THE HEALER’S BOON:
HOW PATIENTS AND PROVIDERS FIND VALUE

Submitted to the College of Graduate and Postdoctoral Studies
In Partial Fulfillment of the Requirements
For the Degree of Master of Science
In the Department of Management and Marketing
University of Saskatchewan
Saskatoon, Saskatchewan

By Benjamin Dunning

© Copyright Benjamin Dunning, June 2020. All rights reserved.
PERMISSION TO USE
In presenting this thesis in partial fulfillment of the requirements for a Postgraduate degree from the University of Saskatchewan, I agree that the Libraries of this University may make it freely available for inspection. I further agree that permission for copying of this thesis in any manner, in whole or in part, for scholarly purposes may be granted by the professor or professors who supervised my thesis work or, in their absence, by the Head of the Department or the Dean of the College in which my thesis work was done. It is understood that any copying or publication or use of this thesis or parts thereof for financial gain shall not be allowed without my written permission. It is also understood that due recognition shall be given to me and to the University of Saskatchewan in any scholarly use, which may be made of any material in my thesis.

DISCLAIMER
The use of Olympus Inc. was exclusively created to meet the thesis and/or exhibition requirements for the degree of Master of Science at the University of Saskatchewan. Reference in this thesis to any specific commercial products, process, or service by trade name, trademark, manufacturer, or otherwise does not constitute or imply its endorsement, recommendation, or favouring by the University of Saskatchewan. The views and opinions of the author expressed herein do not state or reflect those of the University of Saskatchewan, and shall not be used for advertising or product endorsement purposes.

Requests for permission to copy or to make other uses of materials in this thesis/dissertation in whole or part should be addressed to:

Head of the Department of Management and Marketing
Nutrien Centre, 25 Campus Drive
University of Saskatchewan
Saskatoon, Saskatchewan S7N 5A7
Canada

OR
Dean
College of Graduate and Postdoctoral Studies
University of Saskatchewan
Room 116 Thorvaldson Building, 110 Science Place
Saskatoon, Saskatchewan  S7N 5C9
Canada
ABSTRACT

Arthritis is a chronic condition requiring repeated close contact with healthcare providers within a patients' care team. Much of the research on arthritis has focused on the treatment efficacy of arthritis medications. While the gains in treatments designed to reduce pain are significant, there remains little research to describe the lived experience of arthritis patients. Additionally, healthcare appears to be operating, in part, with an outdated managerial logic. Marketing theory is poised to offer an alternative approach enabling healthcare to refine its service techniques. By transforming the obsolete philosophy of standardized care and mass application to one of personalized care and stewardship, patients and providers can find a new sense of value co-creation. This is the basis for Service-Dominant Logic, a metatheoretical framework for examining the process of mutual value creation. Acknowledging the patient's inherent value and dismantling the current barriers to healthcare informed by an outdated goods dominant approach may enhance both the patient and the provider's sense of value co-creation. This study utilized a qualitative approach interviewing arthritis patients and rheumatologists to explore the value co-creation process. The application of service-dominant logic to healthcare contains many implications for increasing patient health outcomes and medication adherence to arthritis therapies.

Keywords: Arthritis, Medical Adherence, Service-Dominant Logic, Value Co-Creation, Consumer Journey, Patient-Provider Relationship
ACKNOWLEDGMENT

I would like to thank the following people whose help and guidance made this work possible.

To my loving wife, Christianne Rooke, and my children, Nadine and Leila, for their support when times were good and bad and everything in between.

To my parents Bob and Karen Dunning for you know.. making me exist, raising me, and shaping me into the person I am today.

To my grandparents Dorothy and John Dunning for teaching me so much about the world and giving me a different perspective.

To my mother and father-in-law, Suzanne and Phil Rooke, for all the support they have given and continue to provide my family and me.

To my Supervisor Dr. Marjorie Delbaere, for putting me on this path and giving me the tools, instruction, and confidence to succeed.

To Dr. Ulrich Teucher, for being a friend, mentor, and source of inspiration during my time at the University of Saskatchewan.

To Professor Vince Bruni-Bossio, for helping me organize my thoughts during our conversations.

To Dr. Michael Macgregor, for converting me to a student of Psychology and being a great listener.

To Dr. Brian Zamulinski for our many great conversations over the years and teaching me the wonders of Venn diagrams.
To my brother Brandon Dunning and my longest friend Brian Staffeld, for helping me de-stress during the off hours.

To all the faculty and students I have met over the years at the University of Saskatchewan, for teaching me in ways large and small and enduring my incessant questions.
TABLE OF CONTENTS

PERMISSION TO USE ........................................................................................................ - i -

ABSTRACT .......................................................................................................................... - iii -

ACKNOWLEDGMENT ........................................................................................................ - iv -

TABLE OF CONTENTS ...................................................................................................... - vi -

1 INTRODUCTION ............................................................................................................. - 1 -
  1.1 SERVICE-DOMINANT LOGIC AND VALUE CO-CREATION ................................ - 5 -
  1.2 SERVICE-DOMINANT LOGIC CONCEPTUAL FRAMEWORK .......................... - 9 -
  1.3 MEDICAL ADHERENCE AND THE PATIENT-PROVIDER RELATIONSHIP ...... - 10 -
      1.3.1 Functional Literacy ..................................................................................... - 13 -
      1.3.2 Health Communication and the Patient-Provider Relationship ............... - 14 -
      1.3.3 Communication, Emotional States, and Liminality ................................. - 15 -
  1.4 THE CUSTOMER JOURNEY .................................................................................... - 16 -
  1.5 ARTHRITIS, HEALTHCARE, AND SERVICE-DOMINANT LOGIC ................. - 17 -

2 METHOD ......................................................................................................................... - 20 -
  2.1 STUDY POPULATIONS ......................................................................................... - 20 -
  2.2 SETTING ............................................................................................................... - 21 -
  2.3 RECRUITMENT ...................................................................................................... - 21 -
  2.4 DATA ANALYSIS .................................................................................................. - 22 -
  2.5 SIGNIFICANCE ..................................................................................................... - 23 -

3 FINDINGS AND DISCUSSION ....................................................................................... - 24 -
  3.1 ACKNOWLEDGING THE LOSS .......................................................................... - 24 -
      3.1.1 Medication Adherence ................................................................................ - 27 -
  3.2 IT IS THE SYSTEM ............................................................................................... - 30 -
      3.2.1 Wait Times .................................................................................................... - 35 -
  3.3 BARRIERS TO VALUE CO-CREATION ................................................................. - 37 -
  3.4 SENSING, EXPERIENCING, AND CREATING .................................................... - 40 -

4 CONCLUSION ................................................................................................................ - 45 -

vi
4.1 LIMITATIONS ........................................................................................................ - 46 -
4.2 FUTURE RESEARCH ........................................................................................... - 46 -

REFERENCES ........................................................................................................... - 47 -

4.3 APPENDIX A – INTERVIEW GUIDE .................................................................. - 53 -
   4.3.1 Section B ...................................................................................................... - 54 -
4.4 APPENDIX B – RHUMATOLOGIST RECRUITMENT LETTER ......................... - 57 -
4.5 APPENDIX C – PATIENT RECRUITMENT LETTER FOR SCPOR .................... - 58 -
4.6 APPENDIX D – PATIENT FAMILY ADVISOR RECRUITMENT (SCPOR) ....... - 59 -
4.7 APPENDIX E – PARTICIPANT CONSENT FORM ......................................... - 61 -
4.8 APPENDIX F – TRANSCRIPT RELEASE ..................................................... - 64 -
4.9 APPENDIX G – ETHICS CERTIFICATE ....................................................... - 65 -
1 Introduction

Within Canada, it is estimated that over 15 percent of the province of Saskatchewan’s population suffers from arthritis (Statscan, 2010). Averaged across all provinces, one in five Canadians experience arthritis symptoms, according to the Canadian Arthritis Society (2019). Arthritis has many sub-groups, but the defining characteristic is chronic inflammation in the joints or other bodily regions. This chronic inflammation leads to swelling, pain, and stiffness. Without treatment, the disease can lead to irreversible damage to the body leading to many quality of life concerns for patients. These concerns range from questions of everyday experience such as driving to work, to additional forms of illness such as lowered mood and depression. Often arthritis symptoms wax and wane, leading to irregular, long periods of intense pain and an inability to work.

When asked what symptoms or factors arthritis patients were most concerned about, systematic literature reviews highlighted the retention of autonomy, relief from pain, and fatigue as important quality of life factors (Sanderson, Morris, Calnan, Richards, Hewlett, 2010; Chauffier, Salliot, Berenbaum, Sellam, 2012; Feldthusen et al., 2013). The retention of autonomy, which is a multifaceted category, is often the most significant concern for arthritis patients and their families (Sanderson et al., 2010; Nikolaus et al., 2011; Chauffier et al., 2012). Pain is often a primary source of sleep disturbance and disability that compromises other factors related to autonomy. For these reasons, the reduction of pain is often the first goal of arthritis treatment. The Canadian Arthritis Society (2019) contains many resources for patients experiencing arthritis concerns. The majority of the resources and articles available focus on the retention of autonomy, teaching the patient how to manage symptoms to continue a healthy lifestyle. Most of the resources do not focus on the relief of pain but on skills and strategies for staying independent.

One understudied aspect of arthritis is the experience of fatigue. In conjunction with other concerns relating to autonomy, the management of fatigue is reported by patients to be unpredictable (Nikolaus et al., 2011). It compromises many different aspects of arthritis management, such as medication adherence, adequate physical exercise, depressed mood, and other emotional concerns (Nikolaus et al., 2011). Research on patient perspectives reveals that fatigue management becomes a primary concern once other symptoms regarding pain have been
addressed (Nikolaus et al., 2011; Chauffier et al., 2012; Feldthusen et al., 2013). However, the difficulty in managing fatigue in arthritis is two-fold. First, it is difficult to accurately quantify the effects of fatigue in a lab setting (Chauffier et al., 2012). This difficulty makes it problematic to assess and transmit knowledge to a clinical setting. Second, treatments for arthritis are typically measured in terms of pain relief and efficacy, leaving fatigue treatment lagging (Nikolaus et al., 2011; Chauffier et al., 2012; Feldthusen et al., 2013).

A problematic aspect of research into arthritis is the heavy focus on treatment efficacy for patients. This research has given us a good understanding of how arthritis treatments and medications affect patients, but little in the way of patients’ lived experiences with arthritis (Tandon, Ellis, Bolge, Iqbal, & Buck, 2011, Gaylis, Sagliani, Black, Tang, Dehoratius, Kafka, & Parenti, 2017). There are some scholars whose work has focused on the patient perspective; however, compared to other severe chronic conditions, arthritis remains woefully understudied, and patients continue to suffer (Sanderson et al., 2010; Nikolaus et al., 2011; Chauffier et al., 2012; Feldthusen et al., 2013). In Saskatchewan, the number of patients with arthritis vastly outnumbers the rheumatologists who provide care to those patients. The Canadian Medical Association (2018) reports 0.8 rheumatologists per 100k in the population of the province of Saskatchewan. This difference can lead to long wait times in certain parts of Saskatchewan, with some estimates between six months up to two years. These wait times suggest that both patients and providers are feeling the stress of this imbalance. This general imbalance between patients and providers, coupled with the general lack of emphasis for the patient’s lived experience with arthritis, is indicative of a gap in our knowledge.

The goal of this research is to examine the lived experience of arthritis patients. Additionally, we sought to understand how healthcare providers view the experience of their patients living with a chronic condition. We also examine what patients and providers expect from one another during a healthcare encounter. Ultimately, this research seeks to answer the following questions: How do patients and providers find value in their relationships with one another? What factors influence this value creation? These are essential considerations for healthcare due to the evidence linking health outcomes to the relationship between patients and providers (WHO, 2003; IOM 2004). To accomplish this goal and answer the previous questions our research utilized a qualitative approach. Arthritis patients and rheumatologists were interviewed to explore the value creation process in healthcare. During these interviews we
explored the nature of the patient-provider relationship. From a marketing perspective, a useful method for examining the strength of a given relationship is through the perceived value that individuals experience.

Briefly speaking, value in marketing is typically an expression of human needs (Sanchez-Fernandez, 2007). Basic human needs become an expression of human wants when regional cultural and environmental influences act upon them (Sanchez-Fernandez, 2007). To understand how to satisfy these wants, marketing must consider what the total marketing offer of a particular firm or organization is (Saren, 2018). The total marketing offer is typically a representation of a firm or organizations resources or end product as it compares to competitors and the expectations of consumers (Saren, 2018). Generally speaking, in marketing and marketing literature, the successful delivery of value rests on the ability of firms to go beyond the consumers expectations (Saren, 2018). This situation would still apply to healthcare systems regardless of whether they are privately or publicly funded due to consumer expectations of that system. There is debate within the marketing literature as to how this process of value delivery and capture is best measured. As such, marketers have long sought to understand the value creation process and the factors that contribute to it. By doing so, marketing has developed several useful theories concerning how individuals find value in the products and services they interact with and consume. Patients in any healthcare encounter are, in essence, another form of consumer. However, for this research, we are not interested in the monetary-exchange aspect of the patient-as-consumer. We are instead focusing on the value creation process and the relevant marketing theories useful for understanding this process.

For example, Service-Dominant Logic (SDL) is a theoretical framework for examining the process of mutual value creation. Service is the application of knowledge, competency, and resources, which is the basis for each exchange. Knowledge and skills are viewed as a resource, and all parties involved in an encounter utilize their knowledge and skills to varying degrees. This theory of mutual value creation has captured a great deal of attention within marketing due to its break from traditional concepts of value creation. We will explore these topics in greater detail; for now, the basic idea is one of Value-in-use vs. Value-in-exchange (Ng, Parry, Smith, Maull, & Briscoe, 2012; Saren, 2018). Typically, value has been viewed as one of exchange (Ng et al., 2012; Saren, 2018). A firm or organization creates an offer, and it is believed to have inherent value (Ng et al., 2012; Saren, 2018). Additionally, the offerings perceived value is
measured only in what it can be exchanged for, typically money (Ng et al., 2012; Saren, 2018). This view of exchange is generally referred to as goods-dominant logic (GDL), and it has been the primary lens through which most firms or organizations have operated (Vargo, Maglio, & Akaka, 2008; Vargo & Lusch, 2010; Ng et al., 2012; Saren, 2018). Service dominant logic challenges this notion by viewing value not in exchange but in use (Vargo & Lusch, 2010; Ng et al., 2012; Saren, 2018). SDL suggests that an offer has no inherent value, only potential value and that the role of value extends beyond the exchange of resources to application in daily life (Vargo & Lusch, 2010; Ng et al., 2012; Saren, 2018).

Consider the notion of value-in-use applied to healthcare. An argument for goods-dominant logic’s influence on healthcare might suggest that we view a provider’s expertise as inherently valuable. Consequently, this view would suggest that a patient has no inherent value, only their ability to provide resources for an exchange. SDL, however, indicates that a provider’s expertise is only potentially valuable as it requires a patient to access and act upon that expertise. Because of this, SDL places emphasis on value co-creation between both patient and provider. This process might feel abstract in healthcare; however, if one considers the application of knowledge and skills inherently valuable to all participants, this places service-dominant logic in lockstep with the concepts of patient-centered care. This harmony is achieved by acknowledging the experience of the patient as a valuable contribution to the healthcare encounter. SDL places emphasis on the patient and provider working together to bring in resources, utilize and generate experiences both personal and professional and integrate these attributes into the broader context of their lives. There are many ways to achieve this without subscribing to a ‘right’ way to co-create value, which we will expand upon.

A secondary aspect of this research will be an examination of the role of medication adherence for patients living with arthritis. Research demonstrates that arthritis patient’s adherent to medication regimes have better health outcomes and fewer emergency room visits (Street et al., 2015; Uckun, Yurdakul & Bodur, 2017). One of the most critical aspects of medication adherence is the prevention of anti-drug antibodies. Many treatments for autoimmune variates of arthritis, such as rheumatoid arthritis, require careful considerations for both patients and providers with regards to medication selection. Should the patient and provider discover the best drug for that patient, one that gets the patient’s symptoms under control with a minimum of side effects, the implications for non-adherence are severe. Non-adherence may
result in the development of anti-drug antibodies, which will render the treatment of the drug inert, extending the time it takes to get the symptoms into remission. Rheumatologists are deeply troubled by this aspect of non-adherence for their patients.

To explore each of these topics we have structured the contents of this document in the following way. We will begin with an overview of the marketing theory pertinent to this research, namely, service dominant logic. Additionally, we will cover value co-creations relationship to patient centered care and healthcare in general. Next, we explore the literature on medication adherence. We investigate medication adherences history and relationship to other topics that influence the patient-provider relationship. These topics include functional literacy and health communication. We briefly describe the concept of the customer journey and its relationship to value co-creation and healthcare. Finally, we conclude the review with an overview of the literature that exists on service dominant logic, healthcare, and arthritis. What follows is a description of the methods we utilized to answer our research question. Lastly, we present a discussion of our findings and avenues for future investigation.

1.1 Service-Dominant Logic and Value Co-Creation

Fundamentally, service is the application of resources and competency, and through the lens of SD-logic, it serves as the basis for all exchange (Payne, Storbacka, & Frow, 2008; Vargo, Maglio, & Akaka, 2008; Vargo & Lusch, 2010). Vargo, Maglio, and Akaka (2008) and Vargo and Lusch (2010) have contributed to the development of SD-logic theory and have offered the following description of the core concepts. The exchange in SD-logic is based on the application of resources, of which knowledge and skills form one part. The other portion of resource application is referred to as operant resources, or resources that act on other resources, often monetary in origin. The researchers state that the combined application of these two types of resources serves as the measuring point for the value that is derived in a given context. Of significant note for SD-logic is the integration of different resources in a given service for service exchange, also known as the service system (Vargo, Maglio, & Akaka, 2008; Vargo & Lusch, 2010). In other words, for value to be created in a given context, the parties involved must be able to utilize resources from both the knowledge and skills category and the operant resources category, and these uses must extend beyond the service encounter and into the lived experiences of the people involved.
Consider this notion from a healthcare or health systems perspective. If we view healthcare from a goods-dominant perspective, then the creation of value would occur when the patient accesses the system and provides operant resources (i.e., pays a fee) in exchange for a service (i.e., the expertise and training of the professional). The patient/consumer, in essence, is a destroyer of value rather than a contributor, due to GDL’s emphasis on value as exchange. After the healthcare encounter is over, the value process stops, and we would judge the success of the meeting based on the health outcome versus the cost. Consequently, this is what much of the traditional research around medical adherence has assumed. Physicians are the experts, and patients are consumers of the value physicians are theorized to be providing or in need of delivering where adherence is lacking (Lusch & Vargo, 2009). However, using a service-dominant perspective, the patient will have a set of personal resources, such as knowledge and skills. They will bring these resources to a given healthcare encounter; health researchers might call this type of resource health literacy, though it is not limited to this. The healthcare professional would then bring their knowledge and skills to the healthcare encounter, and this would form the beginning of service for service exchange. Using this perspective offers healthcare a unique way of viewing the patient-provider relationship. Often it is imagined that healthcare professionals are the only source of service brought to a given healthcare encounter, and the value they stand to derive is the satisfaction of a job well done and the collection of operant resources. By the light of SD-logic, we can see that the patient has something of value to offer the healthcare professional that goes beyond operant resources. Not only does the successful application of the patient's resources allow the healthcare professional to gain experience in applying their knowledge, but it also enables the healthcare provider to refine their service technique. The healthcare professional can also integrate the patient's experience into the context of the healthcare field the provider works in, such as rheumatology.

Additionally, viewing the knowledge and skills of the patient as a valuable resource for a healthcare encounter would be appropriate for a healthcare system seeking a patient-centered approach, as the patient is considered a useful contributor to the healthcare process. The co-creation logic would pay close attention to the healthcare provider’s resources that are being brought to a given healthcare encounter, rather than considering only the patients' resources. This lack of consideration for the needs and pressures on the healthcare professional is a general criticism for many healthcare frameworks which fail to address the limited resources of our
healthcare professionals, especially the resource of time. Furthermore, SD-logic states that value is always uniquely determined by the beneficiary (Vargo, Maglio, & Akaka, 2008). We can understand this by examining the knowledge and skills that both patients and providers are bringing to a given healthcare encounter. For value co-creation to occur, the patient and the provider must feel that the resources they are bringing to exchange are making a difference and apply to their lived experience. The healthcare provider may feel that the knowledge and skills they are applying to a given encounter with a patient are amounting to very little. These feelings could manifest, for instance, if the patient is not cooperating, listening to the provider, or following their advice, this may cause the healthcare provider to disengage from the value creation process. A similar situation may be occurring for the patients who believe they lack the knowledge and skill resources to apply the healthcare professional's advice in the context of their own lives. They may also think that the healthcare professional is not listening to and acknowledging their needs and preferences, causing a similar disengagement from the value creation process. Nakata and colleagues (2018) heard firsthand from patients who experienced this phenomenon when researching the medical adherence of inner-city patients.

Both patients and providers and their experiences and expectations need not be viewed as an obstacle requiring navigation. They can instead be seen as a strength that serves to augment the value creation process, which is another benefit of viewing healthcare issues through a marketing theory lens. When we consider the fundamental premises set out by Vargo and Lusch (2010) that inform SD-logic, such as the notion that a service-centered view is inherently customer oriented and relational. We can adapt the language for the healthcare system by changing "customer" to "patient"; doing so allows us to understand that the ideas that inform SD-logic are commensurate with the goals of patient-centered care. Additionally, the ability of the provider to execute the goals of patient-centered care is, for all purposes, a skill. Sommaruga, Casu, Giaquinto, & Gremigni (2017) found that one of the barriers to patient-centered care is the provider's belief that they lack the skill to do so. Skill is generated by all participants, the application of that skill is a resource, and value is based on the processes that integrate those resources into the lives of those that participate in a service for service exchange. Because of this, healthcare is by no means one-sided; both patients and providers have much to offer one another if we explore this relationship as one of mutual value co-creation (Vargo, Maglio, & Akaka, 2008).
Evidence in both the marketing and health sciences literature exists, suggesting how patients and providers assist in the value co-creation process. For example, Dellande, Gilly, and Graham (2004) found that compliance (adherence) in customers attending a weight loss program could be reliably increased if a robust and positive relationship with the provider could be established and maintained. The relationship with the provider assisted the customers with critical factors for success, such as clarity of purpose, motivation, and perhaps most importantly, the ability to succeed (Dellande et al., 2004). The ability to manage is emphasized because patient self-efficacy, especially with chronic illness, is a reliable indicator of successful health outcomes (WHO, 2003). Additional research on self-efficacy has shown that the role of the provider is critical in overcoming any deficits in self-efficacy (Dimatteo et al., 2002; WHO, 2003). Moreover, as in the case of the providers who feel they lack the skills to be successful in patient-centered care, communication with active, engaged patients could assist those providers. This is done by overcoming any perceived deficits to their self-efficacy by observing that their efforts are leading to patient success.

Finally, it is essential to consider one potentially overlooked aspect of the patient’s interaction with healthcare: expectations. Lusch and Vargo (2009) explain that as we transitioned into the co-creation era, many businesses had already accepted the idea that the enterprise and the customer could no longer be seen as separate. They readily made customers part of their marketing endeavors, and this practice has only become more common in the last decade. One could argue that, with the explosive rise of social media, customers now expect to be a part of the marketing process, they expect value co-creation. The Kano model presents an interesting way of considering the implications for consumer expectations (Kano, 1984). The model suggests that if expectations are not met, perceived satisfaction drops rapidly (Kano, 1984). When considering this perspective in conjunction with service-dominant logic’s claim that we are now in a co-creation era, one has to wonder if patients now expect to be a part of the value co-creation process as much as they expect co-creation from all other consumption channels. It seems then that traditional healthcare research may have overlooked this critical aspect of patient satisfaction.

Based on the evidence provided, it appears that successful health outcomes are dependent on several critical factors. The barriers to access must be eroded, enabling patients to feel that they are a welcome part of the healthcare system. Doing so may also strengthen patient trust in
the healthcare system and facilitate better relationships with healthcare providers. Providers should also focus on the tenets of patient-centered care such as respect for the patient's values, preferences and expressed needs, the involvement of family and friends, coordination and integration of care, information, communication and education, physical comfort, emotional support and alleviation of fear and anxiety, transition and continuity, and access to care (Ortiz, 2018). If patients feel welcome and part of a value co-creation process, as they might expect from other service systems, they are likely to engage with the provider in a meaningful way. Additionally, the life context of both patient and provider should be considered. This should form the basis for the value co-creation predicted by service-dominant logic. This research is situated in the service-dominant logic framework put forth by Lusch and Vargo (2009) and recreated in figure 1.2.1.

1.2 Service-Dominant Logic Conceptual Framework

Figure 1.2.1. The value co-creation process, as outlined by Lusch and Vargo (2009) with the ten supporting premises.

FP1 Service is the fundamental basis of exchange.
FP2 Indirect exchange masks the fundamental basis of exchange.
FP3 Goods are a distribution mechanism for service provision.
FP4 Operant resources are the fundamental source of competitive advantage.
FP5 All economies are service economies.
FP6 The customer is always a co-creator of value.
FP7 The enterprise can not deliver value, but only offer value propositions.
FP8 A service-centered view is inherently customer oriented and relational.
FP9 All social and economic actors are resource integrators.
FP10 Value is always uniquely and phenomenologically determined by the beneficiary.
We believe marketing theory, specifically the application of service-dominant logic, is an ideal choice for investigating the concerns surrounding healthcare at this time. This is primarily due to marketing’s approach to understanding what consumers value and why. Additionally, SDL utilizes a holistic approach to value creation which will naturally encompass the concerns of all parties involved, both patients and providers. Within healthcare literature there is some debate as to whether the emphasis for who is responsible for health outcomes rests more with patients or physicians (WHO, 2003; Salgia, 2018). The actionable statements that may arise from the application of service-dominant logic will not place the emphasis on one group over another, alleviating some of the concerns found within the healthcare literature. Using this conceptual framework to examine the patient-provider relationship will enable us to understand both patient’s and provider’s perceptions of value co-creation simultaneously. This perception could also assist with an understanding as to how value co-creation may lead to better adherence to long term medication therapies for arthritis patients. Medication adherence remains one of the most critical factors in positive health outcomes for patients. Understanding what we know of the phenomenon, how, and why many patients are not adherent is necessary for a complete picture of how SD-Logic might improve the patient-provider relationship.

1.3 Medical Adherence and the Patient-Provider Relationship

Medical adherence has been formally researched since the 1970s, subsequently being identified as a primary contributor to both positive and negative patient health outcomes (Wei, et al., 2002; WHO, 2003; Vlasnik, et al., 2005; Chao, Nau, & Aikens, 2007; Atinga, Yarney, & Gavu, 2018). Medical adherence is defined as “The extent to which a person’s behavior – taking medication, following a diet, and executing lifestyle changes, corresponds with agreed recommendations from a health care provider” (WHO, 2003). The research and information gathered on medical adherence over the past nearly four decades have given us a good scope of the problem and the effects of both positive adherence and negative adherence (WHO, 2003; Atinga et al., 2018).

For example, it is estimated that approximately one in ten prescriptions issued by healthcare providers are never filled by patients. Medications prescribed to patients to treat long term conditions are often discontinued within six months (Zhang, Terry, & McHorney, 2014). Studies have demonstrated that medical adherence rates remain staggeringly low averaging 50% failure rates in developed countries, elsewhere in the globe, adherence rates can drop much lower
(WHO, 2003; Vlasnik et al., 2005; Chao et al., 2007; Iuga & McGuire, 2014; Uckun, Yurdakul & Bodur, 2017; Atinga et al., 2018). In addition to the human cost of poor adherence, there is strong evidence that the economic cost of adherence is staggering with some estimates in the hundreds of billions of dollars annually (WHO, 2003; Iuga & Mcguire, 2014; Zhang et al., 2014). The following section will present a detailed account of our current understanding of the contexts and factors that contribute to failure rates in medication adherence.

The first context occurs when a patient receives advice or recommendations from a healthcare professional designed to target some condition or symptom and fails to follow the recommended timetable or instructions for that medication or treatment regime (WHO, 2003; Iuga & Mcguire, 2014). The second context occurs when a physician or other healthcare professional provides a patient with a prescription intending for the patient to fill the prescription and begin taking a medication, but the patient fails to fill the prescription and never begins the medication (WHO, 2003; Iuga & Mcguire, 2014). In response to these situations, researchers asked what factors could be contributing to medical adherence. So far, research has identified two broad categories that encompass what we know about the factors affecting medication adherence.

The first category is systems factors or health-systems factors that contain all of our concerns about how the health system is structured, which contributes to adherence rates (Wei et al., 2002; WHO, 2003; Atinga et al., 2018). These structural concerns may include ease of access to the healthcare system, ease of navigation of a healthcare system as well as concerns around patient-provider communication needs (Wei et al., 2002; WHO, 2003; Atinga et al., 2018). Thanks to the contributions of researchers investigating these concerns in partnership with healthcare professionals, corrections have been made to many of the health systems concerns identified. The shift away from terms such as "compliance," which many viewed as a potential compromise of the patient-doctor relationship, coupled with the adoption of new models for healthcare such as the patient-centered care model, were all part of a more significant move to target the systems concerns surrounding medical adherence (Vermeire, Hearnshaw, Van Royen, & Denekens, 2001; WHO, 2003; Tilson, 2004; Vlasnik et al., 2005; Atinga et al., 2018). The situation is far from perfect; however, the ability of researchers to transmit knowledge to the healthcare field and make a positive change has led to improvements in many of the barriers to access that were initially identified (WHO, 2003; IOM, 2004).
Despite the improvements that have been made to the healthcare system, medical adherence rates remain disturbingly low, prompting more research into the second category of factors influencing medical adherence: patient factors. Patient factors have proven difficult to identify and describe regarding medication adherence. This lack of clarity is due in part to the subjective nature of patient factors; what is contributing to one patient's adherence rates will not necessarily apply to all patients or even most patients (WHO, 2003). Detailed are some of the patient factors identified.

The first factor is stress, and patients often have many concerns ranging from economic worries to fears about adverse effects from a particular medication to the unknown aspects of a new diagnosis (Vermeire et al., 2001; WHO, 2003; Kaufman, 2008; Iuga & Mcguire, 2014; Uckun, Yurdakul & Bodur, 2017; Nakata et al., 2018). Regimen complexity and medication beliefs are significant sources of non-adherence, patients' beliefs, expectations or previous experience both personally and interpersonally may contribute to whether or not a patient doubts the efficacy of a treatment option (Vermeire et al., 2001; WHO, 2003; Kaufman, 2008). The nature of the disease and its progression, as well as the patient's willingness to accept a diagnosis, have also been shown to affect the seriousness with which a patient adheres to healthcare professionals’ recommendations (Vermeire et al., 2001; Wei et al., 2002; WHO, 2003; Vlasnik et al., 2005; Kaufman, 2008; Atinga et al., 2018). One of the primary purposes for studying patient factors is to identify the specific strengths that each of the elements has on a patient’s medical adherence rates. Healthcare professionals can then be informed as to which patient factors are the most common and the most powerful influencers of patient health outcomes.

One of the core patient factors identified was the concept of health literacy (IOM, 2004; Parker & Ratzan, 2010). Health literacy is defined as: "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Parker & Ratzan, 2010). Health literacy has been linked to medical adherence rates and, thus, patient health outcomes (IOM, 2004; Parker & Ratzan, 2010). Health literacy focuses on the educational and cognitive aspects of the patient and does not fully explain all the patient factors that contribute to adherence rates; it remains, however, a powerful influence on medical adherence (IOM, 2004; Parker & Ratzan, 2010; Ip, Tang, Cheng, Yu & Cheongsiatmoy, 2015). Of importance with regards to education is the issue of adult education
levels. In addressing the issue of adult education, the Institute of Medicine suggests intervention courses designed to bring adults from myriad educational backgrounds up to speed on the latest advances in health knowledge that are of use to improving everyday life (IOM, 2004). However, other researchers have described how resistant adults can be to new health information (IOM, 2004; Kutner et al., 2006; Ngoh, 2009; Ip et al., 2015). This resistance comes in many forms, such as a resistance to the latest information that challenges long-held beliefs and practices or from a desire to avoid feeling condescended too or made to feel ignorant (Parikh et al., 1996). Consequently, there is a third form related to the effects of aging on the human body; all three instances, however, could play an influential role in the relationship between patient and provider (Rootman & Ronson, 2005). Finally, all of these issues could be shaped in some way by the functional literacy level the patient possesses (Lowstein & Bradshaw, 2004; Dewalt et al., 2004).

1.3.1 Functional Literacy

Functional literacy is generally described as reading and writing skills that are adequate for the managing of daily life and the employment of tasks that require reading skills beyond the basic (Lowstein & Bradshaw, 2004; Dewalt et al., 2004; Kutner et al., 2006). Functional literacy plays an often unseen role in the patient-provider interaction. For example, a physician might work with a patient and provide a detailed set of written instructions to achieve the desired health goal. However, if the patient does not possess adequate reading and writing skills, they are unlikely to communicate that with the physician. They will be unable to utilize the resources the physician has provided (Ofri, 2017). This communication concern requires the physician to investigate or detect the functional literacy deficiency in a way that is not awkward or otherwise embarrassing to the patient (Ofri, 2017). Overall, functional literacy could serve as either a boon or barrier to the patient-provider relationship.

When considering the health system factors related to literacy, such as following medical prescriptions or filling out hospital forms, the ability to read and write beyond simple sentences is a core requirement. In Canada, 15% of the population aged 16-65, or approximately five and a half million individuals, were reported to have been unable to meet the criteria for functional literacy (Desjardins et al., 2005). The issue of functional literacy mainly affects seniors over 65+ who were identified to be vulnerable to low health literacy in a unique way as opposed to other groups. Seniors, regardless of educational background and life history, are at risk of losing
reading skills, not because of lack of education, but due to skill atrophy often accompanying decreasing vision (Rootman & Ronson, 2005).

In this way, seniors are a unique challenge for healthcare providers. Healthcare providers interacting with seniors with poor vision and decreasing functional literacy must navigate a particular space between not belittling their patients or making them feel belittled and providing adequate care (Parikh et al., 1996). As detailed further on, this aspect of the patient-provider relationship is critical to the value co-creation process, and the literature reveals the myriad ways in which complications to that process can arise in a health service encounter. How providers communicate with patients, both young and old, educated, literate, or not all belong to the domain of health communication, which makes it a primary component of the patient-provider relationship.

1.3.2 Health Communication and the Patient-Provider Relationship

Communication is about how individuals use messages to create meaning. Health communication is simply a narrow form of communication centered around the context of health, which can take many forms, including media, human interaction, scientific inquiry, etc. (Hannawa et al., 2015). The goal of health communication is rather often to create some form of change in people's beliefs, attitudes, or behaviors (Hannawa et al., 2015). Most health communications are about programs, interventions, or perhaps a product that incites health changes in an individual's life or community. However, some health communication is simply centered on the patient-provider relationship. In this communication between patients and providers, the greater danger is that one or both parties will talk past the other, or fail to recognize the communication needs of the other (Ofri, 2017). In this way, health communication is much more of a skill requiring practice, as opposed to an innate ability. Healthcare professionals are given communication training, but it is during work that the real practice of honing one's skill can begin. When interacting with actual patients where real consequences can occur, healthcare professionals committed to providing diligent care to patients will take the time to develop strategies for communicating with individuals based upon their patient's needs. This may come in the form of using metaphors, or even the elimination of jargon words (Ong et al., 1995). The institute of medicine compiled a detailed report on the importance of accurate and jargon-free communication with patients (IOM, 2004).
To side-step medical jargon often present in healthcare conversations, healthcare providers are encouraged to use metaphors for grounding their communication in a more tangible context. Similarly, patients will often use metaphors to communicate complex sensations or pains to doctors and nurses (Álvarez et al., 2017; Ortiz, 2018). In both instances, the purpose is the clear communication of needs and understanding. If a doctor, nurse, or pharmacist is successful in communicating with a patient, the likelihood of medical error, nonadherence, and patient dissatisfaction decreases dramatically (Ong et al., 1995).

1.3.3 Communication, Emotional States, and Liminality

Another patient factor influencing the patient-provider relationship and medication adherence is a patient’s emotional state; many of the concerns mentioned by arthritis patients will elicit some emotional response with patients such as fear or doubt (Vermeire et al., 2001; WHO, 2003; Kaufman, 2008). The literature on this topic suggests that negative emotional states can influence adherence rates; however, our knowledge as to the extent that emotional states can affect medication adherence remains incomplete (WHO, 2003; Vlasnik et al., 2005; Atinga et al., 2018). Past literature has struggled to differentiate patients’ emotional states from stress, both chronic and acute (WHO, 2003; IOM, 2004; Kaufman, 2008). As a result, we do not fully understand the extent to which emotions can affect medication adherence and, by extension, the patient-provider relationship (WHO, 2003; IOM, 2004; Kaufman, 2008).

Nakata and colleagues (2018) conducted interviews with patients with chronic diseases. They concluded that medication adherence was a liminal state with social, economic, emotional, and educational concerns acting as oscillating forces moving patients towards or away from adherence based on the temporal context of the patient. The aspects of medical marginalization were also touched upon as another barrier to medical adherence, indicating that for some marginalized groups, such as those in impoverished inner-city communities, the barriers to access are still a factor (Nakata et al., 2018). The vital thing to note about medical marginalization and the barriers to access is the complete inability for value co-creation to occur between the patient and the physician. In these situations, patients had limited access to a consistent, competent healthcare provider. They relied on self-diagnosis and assessment leading to distrust in a medical system that the patients viewed as having failed them (Nakata et al., 2018). This raises many concerns about the suffering of arthritis patients’ experiences with wait times of up to two years.
Additionally, individuals managing chronic illness are often required to consume medication once or even multiple times per day. Patients who have experienced great difficulty accessing healthcare systems are denied the opportunity to engage in value co-creation with a healthcare professional. Without the stabilizing force of a trusted physician, these patients are left without an anchor to navigate the complicated journey relating to medical consumption (Nakata et al., 2018).

1.4 The Customer Journey

The concept of the customer journey has been slowly emerging from the literature on consumer experience over the last decade (Lemon & Verhoef, 2016). The customer journey is defined as “the process the customer goes through, across all stages and touchpoints with an organization, comprising the customer experience” (Lemon & Verhoef, 2016). The process driving its creation stems from the ever-expanding number of customer touchpoints through which customers now interact with firms (Lemon & Verhoef, 2016). This increase in customer touchpoints is due in large part to the rise in communication made possible by social media. Consumers now communicate with each other and with firms in fragmented and sometimes siloed ways, leaving firms often unable to control important aspects of the customer experience (Lemon & Verhoef, 2016). The consensus on customer experience is a multidimensional collection of touchpoints situated across time that builds into what is known as the customer journey (Lemon & Verhoef, 2016).

The customer journey can be divided into three major phases, which taken together represent the total experience from pre-purchase intentions to the purchase point onwards to post-purchase considerations (Lemon & Verhoef, 2016). When we consider the customer journey from a healthcare perspective, the three phases offer a way of viewing patient choice beyond the traditional health research perspective. The pre-purchase phase could consist of patients shopping for doctors or pharmacists who will satisfy their needs, especially after having communicated through various channels with others who may have received unsatisfactory service from a healthcare professional (Rodriguez, Appelt, Switzer, Sonel, & Arnold, 2008). A purchase could be considered the act of choosing a healthcare professional or making a pharmaceutical purchase, especially in the context of chronic disease. Post-purchase may be the most impactful element of the three phases since patients with chronic illness need to consume medication for many years (Nakata et al., 2018). This need to remain in the post-purchase state
with the repeat decision to be medically adherent would be a difficult situation for patients who lack a strong relationship with a trustworthy and competent provider (Nakata et al., 2018). This suggests that perhaps from pre-purchase through to post-purchase, some consumers’ relationships with healthcare systems might remain in a fragile state (Lemon & Verhoef, 2016; Nakata et al., 2018). This fragility may underscore the need for co-creation practices to strengthen the ties between the patient and the provider.

1.5 Arthritis, Healthcare, and Service-Dominant Logic

When we bring the topics of arthritis, healthcare and service-dominant logic together, several essential considerations emerge. Chief among these considerations is the argument that our current healthcare system is not informed by service-dominant logic, but rather by a goods-dominant logic (Joiner & Lusch, 2016). This argument is relevant because, as was previously discussed, goods-dominant logic is considered an outmoded managerial philosophy (Joiner & Lusch, 2016). Goods-dominant logic is based on the idea that human improvement is determined by our ability to create more significant amounts of tangible goods or mediation points (Joiner & Lusch, 2016). The distribution method is considered non-specific, non-particular, useful for mass consumption. This was a practical way of considering production during the industrial revolution when a high number of people abandoned the country and began to cluster in larger and larger cities (Vargo & Lusch, 2010; Joiner & Lusch, 2016). If we consider this GD logic approach and how it informs our modern healthcare system, the two appear no longer compatible. We’ve made the argument that individuals expect value co-creation from most of the consumption channels they interact with. Healthcare would be no different; however, healthcare appears to be influenced heavily by GD logic (Joiner & Lusch, 2016). This is decipherable by the measurement tools healthcare often uses to discern its effectiveness. The focus remains on tangible goods and mediations such as hospital beds, medi-clinics, medical devices and images, patient surveys, etc. (Joiner & Lusch, 2016). In each instance, healthcare has attempted to mold a particular product or service to fit a value-in-exchange model. Understanding this, we can ask, is a mass-production style of healthcare something patients’ value? The answer appears to be no, as patients regularly disengage for personal reasons from a healthcare system that is not designed to target or even consider their specific health care needs (Ofri, 2017; Ortiz, 2018).
The average rate of medical adherence hovers around 50% (WHO, 2003; Atinga et al., 2018). This figure is consistent with the literature on adherence in arthritis patients. Across a range of different treatments, arthritis patients averaged less than 50% adherence rates (Joensuu et al., 2016). For some drugs, between 5% and 9% of patients did not even fill the prescription (Joensuu et al., 2016). Rheumatologists have long discussed the positive effects of early detection and treatment for arthritis patients (Kim et al., 2013). The sooner a patient can begin treatment on a drug with tolerable side effects, the more likely that patient can avoid permanent disfigurement (Kim et al., 2013). This is a compelling argument for healthcare to transition out of a GD logic approach into a service-dominant approach. Often terms like patient-centered care are used to argue that healthcare is attempting to transition out of a good’s dominant logic approach (Joiner & Lusch, 2016). This is an excellent first start as patient-centered care shares many of its beliefs with service-dominant logic. Unfortunately, patient-centered care is often measured using a goods dominant approach; regularly, terms such as patient engagement and patient activation are used as markers of good patient-centered care (Joiner & Lusch, 2016). These blanket terms, however, do not reflect an SD logic approach. SD logic places emphasis on value-in-use with verbs designed to bring individuals together, namely the patient and provider (Joiner & Lusch, 2016).

SD logic has gained traction over the last decade and a half as managerial mindsets across the service-scape embrace its principles (Cossío-Silva et al., 2016; Beirão, Patrício, & Fisk, 2017). However, within the context of healthcare, little literature exists exploring the application of SD logic (Joiner & Lusch, 2016). One team of researchers explored how customers create value within a healthcare context (McColl-Kennedy, Vargo, Dagger, Sweeney, & Van Kasteren, 2012). The researchers discovered that there are multiple ways in which customers or patients can engage in co-creation activities (McColl-Kennedy et al., 2012). The authors provided a typology for understanding how patients with different backgrounds will co-create value based on personality and perceived or preferred role (McColl-Kennedy et al., 2012). This demonstrates that there is no ‘right’ way to integrate resources and may hold additional implications for healthcare service providers. Much of the remaining literature utilizes an indirect measurement of value co-creation and, by extension, SD logic (Nakata et al., 2019). McColl-Kennedy et al., (2012) and Nakata et al., (2019) posit that to date, co-creation research has not explored a qualitative, lived experience approach to service-dominant logic.
This research attempts to address this gap by exploring the application of SD logic to the relationship between arthritis patients and arthritis providers. We will discuss how patients co-create value in different ways. We examine how providers gather information based on western medicine using an evidence-based approach. Finally, we provide evidence that SD logic remains highly applicable to a qualitative investigation of healthcare.
2 Method

This research followed a patient-oriented approach. Patient-oriented research is a relatively recent concept that refers to research done in partnership with patients to improve healthcare and projects investigating healthcare concerns (SCPOR, 2020). A patient advisor, an individual with arthritis, joined the research team and contributed to the development of the research question. Additionally, our patient partner has been instrumental in the understanding of the lived experiences of individuals with arthritis. They helped in the formation of and refinement of the interview guide. Our patient partner has provided different ways of thinking about arthritis which has allowed for further refinement of the research question. These new perspectives also prompted a search for additional material in the arthritis literature. This research was funded in part by the Saskatchewan Centre for Patient Oriented Research (SCPOR), which is an organization that works alongside academic researchers to conduct meaningful patient-oriented research and communicate the results with stakeholders. The research questions driving this study are the following: *How do patients and providers find value in their relationships with one another, and what factors influence this value creation? Can Service dominant logic inform a qualitative, lived experience for patients and providers?*

The method for this study was semi-structured interviews with arthritis patients and rheumatologists. An interview guide was constructed by the researchers and patient partner. The interview guide was designed to investigate the possible locations or interruptions to value co-creation between arthritis patients and providers. The dialogues, however, were free to deviate from this guide as the participant was primarily in control of the conversation, see appendix A for the full guide. This research was approved by the University of Saskatchewan Research Ethics Board, see appendix G. Individuals from each group were interviewed, and their responses were examined for common, recurrent, and emergent themes. By doing so, we sought to understand how each group approaches issues around the patient-provider relationship.

2.1 Study Populations

The population for this study was drawn from arthritis patients across the province of Saskatchewan. According to Stats Can (2019), approximately 15% of the 1.1 million people of the province of Saskatchewan are reporting a diagnosis of arthritis. For this study, we did not limit arthritis patients to any subgroup. Arthritis patients have a variety of unique concerns and
considerations; however, they share the need for long term, repeated physician visits once a
diagnosis has been confirmed. The healthcare providers interviewed were limited to
rheumatologists practicing in the province of Saskatchewan, Canada. The Canadian Arthritis
Society reports eight (8) rheumatologists practicing in the province of Saskatchewan. Four
arthritis patients and two rheumatologists were interviewed.

For this study, our arthritis participants have been living with arthritis for several decades
at minimum, one participant had experienced arthritis symptoms their entire life. This gave us a
sense that our participants were very aware of the experience of chronic arthritis symptoms and
interacting with the Saskatchewan healthcare system. This was not a necessary requirement for
participation.

2.2 Setting

Interviews were conducted in person at a location of the participant’s choosing as well as
via teleconference using WebEx for remote participants. The interviews were audio-recorded
and lasted between 45 and 65 minutes.

2.3 Recruitment

Recruiting for rheumatologists was done in person and via email. Patients were recruited
using the SCPOR patient-researcher engagement website. One of the primary goals of SCPOR is
the representation of patient’s perspectives in research. For this study, the patient-researcher
engagement website was utilized as a pilot project. The website enabled patients from across the
province of Saskatchewan to connect with researchers and lend their voice to the discussion (See
appendices B and C). Six (6) participants, four (4) arthritis patients and two (2) rheumatologists,
agreed to participate. For this study we believe that an accurate picture of the issues surrounding
arthritis patients and providers has been achieved. This was accomplished using an in-depth
analysis of the patients concerns surrounding life with arthritis. Arthritis patients and the issues
they experience are complex and our analysis reflects that complexity. Additionally, the
knowledge provided by the rheumatologists who agreed to be interviewed was extremely valuable
for this analysis. Rheumatologist’s knowledge of the issues surrounding healthcare is immense.
Furthermore, these providers see hundreds of different patients from across the province each
year. Gaining the perspective of two rheumatologists gave us a detailed understanding of the
issues surrounding rheumatology and arthritis.
It should be noted that this research intersects the time in which the 2020 Covid-19 pandemic had become a global concern. Due to the pandemic, interviewing after March 2020 became increasingly difficult. Providers were unavailable, as all healthcare workers shifted to deal with the pandemic. Patients were no longer interested in participating in research as the pandemic had overwhelmed public consciousness. Nevertheless, we believe the six participants represent a diverse and qualified perspective on the issues discussed. Before any interviews took place, participants were informed that the interviews would be recorded and were reminded of their rights to confidentiality and withdrawal at any time without question.

2.4 Data Analysis

Interviews were transcribed verbatim by the student researcher. Manual coding, utilizing a line by line approach, was conducted. Given the nature of the topic and the prevailing literature, line by line coding was an attempt to avoid preexisting biases and assumptions about the patient-provider relationship. Additionally, we wanted the themes discovered to be an emergent property of the topic. To accomplish this, a bracketing approach was utilized. Bracketing was critical to understanding the views of the participants without influencing their perspectives based on previous marketing or health sciences literature. To detect the influences of service-dominant logic or goods-dominant logic without succumbing to preconceived structures found in the literature, the researchers set aside previous findings during the coding process. Additionally, by conversing with the patient advisor attached to the research team, the researchers were able to identify prior knowledge about the research topic that may be a source of bias. Considering the nature of the interviews, including when participants would become available, data analysis began before all the interviews had been concluded. Participants’ responses were analyzed for common, recurring, or emergent themes. Responses were coded based on themes, including broad categories and sub-categories. Coding was based on Braun and Clarke’s (2006) approach to thematic analysis. Using this method, four major themes were identified with corresponding subthemes:

1. Acknowledging the Loss
   -Sub-theme: Medication Adherence

2. It is the System
   -Sub-theme: Wait times

3. Barriers to Value Co-Creation
4. Sensing, Experiencing, and Creating

One of the main goals of utilizing a qualitative approach to this topic was to illuminate the direct human experience of having arthritis. Past literature has demonstrated an abundance of research on the efficacy of treatments for arthritis while neglecting the human stories that accompany a long-term chronic condition. Our research has documented the experience of arthritis patients and healthcare providers. We then compared those experiences to the literature surrounding topics of arthritis, medication adherence, and service-dominant logic.

2.5 Significance

This research has added new evidence for the application of service-dominant logic to a qualitative, lived experience approach. In the following discussion section, we explore how different patients co-create value. That there are multiple ways in which patients create and value their interactions with healthcare providers. That in practice, value co-creation is navigated by both enhancements to value as well as barriers. We provide evidence that both patients and providers want good relationships with one another, and the goods dominant logic informing healthcare acts as a continual barrier to functional co-creation activities. This is informed by both patients and providers feeling the stress of a healthcare system that appears overburdened and focused on a goods dominant approach.
3 Findings and Discussion

3.1 Acknowledging the Loss

The first of the main themes, *Acknowledging the Loss*, contains the sub-theme *Medication Adherence*. One of the main aspects of this theme is the description of the lived experience of arthritis patients. Providers, accordingly, also spoke of the need for their patients to understand how their lives would change, including the need for medication, an issue many patients refused to acknowledge. As a result, the theme of medication adherence was included here. In the literature on arthritis, it was difficult to obtain evidence surrounding the patient's lived experience with arthritis. One goal of our research was to offer patients the chance to describe how living with arthritis impacts their day to day experiences as well as their interactions with the healthcare system. When asked how arthritis had impacted their lives, many patients spoke of what they had lost:

“I can't get down on the floor and play with my grandkids. I have a scooter; I go for walks with them on my scooter that’s part of the disease process. Going up and down the stairs is an issue. That’s part of the disease process, so I will make a trip and hope I’ve gotten everything I need for the day out of the deep freeze or whichever. Things like vacuuming are a huge issue.”

This quote shares sentiments many patients revealed regarding daily life with arthritis. They spoke of missed opportunities with grandchildren or hobbies that had become compromised. Each patient described how arthritis created additional burdens for daily living. These additional burdens were part of their disease management but served to deny them aspects of regular life, as one patient describes:

“The way I do things, they are limited, there are a lot of things I cannot do or that I need to push through, with the arthritis it’s very debilitating on top of doing everything I have to do like everybody else does I also have to exercise, I have to make sure I eat properly which means I have to make all my meals from scratch. I eat very healthy in order to keep inflammation down, which also means I have to shop. There are a lot of extra demand when a person wants to treat it well. I can’t take medication, so I have to control it otherwise. I have to go for physiotherapy every two weeks, have to go for a massage every two weeks, and go to the chiropractor because my back has gone out. There are a lot of issues that come up that really affect the person's day tremendously. I’ve learned over time what works
and doesn’t work, and these are the things I have to do. Also, when it comes to work, at this point, I am unable to work, so I will never be able to work full time because I have so many other things I have to do to keep my body going, so it affects a person globally.”

To patients, it seemed rather often that providers were either incapable or unwilling to acknowledge the global nature of the disease and its effects. For many patients, the expression of the illness was internal, or they grew up in a culture where the pain was a sign of hard work. As such, they experienced difficulty in communicating the seriousness of their condition, which served to alienate them at times from their healthcare professionals:

“…and I think its because, I get I don’t show it, so I go, and I say I’m in a lot of pain, and they look and go oh you’re not crying.. so you look fine, and so it wasn’t until I printed off a skeleton and I would take dates, and I did it for a week, and I took morning, lunch, I’d highlighted the areas that were inflamed with pain a lot and then I took it to my doctor, my GP, and then I have a case for when I see the rheumatologist so they have some evidence around here it is and here is where its at. And then he was like oh, wow you really are in… we need to work at this. Well, yeah, that’s what I said. I feel I either need to be extremely vulnerable in front of them, or I need to self-advocate a lot…”

For many patients, this was their experience with the healthcare system. Unless they were willing to express the disease overtly, they felt the medical system would not take them seriously. Additionally, many patients expressed frustration that the disease should not dictate or determine who they were as people:

“…when we think disability, someone in a wheelchair, someone in a cast. Something very visible for us, whereas people with chronic conditions, often it’s very invisible and like for me, I live it everyday so I don’t wanna have it show I just want to be me and live my life and not have my illness rule my life…”

Many patients struggled with this dichotomy between choosing to be vulnerable for acknowledgment, and not wanting the illness to be a defining part of their lives. These issues highlight the missing experiences from previous arthritis literature. Another goal of our research was to capture the provider's perspective on these issues. Service dominant logic is about both actors in any service exchange, and we needed to understand what providers knew about their patients’ experiences. One provider describes what they believe is the experience of arthritis for their patients:
“The pain has always been one of the hardest things, but to some extent, it's also not knowing what it is and not knowing what to expect. It's kind of, everyone expects as you get older to have some aches and pains and some wearing out. That’s something that people are usually ok with, they want to know what to do about it, but they don’t usually worry about it. But an autoimmune disease can come out of the blue, and so people get very concerned. It’s not always easy to get an answer from a family doctor, especially if they’ve not seen much of these kinds of things. And if you go online you’re going to get all kinds of terrible kinds of things popping up, so a lot of people are afraid of the unknown and they want to know number one what it is, and number two what we can do about it.”

This quote from a provider is a powerful indicator that, on a personal level, healthcare providers understand many of the concerns of their patients. There appear, however, to be goods dominant logic barriers between this understanding and the practice. However, what is of note regarding the acknowledgment of the disease is the need sometimes for providers to convince patients of the severity or the seriousness of the condition. Additionally, providers may need to convince patients of the efficacy of our medical techniques:

“…quite a bit depending on the patient, of course, and the disease activity. Arthritis activity can be quite variable from patient to patient, so you cannot just put everybody under the same umbrella because they are different people in the community with a different willingness to get treated or not to get treated or the patient is in denial…remember, if you have a disease, a calamity of some sort, like rheumatoid arthritis, you are in denial, it cannot possibly happen to me. So you have to, at a certain point, confront them, and it helps…”

Much of what concerned providers regarding these topics was the need for patients to understand what the disease is and what it means for their lives going forward. This was framed in terms of action or actionable statements. Providers commented on the need for the patient to be involved in the treatment process. This need is partially a service-dominant perspective and contributed to a significant source of value co-creation as one provider describes:

“Depending on the disease of the patient, compliance with medical advice, and also that includes the treatment and the follow-up. The bloodwork and the constant communication, so basically to do that, you have to establish a boundary and not only a boundary but some trust with the patient. So the patient needs to understand that you are really working for the benefit of their cause, so they get better.”
Providers often made small but regular comments on the importance of medication compliance. Compliance and adherence are interchangeable terms referring to a patient’s agreement to follow medical instructions from providers. Adherence became a clear route for the provider’s sense of value co-creation. For this reason, adherence was an influential gauge of the perceived relationship between patient and provider.

3.1.1 Medication Adherence

Medication adherence is important for a successful outcome (WHO, 2003). This is important for both patients and providers in different ways and depending on the type of arthritis. For providers, their experience of adherence and its importance mirrored what previous literature on the topic had communicated. Additionally, rheumatology and its medications had further concerns for patients as one provider explains:

“There are a lot of concerns around medication, so the medications we use in rheumatology are weird ones, they’re not ones people are comfortable with, they are not off the shelf. Some have had past history as chemotherapy drugs and so when they get the list of side effects from the pharmacist, it can be really long; there are common misconceptions about these medications from other fields as well. And so there is a lot of time lost debunking some of that. There is some legitimate toxicity with our drugs as well, and sometimes that can cause delays and changes with treatment. There are certain parts of the treatment algorithm that are dependant on other specialties, so, for example, we have to do tuberculosis testing before we can move to a biologic medication, so when we move to that point I have to get (the patient) a TB test, so sometimes there can be a delay with that, not usually because I’m proactive and do the step before.”

For this rheumatologist, the first hurdle with medication adherence was simply the nature of the drugs themselves. Patients would see a sizable list of potential side effects as well as the possibility of toxicity, which could cause heightened anxiety in patients who, as we have described, are already experiencing a great deal from a chronic condition. Despite this, the nature of rheumatoid arthritis requires patients to be medically compliant. Rheumatologists expressed the dangerous consequences of non-adherence, something which was reflected in the literature on the topic:

“It’s very important for the auto-immune diseases, medication adherence. If you’re not taking your medication it's not going to work, number one, but a lot of our biologic
medications, they are antibodies and our immune system can recognize these are foreign antibodies and the highest risk for recognition is when that drug is at its lowest point. So the goal is to dose it regularly, so you’ve always got it in your system, but if it dips, then your immune system can recognize it, and then you might get anti-drug antibodies, and you’ll lose the benefit. So, we have a lot of biologics, and we can switch from one to another, but if you find a medication that works, you want to keep that medication working, so there is very real risks to non-adherence and an impact on outcomes for sure.”

For rheumatologists, a source of value co-creation is in delivering excellent medical advice and care to patients. We have described how the provider's sense of value co-creation can be compromised by patient disengagement. Medical adherence appears to be a cornerstone of this disengagement. Providers need patients to be adherent, not just regarding medication but following instructions critical to a physician’s treatment plan:

“…and some of my patients from up north they know, you don’t have to come see me for a review appointment if you haven’t done the bloodwork because I won’t know what to tell you. I don’t know how your disease is responding to the treatment and if you can tolerate this medication…”

There are several concerns around medication adherence from the patient’s perspective, the first being liminality. In our review of medication adherence, we discussed how for many patients adherence is an oscillation between compliance and non-compliance. The reasons for this vary between social, emotional, mental, and financial concerns. For patients with arthritis conditions that could not be addressed with drugs, medication adherence was more about following instructions. However, for patients with osteoarthritis, the best advice from physicians relied upon systems that were not in place in many areas of the province. Physiotherapy, aquacise, and access to care represented barriers for rural families as one patient describes:

“There is no support in terms of transportation. In the city, you have medical transports; in the rural areas you do not. This makes it difficult for rural areas to cope. The physio, well when you have arthritis, you’re supposed to do a lot of exercises in the water. Well, we don’t have a pool! There is no public pool, so if I want to do that, I’d have to drive to Saskatoon. So if I’m driving to saskatoon then I’m getting stiff and sore, and any benefits go out the window. So the government needs to do a lot more to support rural areas big
time. In every aspect of it, every aspect of treatment, addressing the issue, they can do remote technology, that needs to be expanded a lot.”

These gaps in our healthcare coverage served as a point of frustration that disconnected patients from the healthcare system. Patients expressed that this lack of coverage in healthcare was an initiator of doubt about the efficacy of our medical system. What is of particular note is that many patients expressed frustration that medical professionals were too focused on the disease as a function of a compromised body and had neglected the human element and the emotional elements that the progression of the disease brought about. For many patients, pain is an issue as highlighted by previous research. However, more than just the relief from pain, patients described a constellation of concerns stemming from physical, emotional, and mental issues that comprise the experience of those living with arthritis. Patients expressed a desire for the healthcare system to acknowledge this totality. They believe that one of the best ways for our healthcare system to help them was to acknowledge the loss, the emotional and psychological stress that comes from having a chronic condition. This is precisely the kind of prediction that a service-dominant logic approach would expect. Patients found barriers to value co-creation when they felt their humanity was being overlooked. Patients desired a connection found in a verb-like language congruent with SD logic. Terms like struggling, hoping, hearing, caring, and worried define some of the primary concerns of arthritis patients.

Unlike the lived experience of arthritis patients, the literature on medication adherence described the concerns of rheumatologists. It was necessary for patients to be medically adherent in order for healthcare providers to find value and deliver care they felt was effective. For patients with arthritis, however, it may be necessary to sacrifice being medically adherent for the sake of maintaining mental health. For many patients with arthritis, the fear of losing cherished hobbies or activities supersedes the need to be medically adherent despite understanding the cost. The adage “doctor it hurts when I do this” to which the doctor replies, “then don’t do it” might sound like sage advice. However, if the activity is playing guitar or gardening, then the choice is between being medically adherent or pursuing the interests of your life. This becomes a powerful reality for many arthritis patients requiring careful consideration in its effects on value co-creation.
3.2 It is the System

The next central theme is *It is the System*. This theme was given such a title due to the frequent mention from both patients and providers that our healthcare system was failing to live up to expectations. One primary source of disconnect in the healthcare relationship was the lack of face time between providers and patients. This main theme contained the sub-theme of *Wait Times*. Patients regularly commented on the excessively long wait times while simultaneously suffering from a disease that intensifies with time.

Throughout the interview process, patients routinely commented on components of the healthcare system. Patients generally had favorable views toward their physicians, a topic we will explore in greater detail later on. However, they directed much of the source of their frustrations at the healthcare system or the parts of it they felt were the most compromised. Taken together, this myriad of concerns encompassed enough aspects of the healthcare system to refer to it as a whole. Briefly speaking, patients described problems with doctor-patient facetime, wait times, patient/physician interactions, the nature of western medicine, the training of healthcare professionals, the healthcare system being overburdened, and many others. We will cover each of these concerns in detail. This general concern for the healthcare system may serve as further evidence of a goods dominant logic that is informing healthcare and its practices. For older patients, several comments were referring to days gone by. Patients commented that healthcare had changed too much, too quickly, and had the impression that precious things had been lost:

“That’s an interesting question, doctor’s visits are not what they used to be. Over the last I want to say five or ten years, of course, it’s all gone computerized, so you used to walk into a doctors office and they’d say “what’s wrong” and they kind of go through and check everything and go on from there. And now when you go in you basically, and that’s including an annual check-up, which should be more detailed, right? Well, now you go in and state your cause, and you’re in and out. Because the doctors are so busy…there is no personal interaction between doctor and patient anymore, I feel.”

Patients often commented on this loss of a personal touch with many of the healthcare providers they interacted with. This notion also recurs many times during conversations with other arthritis patients in different forms. They felt that the time limits placed on doctor visits were insufficient to communicate their concerns as well as connect with their doctors. Given enough
meetings with a particular physician, they felt they could eventually establish a relationship. However, in the interim, they expressed the issues of having an underdeveloped rapport with their physician:

“It’s distance, I don’t feel comfortable sometimes saying things that I might want a doctor to address because everything is a rush…that would be it, there is no personal interaction. When our family was small, we had our family doctor for twenty-seven years, so they knew the family, knew what was going on with the family and took the time, remembered us, and I know that won’t happen anymore.”

Additionally, the notion that things are rushed was another point of contention. We have already discussed how patients felt the totality of their illness was not being validated by the healthcare system. Patients shared that part of that experience emanates from the average physician visit of 15 minutes:

“…there has to be change on a systemic level because the doctor cannot do enough in 7 minutes or even 15 minutes, you know? And patients with arthritis are complex. If you have arthritis, the different kinds of arthritis, a lot of them are very, they are global and affect the entire body at times.”

For many patients, especially those with severe arthritis symptoms, there was a general sense that a 15-minute visit was insufficient to cover their concerns. This was more than just a matter of a physical check-up or even asking and answering questions. It was an emotional concern due to the length of the visit. Patients began to doubt the efficacy of treatment techniques utilized by our western medical system. This was due in part to the impersonal amount of time offered to them as well as the nature of an evidence-based medical system:

“I expected, in my case, I have really high Lyme antibodies, and there is a question whether my arthritis is caused by Lyme or not. And I saw a Lyme specialist, and he said NO, and I’m wondering how do you know that just from looking at me? So there are issues of extra diagnosis, it is very difficult in Saskatchewan to get an accurate diagnosis, and to have them talk to each other and cross-reference across disciplines. It’s a big, big problem. So, I just do my own thing I go outside of the system and do what I need to do to get better. And if I had relied on the system, I wouldn’t be where I am now.”

This sentiment raises several thoughts. In one sense, we could view this patient’s utilization of their techniques as a success story. By their admission, they were doing better. But it also raises
concerns about why they are feeling disconnected from the healthcare system. Situations like this one were not uncommon with arthritis patients. They may serve as an additional point of evidence that a goods dominant logic is continuing to cause damage to the relationship between patient and provider. In this case, the length of the visit is indicative of a healthcare system struggling to find a balance. The balance is between serving the most significant number of people- which is a goods dominant perspective - and a system that utilizes a patient-centered care approach, something which is closer to a service-dominant view. One provider commented on this duality:

“So, the first thing I implemented in my practice is spending time. First of all, I know it's not that lucrative because we are only paid per person per visit, and the visits can be variable in time. For new patients, from the first day, since I started practicing, I allocated 45 minutes. In 45 minutes, you can get to know your patient to some extent with proper questions…”

Additionally, providers were aware of the limits of western medicine. They understood how it could create doubt. However, understanding this was not sufficient to create change within the healthcare system. Furthermore, the limitations of an evidence-based medical system were seen as unavoidable, the alternatives being unscientific and possibly harmful as one provider put it:

“There are always limitations, western medicine is very evidence-based. If you don’t meet certain criteria, you often cannot provide a diagnosis, to begin with. There is a lot of undifferentiated stuff where you can see a person, and they can have some features that sound autoimmune, but they don’t fit into a box. The training we have suggests that if you’re not meeting that criteria, then you shouldn’t be treating because every drug we have is studied in certain situations, they all have risks and benefits, and you need to know the benefits are going to outweigh the risks. And so yes, it can absolutely be a challenge. There are limitations to western medicine in that we are very evidence-based, but that’s a strength as well, but it does give us some shortcomings as far as dealing with patients’ symptoms.”

This perspective highlights the tension that exists between a patient's desire for wellness and a medical system that takes time to assess. Western medicine relies very heavily on a science-based method, which takes time to develop answers. However, when combined with other system-level concerns, it creates a sense of doubt in the minds of patients. This doubt can extend all the way to concerns about the training providers receive, as one patient put it:
“They don’t know what to do either, and it’s a huge problem. They will send you to physio when there is something wrong. Like for example, I had a torn rotator cuff muscle, which was a symptom of an underlying problem. So I went to the doctor, and they identified something was wrong that I’d torn my rotator cuff and it was worn, and I wondered why, well it turns out that it was so deconditioned from not exercising and not being able to keep up when I had extra demands just walking and lifting tore me, torn things, so they will help you on the surface, but they will not get to the roots or the source of the problem oftentimes. It's always that process of elimination and exclusion, and there just isn’t enough training out there. I don’t know what it is if they are not trained enough, but they don’t ever look at a person holistically. They will look at the one thing, and that’s it.”

Other arthritis patients commented on a similar concern that the training physicians receive was too specialized, too focused. Patients felt that much of what they were feeling and experiencing was being sacrificed for a system that was designed to target for and search for specific markers. Providers view this as sound science, the best way to reach treatment goals; however, for patients, it could become a source of frustration:

“Hmm, listening but maybe not hearing all the time, sometimes I think that information is going in and they have very specific checkboxes that they are trying to check through, and I think that sometimes they miss some of those connections, like my healthcare, yeah like my situation, sometimes I think they are so focused on some things that other things that they don’t think are relevant are kind of slipping off and I think sometimes are relevant.”

This is an important opportunity to point out the interconnected nature of our themes. The previous quote is referring to a combination of systems related concerns and the interaction with a feeling that the system was not acknowledging them holistically. Finally, there appears to be evidence embedded within that indicates a goods dominant logic influencing healthcare. For as much as a science-based approach is the best method for reducing risk, in specific healthcare scenarios, this approach can come across as impersonal and damaging to the relationship between provider and patient. Additionally, there exists a final concern within the area of provider expertise: contradictions.

Patients routinely described instances of contradicting advice from healthcare professionals. This was a very uncomfortable position for many arthritis patients. It raised a series of concerns about our healthcare system due to the liminal state many patients felt existed
when confronted with differing opinions between their family doctor and rheumatologist, as one patient describes:

“...we have had issues with the Xray department in (city removed), and on my right foot they said I had flat feet, but there was nothing wrong with them, my doctor and I looked at the Xray together and said I don’t like the look of this I think they got it wrong and sent me to see the surgeon.”

For many arthritis patients, it was the combination of differing opinions coupled with a loss of time. The issue of time is one that will be covered in greater detail as it encompassed an entire subtheme of this discussion. For now, we will remain focused on the issue of provider to provider communication. Arthritis patients described many instances of breakdowns in communication between providers:

“So I have my family doctor, and then I have my rheumatologist, for me right now it’s sometimes, doctors aren’t great on following through on commitments all the time. My family doctor, the specialist, both said oh, they wanted to talk to each other about some stuff and they haven’t done that for about six to eight months, and I’ve seen them both, and they’re like ‘oh I have to do that.’”

Arthritis patients describe these breakdowns in communication often occurring between a family doctor that is seen more frequently, and the rheumatologist seen more infrequently. Healthcare providers were themselves aware of the issue. For rheumatologists, this was a particularly irritating situation as they felt their expertise was being undermined, as one provider explains:

“…hearing things from different sources is a major thing. It’s very challenging because a lot of patients don’t have a medical background and so they do have a certain amount of trust in the medical professionals around them. So, if I tell them one thing and they go to see the pharmacist, and they hear something else, or they go to a naturopath, and they hear something else or family doctor or anyone. I mean, anyone can have different opinions, but you have to be careful when you disagree with another physician’s opinion because it can do a lot of harm to the therapeutic relationship. So, it’s a bit of a problem in medicine and it’s everyone just trying to do the best job they can do, but sometimes we are giving people mixed messages.”

It is interesting to note that arthritis patients shared portions of this sentiment. Patients believed that both their family doctor and rheumatologist had their best interests in mind. It came down to
a matter of communication. Primarily, patients were frustrated with the apparent lack of communication between providers and believed it mostly rested with an overburdened healthcare system. Patients described their doctors as overworked and attributed many of their perceived failings as indicative of a healthcare system working at its limits.

### 3.2.1 Wait Times

Coupled with other concerns, the view of the healthcare system as overburdened was compounded by the often extreme wait times patients would experience. Unfortunately, as was covered in the review section, arthritis is a progressive disease, and time is a critical factor. Recall that wait times to see rheumatologists in Saskatchewan could last upwards of two years. What is more, the wait times for arthritis patients encompassed much of their care experience, as one patient describes:

“…they are already overloaded, and so it's not a good situation at all. And when you go there, they are nice enough, but they are like well, fine this is what you have, bye. And then they send requests out. Well like in my case my rheumatologist said you have osteoarthritis in the spine, and you need to have consistent physiotherapy treatment, and they sent the referral out. They never sent the report to my family doctor. Then they gave me a referral for physio, which I thankfully had and photocopied, and that was the only thing she (family doctor) had to go by. And then when I took it, physiotherapy, they said this is a chronic condition, you are on a two-year waitlist, I’m like what on earth!?"

It is essential to emphasize the flustered and exasperated tone of this patient. They describe being juggled from one situation to another, only to end up on a waiting list multiple years long. This was an experience that every arthritis patient described in some form. For some patients, they described situations they deemed as “lucky” that enabled them to skip some of the waiting, but there was no avoiding it in one sense or another. Often the wait times were in conjunction with an arthritis-related treatment that was outside the control of rheumatologists, as one patient explains:

“…when I had a shoulder injury that wasn’t responding very well, it took six months to get in to see them. They said I needed some arthroscopic surgery probably and they said prolly four or five months to wait. It’s been seven months now. So things are not fast. Physio, where I live, is horribly overbooked; there is only two that I can access without having
other insurance, and unless you’re a post-op patient, the waits are three or four months at the clinic, and four to six at the hospital.”

These issues highlight another critical aspect of wait times: relationship formation. It is difficult for some patients to form a healthy relationship with their rheumatologist when the time between each visit is several months to half a year. Healthcare providers are also keenly aware of this issue. Unfortunately, there are few things rheumatologists can do to fix the problem. Providers have found small workarounds, gaps in their schedules, answering prodigious numbers of emails, and the quick use of patient no-shows to ease this burden. Ultimately, it is a matter of resources and access, as one provider puts it:

“In an ideal world, they would be meeting with me within about 12 weeks after developing symptoms of pain. However, that is unfortunately not how medicine in Canada works because of resources and access to care…currently, my wait times are about six months, so it’s a minimum of 6 months after the start of symptoms before they can first see me. But there is often a delay in the family physician’s office. But that’s not me casting aspersions on the family physician. It's just a lot of other specialty areas in medicine just don’t see the rheumatological stuff very much. You don’t have that pattern recognition to look at someone and say ‘oh I know what this is they need to go see a rheumatologist’. It’s more ‘I don’t know what this is and I don’t know where I should send you yet, were going to do some tests and maybe eventually we’ll have an idea.”

This research has been an attempt to understand both the lived experience of arthritis as well as the nature of value co-creation between healthcare providers and patients. When we observe how value co-creation occurs in practice, we can examine what the barriers are to that practice. Patient wait times appear to be one of the most substantial obstacles to value co-creation. It serves to create doubt in the minds of patients as to the efficacy of our healthcare system and the expertise of our professionals. It encourages patients to look outside of a science-based system for answers. Perhaps most importantly, it leaves patients in a liminal state, when patients are searching for a sense of wellness and a return to regular function. Healthcare providers are also aware of these issues but have been unable to effect changes at a systemic level to help patients.
3.3 Barriers to Value Co-creation

The next theme, *Barriers to Value Co-creation*, is an examination of how a goods dominant mindset compromises the relationship between patients and providers. Utilizing previous themes, such as acknowledging the loss, it became clear that patients were looking for a healthcare system based upon caring and empathizing. However, it is essential to state that healthcare providers are not interested in delivering a sub-optimal service to patients. The physicians who participated in this study repeatedly demonstrated a genuine desire to help their patients succeed to the fullest. It is also important to state that physicians are a highly skilled and intelligent group of individuals. Therefore the ideas utilized by physicians that represent a goods dominant perspective are indicative of the implicit effects of GD logic on healthcare.

Healthcare providers are often keenly aware of the limitations of the system they operate within, as we have seen in previous sections. Recall that GD logic views value creation as one-sided. There is a creator of value, in healthcare, this would be the provider, and a consumer or destroyer of that value, the patient. Using this mindset, the patient or consumer of value is considered inexperienced and passive. Few physicians would admit to holding this view of their patients. Physicians often spoke of a desire for a partnership with patients making them far from passive recipients. This would also be in line with more service-dominant logic thinking. While patients were willing to accept at times that they were inexperienced about the human body and its systems, patients felt they possessed vast amounts of experience concerning living with their disease. This was the experience they felt was being denied at times. Feeling this denial or the perception of denial left some patients feeling that they were being treated in a passive way as one patient describes:

“It’s just for me with such a long history with my body that, I almost wish we’d have enough time from the first to just be like here is everything that is going on, so they can have a true understanding. `Cause when you’ve had a chronic illness for so long that could be related. I almost want to be like here is my history so they can get all the connections.”

“One thing I’m thinking is the doctors and physicians tend to have, they are the expert often mentality, but also they drop the ball on things…but they kind of like have almost a sense of power over my health…”

This tension with the physician rests in a strange position. This is due to the general sense from many patients that they were indeed being made a partner in their care. It was more of a nagging
sensation that they felt at times, that they were not always in lockstep with the physician. This places physicians in a tricky position as they navigate the space between building rapport with the patient while fulfilling the obligations of western medicine, as one provider describes:

“I try to make it a conversation, but realistically I have to get some information across, and we only have a finite amount of time.”

Concerns like this one leave patients in a tough position. Some patients commented that they were unsure of how the relationship with their doctor should work. For some patients, they would prefer the doctor to have more of a leadership position in their health. For others, they preferred to lead, and still, for some, they preferred a fifty-fifty approach. The concern is compounded when you consider the physician’s take on these issues, as one provider put it:

“Well you know I think that there is, there has been a real shift in medicine in the last 5 to 10 years where we have really gone from being paternalistic to trying to make it a dialogue and recognizing that that is a valuable thing. And so you are going to find different mindsets, in even people who graduated the same year as me. Not everyone is going to want to have a conversation.”

So it would seem that within the philosophy of medicine, there remains some debate around these issues. However, during this soul-searching within medicine, arthritis patients are left wondering why their relationships with some physicians are excellent and with others lacking. For some patients, they have chosen to take the initiative, which has led to increased frustrations, as one patient describes:

“Well, for example, follow up. You’re supposed to let your physician be a leader. No, they never tell you that for any healthcare, like say you need to come in to have this test or that test, forget it, you basically have to fight them on everything. The system is broken, if it’s not patient-initiated or the patient has some kind of an advocate that speaks on their behalf, forget it. You fall through the cracks big time over and over.”

The issue of falling through the cracks may represent a unique problem for patients in Saskatchewan. This could be in part due to the goods dominant logic that is informing healthcare and the systems surrounding it. Recall that goods dominant logic relies upon physical goods and products or ideas and practices meant for mass consumption and application. As a province, Saskatchewan’s population is generally speaking, split, with half living in the larger cities and towns and the other half dispersed throughout the province in rural communities. This has been
one of the cultural strengths of the province, but it is not suited for a GD logic approach to healthcare. This is due to the GD mindset of targeting and promoting to the most significant number of people, which would give preferential treatment to those within the cities. However, fully half of all arthritis patients would be located within rural communities in Saskatchewan. From the patient’s perspective, the healthcare system in Saskatchewan is not interested in resolving this inconsistency. Healthcare providers have also noted this discrepancy, as one provider describes:

“Ideally, I’m sure. And again this is me being biased and we’re calling, the people tell me this, but there are a lot of people who cancel their follow up appointments and just disappear, and I don’t know the numbers of those because those appointments get filled like that, due to the waitlist. But there is probably a substantial portion of people who leave and don’t come back. And I see that I’ll see people who’ve had rheumatoid arthritis for 30 years and have terrible damage who haven’t seen a rheumatologist for ten years because they don’t live nearby.”

There also remains some goods dominant concerns around how providers gather information from patients. As we have discussed, some providers prefer greater or lesser levels of interaction with their patients. However, even with providers with a strong desire for rapport and relationship building with patients, the tools used to gather information rely on methods closer to a goods dominant perspective. This is indicative of an implicit influence on healthcare using outdated managerial logic, even with physicians simultaneously acknowledging the nature of arthritis, as one provider describes:

“Well that is a very broad question really, I think if you look at the data, if you look at quality of life, and you look at medical comorbidities, arthritis consistently ranks as one of the highest impactors on quality of life. So, quality of life is, we have a scoring system for quality of life its called the HAQ (Health Assessment Questionnaire). It looks at all these different sort of arenas of day to day living and the expectations people have when they are getting through an average day, and it looks at how difficult it is for people to do those. So, one of the things we assess in the study is the impact on the HAQ score before, what it was after, and if it changes a certain percent, it's considered to be clinically significant.”

Unfortunately, the HAQ utilizes what could be considered a goods dominant technique for examining patient quality of life. The questionnaire is meant for mass application and, as such,
has been distilled into precise and non-personalized questions. For example, the HAQ and its variant, the HAQ-II, will ask patients Likert scale style questions about specific functions. These functions are things such as opening car doors, going to the toilet, rising from chairs, walking, and doing chores. The idea is that once the provider has the information about how, in general, a patient is doing, a prescribed plan can be developed by the healthcare provider. We have seen some of these concerns voiced by patients. However, the HAQ contains no way for the patient to personalize the care. There is no mention of mental health or hobbies lost or what the patient is looking to achieve or regain with medical intervention. As with many healthcare tools, the focus is on what the patient cannot do and may serve to frame thought patterns in future conversations. A service-dominant reframing of these concepts would place greater emphasis on customization and determining what a particular patient values and the steps needed to maximize that value proposition. This requires more than just the utilization of tools by healthcare providers to prescribe to patients a course of action. Instead, the emphasis is on value co-creation between patient and provider, and it generates a health plan rooted in activities that focus on what the patient can do to regain the experience of health.

3.4 Sensing, Experiencing, and Creating

The final theme is Sensing, Experiencing, and Creating. Throughout the analysis, it became clear that patients and providers truly value their interactions with each other. They focused on the positives when speaking of each other and referred to external sources that compromised the relationship. We examined how providers would utilize strategies that, by necessity, required them to step out of a goods dominant approach to maximize value for their patients. Up to this point, we have focused a great deal on the interruptions to value co-creation. This was necessary to fully understand where patients and providers lose the ability to find value in their interactions. However, the fact remains that patients and providers do find a lot of satisfaction in their interactions with one another. One of the goals of this research was to attempt to detect whether or not the ideals of service-dominant logic could be detected using a qualitative approach. The precepts that service-dominant logic highlights can indeed be discovered in these interactions. When we observe the application of these principles, it serves as a powerful and persuasive form of evidence that SD logic enhances the exchange between two actors. As was discussed, service-dominant logic is about actors (patient and provider) sensing,
experiencing, and creating, while integrating resources to create outcomes together. We can observe evidence of this phenomenon directly, as one patient describes:

“…but he’s also really caring and includes me in the decisions, and we’ll go over various medications pros and cons. ‘Which one do you want?’ And I like that I get to have a say, these are the side effects which one will work for the way I want to live. And I like being able to be in the decision making, not just ‘here is your prescription’, but to have that ownership on which medications I’m on and why.”

This situation is precisely what service-dominant logic would predict when both actors can integrate their knowledge, skills, and experience. Additionally, the feelings of co-creation are often integral to addressing earlier concerns for physicians, especially those related to medication adherence, as one patient describes:

“I think for me, the way my brain works, I like to understand why. So when I’m taking medications, I have to understand why it’s making me feel better. So for me then, oh great this medication’s gonna help me with this. So I know when to take it, so when I’m in those places, I take it. Not just for the sake of taking it, otherwise I’ll forget. And then, it feels because I’ve had a chronic illness for so long, it feels like I’m not being told what to do for my health. It’s that I have ownership and get to be part of my own healing and becoming better. And I think that even though my doctor is forgetful, why I stay with him is because I really love that we are a team working together on my health.”

For this patient, part of the ability to be medically adherent rested on the ability to integrate their healthcare experience and the advice of the physician into their life. It was more than just taking the medication on time but fully understanding how the medication works. This serves as a strong point of counter-evidence to any notion that patients are passive and inexperienced. The idea of being part of a team, of viewing their relationship as one of mutual respect and trust was one patients could not emphasize enough:

“I think they are all very kind, compassionate, and caring, which is wonderful. And it's not for lack of skill. I really feel that they are all willing to help… I know my rheumatologist. They are incredibly competent. I have no issues with them whatsoever. They are awesome I respect them like I said they respect me, we work together as a team and they’ve always been the one where if things were questionable, they said ‘I’ll just follow up on certain things’. Like there was a question of whether I had lupus or this was going to turn into
lupus, and they followed me and didn’t abandon me and said ‘nope we’ll see you at regular intervals’. It’s like ‘I’ll be there for you if you need me’. They are awesome.”

For some providers, the notion of forming and maintaining good relationships with their patients was equally important. As predicted by service-dominant logic, providers experienced a heightened sense of value co-creation when they could notice the real changes their expertise was having on their patients and their health outcome, as one provider describes:

“I think it's good. I think if you want to have a good relationship with patients, rheumatology is the best thing to be in. Because you see people at their worst or when they are really unhappy and unwell, and you walk them through this process, and you watch them get better. It's very gratifying because you can see that improvement day to day, and you can hear the feedback, and it’s a very positive feedback loop. And we have such a longitudinal relationship with patients. Like I have a few patients with some disease I see once a year, but most of them I see every sixth months. And I would recognize most of my patients like if I was out shopping, you know them, you can talk to them, you know what their families are doing. You know what their interests are all that kind of stuff.”

For many providers, the exchange that occurs has implications that extend far beyond the meeting of the patient and provider. Additionally, while patients may have expectations of the healthcare system and its providers, it would also be realistic that providers would have expectations of their patients. This is predicted by service-dominant logic and serves as a powerful indicator of the provider’s sense of value co-creation, as one provider describes:

“I expect them to be honest with me, and I expect them to tell me when they have concerns, and I expect them to do their blood test. I want them to be a part of the team. I want them to be a part of the conversation. They need to do their part. I can’t just patronize them and force them to take a shot every month. They have to be actively involved, and the more actively involved they are, the more likely there is a better outcome.”

The principles of service-dominant logic also provide a template for what occurs when actors cannot integrate resources and skills. For patients, it might be an issue of being unable to utilize the advice of their physician. For physicians, it might be that their knowledge and skills appear incapable of changing the health outcomes of their patients. One provider describes an instance where this can be observed:
“It also means that I have to try to focus as much as I can on the inflammatory disease, the stuff that the biologic medicines, for example, make most of an impact. I try not to see a lot of osteoarthritis; I would drown because everyone has osteoarthritis, and I have training in it and can help with it. but you can't because you can't fix osteoarthritis. The outcomes don’t change, doesn’t matter what you do, you can help with symptoms. But you can change the progression on inflammatory diseases. So, you really have to focus most on what you can change and who needs it.”

A significant take away in these instances is that both patients and providers hunger for value co-creation. It could be argued that this is evidence for a foundation upon which the entire interaction is based. For some patients, they found themselves in a transitional period. Either their doctor had recently moved, retired, or the patient had recently come to Saskatchewan. In these instances, patients described how being in between relationships with a trusted healthcare provider left them feeling unmoored with regards to healthcare decisions:

“When there is a personal interaction, you are more likely to say things that are bothering you that the doctor can help with, you know? Mental, physical that kind of thing… I still have that trust… I know they want to help.”

Potential break downs in the patient’s and provider’s sense of value co-creation could also be detected with some patients. We have already explored some of the risks to value co-creation in the form of patient perceptions and systemic roadblocks. However, it is still possible for patients to be unable to connect with their physician under certain circumstances, as one patient describes:

“And I think there is almost an assumption that because they are a physician, I should feel comfortable just spewing out my whole medical life history for you because it’s my responsibility to get my care rather than them also meeting me halfway in creating that space for me to share.”

When we examine the language being used by both patients and providers up to this point, an interesting pattern emerges. This pattern could be predicted with the application of a service-dominant lens. Both patients and providers routinely use a language describing collaboration, sharing, conversation, and togetherness. What characteristically follows from the successful application of this verb like language is a healthcare approach that feels more personalized; it empowers the patient and provider to find a solution that can be acted upon. From there, the
hindrances seem to be coming from outside this relationship. Mainly the obstacles arise from systemic issues stemming from a goods dominant logic insidiously and perhaps nearly invisibly clinging to many healthcare practices. This need not be the case; however, as we have demonstrated, the precepts of service-dominant logic can be detected in the interaction between patients and providers. It is a matter of bad ideas (GD logic) being replaced with better ones (SD logic). We have presented evidence that this can be done. As discussed in the review, most service mediums have already transitioned into fully embracing service-dominant logic. It is a question of why healthcare is lagging so far behind in this respect when both patients and providers already prescribe to many of SD logics core philosophies. As the next healthcare revolution unfolds, perhaps with continued investigation and suitable nudging, healthcare systems will discard the last vestiges of goods dominant logic.
4 Conclusion

This research sought to address the gap in the literature surrounding the lived experience of arthritis patients. We have provided evidence that patients with arthritis are complex. The effects of arthritis on their lives extend beyond merely the management of pain. It has implications for how an individual defines themselves and their life. Patients often have to choose between continuing cherished activities and disease management. Patients are looking for a healthcare system that understands these concerns in addition to providing solutions that bring them closer to the experience of healthy living and wellness.

Additionally, this research has made contributions to the marketing theory of service-dominant logic. Previous work suggested that a qualitative approach to service-dominant logic was lacking. Our investigations revealed that service-dominant logic is a detectable and critical component of the patient-provider relationship. The philosophies inherent to service-dominant logic were discoverable in the interactions between healthcare providers and patients. Using an SD Logic lens, we explored how different patients and providers co-created value. We uncovered clues as to why patients and providers value their interactions with one another through the use of verb-like, action-oriented, and relational language.

Value co-creation in practice appears to contain both enhancements to value as well as barriers. The enhancements are SD logic in orientation, such as collaborative language and personalized care. The barriers, often systemic, are rooted in outdated GD logic with attempts to standardize care. Our evidence demonstrated that both patients and providers valued good relationships with one another. We conjecture that the goods dominant logic informing healthcare acts as a continual barrier to functional co-creation activities. Both patients and providers commented on the feelings of stress emanating from a healthcare system that appears overburdened and requiring a reconsideration as to what both patients and providers value. The next step in the evolution of healthcare will be to learn these lessons as soon as possible. To address the concerns of patients and by extension, their healthcare providers, governments must be alert to what is happening. Governments that act and begin an investigation sooner rather than later can restore a patient’s faith in the healthcare system. When this is not the case, then the indicator for patients that something is amiss comes in the form of wait times that extend for months and years or in barriers to accessing care. The sooner healthcare can transition fully into
the value co-creation era, the sooner one further obstacle for both patients and providers can be removed.

4.1 Limitations

The limitations of this research are corresponding with many of the concerns common in some forms of qualitative investigation. The sample size of six (6) cannot represent the totality of all the parties involved. Additionally, researcher bias is an ever-present factor in qualitative analysis. This research did benefit from the addition of SCPOR patient-partnership; however, perhaps with a hundred different partners and multiple researchers, a different conclusion could be drawn. The participants could be considered a limiting factor, as well. Our sample represented the views of arthritis patients and providers within some areas of Saskatchewan. Perhaps patients and providers in other provinces would have a different perspective.

4.2 Future Research

There are a few avenues of potential for future investigations. The application of SD logic using a qualitative approach could be expanded into other areas of healthcare. This would give us a more well-rounded image of what a health system informed by SD logic is capable of. Understanding the specifics of what patients and providers expect from the healthcare system could be expanded upon. By narrowing the focus of the healthcare system, perhaps we can discover areas where resources are not being optimized for patient-provider expectations. Further exploration of the influences of goods dominant logic on healthcare outcomes may lead us to more desirable solutions. This could be done by pinning down where the impacts of GD logic may be emanating from. Providers would be the most ideally situated to uncover these mysteries. It remains to be seen whether the influence of GD logic is top-down or bottom-up or some combination, and more research is needed in this respect.
References


https://www150.statcan.gc.ca/n1/pub/82-229-x/2009001/status/art-eng.htm


4.3 Appendix A – Interview Guide

Section A

Questions for Patients

1. I am interviewing you today to get your perspective on interacting with the health care system. To start our interview, could you please describe your arthritis?

2. As someone who has little experience with arthritis, help me understand, how has arthritis affected your day to day life?
   - How has the impact of arthritis on your day to day life changed over the years?

3. For you, what has been the hardest thing about having arthritis?
   - How has this changed over time?

4. How has the health care system worked with you (or not) during your discovery of arthritis?
   - Did you suspect anything before a diagnosis or was it your doctor who first made the suggestion?
     - Medi-clinic? - Family doctor? - Internet search?
     - What were your expectations about dealing with the health care system prior to being diagnosed?
     - How have you (and your family...) been treated during this process?

5. Were you referred to a rheumatologist? If so, how long was the wait time?

6. Can you describe your most recent visit with a healthcare professional (Rheumatologist)? Was it a positive or negative experience for you? Please explain why?
   - What were you expecting from the doctor?

7. Describe your relationship with your rheumatologist.
   
   Prompt(s)
   - What are some of the things you feel your doctor gets right?
   - What are some of the things you feel your doctors gets wrong?
   - Do you feel you can act on the advice of your doctor?
   - Do you agree with the advice of your doctor?
   - If you disagree with your doctor do you feel you can communicate that disagreement?
     - What happens if you do communicate that disagreement, how do you and your doctor work past disagreements?

8. How often do you meet with your rheumatologist?
   
   Prompt(s)
- Is this too often, too few?
- What are you looking for when you meet with your doctor?
- During the meeting who talks more?
  - How do you feel about that?

9. What kinds of questions does your doctor ask you? (Leaving out anything very personal)
  - How does your doctor ask questions.
  - Do you feel like you can answer them.
  - Do you feel like they are listening.
  - What do you feel happens to the information you give to your doctor?

10. Since meeting with a rheumatologist what has changed about your experience with arthritis?

11. What do you think our healthcare system could do better to help those living with arthritis?

12. In terms of your interactions with the health care system, your rheumatologist or anything to do with the treatment of your arthritis, is there anything else you want to say? Anything you think we should consider?

13. Thank you for your time today, at the University of Saskatchewan our ethics policies give you the option of reviewing your interview transcript before I use it in my research. Would you prefer to review the transcript or if you’d like you can sign off on it now?

4.3.1 Section B

Questions for Providers

1. I’m interested in your professional experience with your patients, how do you feel arthritis impacts the lived experience of your patients?
  - What are some of the factors you feel influences the variability in the patients you see?
    - Age? - Family support? - Profession? - Activity level?
  - What do you believe is the hardest thing about having arthritis for your patients?

2. At what point in the patient’s journey do you typically meet with them for the first time?
  - How long do patients wait to see a rheumatologist for the first time?
  - How do you feel the wait time effects the patient?
    - Speaking in general terms some patients have experienced wait times of almost two years, how do you think would that impact the patients experience?
3. Generally speaking, how often do you meet with your patients?
   - What are some of the recurring concerns your patients share with you?
   - Do you have a sense of what your patients are expecting when they meet with you?
   - During the meeting who talks more?
   - How do you feel about that?

4. In general how would you describe your relationship with your patients?

5. Do you feel you patients are able to ask and act on your advice?

6. Do your patients ever disagree with your advice?

7. Overall, are there things you can identify that have led to good relationships with your patients?

8. Are there any factors you can identify that may compromise the relationship with your patients?

9. Lastly, how important is medication adherence for the management of your patient’s health?

10. In the work you do with patients how important is trust?
    - Given how often you meet with your patients and the time you get to work with them, do you feel you have the time to build a trusting relationship?
    - In general, is there anything you expect from your patients?

11. In Saskatchewan there are very few rheumatologists as compared to the population, how does ‘the low number of rheumatologists’ impact your work?
    - Do you meet with patients from all over the province?
    - What are some of the critical limitations that impede your work?
    - How would you prefer they were resolved?
    - What is the most difficult thing about your work that you wish your patients could understand?
    - What could our healthcare system do better to improve your practice and the health of your patients?

12. What are some things patients can do to reliably improve their healthcare experience?
    - Patterns you’ve observed, must account for, challenges to helping patients.

13. In terms of the relationship with your patients is there anything we missed that you want to discuss? Anything that you think we should consider?
14. Thank you for your time today, at the University of Saskatchewan our ethics policies give you the option of reviewing your interview transcript before I use it in my research. Would you prefer to review the transcript or if you'd like you can sign off on it now?
Dear Recipient,

I am a health researcher in the masters of marketing program at the University of Saskatchewan interested in interviewing you for a research study on arthritis. I am interested in the lived experience of individuals with arthritis, which remains a relatively unexplored topic in health research.

A great deal of attention has been paid to the efficacy of treatments and therapies targeting pain associated with arthritis, but not how individuals with arthritis navigate their journey. As you know, most individuals with arthritis share this journey with healthcare professionals.

As a rheumatologist, I believe you are in a unique position to comment on the healthcare needs and concerns of arthritis patients.

By involving you, the healthcare provider, I hope to understand how you navigate the space between providing excellent care to each of your patients while adjusting your delivery method to meet the individual needs of each patient. I also seek to understand how healthcare providers view the state of our healthcare system with regards to arthritis patients.

The interview should take no longer than 30 minutes. I understand time is an important aspect of your work and am willing to work with your schedule to find the best time.

Thank you for your time and consideration.

Best regards,

Ben Dunning
Call for Research Participants

We are seeking 6 Participants for an interview research project regarding arthritis.

Role Description:

Organization: University of Saskatchewan, Edwards School of Business.

Overview: I am a health researcher in the masters of marketing program at the University of Saskatchewan interested in interviewing you for a research study on arthritis. I am interested in the lived experience of individuals with arthritis, which remains a relatively unexplored topic in health research.

A great deal of attention has been paid to the efficacy of treatments and therapies targeting pain associated with arthritis, but not how individuals with arthritis navigate their journey. As you know, most individuals with arthritis share this journey with healthcare professionals.

As an individual living with arthritis I am interested in your experience both in coping with this condition and your experiences with rheumatologists and the healthcare system in Saskatchewan.

Time Commitment: Interviews should last between 1 and 1.5 hours.

If you are interested in this opportunity please contact:

Ben Dunning, Dunning.ben@usask.ca
Call for Patient & Family Advisors

We are seeking 1 Patient & Family Advisor to be a partner on a research project regarding arthritis.

Role Description:

Position Title: Patient/Family Advisor.

Organization: University of Saskatchewan, Edwards School of Business.

Role Overview: Assist the researcher in understanding the lived experience of individuals living with arthritis. Provide an alternative perspective enabling the researcher to consider points of view they would have otherwise missed. Assist the researcher in examining the interview guide as well as the perspectives of participants who have been interviewed.

Knowledge, Experience, Skills: We are searching for an individual who has lived with arthritis for many years and would be willing to contribute their knowledge of this experience to the researcher.

Responsibilities: Meet with the researcher at least one per month, possibly twice. Examine research materials, interview guides, transcripts etc. and provide a personal interpretation of the material.

Time Commitment: Meetings should last no longer than 1.5 hours.


What you can expect from the staff? The researcher is willing to make the necessary accommodations in consideration of the needs of the PFA such as: Traveling to a convenient public location, covering travel, parking, and other related costs.

Orientation Provided: An initial meeting with the researcher and their supervisor to cover the breadth of the research topic and the goals as well as answer any questions.

Supports available to participate:
☐ Honoraria
☐ Expense Reimbursement
☐ Other: _______________________

If you are interested in this opportunity please contact:

Ben Dunning, Dunning.ben@usask.ca
Appendix E – Participant Consent Form

You are invited to participate in a research study entitled:

The Healer’s Boon: How Patients and Providers Find Value

Researcher: Ben Dunning, Masters Student Researcher

Supervisor: Dr. Marjorie Delbaere, Associate Professor delbaere@edwards.usask.ca, 306.966.5916

Purpose(s) and Objective(s) of the Research:

- The lived experience of individuals with arthritis is understudied in health research. Much has been done to understand the treatment efficacy of therapies targeting arthritis, but not how individuals with arthritis navigate their journey. The goal of our research is to explore the needs and concerns of arthritis patients as well as the perspective of physicians on the needs and concerns of their patients.

Procedures:

- Study participants will engage in a semi-structured interview with the researcher. The duration of the interview is largely up to the participant; however, it would not be uncommon for an interview to last at least 45 minutes and up to 1.5 hours. During this time, the conversation will be audio recorded for future transcription. You will be provided with a copy of the transcript to allow for corrections, omissions or withdrawal before the data is used.

- Participants are free to ask any questions regarding the procedures and goals of the study or their role at any point during the interview.

Funded by: Saskatchewan Center for Patient Oriented Research (SCPOR)

Potential Risks:

- There are no known or anticipated risks to you by participating in this research.
• Participants will receive a copy of this form stating the goals of the study and all the relevant contact information for future inquires.

**Potential Benefits:** By involving patients directly in the research process, patients will be able to communicate their point of view on the healthcare system and their relationship with their healthcare providers and how that relationship impacts their healthcare outcomes. By involving healthcare providers, we hope to understand how healthcare providers view the state of our healthcare system.

**Confidentiality:** The identity of participants will be known only to the researcher as per the nature of interview studies. Your identity will never be shared with anyone. A pseudonym will be used in place of your name.

**Storage of Data:** Data will be stored on secure password protected devices maintained by the University of Saskatchewan. When the study is complete the data will no longer be required and will be destroyed beyond recovery.

**Right to Withdraw:**

• Your participation is voluntary and you can answer only those questions that you are comfortable with. You may withdraw from the research project for any reason, at any time without explanation or penalty of any sort.

• Should you wish to withdraw, your data including interview recordings or transcripts will be destroyed beyond recovery.

• Your right to withdraw data from the study will apply until May 1st, 2020. After this date, it is possible that some form of research dissemination will have already occurred and it may not be possible to withdraw your data.

**Follow up:**

• To obtain results from the study, please email Ben Dunning at Dunning.ben@usask.ca or Marjorie Delbaere at delbaere@edwards.usask.ca.

**Questions or Concerns:**
• Contact the researcher(s) using the information at the top of page 1;

• This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office ethics.office@usask.ca (306) 966-2975. Out of town participants may call toll free (888) 966-2975.

Your signature below indicates that you have read and understand the description provided; I have had an opportunity to ask questions and my/our questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records.

_________________________________________  ________________________  __________
Name of Participant                         Signature                                     Date

_________________________________________  ________________________
Researcher’s Signature                       Date

A copy of this consent will be left with you, and a copy will be taken by the researcher.
4.8 Appendix F – Transcript Release

TRANSCRIPT RELEASE FORM

Title: The Healer’s Boon: How Patients and Providers Find Value

I,______________________________, have reviewed the complete transcript of my personal interview in this study, and have been provided with the opportunity to add, alter, and delete information from the transcript as appropriate. I acknowledge that the transcript accurately reflects what I said in my personal interview with [name of the researcher]. I hereby authorize the release of this transcript to [name of the researcher] to be used in the manner described in the Consent Form. I have received a copy of this Data/Transcript Release Form for my own records.

_________________________   __________________________
Name of Participant   Date

_________________________   __________________________
Signature of Participant   Signature of researcher
4.9 Appendix G – Ethics Certificate

Certificate of Approval

Application ID: 1488
Principal Investigator: Marjorie Delbaere

Department: Department of Management and Marketing

Locations Where Research Activities are Conducted: Saskatoon, Saskatchewan, Canada
Student(s): Benjamin Dunning
Funder(s):

Sponsor: Saskatchewan Centre for Patient-Oriented Research
Title: The Healers Boon: How Patients and Providers Find Value

Approved On: 28/Oct/2019
Expiry Date: 27/Oct/2020

Approval Of: Behavioural Research Ethics Application
Appendix A: Interview Guide Questions
Appendix B: Rheumatologist Recruitment Letter
Appendix C: Patient Recruitment Letter for SCPOR
Appendix D: Patient Family Advisor Recruitment (SCPOR)
Appendix E: Participant Consent Form
Appendix F: Transcript Release

Acknowledgment Of:

Review Type: Delegated Review

CERTIFICATION
The University of Saskatchewan Behavioural Research Ethics Board (Beh-REB) is constituted and operates in accordance with the current version of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2 2014). The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this project, and for ensuring that the authorized project is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

ONGOING REVIEW REQUIREMENTS
In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month prior to the current expiry date each year the project remains open, and upon project completion. Please refer to the following website for further instructions: https://vpresearch.usask.ca/researchers/forms.php.

Digitally Approved by Patricia Simonson, Vice Chair
Behavioural Research Ethics Board
University of Saskatchewan