be educated about the pathogenesis, associated comorbidities and management of gout, including both pharmacological and non-pharmacological management."
Fields & Batterman [47]	Explore literature on gout patient education suggest future research directions.	Literature review	Key concepts highlighted in the literature include genetic and metabolic causes of gout, the risk of progressive damage with inadequate treatment, goal serum urate levels and why they are monitored, rationale for short- and long-term	pathophysiology, disease progression, treatment, lifestyle, labs	Optimal patient education requires multifaceted approach.

Publication	Objective	Methods	Findings	Information Type	Conclusion
			management, impact of comorbidities, and dietary management.		

Table 7

Gout Value Chain

Screening/ Preventing	**Diagnosing**	**Preparing**	**Intervening**	**Recovering/Rehabbing**	**Monitoring**
signs/symptoms	Specifying/Ordering Labs/Tests	Intervention Education	Ordering/ Administering Drug Therapy	Therapy Fine Tuning	Monitoring / Managing to Avoid Complications
Genes	Confusing Conditions	side effects	Treatment	Non-pharmacological Interventions	acute attacks
A BC G2	pseudogout	compliance	efficacy	rest	Lifestyle Modifications
SLC 2A9	Interpreting Test Results	Existing Medications	side effects	topical ice	Complications
SLC 22A12	Consulting with Experts	interactions/counter effects	compliance	reduce alcohol / red meat intake / soft drinks	kidney stones
Preventive Strategies	PCP / GP	Contact Further Resources	Performing Procedures	encourage cherry / skim milk powder intake	recurrent gout
diet / exercise	Rheumatologist	paid		avoid low temps / dehydration	advanced gout
Medical History	Determining Treatment Plan	non-paid		increase vitamin C / omega-3 fatty acids	Monitoring Therapy Compliance
family history	NSAIDS	Choosing Care Team		bariatric surgery	ULT
etiology	ULT (dosage)	rheumatologist / gout specialist		Inpatient Recovery	
Risk Factors	Acute vs. Chronic			Inpatient / Outpatient Rehab	
behavioral causes	Medical History			Developing Discharge Plan	
current medications	confirmatory signs / symptoms				