

MANAGEMENT OF GOUT FROM THE PATIENT PERSPECTIVE

by

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Abstract

Introduction: Suboptimal medication adherence and poor health outcomes in patients with gout, the most common inflammatory arthritis, has prompted efforts to optimize care delivery. The Virtual Gout Clinic, an electronic health technology supported collaborative care model for gout involving rheumatology, pharmacy, and dietetics, offers a promising solution. The purpose of this thesis is to gain an in-depth understanding of how individuals engage in managing their gout and also explore the complexity of the Virtual Gout Clinic using mixed methods to optimize the context and delivery of this care model.

Objectives: 1) To explore individual experiences with gout in a Canadian population and to understand the phenomenon of becoming actively engaged in the management of gout with an emphasis on factors which facilitate management; and 2) to explore how participants with gout experience the Virtual Gout Clinic and to understand and explain quantitative outcomes from the evaluation of this care model.

Methods: For the first objective, I used a constructivist grounded theory design and conducted semi-structured telephone interviews with participants diagnosed with gout completing the Virtual Gout Clinic. I applied an explanatory sequential mixed methods design for objective 2, as this design enables interview questions used in the qualitative component to be informed by quantitative outcomes of the Virtual Gout Clinic (adherence, serum uric acid) for a comprehensive final interpretation.

Results: 1) Analysis of 12 interviews constructed four themes: describing the severity of gout; processing the diagnosis and management of gout; interfering with management of gout; and facilitating management of gout. 2) The experience of the Virtual Gout Clinic was described by three conceptual categories: learning through the Virtual Gout Clinic; receiving personalized support; and knowing someone cares. Suboptimal health outcomes were explained by practical and perceptual barriers to gout management, such as lacking knowledge and fearing side-effects of medications.

Conclusion: This thesis provided novel insight into the process of patients becoming actively engaged in the management of gout with an emphasis on facilitating factors. An interdisciplinary model of care is a promising approach to optimize care delivery by providing both emotional and practical support as well as ongoing individualized education.

Lay Summary

Gout, the most common form of inflammatory arthritis, is characterized by painful flares and potential joint destruction. Despite effective medication being available, individuals with gout experience poor health outcomes. The Virtual Gout Clinic, which includes rheumatology, pharmacy, and dietetics was established to improve care delivery and health outcomes. I used qualitative research methods to interview 12 people with gout to address gaps in quality of care through understanding the patient experience with managing gout. In addition, I combined qualitative data (words) and quantitative data (numbers) to explore how participants experienced the Virtual Gout Clinic and to explain the outcomes of this care model. Results indicate how participants' beliefs and knowledge about their gout can influence active engagement in management of gout. The Virtual Gout Clinic can support patients with gout by showing someone cares, building knowledge, and offering individualized care.

Preface

The entirety of this thesis including design, data collection, analysis, and writing is the original work of Alyssa Howren.

The studies conducted in this thesis were reviewed and approved by the University of British Columbia Behavioural Research Ethics Board (H16-02061) and the Clinical Research Ethics Board (H14-01465).

The premise of Chapter 3 builds on preliminary results from the Virtual Gout Clinic, a project for which Dr. Mary De Vera at the Faculty of Pharmaceutical Sciences at the University of British Columbia is the Principal Investigator.

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List of Abbreviations

ACR – American College of Rheumatology

CQR5 – Compliance Questionnaire Rheumatology 5-item

eHealth – electronic health technology

EMR – electronic medical records

EULAR – European League Against Rheumatism

QOL – quality of life

SUA – serum uric acid

ULT – urate lowering therapy

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Dedication

To my mom, Joanne Howren – your perseverance, courage, and kindness through life inspire me every day. This would not have been possible without you.

Chapter 1: Introduction

1.1 Thesis Overview

1.1.1 Research Statement

Suboptimal medication adherence and poor health outcomes in patients with gout, the most common inflammatory arthritis, have prompted urgent questions on how to optimize care delivery. The “Virtual Gout Clinic”, a longitudinal study of a novel electronic health technology (eHealth) supported collaborative care model for gout involving rheumatology, pharmacy, and dietetics, offers a promising solution. Models of care delivery employing a multidisciplinary team are encouraging avenues for gout care. Indeed, rheumatology plus pharmacy or nursing interventions demonstrate the ability to reduce serum uric acid (SUA) levels in patients with gout (1-3). However, we cannot specifically determine from objective quantitative results the factors that contribute to improving health outcomes within these interventions. Only with qualitative or mixed methods approach can we gain knowledge of patient perspectives and how novel interventions operate in reality (4). Thus, the purpose of this thesis is to explore the complexity of an individual’s experience with gout and the process of receiving care within the Virtual Gout Clinic through a qualitative and mixed methods approach, respectively. Such an approach will enrich our understanding of the gout experience and further optimize the context and delivery of this multidisciplinary care model.

1.1.2 Overview of Research Themes and Chapters

This thesis is comprised of two investigations that together provide insight into the factors interfering with and facilitating adherence, as well as understanding how a multidisciplinary intervention can support optimal management for individuals with gout.

Chapter 1, the introductory section, will present relevant background literature, introduce the dynamics of the Virtual Gout Clinic, and build the rationale for incorporating a qualitative and mixed methods design. **Chapter 2** constitutes the first investigation and applies qualitative methodology to strengthen the existing literature exploring the individual's experience with gout and to further understand the phenomenon of being actively engaged in the management of gout from the patient perspective. **Chapter 3**, the second investigation, will draw upon an explanatory sequential mixed methods design to gain a comprehensive understanding of the patient experience of receiving care from the Virtual Gout Clinic, an interdisciplinary care team utilizing eHealth and telehealth. The mixed methods approach will also aid in explaining quantitative findings from the Virtual Gout Clinic. By collectively exploring an individual's experience with gout while receiving a care intervention we can advance towards understanding the context in which an intervention for gout can align with patient needs. Lastly, **chapter 4** will summarize conclusions drawn from both investigations and address the strengths and limitations inherent in each project. The concluding chapter will additionally discuss future directions and clinical applications of the thesis work.

1.2 Gout

Gout, the most common form of inflammatory arthritis, is characterized by uric acid crystallization within the joints, which can lead to painful flares, inflammation, and joint destruction (5). Gout significantly impairs an individual's quality of life (QOL) primarily in the physical domain and QOL is further worsened by comorbidities (6). The development of urate lowering therapy (ULT), such as probenecid in the 1950s and later allopurinol in the 1960s, established gout as an essentially curable condition with access to safe medication therapy (7, 8). However, the literature persistently indicates suboptimal health outcomes (9, 10), constant excess mortality rates (11) with increasing prevalence (12), and poor physician adherence to treatment guidelines (13-16).

1.2.1 Epidemiology of Gout

Evaluation based on the US 2007-2008 National Health and Nutrition Examination Survey (NHANES) indicates the prevalence of gout was 3.9%, with prevalence among men and women at 5.9% and 2.0%, respectively (17). Based on the 1988-1994 NHANES the prevalence of gout in the US was estimated at 2.9%, thus representing a steady increase over two decades (17). In addition, the estimated prevalence of gout in British Columbia (BC) in 2012 was 3.8% (males 5.2%, females 2.4%) and the incidence rate was 2.9 per 1000 person-years (12). There are however conflicting reports regarding whether the incidence of gout is rising or remaining consistent (18). Surprisingly, the excess mortality rate for individuals with gout has remained stable from 1999 through to 2014, thereby suggesting the need for an innovative and concerted effort to improve quality of care for gout (11).

The primary risk factor for gout is hyperuricemia, which is described as an elevation of uric acid above the threshold for monosodium urate (MSU) crystal precipitation. The risk of incident gout and repeated gout flares increases with elevated SUA (19). A review including seven studies with non-gout controls showed those with newly diagnosed gout had a mean SUA ranging from 6.1 mg/dl up to 8.8 mg/dl, while SUA of controls ranged from 5.0 mg/dl to 6.8 mg/dl (19). There are several identified risk factors for gout and hyperuricemia and one of great interest to patients is diet. An increased risk for developing gout is associated with consumption of meat, seafood (20), alcohol (21), and soft drinks containing sugar (22). In contrast, dietary factors that decrease the relative risk of incident gout include low-fat dairy (20), vitamin C (23), and coffee (24).

The management of gout is complicated by several comorbidities. Specifically, gout is associated with increased risk for developing cardiovascular diseases, metabolic and endocrine diseases, genitourinary diseases, and chronic pulmonary diseases (25). Gout is also linked with an increased all-cause mortality and cardiovascular mortality (25-27). Evidence also suggests increased risk for incident depression or general unhappiness in those suffering with gout (25, 28). The abundance of physical and psychological comorbidities associated with gout can understandably lead to complexities in designing and implementing effective therapy.

1.2.2 Direct and Indirect Costs

Patients with gout also incur significant direct and indirect costs during the course of management. A systematic review completed in 2015 estimates total gout-related direct costs for US employed, elderly, and treatment-refractory gout patients of \$172, \$1006, and \$6179, respectively (29). A recent retrospective case-control economic evaluation of incident gout cases

(≥ 66 years) in Canada indicates the initial 5-year direct healthcare cost is \$10,332 higher for patients with gout compared to the general population and the greatest expenditures are observed during the first year of diagnosis (30). In addition, employed individuals with gout in a US population accumulated significantly higher annual indirect costs, specifically in domains of sick leave (\$731 gout, \$424 non-gout), short-term disability (\$646 gout, \$288 non-gout) and workers compensation (\$1506 gout, \$809 non-gout) (31). Given the increasing prevalence of gout (12, 17) and associated economic burden, including gout-related health care costs (30-33), it is crucial to optimize care in a manner that is relevant and acceptable to individuals with gout.

1.2.3 Pathogenesis and Treatment of Gout

The pathogenesis of gout is well known and effective treatment in the form of urate lowering therapy (ULT) is recommended for the prevention of recurrent attacks and complications associated with crystallization of uric acid (34, 35). ULT, which include xanthine oxidase inhibitors (allopurinol, febuxostat) and uricosuric agents (probenecid, sulfapyrazone, and benzbromarone), prevents gout attacks by inhibiting the formation of uric acid (xanthine oxidase inhibitors) or increasing the excretion of uric acid (uricosuric agents) to effectively maintain plasma urate below saturation levels (36). Despite proven preventative therapy, evidence suggests suboptimal medication adherence (37) and poor health outcomes (9, 10) in patients with gout. The percentage of patients with gout adherent to ULT ranges from 10% to 46%, with 70% stopping ULT in the first year of therapy (37, 38). A major problem implicated in the suboptimal management of gout, an essentially curable disease, is the quality of care in gout, which encompasses medication adherence (9).

1.2.4 Quality of Care

Quality of care at the individual level can be defined as “whether individuals can *access* health structures and processes of care which they need and whether the care received is *effective*” (39). A major detriment to gout quality of care is the underutilization of ULT, which covers issues of patient non-adherence with ULT and unsatisfactory physician prescribing, dosing, and monitoring of ULT (40). In an effort to address the challenges in managing gout and improve outcomes, several guidelines for the treatment and prevention of gout have been published, including those from the American College of Rheumatology (ACR) (34, 41) and the European League Against Rheumatism (EULAR) (35, 42). The published guidelines harmoniously suggest providing patients with education and counselling on important lifestyle modifications, such as a healthy and low purine diet, exercise, and reduced alcohol consumption (34, 35). In addition, all guidelines are in agreement with setting the target uric acid level below 360 $\mu\text{mol/L}$, initiating ULT in the form of allopurinol at a dose of 100 mg, and up-titration of ULT to achieve target SUA (34, 35, 41, 42).

Published audits of gout management reveal poor quality of care for gout (13-16, 43). Evidence suggests insufficient counselling regarding diet, weight, and alcohol consumption (14, 15). Fifty-eight percent of all patients with gout prescribed ULT in a specialized rheumatology clinic in Ireland had an SUA below the target of 360 $\mu\text{mol/L}$ (13). While in UK primary care setting only 38% of individuals with gout taking allopurinol had an SUA below 360 $\mu\text{mol/L}$ (14). Sixty-two percent of patients with gout had their initial dose of allopurinol starting at 100 mg (14), with some authors reporting up to 70% of patients currently taking 300 mg daily (15). Evidence of subsequent up-titration was poor and requires further investigation (14). The monitoring of SUA

proved to be suboptimal, with only 34% of those taking ULT having their SUA recorded within a 12 month period (14). Similarly, only 24% of those receiving their first ULT prescription in a US cohort had their SUA monitored within the subsequent 6 months (16).

1.3 Patients' Experience with Gout and its Management

Several qualitative studies have worked with patients with gout to understand their experience with gout, their knowledge surrounding the condition, and to identify barriers faced by patients (44-49). Major themes consistently identified across studies span personal and social stigma connected to gout, medication related issues, and concerns surrounding the role of diet.

The potential for stigma surrounding gout has been identified as one of the barriers to seeking care (49). Patients with gout have referred to the association of gout with indulgence in alcohol and rich foods and an overall unhealthy lifestyle (44, 45, 48). Along with these thoughts arise feelings of self-blame, embarrassment, shame, and isolation (44, 45). It is also seemingly a misconception that women cannot be diagnosed with gout, leading to confusion and feelings of disconnect with the diagnosis (48, 50). Men on the other hand appear to experience masculinity as a barrier to seeking medical attention, feeling a need to push through and endure the pain (48). The following quote accentuates the lack of education about gout and common stigmatizing reference to Victorian-style cartoons (48).

“I was quite surprised when he told me I had gout. I thought gout, I mean, I associated gout with rich old men who drank port. I remembered seeing old pictures of men suffering with gout in bath chairs with bandages up to their thighs. I didn't think that women suffered with gout” (48)(p. 2)

Medication related issues are a common theme presented in the literature. Concepts identified include concern around side effects, inconvenience of taking medication daily, and worry regarding drug interactions (44, 45, 47-49). Additionally, there appears to some confusion, perhaps due to lack of provider to patient education, surrounding the role of ULT in disease management.

“I took the Allopurinol for some time (a couple of years) and didn’t have any attacks, so I thought I had cracked it. I thought it had gone so I took myself off the Allopurinol and I thought I would be fine” (48)(p.2)

Diet also proves to be an area fraught with disorientation (45, 48). However, some individuals demonstrate awareness that dietary changes can influence severity of the disease. The pair of quotes published by Singh et al. (45) accentuates the spectrum of knowledge regarding diet.

“You get different lists when you Google this question. It says that everyone has to find what starts the attack for them” (45)(p. 9)

“Unsure of what and what not to eat” (45)(p. 9)

1.4 Multidisciplinary Interventions for Gout

To address sub-optimal quality of care in gout, recent interventions have followed published guidelines and also incorporated either pharmacy (1, 2) or nursing (3) in combination with rheumatology to provide a structured inter-disciplinary approach to management of gout. Indeed, reported outcomes from pilot studies utilizing collaborative care include 82% of patients reaching target SUA and improvement in bodily pain in the model integrating pharmacy (2) and 92% of patients reaching target SUA in the model incorporating nursing (3). A randomized

clinical trial of a structured pharmacist program demonstrated that significantly more patients with gout receiving intervention reached SUA below 360 $\mu\text{mol/L}$ at 26 weeks in comparison to controls under usual care (1). The findings of these reports suggest a positive role for a collaborative care approach to gout management with respect to treatment of gout as well as appropriate lifestyle and medication education.

Table 1-1. Review of multidisciplinary care interventions for gout

	Rees, 2013 (3)	Goldfien, 2014 (2)	Goldfien, 2016 (1)
Study Design	Observational proof-of concept	Observational proof-of concept	RCT
Research Approach	Quantitative	Quantitative	Quantitative
Duration	1 year	3 months (minimum)	26 weeks
Team	1 rheumatologist + 1 nurse	1 rheumatologist + 1 pharmacist	1 rheumatologist + 1 pharmacist
Participants, N	106	95	64
Primary Outcome	SUA <360 $\mu\text{mol/L}$ (at 1 year)	SUA <6.0mg/dL (minimum of 3 months)	SUA <6.0mg/dL (at 26 weeks)
Results	92% below target	82% below target	35% intervention below target; 13% control.

1.5 Virtual Gout Clinic Study

Research in the realm of gout has been enhanced with qualitative exploration into the barriers and facilitators to optimal management. Patients and care providers have identified two areas of care that are well suited to an intervention, specifically diet and medication related issues (44, 45, 47, 48). Thus, a novel eHealth supported collaborative care model for gout that facilitates interactive communication among rheumatologists, a dietician, and a pharmacist offers a promising solution and is the intervention of interest in the ongoing Virtual Gout Clinic. In this

study, shared access to electronic medical records (EMR) supports remote communication and collaboration between healthcare professionals, placing the patients at the centre of care. Quantitative measures of medication adherence and health outcomes are monitored through the duration of the study to assess the impact of the clinic on patient outcomes. Preliminary findings of such measures suggest that qualitative approaches are needed to understand the patient experience, and thereby contribute to an insightful and well-rounded evaluation of the Virtual Gout Clinic.

1.6 Qualitative and Mixed Method Approach in Clinical Research

Qualitative research allows us to gain valuable insight and broaden our understanding of an individual's experience. Simply, while quantitative inquiry permits hypothesis testing, through qualitative research we can explore the what, why, and how questions pertaining to the entirety of a lived experience (51). From a clinical perspective, knowledge gained from a qualitative inquiry applied to the Virtual Gout Clinic can glean "awareness of social dynamics in the clinical setting...[which] can influence powerfully the process of care and consequentially the outcomes" (52)(p. 481). Moreover, qualitative inquiry has the promise to illustrate the dynamics of communication between patients and their health care providers (52). A qualitative research approach is increasingly being integrated into all phases of clinical trials. From 2008 to 2010 there were 296 published articles that reported the use of qualitative methods in randomized control trials (RCTs) (53). Qualitative research enhanced RCTs by understanding participants' beliefs about the intervention, providing clarification of findings, and identifying cost saving opportunities by directing researchers away from ineffective interventions (53).

Mixed methods offer a merger between the quantitative and qualitative research worlds, strengthening our understanding of a phenomenon by counteracting the biases and weaknesses inherent in quantitative and qualitative approaches (54). The mixed methods approach is steadily gaining ground in health research, as evidenced by journals such as the Journal of Mixed Methods Research and the International Journal of Multiple Research Approaches. From 1994 to 2004, 18% of health services research in the UK utilized a mixed methods approach (4). Mixed methods invite a fresh and integrative research method with the strength of enabling a comprehensive evaluation (54). Health care research is a complex construct composed of several dimensions that cannot be thoroughly comprehended through one methodology (4, 55). Of particular interest is the role explanatory sequential mixed methods can occupy when initial quantitative results are ambiguous or unexpected and require further explanation (54).

1.7 Description of Thesis Studies

Collectively this thesis contributes to understanding how to improve health outcomes in gout through a qualitative and mixed methods approach. The work of this thesis is built on the premise that knowledge constructed from exploring the participant experience will illuminate novel insight into the complex problem of suboptimal health outcomes in gout and thereby indicate opportunities to optimize care delivery. A constructivist paradigm recognizes the uniqueness of each participant's construction of reality and an emergent design creates a flexibility to adapt the research process to align with that of the participants.

1.7.1 Specific Objectives of Thesis Studies

Objective 1. To explore individual experiences with gout in a Canadian population and to understand the phenomenon of becoming actively engaged in the management of gout with an emphasis on factors which facilitate management.

Chapter 2 is a qualitative study following a constructivist grounded theory design exploring participant's experience with managing gout.

Objective 2. To explore how participants with gout experience the Virtual Gout Clinic and to understand and explain the quantitative outcomes from the evaluation of this care model.

Chapter 3 is an explanatory sequential mixed methods design exploring the participant's experience within the Virtual Gout Clinic and linking the quantitative and qualitative results for a comprehensive evaluation of this care model.

1.7.2 Towards Patients Becoming Actively Engaged in Gout Management: A Constructivist Grounded Theory Study

The constructivist grounded theory study of chapter 2 adds to the current body of literature through understanding the process in which individuals become actively engaged in management of gout. A key component of this chapter is the construction of categories which describe facilitators of gout management. Prior qualitative studies have explored a range of research

questions pertaining to gout, however to my knowledge none have recruited from a Canadian population with gout and few have directly elucidated factors facilitating gout management.

1.7.3 Explanatory Sequential Mixed Methods Evaluation of eHealth Supported Collaborative Care Model for Gout

Chapter 3's mixed methods design explores the participant's experience within the Virtual Gout Clinic, a collaborative care model for gout. In the last four years, studies in the UK and US have shown the varying success of interdisciplinary care models for improving gout care (1-3). This is the first study to provide a comprehensive evaluation using both quantitative and qualitative methodologies to understand and explain the Virtual Gout Clinic in an effort to improve the context and delivery of gout care.

Chapter 2: Towards Patients Becoming Actively Engaged in Gout

Management: A Constructivist Grounded Theory Study

2.1 Introduction

Gout, the most common form of inflammatory arthritis, has an estimated prevalence of 3.8% (12) to 3.9% (17) in North America and is characterized by inflammation, painful flares, and joint destruction. Despite the availability of effective medication therapy in the form of urate lowering therapy (ULT) studies have consistently reported suboptimal patient outcomes including repeated gout flares (10), increased cardiovascular mortality (56), as well as excess all-cause mortality (11, 56). Factors contributing to suboptimal patient outcomes include substantially low medication adherence to ULT, with only 10% to 46% of patients estimated to be adherent (37), and insufficient quality of care (14-16). An audit of primary care practice in the UK published in 2013 found only 38% of patients prescribed ULT had serum uric acid (SUA) below the recommended target of 360 $\mu\text{mol/L}$ and evidence for up-titration of ULT was poor (14). Singh et al. similarly found US patients with gout receive suboptimal quality of care with only 24% of patients prescribed ULT receiving proper SUA monitoring (16). In the Canadian context research in gout is emerging with recent data showing that prevalence and incidence rates of gout have increased by 59% and 46% respectively, from 2000 to 2012 (12). In addition, a Canadian population-based study reported a two-fold increase in the hospitalization rate for patients with gout from 2000 to 2011 (57). As such, efforts are presently focused on optimizing care delivery and improving outcomes for patients with gout (9, 58).

The implementation of qualitative inquiry to understand the complexity of managing gout from the patient perspective is a promising approach to enhance care delivery with a patient-centered lens. Indeed, a qualitative approach has the capacity to elucidate the discordance between evidence based practice and the reality of managing gout by understanding the context of care delivery and the perceptions held by patients (59). Qualitative studies of gout have been published in the US, UK, Australia, New Zealand, and Netherlands (60). Explorations of gout from the patient perspective have provided vivid depictions of individual experiences with gout pain, describing the pain of flares as feeling as though their “flesh is trying to rip” (44)(p.2) and becoming so sensitive to touch that they “couldn’t even put the sheet on [their] toe because it was that painful” (49)(p.4). Qualitative research has also elucidated barriers to optimal patient management of gout, including misunderstanding medications, a common narrative being “it had gone so I took myself off the allopurinol and I thought I would be fine” (48)(p. 1491). Few qualitative studies have explicitly focused on exploring factors that facilitate patient management of gout and to date there has been no qualitative research on patients with gout in Canada (60, 61). The aim of this constructivist grounded theory study is to further explore individual experiences with gout in a Canadian population and to understand the phenomenon of becoming actively engaged in the management of gout with an emphasis on factors which facilitate patient management.

2.2 Methods

This qualitative study was nested within the Virtual Gout Clinic (British Columbia, Canada), a proof-of-concept longitudinal observational study of a collaborative care model in gout involving rheumatology, pharmacy, and dietetics that takes advantage of electronic health technology

(eHealth), namely shared access of electronic medical records (EMR) to support communication and information exchange between health care providers.

2.2.1 Research Ethics

Guillemin and Gillam (62) outline two dimensions describing ethics: 1) procedural ethics, typically pertaining to ethics review board and signed consent, and 2) “ethics in practice”, which refer to the usually unexpected and ongoing ethical considerations that arise during the research process. With respect to procedural ethics, this study was reviewed and approved by the Behavioural Research Ethics Board at the University of British Columbia (H16-02061). Eligible participants were those in the Virtual Gout Clinic who had either provided written consent to be contacted for future studies related to gout and/or had expressed an interest during their enrolment in the Virtual Gout Clinic. An information and consent form for this qualitative study was mailed to all eligible participants. I contacted potential participants by telephone to review to the purpose of the study, field questions, and discuss if they would wish to participate. If not already completed, those wanting to participate were asked to sign and submit the consent form.

With regards to practical ethics, ahead of the interviews I was aware of the stigma surrounding gout (44, 45, 48) and stoicism (48) from familiarity with the literature. Although the scope of the interview did not present any imminent concerns for sensitivity, I was aware of the vulnerability created through in-depth interviews and the potential for unexpected topics to arise. Given my training and experience in distress services, I was confident in my ability to provide empathy, support, and a non-judgmental space for participants if warranted during the interview. I engaged with participants as a responsive listener and provided the opportunity to call back if participants

became fatigued. Given that fatigue often accompanies chronic disease, the use of telephone interviews suited the population such that it minimized the potentially harmful impact for participants. Being reflexive regarding the relationship between the researcher and participant also prompted the need to establish myself as a student researcher as opposed to the Virtual Gout Clinic coordinator. In addition, emphasis was placed on establishing participants as experts in describing the gout experience from study enrolment through to the interview. To protect the autonomy of participants, identifying information was removed from data sources. Participant IDs generated from the original Virtual Gout Clinic were utilized and the final published material identified participants by IDs 1-12 and gender. In addition, participants were advised to use pseudonyms or pronouns at their discretion during the interview to maintain confidentiality.

2.2.2 Design

The qualitative study was guided by Kathy Charmaz's work in *Constructing Grounded Theory* (63). The traditional grounded theory methodology presented by Glaser and Strauss (64) arose during a time when positivistic worldviews of the mid-20th century held greatest influence over research design. During this period the positivistic lens limited research to the evaluation of existing theory, as opposed to generating original theory (63, 64). In an effort to exemplify the rigor central to quantitative research, Glaser and Strauss proposed a systematic qualitative approach to generating theory (63, 64). Since the publication of *The Discovery of Grounded Theory* by Barney Glaser and Anselm Strauss, grounded theory has become a widely applied and adapted methodology. Two adaptations of grounded theory have emerged since, specifically Straussian in 1990 (65) and constructivist grounded theory in the mid-1990s (66, 67). All three grounded theory methodologies utilize comparative analysis, memo-writing, saturation, and

theoretical sampling (63, 68). Constructivist grounded theory is elevated through acknowledging the subjective nature that both the researcher and participants bring to describing a phenomenon. I engaged in developing theoretical sensitivity which is the construction of conceptual meaning from the emergent data and connections between categories to expand analytical capacity (63). For the purpose of this study, features of the constructivist grounded theory design informed the qualitative description of how individuals with gout become actively engaged in gout management (69).

2.2.3 Participant Recruitment

Participants with gout were purposefully sampled from the Virtual Gout Clinic and were eligible for enrolment in the qualitative study after they had completed a minimum of 6-months of follow-up. Individuals with gout were enrolled if they met the following criteria: 1) enrolled in Virtual Gout Clinic; 2) received at least one pharmacist and one dietician consult through the Virtual Gout Clinic; 3) able to provide informed consent; 4) have access to a phone; and 5) able to comprehend and speak English.

2.2.4 Data Gathering

All interviews were conducted by a single researcher (AH) over the telephone. The use of telephone interviews emulated the telehealth delivery of the Virtual Gout Clinic and enabled recruitment of participants outside of the lower mainland. Interviews were semi-structured and were therefore guided by overarching questions yet integrated the flexibility to explore experiences brought forth by participants during the conversation (70). The interview started by briefing the participant to the subject matter and purpose of the interview (70). The briefing also

situated the participant as the expert early in the interview (70, 71). The interview guide was sectioned into areas of inquiry with suggested questions (Appendix A). The structure of the interview and phrasing of questions were adapted to the flow of conversation unique to each participant. For example, some participants would answer questions before interview prompting or the dialogue would move back and forth between topics on the interview guide. I applied active listening to establish connectedness and engagement with the participant during the interview (72). This technique is characterized by reflecting back to participants their responses and summarizing content of the interview. Active listening therefore contributed to obtaining clarification of the meaning behind experiences described by participants. I also used probing in the form of focused questions to elucidate in-depth responses. The interview concluded with a debriefing to inquire if participants had any final questions or additional information to share. Interviews were recorded using an Olympus Digital Voice Recorder WS-853.

2.2.5 Analysis

Professional transcription services transcribed each audio-recorded interview. Transcribed interviews were reviewed for accuracy and imported as Microsoft Word documents into NVivo 11 (QSR International) for analysis. NVivo 11 is a qualitative data analysis software that provides a platform to support the researchers' analysis of transcripts while keeping the analysis process organized. The use of NVivo 11 therefore supported the auditability of the analysis process.

Coding establishes a framework for the analysis and its stepwise recording is a key component in demonstrating confirmability of research findings (73). As such, consecutive versions of NVivo

11 workbooks as well as notes detailing significant decisions made during the coding process were kept. The analysis of interviews began immediately after the first interview was transcribed. I followed three main steps of the coding process of constructivist grounded theory: 1) initial coding; 2) focused coding and categorizing; and 3) theoretical coding (63). For the initial coding phase I conducted line-by-line coding and exercised the use of gerunds and in vivo codes to be representative of the participant experience. Coding with gerunds involves using the *-ing* form of verbs to be representative of the participant narrative (63). The initial coding then progressed to incident-by-incident coding after five to six interviews as the analytical direction of the data began to take form. Focused coding narrowed the scope of the qualitative analysis by identifying initial codes that held analytical significance and/or were repeated among participants. Lastly, theoretical coding can “help you specify possible relationships between categories you have developed during focused coding” (63)(p. 150). Theoretical coding makes use of a known phenomenon or theory to help interpret such relationships between constructed categories (63). Based on the emerging analysis as well as prior knowledge that poor ULT adherence (37) and management (13-16) underlie suboptimal health outcomes in gout, I explored previous analytic constructs that pertain to adherence to medications and treatment in chronic conditions to shape some of the emerging theoretical codes. Specifically, a qualitative review by Van Camp et al. (74) which summarized common facilitators and barriers to medication adherence reported findings similar to the conceptual categories of the current analysis and expedited coherence of the data. The findings from this study expand beyond adherence to the broader scope of disease management, and therefore conceptualization of the participant experience encompasses becoming engaged in management of gout. Final theoretical codes were reported as themes.

Throughout the research process I utilized techniques pervasive to grounded theory. I used memo-writing during the analysis and manuscript writing as an intermediary space for reflexivity as well as to describe constructed categories. Memo-writing in the form of mind-mapping also enabled the exploration of relationships between categories. In addition, I applied the constant comparative method through the entire analysis phase to ensure the findings are grounded in the data (64). The constant comparative method is the repetitive scrutiny of comparing data, codes, and categories throughout the analysis process and also compares constructed categories with results in the literature (64). Through the process of constructing focused codes and tentative categories the interviews were also shifted to explore areas of analytical direction. Specifically, questions from the interview guide underwent revision and I would intentionally probe on areas of conceptual interest during the interviews to increase the comprehension and precision of tentative categories. Finally, data saturation refers to reaching a point of redundancy in the data set, whereby recruiting additional participants into the study does not generate new concepts and the constructed categories and themes are considered to be exhaustive (75). After 12 interviews data saturation was achieved as no new insight into the constructed categories and themes emerged.

I independently analyzed the data through to categorizing for the first round of analysis. The review of tentative categories occurred over meetings with a study author (MDV) to scrutinize the full coding process. Further review of data analysis by additional researchers (MDV, SMC) was done to explore alternative perceptions of the data and challenge the analytical interpretation. One interview initially identified as an outlier was archived and later analyzed

once tentative categories had been developed. Therefore, the eventual analysis of this interview helped to evaluate the credibility and robustness of the findings (76).

2.3 Results

Twelve participants with gout were interviewed over the telephone (**Table 2-1**). The average duration of the interview was 33 minutes (range 17 to 49 minutes). The analysis resulted in the construction of four themes that collectively characterize the experience of having gout and the process of becoming engaged in optimal management: 1) *describing the severity of gout*; 2) *processing the diagnosis and management of gout*; 3) *interfering with management of gout*; and 4) *facilitating management of gout*.

Table 2-1. Participant characteristics

	N (%)
Male	10 (83%)
Female	2 (17%)
Age (yr)	
40-49	2 (17%)
50-59	1 (8%)
60-69	2 (17%)
70-79	6 (50%)
80-89	1 (8%)

2.3.1 Experiencing Gout: Describing the Severity of Gout and Processing the Diagnosis and Management of Gout

The experience of living with gout constructed from the interviews was captured by two complementary themes, specifically *describing the severity of gout* and *processing the diagnosis and management of gout* (**Table 2-2**).

Table 2-2. Representative quotes for themes pertaining to experiencing gout

Conceptual Category	Example Quotes
<i>Describing the severity of gout</i>	
Experiencing gout episodes	<p><i>“You can't sleep with gout, you just can't sleep. You can't even have a sh- a sheet over, nothing else, just a sheet over. You can't have any of that because of the pain, the level of pain” (Participant 7, female)</i></p> <p><i>“It's terrible. You get up in the morning and it's like you get out of bed and you're walking on marbles” (Participant 11, male)</i></p> <p><i>“I am thinking when it will flare up, when, always, I always think about that. Like now, I hope it will not flared up again and then I'm thinking when, when this will gonna flared up again” (Participant 5, male)</i></p>
Impacting one's life	<p><i>“when I was experiencing the symptoms, what it really meant was that I was unable to participate in many of the activities I would normally be participating in.” (Participant 8, male)</i></p> <p><i>“if it was in my hands, yeah, it was still pretty painful to work ... I've had to take the whole week off work, so yeah, it's, it's pretty debilitating” (Participant 2, male)</i></p> <p><i>“it has not impacted me in any way, in any way, shape or form. I do all the activities I did before. I have no restrictions and you know my diet is the same” (Participant 12, male)</i></p>
<i>Processing the diagnosis and management of gout</i>	
Adapting to gout	<p><i>“I'm very, I'm very careful for what I am eating or, or drinking” (Participant 5, male)</i></p> <p><i>“You plan your day around how you feel.” (Participant 11, male)</i></p>
Searching for reason	<p><i>“I don't know whether it was because I was particularly dehydrated when I took the blood test or maybe I'd consumed more of the triggers leading up to it” (Participant 8, male)</i></p> <p><i>“if I have a, a gout what's this, a flared up, I always have tears in my eyes, why me, why me, I ask myself, why me.” (Participant 5, male)</i></p>
Testing the waters	<p><i>“because I hadn't been having flare ups, I, I felt I could indulge a little bit more in some of the foods that I knew that were triggers.” (Participant 8, male)</i></p> <p><i>“So I took it [allopurinol] every other day for a while and I held my own and then I tried every second day for maybe a couple of weeks” (Participant 7, female)</i></p>

In regards to the first theme of *describing the severity of gout*, the first conceptual category formed was *experiencing gout episodes*. Many participants described gout flares in terms of the redness, swelling, burning, and excruciating pain. Often gout flares were localized to their feet and in particular the big toe. Other participants recalled having attacks in their ankles, elbows, and hands as well. The pain was described as all-consuming and worse than childbirth, as one female participant stated “*I would rather have a baby so that would give you a clue*” (**Participant 7, female**). Two participants had similar narratives of the pain feeling “*like a jabbing knife*” (**Participant 11, male**). While a number of participants referred to the intense sensitivity during a flare, so much some would “*wake up with [their] toe throbbing with it, hurting to just have a sheet on*” (**Participant 9, male**). Gout flares were also depicted as intermittent and unpredictable. The spontaneity of flares created a sense of fear for some participants as they were “*pretty aware of the fact that [they] could have an episode any time*” (**Participant 9, male**).

Also under the first theme of *describing the severity of gout*, was a second conceptual category, *impacting one’s life*, that is, the impact of gout on living, which varied according to the severity and frequency of flare activity. Participants either noted gout had little impact on their daily life or could recall instances where gout affected participation in daily activities. One participant expressed being unbothered by gout, and noted being “*never bedridden [...], never inactive*” and identified as “*not a typical gout sufferer at all*” (**Participant 12, male**). Another participant simply expressed that gout “*doesn’t bother me*” (**Participant 3, female**). On the other hand, participants described how gout “*made life a whole lot more restrictive than it would normally have been*” (**Participant 4, male**), experiencing restrictions related to leisure activities, work,

general mobility, and day-to-day tasks. Many spoke about how gout flares impacted their mobility, especially with regards to walking or movements such as getting up from a chair or out of bed. Some participants shared how they “*couldn’t go for [their] walks*” or “*had trouble opening jars*” (**Participant 1, male**). While others noted how their “*fitness just it went down because I wasn’t able to do, you know I wasn’t able to go hiking, I wasn’t able to go climbing*” (**Participant 8, male**). The pain seemed to create a sense of loss through limitation of activities and hopelessness when stuck in bed, unable to move or make the pain subside. One participant shared being “*a pretty miserable person to live with*” (**Participant 7, female**) during gout attacks, while another recalled being on vacation and having to “[*stay*] in bed, because it just, there was nothing that seemed to make any difference” (**Participant 4, male**). Additionally, the intermittent nature of gout attacks established challenges with planning ahead for vacations or certain activities.

A second theme related to experiencing gout was *processing the diagnosis and management of gout*, which encompassed how participants learn to live with gout as well as how they internalize and explore their diagnosis, a process which appears to be driven by the participant. Three conceptual categories form this theme: 1) *adapting to gout*, 2) *searching for reason*, and 3) *testing the waters*. *Adapting to gout* describes how participants found ways to modify their lifestyles, including making practical changes, acclimatizing to the pain, and modifying their diet. While *searching for reason* was a process for some participants during which they sought to find reason for having gout. For example, questioning the relationship between diet and a high SUA result. While for one participant it was an emotional experience of questioning why they

have gout and have to live with such pain. Lastly, *testing the waters* is a process in which participants mentioned instances when they trialed their diet or modified their medications. In some cases participants completely stopped taking their ULT. The self-experimentation often occurred during a period when participants reached a level of comfort with gout management or a dormant period where attacks have decreased in severity or ceased altogether. For another participant, concern about the side-effects from gout medications preceded modification to their medications.

2.3.2 Interfering with Management of Gout

The third theme, *interfering with management of gout*, describes a number challenges that participants with gout encounter when working to control their symptoms. The five conceptual categories building this theme are: 1) *disliking taking medication*; 2) *fearing side-effects*; 3) *affecting personal identity*; 4) *forgetting medications*; and 5) *lacking knowledge or being misinformed*. Quotes to illustrate each category are found in **Table 2-3**.

Table 2-3. Interfering with management of gout

Conceptual Category	Example Quotes
Disliking taking medication	<p><i>"I don't particularly like relying on medication in general so I guess it's just personal philosophy."</i> (Participant 8, male)</p> <p><i>"You see I am not, I don't like to take medicine."</i> (Participant 3, female)</p> <p><i>"I ended up at you know taking more and more medications to the stage that it, I wasn't really comfortable with that"</i> (Participant 9, male)</p>
Fearing side-effects	<p><i>"And I guess not knowing, not knowing what the medication's really gonna do say 10 years from now. Obviously they don't make medications to kill you, right?"</i> (Participant 2, male)</p> <p><i>"But then again you know the side effect and all that is I'm so scared."</i>(Participant 3, female)</p> <p><i>"So I told her sometimes I take my medicine, sometimes when I feel good, I don't take it because I'm afraid of my kidney, yeah."</i> (Participant 5, male)</p> <p><i>"cause I did ask him one time what if I took it every other day because I was concerned about my kidneys."</i> (Participant 7, female)</p>
Affecting personal identity	<p><i>"But what I am thinking he is, he has a severe gout when he is age is around 65 up. Me, I'm just only 43 now and I'm experiencing what my father, my father experienced before because I saw it."</i> (Participant 5, male)</p> <p><i>"I'm not sure what to call it but reluctance to admit that I have a chronic disease as, or condition is part of taking that pill every morning."</i> (Participant 9, male)</p> <p><i>"You know like if I had, if I had any choice in the matter, I'd, I'd rather be in a position where you know like I'm, I have my health back that I had in my youth but that's a dream"</i> (Participant 12, male)</p>
Forgetting medications	<p><i>"I mean I may, I may miss a day um in a week once or twice, you know out of 30 days I may miss it like four days but it really has no effect so..."</i> <i>"but I didn't take the allopurinol for three days, I just for some reason I don't know why"</i> (Participant 2, male)</p> <p><i>"Not on purpose. I, I go away for a weekend for example and leave it at home, just because I'd forgotten it."</i> (Participant 9, male)</p> <p><i>"Well if I do, I just take it a little bit later, that's all"</i> (Participant 10, male)</p>
Lacking knowledge/ being misinformed	<p><i>"Well, I only took it periodically, maybe for a week and my gout rescinded. So I didn't see any sense in taking it again."</i> (Participant 1, male)</p> <p><i>"Yeah, it's, because you know just my understanding of, of my medications, I took it wrong."</i> (Participant 5, male)</p> <p><i>"They can't do a wand over you and then say you're cured"</i> (Participant 10, male)</p>

The first three categories, *disliking taking medication*, *fearing side-effects*, and *affecting personal identity*, represent perceptual barriers held by participants. The conceptual category *disliking taking medications* captures a general aversion held by some participants towards consuming medications. Many expressed feeling uncomfortable with taking medications, especially daily medications or a number of different medications. The source of discomfort was not explicitly mentioned by participants. However one participant shared "*nobody wants to take medication if they can help it*" and how you can "*just have a mental block in your head about taking medications*" (**Participant 2, male**). This highlights the personal disposition held by some participants towards taking medications in general that was present during their journey in managing gout. Alternatively, four participants expressed *fearing side-effects* of their gout medications. Mentioned by two participants was the concern of how the medications could harm their kidneys. One participant had low functioning kidneys and expressed feeling "nervous" about taking gout medications because of the potential for further kidney damage. It also seems previous adverse reactions can dispose a fear of taking medications, as one participant referenced a reaction to indomethacin as the reason "*why I'm afraid to take medicines*" (**Participant 5, male**). *Affecting personal identity* describes a phenomenon during the comprehension of the gout diagnosis in which some participants undergo a process of self-reflection and may face a reluctance to accepting the diagnosis. For some participants this stems from having misconceptions about gout or knowledge of the misleading stereotypes associated with gout. For example, female participants at one point believed that only "*rich people get gout*" (**Participant 3, female**) and that gout was limited to "*rich old men that ate [...] all those rich foods*" (**Participant 7, female**). One participant shared an experience in which she attended an appointment to seek a diagnosis for her symptoms. However, she was instead told by the

physician that "*women don't get gout*" (**Participant 7, female**). For other participants being diagnosed with a chronic condition prompted reflection on their own age and health status. Taking long-term medications heightens awareness of undesired health status for some individuals and seemed to manifest as a reluctance to accepting the diagnosis: "*he (doctor) suggested that I should take something every day and I said I was a little reluctant to do that 'cause I didn't really want to admit that I had a chronic disease that was going to be with me for a long time.*" (**Participant 9, male**).

The final two categories identified practical barriers to optimal gout management, specifically *forgetting medications* and *lacking knowledge/being misinformed*. The category *forgetting medication* describes participants unintentionally forgetting to take medications as opposed to making a deliberate decision to discontinue gout medications. One participant shared how forgetting allopurinol was "*not on purpose*" (**Participant 9, male**), another describes how for him "*it's just not forgetting, it's just ah, just being lazy*" (**Participant 2, male**). Missing a dose did not appear to create concern and 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?*" (**Participant 2, male**). An additional frequent barrier voiced by participants was insufficient education about gout or the medications being prescribed. Narratives expressed by participants included the misconception of thinking there is no "cure" for gout, believing that ULT has a cumulative effect to prevent against future gout attacks, and misunderstanding medication directions. For one participant, the confusion over medications lead to a reversal of colchicine and allopurinol

directions. A common experience shared by three participants with a history of gout and ULT treatment was the decision to discontinue their ULT early. This occurred prior to joining the Virtual Gout Clinic and one participant recalled thinking "*well, I was fine, so I quit it*" (**Participant 6, male**). Those experiencing a dormant period in gout activity seemed unconvinced of the need for daily medication and were unaware of the preventative nature of ULT: "*My uric acid count was quite high. I never, I never did experience any sort of gout issues at the time but as a precaution, he did put me on allopurinol. [...] I stayed on it, I took it on a daily basis, goodness, I, I forget now, but it was maybe, maybe a few years and then you know like I asked him repeatedly why I'm taking this [...] And he just said it was a precaution. So finally I stopped taking it and, and went without for many, many years.*" (**Participant 12, male**).

2.3.3 Facilitating Management of Gout

The fourth and final theme constructed in this analysis is *facilitating management of gout*. Participants described six conceptual categories within this theme: 1) *being organized*; 2) *identifying motivation*; 3) *taking control*; 4) *seeing a difference*; 5) *resonating importance of gout medications*; and 6) *developing acceptance* (**Table 2-4**). Each conceptual category eased the progress through to managing gout by overcoming practical and perceptual barriers as well as establishing an intrinsic interest in managing gout.

Table 2-4. Facilitating management of gout

Conceptual Category	Example Quotes
Being organized	<p><i>“Well, I’m on other medications so I’ve got a very regimented schedule when I take a medication.” (Participant 1, male)</i></p> <p><i>“It’s like brushing my teeth now, I gotta do it” (Participant 2, male)</i></p> <p><i>“I’m quite disciplined that way. I don’t know why but I am” (Participant 4, male)</i></p>
Identifying motivation	<p><i>“Gout is damn uncomfortable” (Participant 8, male)</i></p> <p><i>“If I don’t take my medication, I don’t want to get sick, right, because I’ve got to take care of my family and my husband and my housework too... and then I do my volunteering too” (Participant 3, female)</i></p> <p><i>“Remembering what it’s like to have difficulty getting, getting your shoe on and walking around.” (Participant 9, male)</i></p>
Taking control	<p><i>“I mean the bottom line is I’m the patient and know my body so ultimately it becomes my responsibility” (Participant 12, male)</i></p> <p><i>“then in my you know research online, I did a little bit more, I discovered a few more things and what the, what the causes were” (Participant 8, male)</i></p>
Seeing a difference	<p><i>“Now it’s down to about 350, 360, which is obviously a huge difference taking the medication” (Participant 2, male)</i></p> <p><i>“Well, it was about a year after but yeah, it (gout) came back, and I stopped it (medication) myself. I, I shouldn’t have. I probably should just have continued, you know” (Participant 6, male)</i></p>
Resonating importance of gout medications	<p><i>“I really had the suspicion the way in which I’ve, I’ve reacted to the sole, solely to the medication change” (Participant 9, male)</i></p> <p><i>“the only thing, the lesson I’ve learnt is not to stop the allopurinol” (Participant 6, male)</i></p>
Developing acceptance	<p><i>“I mean I read about the, the side effect and then I think now I have accepted it” (Participant 3, female)</i></p> <p><i>“[rheumatologist] said it’s probably taken me 30 years to get this bad so it’s not gonna go away in five minutes.” (Participant 11, male)</i></p> <p><i>“I mean you know like you wake up one day and you’ve got, got this funny pain in your body, you go to see the doctor and ultimately you go through the process.” (Participant 12, male)</i></p>

A common facilitator of managing gout identified by participants was a sense of *being organized*, whether inherent or an acquired behaviour. The mechanism used to remind themselves to take their medication differs from one person to another. Some participants take several medications for other conditions and therefore there is an emphasis on the necessity of taking medications along with the need to schedule multiple medications. Others use pill organizers such as a blister pack or pill box. Many participants discussed how taking their gout medications has become a routine integrated into their daily schedule. For example, associating medication taking with a time of day or with an activity already established in their daily routine. *“I keep my medication in a Tupperware container right next to the tea bags. I drink tea and I, I gasp for tea in the morning so when I open it and see the tea bags...There are my pills”* **(Participant 7, female)**.

The category *identifying motivation* describes the reason why participants are compelled to take their gout medications. Most participants stated they continue to take their medication to avoid the immense pain experienced during gout flares. As such, it seems that most participants have made the connection between adhering to daily ULT and the prevention of future pain from gout. A few participants mentioned the need to get back to day-to-day activities and therefore improving their health was of significant importance. Such activities included time with family, walking, volunteering, or regaining a more active lifestyle. A couple of participants also spoke about wanting to avoid visits to the hospital or their physician’s office and linked medications as a means to prevent that from happening.

Taking control refers to participants having an active role in managing their gout. Participants relayed a sense of personal responsibility such as being proactive and taking initiative, and also acknowledged the importance of knowing one's own body. Many participants expressed a sense of ownership over their health and believed they had an important role to play in the treatment process, as demonstrated by a participant stating "*my health is my concern*" (**Participant 5, male**). Also mentioned by participants is being proactive in terms of searching for information about gout online and requesting an appointment with a specialist to receive a comprehensive diagnosis. In addition, some participants mentioned having a personal plan to deal with future gout flares. Having a plan, such as knowing when to take colchicine or to reach out to a health professional, seems to establish confidence with regards to managing a future flare. Participants also communicated the importance of knowing their own body, relaying how "*you have to know yourself and what sets you off*" (**Participant 7, female**).

The category *seeing a difference* refers to moments during treatment in which participants connect the role medications play in managing their gout symptoms. Specifically, either when stopping or initiating gout medications and then noticing a change in disease activity. Some participants described stopping their ULT because they were asymptomatic, however over time experienced a recurrence. The process of altering ULT and observing a reaction describes a self-initiated learning experience for participants. From another perspective, participants with high SUA or experiencing gout flares noticed the reduction of symptoms after starting their allopurinol: "*there was a drastic improvement after six months and the gradual improvements ever since*" (**Participant 1, male**). Eleven participants contributed to the construction of the

category *resonating importance of gout medications*. This category details how participants attribute the improvement in their gout symptoms as a direct result their gout medications. Consequently, the majority of participants expressed being committed to taking their medication and shared the common sentiment of “*I won't stop taking those medicines*” (**Participant 5, male**).

Several participants with gout remarked on *developing acceptance* in terms of medications and the prognosis of gout. Developing acceptance covers the hurdles overcome by participants towards being in a position to actively manage their gout. Some participants discuss the acceptance of medications such as accepting the side-effects and the longevity of ULT. This encompasses knowing the potential side-effects and ultimately deciding that the benefits of medication outweigh the potential for adverse reactions. The resistance to taking medications seems to be involved in this process as one participant reflected on their decision making, “*I don't wanna take it but I have no choice. I have to take it every day*” (**Participant 5, male**). An understanding and commitment towards taking medications guides towards accepting the need to take medication. This is illustrated by one participant stating simply “*you stay on the meds or you have trouble*” and that taking medications for this person is “*a fact of life*” (**Participant 11, male**). Participants also remarked on accepting their gout diagnosis and the accompanying lifestyle. Having gout becomes something that participants realize they have to live with, while aiming to “*enjoy the good days*” (**Participant 11, male**). It seems that reaching acceptance also incorporates being realistic, with a participant referring to how it took 30 years for the gout to get this bad and subsequently understanding that gout will not quickly dissipate. It is interesting to

read that a few participants described that gout is something they have to accept, as if this is a necessary to move forward and "*ultimately go through the process*" (**Participant 12, male**).

2.3.4 Integration of Constructed Themes

Although theory development was not intended, the exploration of how themes and conceptual categories are interconnected resulted in the construction of an framework to represent the findings. The abstract relationship between the three themes *interfering with management of gout*, *processing the diagnosis and management of gout*, and *facilitating the management of gout* is represented by the schematic in **Figure 2-1** to illustrate the dynamic process of being actively engaged in the management of gout.

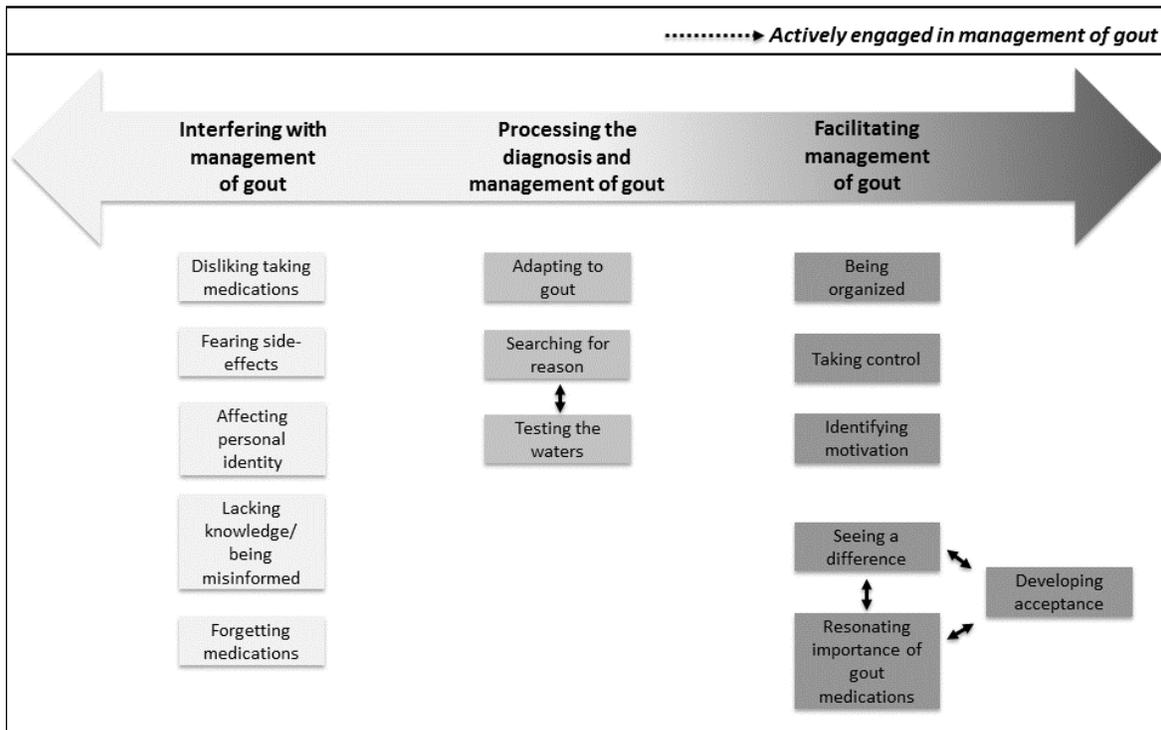


Figure 2-1. Schematic of three main themes constructed in the qualitative analysis to describe the process of being actively engaged in management of gout.

(Themes are shown in the bold gradient arrow at the top of the figure and the gradient represents the dynamic linkage among the themes. Beneath each theme are boxes containing the corresponding categories. Solid black arrows within each theme depict relationships between categories.)

The dynamic nature of the process of being actively engaged in the management of gout represents how some participants shared the experience of previously taking ULT, then experiencing an asymptomatic stretch, which leads to them deciding to discontinue ULT, but as a consequence experiencing a recurrent gout flare, and then restarting ULT and managing their gout. In addition, the schematic captures the weighing of practical and perceptual factors that modify the level of engagement in gout management. One participant described weighing the fear of side-effects with wanting to avoid pain and ultimately decided to follow “*the don’t have*

the pain route” (**Participant 7, female**). Another participant stated that “*if taking the medication is what I have to do to avoid the gout attack, I’ll take the medication. It’s a tradeoff.*” (**Participant 12, male**).

It is important to note the position of the themes in the process of being actively engaged in the management of gout. Specifically, *processing the diagnosis and management of gout* is at the centre of the spectrum, mediating movement between *interfering with management of gout* and *facilitating management of gout*. Through processing the diagnosis and management of gout, participants gain an understanding of the causes of gout and discover methods to adapt. Also within processing the diagnosis is *testing the waters*, which from the participant accounts can move towards either facilitating or interfering with adherence to treatment. In addition, *testing the waters* and *searching for reasons* are connected, as demonstrated by a participant mentioning “*you’re trying to figure what are you doing, what are you in taking in your system*” and the curiosity of dietary triggers caused the participant to “*test it for a while*” (**Participant 2, male**).

Intrinsic processes closely linked to participants *developing acceptance* are *seeing a difference* and understanding the *resonating importance of gout medications*. Through noticing a change in their gout activity many attributed that change to their medications, thereby reinforcing the importance of ULT: “*I mean it’s a big, very, very big help for me those medicines, yeah, it helps me a lot, and my uric acid [...] went down. Yeah, from 500 plus to down to 300 something so it’s a very, very big help.*” (**Participant 5, male**). The combination of noticing an improvement in

their health and taking ULT ultimately supported the development of acceptance in terms of actively managing their gout. For example, one participant shared their perception of how gout medications “*help me keep mobile, you know, so it's just a fact of life*” (**Participant 11, male**).

2.4 Discussion

This qualitative study used constructivist grounded theory to explore how individuals with gout experience their chronic condition and elucidated factors that interfere with or facilitate active engagement in the management of gout. The analysis of interviews revealed insight into two themes describing the experience of gout, specifically *describing the severity of gout* and *processing the diagnosis and management of gout*. This qualitative study also characterized perceptual and practical factors that influence the management of gout which are distinguished as the themes *interfering with management of gout* and *facilitating the management of gout*. This study provides a deeper understanding into the dynamic process of managing gout from the patient’s perspective and outlines facilitators of gout care such as the development of acceptance and motivation. In addition, this study adds to the qualitative literature by understanding the perspectives of a Canadian population with gout.

Several qualitative studies have described the experience of living with gout in terms of the pain and impact on daily life (28, 44, 45, 48-50, 61, 77-82). Common in the literature and confirmed in this study, is the unbearable pain caused by a gout flare (28, 44, 45, 49, 61, 77-81) and the prevalent description of being incapable of even having a sheet over the flaring area (45, 49) or comparing the pain of gout to child birth (28, 79). The spontaneity of gout flares creates added

challenges for patients, especially in terms of planning ahead (45, 82). A systematic review of twenty-two studies exploring health related quality of life identified physical health as the primary domain impacted by gout (83). Participants in this study echoed the difficulty of being active, often missing work and cutting down on personal activities. This study offers insight into the emotional impact of gout, with participants expressing feelings of hopelessness, isolation, and irritability during gout attacks. In addition, results show a balanced representation of the perceived burden of gout wherein some participants expressed feeling unaffected. Importantly, the results captured the continuity of the gout experience in a Canadian population with those of other countries such as the US, UK, Australia and New Zealand. Although differences exist in the healthcare systems across these nations, innovations to optimize quality of care and quality of life may be applicable across settings.

Research in gout has been extensively focused on deciphering the paradox of having a “cure” in the form of ULT yet consistently observing poor health outcomes. Explanations for poor outcomes have pointed to inappropriate ULT prescribing (14, 16), low medication adherence with up to 70% of patients discontinuing ULT within the first year (38), and the treatment of gout as an acute condition rather than a chronic condition requiring long-term medication (9). This study adds to our comprehension by constructing a theme to describe the participant’s processing of the diagnosis and management of gout. Participants referred to making adaptations to improve functioning as well as learning to live with the reality of gout. While published articles have highlighted lifestyle adaptations (44, 45, 49, 61, 78), the resolution to live with gout widens the scope to include how an individual incorporates gout into their life. During the diagnosis patients may also search for reasons for having gout and the cause of gout flares.

Liddle et al described a similar narrative among UK patients with gout in which they sought to investigate the cause of their gout and course of action (79). The behaviour characterized as testing the waters in this study was predisposed by lacking knowledge about medications or being unconvinced of one's susceptibility to future gout attacks. Participants sometimes stopped taking ULT when having few symptoms, thereby cycling away from engagement in gout management. In other instances, trialing diet or ULT reinforced the need to be engaged in gout management as gout symptoms reappeared. This study shows how the phenomenon of processing the diagnosis and management can mediate between interfering and facilitating optimal management of gout.

Five categories which interfere with management of gout were identified in this study. The two practical barriers, forgetting medications and lacking knowledge/being misinformed, are viewed as unintentional forms of non-adherence. Gaps in patient knowledge about gout are well documented and include gout etiology, medication use, and lifestyle modifications (44, 46-49, 61, 77, 78, 80-82, 84). Pronounced in this present study were education gaps regarding the mechanism of action of allopurinol which lead to discontinuation of ULT. Qualitative research exploring the complexity of behaviours involved in patient management of chronic diseases including gout have reported finances as a frequent barrier (47, 49, 74, 78, 80). However, in this study participants did not speak about financial barriers. It is possible that Canada's universal public healthcare as well as personal insurance or assistance programs for prescription drugs offset cost as a concern for participants. Presently, allopurinol is covered under the PharmaCare formulary in British Columbia and the cost of allopurinol (100 mg) ranges from \$0.07 to \$0.09 per unit. Perceptual barriers to management of gout identified in this population included fearing

side-effects and disliking medications. Both of these sentiments are shared among patients with gout in the US, UK, New Zealand, and Australia (45-49, 61, 77, 78, 84, 85). Lastly, this study discovered how a diagnosis and daily medications contribute to affecting personal identity. Gout stereotypes and the meaning one attaches to a chronic condition has the potential to establish a disadvantage in treatment outcomes and leave patients questioning their diagnosis of gout. The stigma situating gout as a man's disease and the association with rich foods and alcohol consumption is common (44, 48-50, 77). Participants in this study extended beyond the notion of stigma and shared deeper insight into the internalization of their diagnosis and reflection of self, thereby indicating the importance for health care providers to consider the psychological aspect of the diagnosis and the potential impact of such perceptions on the management of gout.

A considerable proportion of qualitative research in gout has described barriers to adherence and management (44-50, 61, 77-82, 84), however our understanding of facilitating factors is incomplete. This study interviewed participants who presented with suboptimal outcomes (SUA >360 $\mu\text{mol/L}$) and were therefore enrolled in a collaborative care intervention for gout. Therefore, this study design permitted an opportunity to understand the determinants that facilitate management of gout. Many participants in this present study and the literature have identified the acquired skill of being organized (pill box, blister pack, daily routine) as a facilitator for improved management of gout (47, 49, 61, 78, 81, 82). The leveraging of pain and gout flares as motivation for adhering to treatment is common as well (44, 47, 61, 78, 79, 81, 84). The category taking control describes how participants became active in managing their gout and acquired personal responsibility. Three studies similarly reported patients seeking information about their gout (49, 61, 79). One study has reported the notion of being proactively

involved in gout management (79), as was identified by participants in this study. When the behaviour of taking control of gout management appears absent, health practitioners can assist patients by providing a thorough plan for medication taking and coping with gout flares, as well as encouraging patients to read recommended resources. All three categories identified describe behaviours intrinsic to participants that promote engagement in management of gout and the motivation to sustain such involvement.

An unexpected finding in this study was the integrated process of participants developing acceptance, seeing a difference, and understanding the importance of gout medications. Demonstrated by these findings is the power of patient perceptions regarding illness and medications within the process of increasing active engagement in management of gout (86). When participants see a difference in terms of subsiding gout flares and pain it facilitates being convinced of medication benefits and strengthens the importance of daily ULT. Providers can encourage this resolution by reviewing with patients their SUA over time, tracking gout activity, and discussing gout pathogenesis.

There are strengths and limitations to this study that warrant consideration. Strengths include the study design, as a constructivist grounded theory approach utilizes techniques such as inductive analysis, constant comparison, and reflexivity to ensure results are representative of the participant experience. A study limitation was the recruitment from a cohort of individuals completing a novel model of care for gout, as participants may have been more inclined to discuss facilitators to gout management and those enrolled in research studies generally display healthier behaviours. The purposeful sampling strategy helped to compensate for this problem by

selecting participants with both unmanaged and well-managed gout to represent range of experiences. A second limitation is the restriction of recruitment from rheumatology practice, as the majority of individuals with gout are treated in primary care. However, thick description allows for the transferability of results and the patient process of managing gout described in this study is confirmed with qualitative publications from both rheumatology and primary practice.

In conclusion, this study has provided an understanding of how participants process and facilitate management of gout as well as deeper insight to perceptual barriers interfering with optimal management. This is the first qualitative study to explore experiences with gout in a Canadian population and these findings draw similarities among studies conducted in several countries in terms of the pain of gout flares, impact of gout, and barriers to gout care such as gaps in patient knowledge. By understanding the behaviours that facilitate patient engagement in the management of gout providers can adapt care delivery to patients who require support in these domains (87). For instance, providers could discuss with patients the utility of SUA in understanding the importance of gout medications to support the process of patients seeing a difference through to developing acceptance. Indeed, the process of becoming actively engaged in gout management is a complex and dynamic phenomenon and therefore patients require individualized support.

Chapter 3: Exploring How Individuals with Gout Experience an eHealth Supported Collaborative Care Model: An Explanatory Sequential Mixed Methods Study

3.1 Introduction

Gout has continued to perplex health care providers and researchers as despite the availability of effective treatment, individuals with gout are repeatedly characterized as having suboptimal adherence (37, 88) and poor health outcomes (9, 10). A study of medication adherence among seven chronic diseases including gout, hypertension, and type II diabetes reported worse adherence among patients with gout, with 63.2% of patients classified as non-adherent (88). A systematic review found only 10% to 46% of patients with gout are adherent to urate lowering therapy (ULT) (37) and 70% discontinue ULT in the first year of therapy (38). Factors associated with non-adherence for individuals with gout beginning ULT include few comorbidities and being under 55 years of age (38, 89), perhaps suggesting healthier and younger patients are less inclined to adopt a medication regimen for a chronic disease such as gout. A number of prior qualitative studies reveal patients with gout may not possess sufficient knowledge regarding the cause and prognosis of gout, the role of ULT, and are centered on treating acute symptoms (44, 47, 48, 82). Thus, it may be time for a paradigm shift in the approach to managing gout as well as the subsequent evaluation of interventions that aim to optimize health outcomes (9).

The Virtual Gout Clinic, a decentralized collaborative care model involving rheumatology, dietetics, and pharmacy supported by electronic health technology (eHealth), is a promising

intervention to improve the management of gout and ultimately patient outcomes. The integration of both eHealth and telehealth creates a dynamic model of care delivery which can best be understood through implementing a mixed methods approach (90). Specifically, mixed methods research, combining both quantitative and qualitative data, provides a comprehensive approach to understand complex research questions on the implementation of novel care models (54). With demonstrated use in evaluating care delivery in chronic diseases, a mixed methods approach provided insight into why diabetic participants were unable to achieve glycemic control following a structured education intervention (91). Most recently a mixed methods design explored the clinical practice behaviours of primary care physicians treating gout (92). Interviews with physicians further elucidated challenges faced in primary care such as gaps in knowledge of ULT, appropriate prescribing of prophylaxis for gout flares, and monitoring of patients' medication adherence (92). A depth of qualitative research has provided insight into patient (28, 44-48, 50, 61, 78-82, 85, 93) and provider (48, 49, 78, 92, 94-96) experience with gout, but absent in the literature is exploration into participants' experience within a targeted intervention. As such, with the recent implementation of the Virtual Gout Clinic, the aim of this study is to apply a mixed methods approach (1) to explore how participants with gout experience the eHealth supported collaborative care model and (2) to understand and explain quantitative findings from the evaluation of this care model.

3.2 Methods

3.2.1 Mixed Methods Approach

I implemented an explanatory sequential mixed methods design. This design implements data gathering and analysis in two distinct and sequential phases in which the quantitative phase

informs the subsequent qualitative phase (54, 97). As such, the methods and results sections are separated into the respective qualitative and quantitative phases. The preliminary quantitative results inform and plan the topics to be explored in the qualitative phase (**Figure 3-1**). Data is further integrated as the qualitative phase refines and deepens our understanding of the quantitative results. The same interviews conducted in chapter 2 comprise the qualitative data set for chapter 3. Specifically, this chapter draws upon the same sample and transcripts, but focuses on the excerpts related to the objectives of chapter 3.

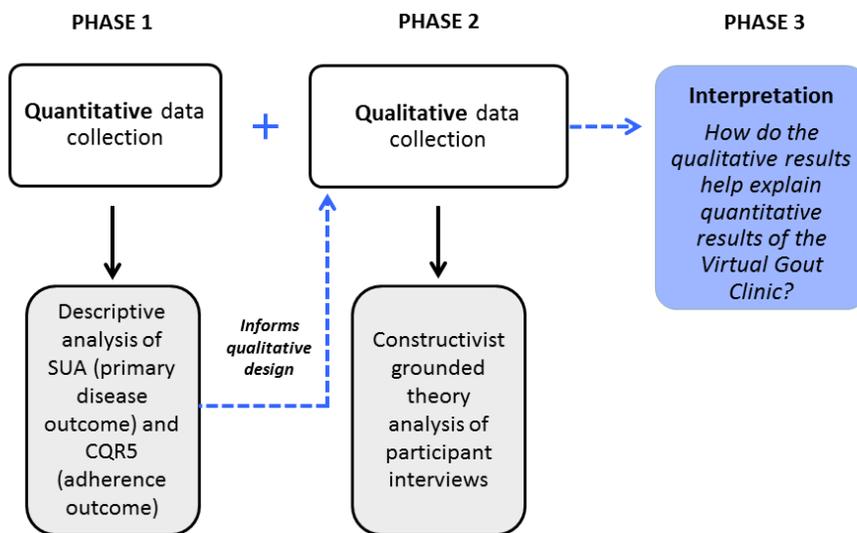


Figure 3-1. Overview of explanatory sequential mixed methods design
Abbreviations: SUA – Serum uric acid; CQR5 – Compliance Questionnaire Rheumatology 5-item

3.2.2 Research Paradigm

A paradigm is described as “a basic set of beliefs that guides action” (98)(p.17). It has also been defined as a researcher’s worldview (54), organizing structure, or underlying philosophy (99). Conducting a mixed methods study raises controversy due to the distinct and competing paradigms guiding either quantitative or qualitative research (100). It is proposed that researchers adopt a viewpoint that is a-paradigmatic, multiple paradigm, or single paradigm (101). The a-paradigmatic view removes the notion of a paradigm altogether (102). This study utilized the multiple paradigm approach, thereby setting aside philosophical tensions to provide a comprehensive understanding of the research question (103).

Post-positivism is the paradigm for the quantitative research component and is characterized by a critical realist ontology and a modified objectivist epistemology (98). This essentially means that a reality exists but can never be completely measured and instead the researcher aims for an objective stance in the research process but recognizes pure objectivism cannot be achieved (98). The paradigm that best resonates with the qualitative component of my thesis is the constructivist paradigm. The constructivist paradigm disagrees with the notion that a single reality exists and can be objectively understood. A constructivist assumes a relativist ontology, recognizing that there are multiple realities and likewise the existence of a reality is subjectively understood or constructed by the inquirer (98). In other words, the reality is shaped by the context of the individual’s world (104). Epistemologically, constructivists take a subjectivist stance whereby the researcher and participant are seen as co-creators of meaning and understanding (98).

3.2.3 Study Intervention

The Virtual Gout Clinic is a novel eHealth supported collaborative care model for gout involving rheumatology, pharmacy, and dietetics. Shared access to electronic medical records (EMRs) establishes a decentralized virtual clinic in which health care providers across British Columbia can communicate and collaborate remotely. All health providers had access to the British Columbia based Plexia Electronic Medical Systems (www.plexia.ca) as the shared EMR platform.

Participants in the Virtual Gout Clinic see their rheumatologist in person on an as needed basis. The study pharmacist provides an initial medication review at baseline. The study pharmacist also conducts telephone follow-up calls with patients to discuss any reactions, adverse events and any other issues with medications, until serum uric acid (SUA) target is reached. The dietician conducts one telephone consult to discuss with participants their current dietary habits and/or concerns.

3.2.4 Quantitative Methods

3.2.4.1 Design

A proof-of-concept, longitudinal observational study design was used to evaluate the Virtual Gout Clinic.

3.2.4.2 Participant Recruitment

There were four rheumatology clinics in British Columbia identifying potential participants for the Virtual Gout Clinic. Participants were eligible for recruitment if they met the following

criteria: 1) have been diagnosed with gout by a rheumatologist ≥ 2 years; 2) experienced ≥ 1 gout flare in the past year; 3) have SUA above target or $>360 \mu\text{mol/L}$ within the last 2 months; 4) ≥ 19 years of age; 4) able to provide informed consent and complete study assessments. Participants meeting inclusion criteria are followed over a 1-year period.

3.2.4.3 Follow-up and Outcomes

Participants in the Virtual Gout Clinic were followed up from baseline to 12 months. Outcomes data were collected at 3, 6, and 12 months using the EMR and questionnaires administered over the Internet.

Serum Uric Acid. SUA is a key indicator of gout severity and is the primary quantitative outcome. An elevated SUA is indicative of hyperuricemia, which is associated with an increased likelihood of uric acid build up in tissue increasing the risk of joint destruction, renal dysfunction, and flares. Consensus among the European League Against Rheumatism (EULAR) and the American College of Rheumatology (ACR) establishes a target SUA below $360 \mu\text{mol/L}$. Access to PathNet interface on Plexia which includes results from laboratory tests enabled extraction of SUA. Evaluated outcomes were participants' SUA levels and the percentage of patients achieving target SUA levels.

Medication Adherence. Medication adherence was evaluated using Compliance-Questionnaire Rheumatology (105, 106) 5-item (CQR5). The original 19-item CQR is a self-administered questionnaire that has been validated in rheumatic diseases (rheumatoid arthritis, polymyalgia rheumatica, and gout) against electronic medication event monitoring data (105). The CQR5 has

subsequently demonstrated reliability in a rheumatoid arthritis population (107). The 5-item questionnaire is composed of the following statements: 1) I take my anti-rheumatic medicines because then I have few problems; 2) I definitely don't dare miss my anti-rheumatic medications; 3) My medicines are always stored in the same place and that's why I don't forget them; 4) I take my medicines because I have complete confidence in my rheumatologist; and 5) What the doctor tells me, I hang on to (108). Participants rated their response on a four point Likert scale ("Don't agree at all" to "Agree very much"). I applied the questionnaire scoring algorithm (108) to identify participants who were adherent or non-adherent.

3.2.4.4 Analysis

I obtained descriptive statistics to summarize final SUA (mean, % of participants) and CQR5 (% non-adherent). Interim results of the Virtual Gout Clinic indicated that 30.4% (n= 7/23) of participants had an SUA >360 $\mu\text{mol/L}$ and 57% of participants were non-adherent at end of follow-up at 12 months (n=8/14). These interim quantitative results prompted inquiry into exploring why participants did not reach ideal outcomes and were used to inform the interview topics for the qualitative phase. This connection between the quantitative and qualitative data was the first instance of data integration or mixing (**Figure 3-1**).

3.2.5 Qualitative Methods

3.2.5.1 Design

The qualitative design followed in this project was constructivist grounded theory as it is elevated through acknowledging the subjective nature that both the researcher and participants bring to describing a phenomenon (63). Charmaz's constructivist grounded theory draws on the

emergent design, inductive approach, and constant comparative method described in the original grounded theory (63). Traditional grounded theory is said to “fragment[] the respondent’s story” (63)(p. 13). Constructivist grounded theory removes the positivist mindset and repositions the researcher as a constructor, instead of discoverer, of the reality and meaning of the story (63, 104). Further, the constructivist grounded theory design introduces a more open-ended framework and reflexive process for constructing theory (63).

3.2.5.2 Participant Recruitment

I selected participants from the Virtual Gout Clinic after they had completed a minimum of 6-months of follow-up. I aimed to purposefully include participants with an SUA >360 $\mu\text{mol/L}$ and/or identified as non-adherent according to the CQR5. Individuals with gout were enrolled if they met the following inclusion criteria: 1) enrolled in Virtual Gout Clinic; 2) received at least one pharmacist and one dietician consult through the Virtual Gout Clinic; 3) able to provide informed consent; 4) access to a phone; and 5) able to comprehend and speak English.

3.2.5.3 Data Gathering

I conducted one-on-one semi-structured interviews with participants over the telephone. The interview setting was designed to be “an interpersonal situation, a conversation between two partners about a theme of mutual interest” (70)(p. 125). Intensive interviewing is the mainstay approach to interviewing in grounded theory. It is characterized by open-ended questions, in-depth exploration of participant’s experience, exploring unexpected avenues, and obtaining a comprehensive reply (63). Participants were briefed during the enrolment process and immediately before the interview about the purpose of the interview. Specifically, I outlined the

aim to learn about their experience with the Virtual Gout Clinic and situated the participants as experts in providing insight to this experience. The interview guide consisted of three sections containing interview questions stems and adaptable prompts and probes (Appendix A).

The semi-structured interview was designed to be flexible through use of planned and unplanned probes or prompts. Inherent in qualitative research is the concept of emergent design whereby aspects of the study design can adapt based on the influence of participants and ideas learned through the progression of the study (54). Therefore, through the study process, I continuously reviewed incoming data to ensure future data gathering complemented the analytical direction. As such, the questions of the interview guide were revised and I would intentionally probe on areas of conceptual interest within participants' stories to gain a more comprehensive understanding of tentative categories.

Interviews were audio recorded using an Olympus Digital Voice Recorder WS-853.

3.2.5.4 Analysis

Interviews were transcribed verbatim by professional transcription services, reviewed for accuracy, and imported to NVivo 11 (QSR International). NVivo 11 is a software that supports qualitative and mixed methods research by providing a single platform to organize data and facilitating systematic analysis with functionalities such as codes, collections, and memos. Analysis began after the first interview and I used an inductive approach to constructing codes. Underlying the entire analysis is the constant comparative method, an inductive process that makes comparisons within and between all levels of analysis from data, to codes, to categories,

through to concepts (64). Applying a bottom up, inductive approach central to grounded theory design ensured that the results were grounded in rich data. I conducted interviews until data saturation was reached. Data saturation refers to reaching a point of redundancy in the data set, whereby recruiting additional participants into the study does not generate new concepts and the constructed categories and themes are considered to be exhaustive (75).

I followed the Charmaz's coding methodology which moves from initial coding, focused coding and categorizing (63). For the purpose of this chapter, I did not move with the data through to theoretical coding. Therefore, the findings are that of a descriptive analysis guided by constructivist grounded theory (69). I exercised line-by-line coding during the initial coding stage to stay close to the data and intricately discover each participant's story. After five or six interviews I was able to widen the scope of my initial coding to be incident-by-incident because analytical direction was becoming clearer. When applicable I coded with gerunds to facilitate thinking in the form of action and processes, which can lead to discovering connections in analysis (63, 109). I also utilized in vivo coding to construct codes which stayed connected and representative of the participant experience.

Through focused coding, larger amounts of data were coalesced by reducing, connecting, comparing, and highlighting initial codes (63). Focused codes were built by identifying initial codes with high repetition and conceptual potential. Focused coding supports a transition to constructing conceptual categories as the focused codes have been closely analyzed and scrutinized for analytical power (63). Memo-writing also facilitated the development of categories by providing an intermediate space to explore whether tentative categories linked

together ideas and processes to elevate the data towards understanding the phenomenon under study (63).

I independently analyzed the data through to categorizing for the first round of analysis. Once tentative categories were developed the analysis was reviewed in meetings with a study author (MDV) to scrutinize the coding process and arrive at a consensus for the final interpretation.

3.2.1 Integration of the Data

I connected the quantitative and qualitative data by using the “sets” function in NVivo 11 to distinguish between participants who were identified as adherent or non-adherent and with SUA $>360 \mu\text{mol/L}$ or SUA $\leq 360 \mu\text{mol/L}$. Once participants were classified according to their respective quantitative outcomes I executed a matrix coding query to filter qualitative data in order to facilitate interpretation of how the differing quantitative groups spoke about their experience during the Virtual Gout Clinic. To retain congruence with the research question at hand, I focused on exploring how participants spoke about behaviours related to the theme “*interfering with management of gout*” detailed previously in Chapter 2 (page 26). Therefore, I cross-tabulated quantitative classifications with the following conceptual categories: 1) *disliking taking medication*; 2) *fearing side-effects*; 3) *forgetting medications*; 4) *lacking knowledge/being misinformed*; and 5) *affecting personal identity*.

Access to Plexia enabled triangulation of select qualitative findings with physician, pharmacist, and dietitian consultations. Triangulation in this case specifically refers to methodological

triangulation, whereby the findings from different sources of data are compared and contrasted to improve validity (110).

3.3 Results

3.3.1 Participant Characteristics

Twelve participants (83% male) consented to take part in the telephone interviews. The interviews were 17 to 49 minutes in length (mean 33 minutes). Mean age of participants at the time of interview was 67 (range 41-82 years).

3.3.2 Quantitative Results

All participants were prescribed ULT in the form of allopurinol. Two participants did not complete the CQR5 and one did not have a final SUA reading. Three participants were characterized as non-adherent according to the CQR5. While four participants had an SUA above 360 $\mu\text{mol/L}$. The average SUA of all participants was 387 $\mu\text{mol/L}$ (range: 202 $\mu\text{mol/L}$ to 598 $\mu\text{mol/L}$, SD: 109.5 $\mu\text{mol/L}$) near the time of interview (**Table 3-2**).

3.3.3 Qualitative Results

The exploration of a participant's experience in the eHealth supported collaborative care team was classified into two main themes, namely *describing experience with Virtual Gout Clinic* and *logistical considerations*. These themes are described below and illustrative quotes are shown in **Table 3-1**.

Table 3-1. Participants’ experience in the Virtual Gout Clinic and logistical considerations

Conceptual Category	Example Quotes
<i>Describing experience the Virtual Gout Clinic</i>	
Learning with the Virtual Gout Clinic	<p><i>“I was delighted to hear that I could drink wine again. So that’s a big factor.” (Participant 1, male)</i></p> <p><i>“we went over... you know things to avoid eating” (Participant 7, female)</i></p> <p><i>“the CT scan that, that she ordered that displayed exactly where the crystals in my feet and my hands was pretty dramatic” (Participant 9, male)</i></p> <p><i>“If I just went onto allopurinol on its own, that in itself might trigger a gout attack” (Participant 12, male)</i></p> <p><i>“the blood tests that kind of showed whether it was working or not” (Participant 4, male)</i></p>
Receiving personalized support	<p><i>“seeing what the results and the confidence [the health providers] have instilled in me of taking it, has changed my opinion of taking it on a regular daily basis” (Participant 2, male)</i></p> <p><i>“it was nice having her check on the blood tests.. and interpreting them, and I remember one in particular where it looked like stuff was going the wrong way so it was, it was nice having that kind of feedback” (Participant 8, male)</i></p>
Knowing someone cares	<p><i>“I felt that somebody really cared who wanted to know how I’m doing” (Participant 3, female)</i></p> <p><i>“even though I’m far or I don’t know where I, where I was, they, they also care for.. my health.. I feel so happy, happy because they care, that’s the, that’s the point, that’s the big thing I cannot, I cannot pay.” (Participant 5, male)</i></p> <p><i>“I hate to say it, you know being, you know it’s just that you feel you know that somebody cares. The information is useful but just to have somebody you know suddenly to have all this attention around something that you’re experiencing is, you know it feels good.” (Participant 4, male)</i></p>
<i>Logistical Considerations</i>	
Optimizing timing of Virtual Gout Clinic	<p><i>“but certainly the consults would be very useful if the medications weren’t as effective as they were for me” (Participant 9, male)</i></p> <p><i>“a year ahead when my gout was so extreme before I got referred to a rheumatologist, it would have been a lot more helpful” (Participant 7, female)</i></p> <p><i>“I don’t think the gout right now is an issue” (Participant 6, male)</i></p>
Coordination and accessibility	<p><i>“I already told the dietician, the pharmacist, [the rheumatologist], I told them that I always.. work out of town, but they insisted that we will give you a call” (Participant 5, male)</i></p> <p><i>“I think she called me, he or she called me and I was not home. But then I called and left a message, but then I don’t think she called me back” (Participant 3, female)</i></p>

3.3.3.1 Participants' Experience with the Virtual Gout Clinic

Three conceptual categories formed the theme of describing how participants experienced the Virtual Gout Clinic: 1) *learning with the Virtual Gout Clinic*; 2) *receiving personalized support*; and 3) *knowing someone cares*.

Eleven participants described instances of being engaged in learning during the Virtual Gout Clinic with at least one health care provider. Areas of learning covered diet, medications, meaning of SUA, and knowledge about gout. In terms of diet, most participants described learning about “triggers” that can cause gout symptoms to flare and found it useful to discuss with providers their own findings about how the dietary factors seem to affect their gout. For some, learning during the Virtual Gout Clinic meant understanding the characteristics of gout and being shown the severity of their own gout when reviewing imaging results with their rheumatologist. Learning about SUA enabled participants to understand “*the level it should be at*” (**Participant 6, male**) and participants often referenced observing how their uric acid went down. As such, participants seem to have a greater capacity to fully ascertain the impact of lifestyle and medication changes can have on lowering SUA. Additionally, participants seemed to gain an understanding about gout medications. For example, learning “*how to use the colchicine if I had a flare up*” (**Participant 4, male**) and how ULT medications work.

The majority of participants referenced occasions during which they received support in managing their gout that was specific to their needs. Examples include reviewing lab test results, receiving confirmation, and receiving direct advice and instructions. Specifically, participants mentioned reviewing the SUA results together with the pharmacist and being monitored by the

pharmacist with regards to medications and gout activity. Others recalled having their own findings or knowledge about gout, such as personal dietary triggers, validated when speaking with a health professional. Support also came in the form of getting direct advice or instructions particularly about how to properly take medications. Beyond receiving advice related directly to gout treatment, two participants mentioned how personalized support and “*having to explain it all kind of helped... formulate [their] feelings*” (**Participant 4, male**).

Lastly, an unexpected finding constructed from the analysis was the perception held by seven participants of knowing someone cares while enrolled in the Virtual Gout Clinic. Comprising this category was a general feeling as though one or more of the health professionals cared for them while being in the Virtual Gout Clinic and that a concerted effort was being made to improve their health. The category spans the notion of having someone listen, establishing a genuine connection, and feeling emotionally supported. From the participant point of view, establishing a caring provider-patient relationship can include providers removing “*professional hats*” (**Participant 4, male**) and going beyond giving “*the prescription to get rid of some symptoms and get [the patient] out of the door*” (**Participant 9, male**).

3.3.3.2 Logistical Considerations

Interviews with participants revealed key insight into care delivery processes of the Virtual Gout Clinic that could be improved. The timing of participant enrolment presented as a prominent topic, especially for six participants who sensed their gout was well-controlled. Being under control meant feeling unrestricted by the symptoms, having only a few previous flares, and

feeling relatively better with minimal pain. A number of participants shared that it would be optimal to be in the Virtual Gout Clinic at a time when their gout was flaring and causing pain or when they were not already taking ULT appropriately.

The utilization of telehealth seemed to have both benefits and drawbacks for participants. Some participants noted the added convenience and time saving offered by the Virtual Gout Clinic delivery structure. The anticipated convenience often factored into the decision making process when enrolling in the Virtual Gout Clinic. The convenience was particularly noticed for those who traveled a distance to see their rheumatologist. Telehealth also was advantageous for those with inflexible work hours or working out of town. It is important to note that although many participants found telehealth to be an appropriate conduit for providing care, one participant did emphasize the value of face-to-face interactions. The coordination of pharmacist and dietitian telephone presented issues on occasion. Participants referenced instances where telephone calls were missed and they had trouble reconnecting after missed calls.

3.3.4 Mixed Methods Results

Integration of primary outcomes from the Virtual Gout Clinic with qualitative interviews facilitated exploration of factors that may influence achievement of optimal health outcomes. The mixed methods evaluation focused on connecting factors that pertain to *interfering with management of gout*, identified in previous work (page 26), to participants characterized as non-adherent or above target SUA (**Table 3-2**). Examples of quotes providing context to the qualitative results are provided in **Table 3-3**.

Table 3-2. Mixed methods review of participant experiences related to interfering with management of gout

Quantitative			Qualitative *				
Participant ID	Adherence	SUA (μmol/L)	Disliking taking medication	Fearing side-effects	Affecting personal identity	Forgetting Medications	Lacking knowledge/ being misinformed
1	adherent	≤360					
2	non-adherent	>360	x	x		x	x
3	adherent	--	x	x			
4	adherent	≤360					
5	--	>360		x	x		x
6	--	≤360					
7	adherent	>360		x			
8	non-adherent	≤360	x			x	
9	non-adherent	≤360	x		x		
10	adherent	>360				x	x
11	adherent	≤360					
12	adherent	≤360			x		

* Identified content pertaining to non-adherence only during the Virtual Gout Clinic. Some participants mentioned these characteristics before the Virtual Gout Clinic which assisted in forming the contents of chapter 2.

Four participants had an SUA level above recommended target of 360 μmol/L (mean 517 μmol/L) near the time of interview. In addition, three of ten participants fully completing the

CQR5 were characterized as non-adherent. Qualitative exploration and data integration provide insight to explaining these suboptimal outcomes. Those participants with poor outcomes were characterized as having up to four of the factors relating to interfering with management of gout. Lacking knowledge or being misinformed seemed to be a consistent factor among those participants not achieving target SUA. It was evident that three participants with SUA >360 $\mu\text{mol/L}$ identified knowledge about gout as a determinant of treatment non-adherence. They described either the common misconception of thinking there is no “cure” for gout, misunderstanding medication directions, and believing that ULT can build up to prevent against future flares. For one participant, the confusion over medications resulted in the switching of directions for colchicine and allopurinol. Fortunately, this mistake was corrected by the study pharmacist. Review of health care providers’ consultations confirmed understanding of gout or medications was a concern during the Virtual Gout Clinic.

Factors such as fearing side effects also influenced one participant’s medication taking regimen. In this case, fearing side effects led to the participant trialing a decrease in their allopurinol:

“So I took it every other day for a while and I held my own and then I tried every second day for maybe a couple of weeks and then I started to feel twinges in my toes so I went back to every other day and then it didn't improve so then I went back to taking it every day.”

(Participant 7, female)

One participant whose SUA remained significantly above 360 $\mu\text{mol/L}$ from baseline through to 12 months described fearing side-effects and facing a “*mental block*” towards taking gout

medications on a daily basis. In addition, the participant recalled periods during the Virtual Gout Clinic in which he either tested dietary intake or medication to observe the subsequent impact on SUA:

“So I did test it, I did test it, I did, I had two beers at a wedding in May and my gout when I went the next day, [...] you know I'm taking the medication religiously. Sure enough, my gout level spiked [...] 'Cause the next time, the next two weeks I didn't have any beers, it went back down.” (**Participant 2, male**)

The resistance to taking medication seemed to be a long journey for this participant during which allopurinol was taken casually, essentially treating intermittent flares as opposed to adopting a preventative approach. It appears the participant was able to reach a point of accepting the necessity of gout medications with the encouragement of health care providers and seeing the impact of medication adherence and diet modification first hand:

“Everything changed after uh he convinced me that realistically [...] I should really be focused on taking the medication even though I don't particularly want to take medication every day” (**Participant 2, male**)

Table 3-3. Quotes from participants identified as non-adherent or SUA >360 µmol/L

Example Quotes	
Disliking taking medication	<p><i>“Truly, you know, nobody wants to take medication if they can help it every day” (Participant 2, male)</i></p> <p><i>“I don’t, I don’t particularly like relying on medication in general so I guess it’s just personal philosophy.” (Participant 8, male)</i></p> <p><i>“I ended up at you know taking more and more medications to the stage that it, I wasn’t really comfortable with that” (Participant 9, male)</i></p>
Fearing side-effects	<p><i>“And I guess not knowing, not knowing what the medication’s really gonna do say 10 years from now. Obviously they don’t make medications to kill you, right?” (Participant 2, male)</i></p> <p><i>“So I told her sometimes I take my medicine, sometimes when I feel good, I don’t take it because I’m afraid of my kidney, yeah.” (Participant 5, male)</i></p> <p><i>“cause I did ask him one time what if I took it every other day because I was concerned about my kidneys.” (Participant 7, female)</i></p>
Affecting personal identity	<p><i>“But what I am thinking he is, he has a severe gout when he is age is around 65 up. Me, I’m just only 43 now and I’m experiencing what my father, my father experienced before because I saw it.” (Participant 5, male)</i></p> <p><i>“I’m not sure what to call it but reluctance to admit that I have a chronic disease as, or condition is part of taking that pill every morning.” (Participant 9, male)</i></p>
Forgetting medication	<p><i>“I mean I may, I may miss a day um in a week once or twice, you know out of 30 days I may miss it like four days but it really has no effect so...” (Participant 2, male)</i></p> <p><i>“but I didn’t take the allopurinol for three days, I just for some reason I don’t know why” (Participant 2, male)</i></p> <p><i>“Not on purpose. I, I go away for a weekend for example and leave it at home, just because I’d forgotten it.” (Participant 9, male)</i></p> <p><i>“Well if I do, I just take it a little bit later, that’s all” (Participant 10, male)</i></p>
Lacking knowledge/ being misinformed	<p><i>“she sends it (lab results) to the doctor and that’s all I know. They don’t tell you the outcome” (Participant 10, male)</i></p> <p><i>“I don’t know which it is (medication), I mean it’s all Greek to me” (Participant 10, male)</i></p> <p><i>“I don’t, because I’m thinking to myself that the resistance is already billed out, built up after you know a week of taking it straight.” (Participant 2, male)</i></p> <p><i>“Yeah, it’s, because you know just my understanding of, of my medications, I took it wrong.” (Participant 5, male)</i></p>

3.4 Discussion

This mixed methods study describes how participants with gout perceive the delivery of an eHealth supported decentralized collaborative care model involving rheumatology, pharmacy and dietetics. Incorporation of a qualitative approach enabled comprehension of elements within the Virtual Gout Clinic that describe the participant experience beyond an objective quantitative investigation. Namely, three categories describe the participant experience: 1) *learning through the Virtual Gout Clinic*; 2) *receiving personalized support*; and 3) *knowing someone cares*. Furthermore, this study provides a comprehensive understanding of problems individuals with gout encounter during treatment management that could potentially influence health outcomes. The mixed methods study specifically elucidated novel insight into understanding why some individuals do not achieve target outcomes after receiving a collaborative care intervention. Reasons for suboptimal health outcomes described through qualitative interviews range from fearing side effects and disliking medications to knowledge deficits regarding gout management.

A collaborative care approach utilizing telehealth for provider-participant communication is a promising avenue for enhancing patient knowledge about gout. Indeed, quantitative and qualitative research shows patients have poor knowledge about gout, which presents as a consistent barrier to gout management (44, 47, 48, 111). Often patients lack knowledge regarding the fact that gout is a long-term chronic disease and the preventative nature of ULT (44, 47, 48). The lack of information does not however represent resistance to learn more information as qualitative research has revealed that individuals with gout are interested in gaining knowledge about gout etiology (79, 81). Guidelines from EULAR and ACR, as well as reviews on gout management all point to enhancing patient education as a critical aspect of care

delivery (9, 34, 35). Through this present study, insight has been gained into to the processes and content of knowledge translation within a collaborative care intervention for gout that resonates with participants. Aspects of learning that appear to connect with patients are learning about the meaning of SUA and how it pertains to their gout severity, review of medication information, and review dietary and lifestyle recommendations. During gout treatment there is also the opportunity to demonstrate through clinical measures such as imaging, the physiological burden of gout. This direct visualization may be an approach to improving future outcomes as an individual's awareness of their disease severity is associated with adherence (112).

Many participants described how the Virtual Gout Clinic created an individualized environment to receive care, which may have an impact on adherence as research suggests that adherence may improve when an individual receives both practical and emotional support (74, 113). Participants in the Virtual Gout Clinic relayed experiencing either one or both personalized support (*practical*) and knowing someone cares (*emotional*). The absence of studies qualitatively exploring a participant's experience within a health care intervention for gout limits our ability to compare findings with the literature. However, evidence suggests that 70% of patients experience gaps (>60 days) in ULT prescriptions during the initiation of therapy (38), thereby highlighting the utility of providing personalized support for treatment adherence. Through personalized support health care providers have the opportunity to mitigate common practical barriers faced by individuals with gout. The role of emotional support in improving adherence and health outcomes is a complex relationship with mixed findings (114, 115). Insight into care delivery of the Virtual Gout Clinic highlights that health care providers can lend to this support

network through showing that “*somebody really cares and wanted to know how [they are] doing*” (**Participant 3, female**).

Along with the potential benefits of the Virtual Gout Clinic, interviews also informed logistical considerations for its delivery. Specifically, through interviews it became apparent that the Virtual Gout Clinic may not be necessary for all individuals with indicators of poorly managed gout. Despite the enrolment of participants limited to those with SUA >360 µmol/L, several participants questioned their need to be in the study or noted that starting the Virtual Gout Clinic earlier in their gout diagnosis would be more beneficial. Specifically targeting a gout intervention beyond the criteria listed for the Virtual Gout Clinic and similar studies presents difficulty because adherence is a dynamic phenomenon and subject to the person’s lived experience (74). Engaging in a conversation about adherence and understanding a participant’s attitude toward the treatment protocol and knowledge about treatment goals could support determining if an individual requires additional education and social support (74).

Integration of quantitative and qualitative datasets provided a comprehensive understanding of why a subset of participants were unable to reach target SUA. Although multidisciplinary interventions drawing on published guidelines have shown effectiveness in improving management (2, 3), a recent randomized control trial reported 35% of intervention participants reaching target SUA at trial endpoint (control 13%, risk ratio [RR]= 2.8, 95% confidence interval= 1.1 to 7.1, p=0.03) (1). Qualitative insight can surpass the difficulty of identifying determinants which lead to non-adherence, elevated SUA, and increased flares. Some participants referenced instances of forgetting to take their medications. Forgetfulness is an

unintentional form of non-adherence frequently mentioned by individuals with gout (47, 78, 81). Lacking knowledge or being misinformed is a common practical barrier to optimal management thoroughly identified in individuals with gout (44, 47, 48) and was an instrumental factor in explaining suboptimal outcomes after treatment intervention in this study. Participants with unmanaged gout referred to knowledge gaps spanning medication use and the utility of reviewing lab results. These misconceptions often led to improper medication taking behaviour and likely contributed to the unexpected quantitative findings. Being unconvinced of the effectiveness of medications is a common barrier to adherence (74). The process of intentionally decreasing or stopping medications or trialing diet, as observed in this study, is potentially a way in which individuals can convince themselves of the advantages of following their treatment.

Also depicted through data integration were the perceptual barriers intrinsic to the individual present during the Virtual Gout Clinic. Many participants mentioned a discomfort to taking medications, being fearful of potential side-effects, and processing how a diagnosis affects their identity. Participants with well-managed gout had a total of zero to two of these perceptions as well, suggesting that perceptions do not always influence an individual's willingness to adopt a recommended treatment. Concern about side effects is a long-standing barrier to adherence in the literature (116). In this present study the fear centered on uncertainty about future harm or the possibility of exacerbating an existing health problem. For one participant, we observed how the fear of medication initiated a period of secondary non-adherence, wherein the participant initiated a change in medication dosage. A spectrum of behaviours and perceptions of medications and disease are held through an individual's treatment process which can

undoubtedly influence health outcomes (74, 117). These barriers faced by participants therefore offer discussion points to consider when prescribing ULT to individuals with gout.

The strengths and limitations of the study require discussion. First, this is the only study to apply a mixed methods approach to understand the participant's perspective of a collaborative care model for gout, thereby offering novel insight into this phenomenon. An additional strength is the diversity of experiences explored as the sampling strategy yielded a mix of participants with both well-managed and unmanaged gout. Prior studies have focused on recruiting individuals either according to medication adherence (47, 61) or uncontrolled gout indicated by SUA >360 $\mu\text{mol/L}$ (48). While this study purposively sampled a variety of participants based on both patient-reported adherence as measured by the CQR5 and SUA. One limitation was the time lapse between completion of the Virtual Gout Clinic and the interview as this may have influenced a participant's ability to recall details of their experience. The subjective nature of interactions underpinning constructivist grounded theory establishes that through qualitative research one is going to learn about a phenomenon based on what participants are prepared to share in a given instance and in this project the data was fortunately rich and insightful. Another limitation is the setting of care delivery. The majority of individuals with gout receive care in primary practice (118) as opposed to specialized care in this study. However, the findings of this research are consistent with those of other chronic diseases (74, 119) and gout (44, 47-49, 79) and as such demonstrate transferability of findings to different contexts.

In conclusion, this mixed methods study provided explanations for suboptimal outcomes observed during the Virtual Gout Clinic, namely a fear of side-effects, disliking medications,

lacking knowledge or being misinformed, forgetting medications, and the influence of diagnosis on an individual's identity. This study also gave insight into the nature of interactions within an eHealth supported collaborative care model from the patient perspective and identified inherent strengths and limitations to inform future design of similar interventions. Demonstrated in this study is the importance of learning about gout, receiving personalized care, and having emotional support to contribute in guiding an individual with gout towards optimal management. Incorporation of allied health professionals such as dieticians and pharmacists is a promising method for providing increased support and collaborating with participants during the treatment process.

Chapter 4: Conclusions

This thesis contributes to a greater understanding of the complex problem of poor quality of care and suboptimal health outcomes in gout by exploring the patient's experience of managing gout. The final chapter will discuss key results of the thesis, integrate findings from chapters 2 and 3 as well as the literature, review strengths and limitations of the research, and propose future directions for improving health outcomes in gout.

4.1 Key Findings

Collectively this thesis provides insight into barriers to gout management, novel exploration of the factors which facilitate patient engagement in management, and an understanding of how individuals with gout experience an electronic health technology (eHealth) supported collaborative care model. Additionally, the rising prevalence, incidence, and hospitalization rates of gout in Canada (12, 57) emphasize the relevance of understanding the perspectives of Canadians with gout. **Chapter 2** of this thesis explores how participants experience gout and advances understanding of the factors that interfere with or facilitate patient engagement in management of gout. In this chapter, barriers to management included perceptions such as influence on personal identity, fear of side-effects, and aversion to taking medications. Also identified were practical forms of non-adherence such as gaps in knowledge and forgetfulness. Participants shared insight into the mediating effect that processing the diagnosis of gout has for level of engagement in gout management. An important contribution of this chapter is the depth of insight into the determinants which facilitate patients becoming actively engaged in management of gout, as the qualitative literature has focused heavily on barriers to management or adherence (44-50, 61, 77-82, 84). Factors that encouraged gout management were primarily

perceptions intrinsic to patients, such as developing acceptance regarding the diagnosis and medication therapy and identifying motivation to prevent future gout complications.

The Virtual Gout Clinic, a proof-of concept longitudinal study of a collaborative care intervention for gout, was established to improve health outcomes and quality of care. **Chapter 3** applied a mixed methods approach to provide a comprehensive evaluation of how participants with gout experience this eHealth supported collaborative care model and to explain the quantitative findings from the evaluation of this model of care. An eHealth supported collaborative care model was able to promote learning, offer personalized support, and strengthen participant's support network through showing that someone cared about their health. Furthermore, analysis of interviews emphasized the need to tailor future interventions to patient needs and gout activity, as well as identified issues with care delivery through telehealth. Persistent non-adherence to urate lowering therapy (ULT) and/or high serum uric acid (SUA) for participants in the Virtual Gout Clinic was attributed to both unintentional and intentional forms of poor management. Specifically, insufficient knowledge about medications and forgetting medications were practical barriers faced by those participants with suboptimal health outcomes. In addition, the analysis of interviews highlighted the existence of perceptual barriers such as fearing or disliking medications and the impact a diagnosis of gout has on personal identity. Altogether, this chapter described the strengths and weaknesses within the Virtual Gout Clinic to inform future care delivery. Endeavors to improve quality of care need to consider how patients' perceptions influence readiness to engage in management of gout. Patients can also be supported by health providers to become informed partners for shared decision-making through personalized support and education.

4.2 Integration of the Research

Prior research in other jurisdictions that evaluated interdisciplinary approaches for management of gout comprised of a rheumatologist along with a pharmacist or nurse have demonstrated varying degrees of success in lowering SUA (1-3, 120). An understanding of why these models of gout care varied in effectiveness is not clear. Through qualitative inquiry we can answer such questions by exploring the context of care delivery and the patient perspective. The design of this thesis provided the opportunity to explore participants' process in moving towards active engagement in management of gout by identifying current or past barriers and instances which facilitated management. Integration of results from **chapter 2** and **chapter 3** elucidated how an intervention, such as the Virtual Gout Clinic, can interact with the process of patients becoming engaged in the management of their gout. As such, **Figure 4-1** is the final explanatory framework constructed to depict effective gout management.

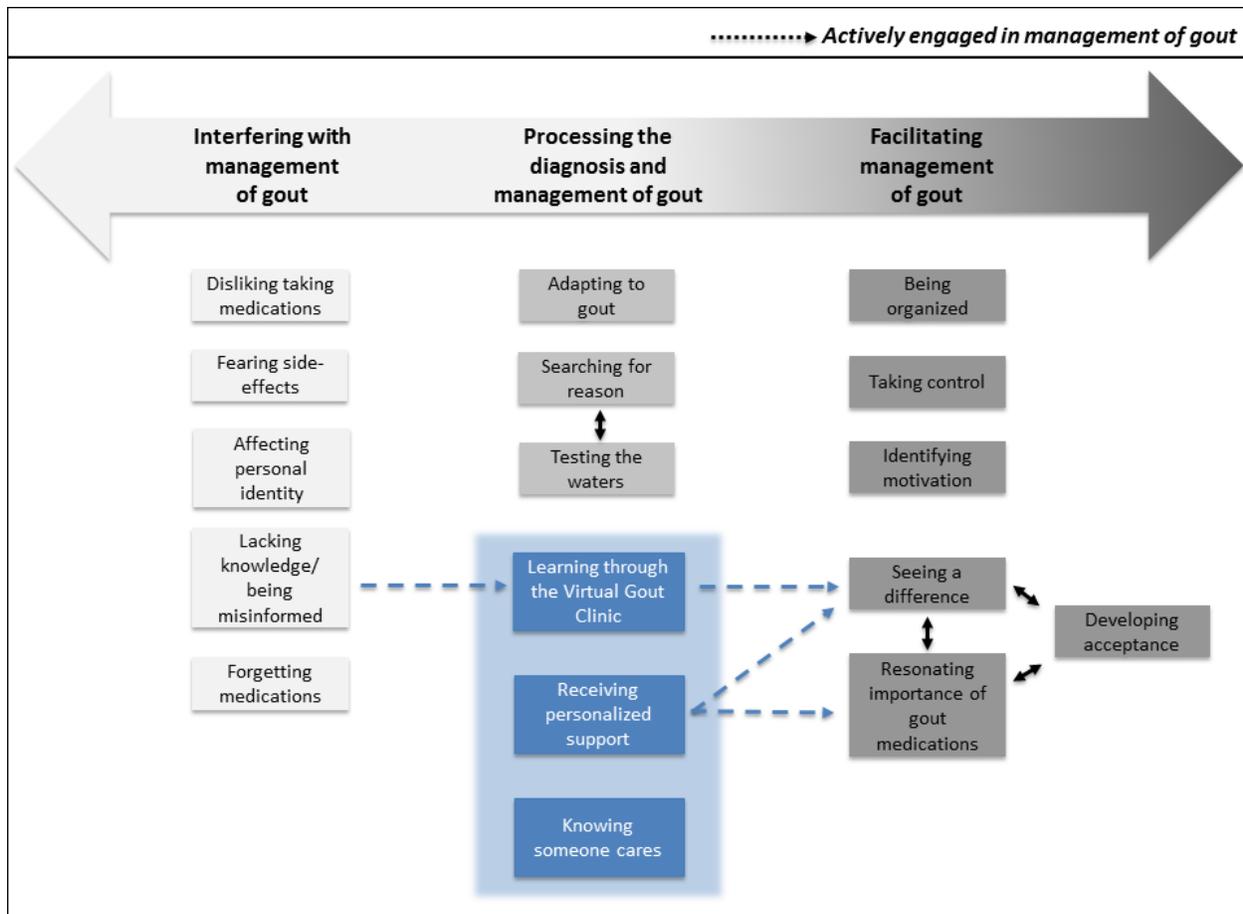


Figure 4-1. Schematic exploring the relationship between the Virtual Gout Clinic and participants' experience of becoming actively engaged in management of gout.

(Items in grey pertain to the themes and conceptual categories constructed in Chapter 2. Areas in blue are the conceptual categories presented in Chapter 3 to describe the experience of the Virtual Gout Clinic. Dotted blue arrows describe interactions between the Virtual Gout Clinic and the participant experience of being actively engaged in management of gout).

The role of the Virtual Gout Clinic within the construct of being actively engaged in management of gout is based on the analysis of relationships between conceptual categories. Factors describing the participant's experience with the Virtual Gout Clinic are shown in **Figure 4-1** under the theme *processing the diagnosis and management* as they appear to mediate participants moving through this stage. The expression of one participant helped to clarify this

relationship, by stating “*one of the most useful parts of it [Virtual Gout Clinic] was to kind of understand what was going on*” (**Participant 4, male**), seemingly anchoring participants in their journey towards engagement in gout management. *Learning through the Virtual Gout Clinic* supported gout management by building patient knowledge pertaining to diet, the severity of gout as seen through imaging reports, gout medications, meaning of SUA, and prognosis of gout. Through a better understanding of gout, participants acquire the knowledge base to independently recognize the impact of proper gout management, make the connection between outcomes and taking ULT, thereby potentially leading to *developing acceptance*. As such, this model conceptualizes how education imparts the ability to influence perceptions within the construct of engaging in management of gout. *Receiving personalized support* further supported the phenomenon of *developing acceptance* by reviewing lab test results, providing validation, and providing direct and tailored instructions for care. Finally, the extent to which *knowing someone cares* contributes to patients being actively engaged in management of gout is unresolved. A meta-analysis exploring the role of social support in regards to adherence to treatment identified emotional support as having a positive effect, however an understanding of the mechanism for this relationship requires further investigation (115). It is plausible that knowing someone cares contributes to establishing a positive frame of mind, to “*have all this attention around something that you’re experiencing is, you know it feels good*” (**Participant 4, male**), and facilitates a readiness to develop acceptance. It is important to note that some participants entered the Virtual Gout Clinic identifying with many perceptions under the theme *facilitating management of gout*, such as being committed to taking their medications and identified as taking control and having motivation. Therefore, the Virtual Gout Clinic may have been unnecessary for some participants or effective for a reduced length of time. As participants

explained, “*the consults would be very useful if the medications weren't as effective as they were*” (**Participant 9, male**) or “*when my gout was so extreme before I got referred to the rheumatologist, it would have been a lot more helpful*” (**Participant 7, female**).

Two qualitative studies have created models to conceptualize the gout experience and its management from the patient point of view. First, a study by Richardson et al. in 2016 applied a narrative approach with UK patients in rheumatology and primary practice to understand determinants of ULT uptake. Findings from this UK study reinforced the need for ongoing support, dialogue, and monitoring throughout treatment to reflect the changing perceptions of patients and the fluctuation of gout severity (84). The second publication by Singh et al. interviewed African-American men with gout and ULT adherence $\geq 80\%$. Six themes describing patient self-management were presented and conceptualized using an existing framework, the health beliefs model (61). Five of the six themes described drew clear similarities with the findings from the conceptual categories in this thesis under the theme *facilitating management of gout*. This US study reported patients *identifying motivation* through ‘fear of pain’, observed a *resonating importance of medications* through ‘adherence to medication’, identified *being organized* in taking medications with ‘self-discipline’, noted *taking control* as ‘information gathering’, and found similar instances of *developing acceptance* wherein patients had a ‘positive outlook’ (61). The parallels outlined strengthen the findings of this thesis and the importance of patient perceptions and behaviours throughout the process of becoming actively engaged in management of gout. Indeed, it is imperative to understand the perceptions held by patients as they encounter health care providers holding these beliefs that undoubtedly influence

the impending course of management (74, 117). Novel to this thesis and offering recommendations for practice is the process of developing acceptance through seeing a difference and the resonating importance of gout medications.

4.3 Strengths and Limitations

There are strengths and limitations to this thesis that influence the study findings. To begin with strengths, the participants interviewed had a rheumatologist confirmed diagnosis of gout, compared to other studies which relied on self-report diagnosis (50, 79, 82, 84) or diagnostic code (45-47, 78). An additional strength is the wide range of experiences explored as the sampling strategy identified participants with both well-managed and unmanaged gout by assessing adherence to ULT using the Compliance Questionnaire Rheumatology 5-item (CQR5) and SUA. Previous qualitative studies that recruited according to health outcomes focused on either medication adherence (47, 61) or insufficiently managed gout indicated by SUA >360 $\mu\text{mol/L}$ (48). Lastly, this is the only study to apply a mixed methods approach to explore the participants' experience of an interdisciplinary collaborative care model for gout utilizing electronic health (eHealth) technology, thereby offering novel insight into this phenomenon.

A limitation is the restriction of recruitment from rheumatology practice, as the majority of individuals with gout are seen in primary care setting (118). Thick description of the participant experience supports the transferability of results. Indeed, the conceptual categories in this thesis describing the experience of gout and becoming actively engaged in management of gout drew similarities with qualitative publications from both rheumatology and primary practice. Another

limitation was the delay between completion of the Virtual Gout Clinic and the interview, which potentially influenced participant recall. The design of constructivist grounded theory recognizes the subjective nature of interviews, addressing this concern by acknowledging interviews provide a glimpse into the participant experience (63).

4.4 Implications and Future Research Directions

Gout is a thoroughly studied chronic disease, as research thus far has provided a clear depiction of the pathogenesis of gout, course of treatment, disease burden, and suboptimal quality of care. Efforts are therefore currently focused on improving quality of care and health outcomes (9, 58, 121). Considerable attention has been given to the promising approach of incorporating allied health care professionals to interventions for gout. Interventions combining rheumatology along with nursing or pharmacy practice have demonstrated varying success quantitatively (1-3, 120). Most recently a 5-year follow-up of the initial proof-of-concept study utilizing nursing found that 90.7% of patients remained on ULT and the average SUA of the followed cohort was below recommended target at 292.8 $\mu\text{mol/L}$ (120). Notably absent from the research design of these interventions are the experiences of participants, which have the power to inform and optimize care delivery. Quality of care can be further informed by understanding a wider range of experiences such as that from a Canadian population and by exploring the factors which facilitate active engagement in management of gout.

The translation of results of this thesis into future directions for improving quality of care and health outcomes involve two dimensions, namely informing: 1) **practice** by understanding the process of becoming actively engaged in management of gout with an emphasis on facilitating

factors and 2) the design of **future interventions** for gout. First, the explanatory framework constructed in this thesis serves as a starting point for future research to build and verify a theory related to facilitating active engagement in gout management. It is widely acknowledged that adherence to medications and treatment is a complex behavioural phenomenon involving ongoing change from the patient perspective (74, 113). Further complicating the phenomenon for individuals with gout is the intermittent nature of symptoms and thus the inconsistent perception of being susceptible to the complications of gout. Although qualitative research has consistently identified education as a gap in gout care (44, 46-49, 61, 77, 78, 80-82, 84), an understudied area includes the perceptions held by patients, in particular those which facilitate engagement in gout management. Patient perceptions about medications and their disease are known to impact adherence to treatment (86). Therefore, measures of health outcomes in gout should extend beyond patient reported outcomes (PROs) and prescription-based measures of adherence to include items such as the beliefs about medicine questionnaire (122). In the practice setting, professionals can be attuned to the perceptual and practical determinants of active engagement in management of gout constructed in this thesis and modify care accordingly. In regards to informing future interventions, results from this thesis have elucidated through a qualitative approach the actual experience an interdisciplinary intervention for gout can offer to patients. Allied health professionals are well-suited to improve the quality of care for gout through offering personalized support and the empathetic nature to show that someone cares. Further, this study indicates the need to modify future interventions to adopt a targeted recruitment approach to ensure patients needing a personalized intervention for their gout are reached.

4.5 Conclusion

Significant focus in the literature has been on practical barriers to gout management, specifically patient knowledge gaps pertaining to gout (44, 46-49, 61, 77, 78, 80-82, 84, 123). Findings from this study reveal the importance of perceptual barriers held by patients with gout, as well as novel insight into factors facilitating active engagement in the management of gout. An interdisciplinary model of care, such as the Virtual Gout Clinic, is promising approach to optimize quality of care and outcomes by providing both emotional and practical support as well as ongoing individualized education.

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Appendices

Appendix A: Semi-structured interview guide

Virtual Gout Clinic Study - Interviews

Interview Guide

Opening Statement

I really appreciate the time you have offered to provide insight into your experience in the Virtual Gout Clinic. Learning about your experience will help us to enrich our understanding of the virtual gout model of care. Essentially, I hope to be able to gain knowledge on what the virtual gout clinic looks like from your perspective.

- Be as detailed as possible, assuming that I don't know anything
- MSc thesis project
- Encourage to be open/honest
- Information will not be shared directly with health care providers

Through this interview I hope to be able to gain a glimpse of what the Virtual Gout Clinic through your eyes. On the periphery of the clinic I have some idea of the basic interactions, but cannot truly understand the experience itself. Only you, the participant, can serve as the expert in answering this question.

Confidentiality

In order to maintain confidentiality during this interview, it can be helpful to use pseudonyms or pronouns when referring to yourself or others.

If it is okay with you I would like to turn on the recorder in case we miss anything important.

Debrief

Just before I start with the interview questions, do you have any questions about the purpose of this research project (the interview piece in particular)?

If we get to the one-hour mark we will reassess how tired you are and perhaps schedule to continue at another time.

<p style="text-align: center;">Initial Open-ended Questions</p>	<ul style="list-style-type: none"> • What does a typical day living with gout look like? • Can you describe your experience with gout before your involvement with the clinic? • Can you tell me about how you came to the Virtual Gout Clinic? What made you decide to participate? 	<p style="text-align: center;"><i>Ask one or two of these questions to open the conversation.</i></p>
<p style="text-align: center;">Intermediate Questions (Part I)</p>	<p>1. Experience with the Virtual Gout Clinic</p> <ul style="list-style-type: none"> • What were your expectations for treatment during the Virtual Gout Clinic? • Could you describe what it is like being a patient in the Virtual Gout Clinic? • How did the Virtual Gout Clinic fit with your lifestyle? • Could you tell me about your telephone consultations with the dietician? The pharmacist? • Could you describe your interactions with your rheumatologist during the virtual gout clinic? (management by Rheumatologist) • How did you find the communication between the rheumatologist, pharmacist and dietician in managing your gout? [→ Was it unlike your usual care? → Did you notice a difference with this communication between the health care providers? → Did you find this helpful?] • What aspects of the Virtual Gout Clinic did you find particularly helpful for managing your gout? <i>May need to prompt on “aspects of health support”</i> • Can you describe any aspects of your experience with the Virtual Gout Clinic that were not helpful for gout, or any areas for improvement? • Can you describe any changes regarding the management of your gout since joining the Virtual Gout Clinic? • How would you describe your gout-related health since completing the Virtual Gout Clinic? (for those reaching 12 mos endpoint) 	<p style="text-align: center;"><i>Exploring how patients experience an eHealth supported collaborative care model for gout.</i></p> <ul style="list-style-type: none"> - Rheum - Pharmacist - Dietician - Role of telehealth and eHealth (shared EMR)

Intermediate Questions (Part 2)	<p>2. Exploring personal gout-related health</p> <ul style="list-style-type: none"> How did you feel about taking your gout medications during the Virtual Gout Clinic? → +/- Anything that helped you to decide to take gout medications? → +/- Anything in particular that helped you with taking your gout medications? → +/- Can you remember any times that you stopped taking your gout medicine (allopurinol)? What made you decide to stop taking the medication? How was your gout [disease activity] while you were in the Virtual Gout Clinic? OR What was your experience with gout flares/episodes like during the clinic? I'm wondering if you could describe what an improvement in gout looks or feels like from your perspective. Could you tell me about any services, approaches, or resources that you feel would help in managing your gout? 	<p><i>Specifically want to explore how they perceived their own health through the duration of the Virtual Gout Clinic.</i></p> <p><i>- medication adherence</i></p> <p><i>- disease activity (flares, SUA)</i></p>
Ending Questions	<ul style="list-style-type: none"> Is there anything thing else about your experience with the Virtual Gout Clinic that you would like to share? Do you have any other questions you would like to ask me? 	

Interview Prompts & Probes

Prompts:

- I'm wondering if you could elaborate further.
- What about ___ caused/made this [feeling]?
- Could you explain this further? In greater detail?
- Could you tell me more about ___?
- I'm wondering what ___ means?
- How did the Virtual Gout Clinic, if at all, fit in with this?
- Anything that stuck out for you ___?
- How did you feel when ___?
- Is there a specific moment or trigger that caused you to feel this [emotion/need]?

Probes:

- Probe about how participants own environment works with the Virtual Gout Clinic.
- Probe about the nature of interactions with rheumatologists, pharmacist, and dietician.
- Probe on the participants whereabouts during an interaction with the dietician or pharmacist