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Hear My Voice: Qualitative Studies to Explore What Empowers Patients to Talk With Their Doctor and Participate in Making Health Care Decisions

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HEAR MY VOICE: QUALITATIVE STUDIES TO EXPLORE WHAT EMPOWERS PATIENTS TO TALK WITH THEIR DOCTOR AND PARTICIPATE IN MAKING HEALTH CARE DECISIONS

by

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DEDICATION

Wherever you are on your journey with fibromyalgia, may your voice be heard.

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ABSTRACT

Patients with fibromyalgia are faced with many decisions throughout the process of seeking and obtaining health care. For patients to feel empowered to take action, it is essential they feel as if they can play a role in making decisions up to their desired level of participation. However, it is unclear what constitutes empowerment in shared decision making between patients and providers. For patients with fibromyalgia, who deal with complex symptomology and individualized treatment choice, it is important to know what makes them feel empowered to participate in care. The objective of this dissertation is to create a patient-centered definition and context for empowerment within shared decision making between patients with fibromyalgia and their doctor. The findings presented here provide perspectives on empowerment and shared decisions directly from the voices of patients with fibromyalgia.

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CHAPTER 1

INTRODUCTION

This dissertation creates a patient-centered definition of the fundamental elements empowering patients to engage in making decisions with their provider during the course of clinical care. It builds on the existing literature by gathering patient perceptions of what constitutes empowerment when making decisions about treatment or disease management. These perceptions will be used to form two conceptual frameworks regarding how empowerment translates into shared decisions patients make with their health care provider. Evidence suggests improving patient involvement in decision-making improves clinical outcomes and may reduce the cost of care (Rathert et al., 2013; Street et al., 2009).

This dissertation focuses on those who have a chronic condition called, fibromyalgia syndrome (FMS). Fibromyalgia syndrome has a complicated, dynamic etiology with patients going through periods of symptom flare-ups and remission. Patients and providers must also consider many combinations of available treatment. Given these factors, patients and providers need to continuously work together to make decisions to optimize the treatment for the patient. However, within the literature, current evidence about patient perceptions about being a part of shared decisions are derived from theories developed using provider insight rather than from patients themselves.

Since FMS affects each person in unique ways, a high level of personalization in treatment is required. Therefore, it is imperative to understand what patients perceive they need to participate in shared decisions regarding disease management. The findings of this investigation and the conceptual frameworks developed from the data will assist in discovering how empowerment plays a role in shared medical decision making and holds the potential to create evidence-based interventions that integrate the patient voice.

Patient Empowerment, Patient Centered Care, and Shared Decision Making

As a patient, the experience of interacting with the doctor is often rife with frustration. For many patients, this frustration stems from a lack of understanding what is wrong with them and poor communication during the clinical encounter (Benham-Hutchins et al., 2017; Ong et al., 1995). Poor communication often occurs because physicians talk to patients in a way that does not resonate with them (Ubel et al., 2017). Additionally, patients feel that doctors misinterpret what they are saying when it comes to their symptoms. Overall, this miscommunication between patients and doctors leads to lack of trust regarding treatment decisions (Bieber et al., 2008).

Patient centered care (PCC) is a holistic approach based on individual preferences, values, and needs (Institute of Medicine (U.S.) & Committee on Quality of Health Care in America, 2001; The American Geriatrics Society Expert Panel on Person-Centered Care, 2016). PCC exemplifies the core principles of improving health care quality and patient experience. In order for care to be focused on individual needs, the patient and provider must have open communication and mutual trust between them. Only then will the translation of PCC into clinical practice be effective in addressing issues related to quality. Utilized in this way, PCC improves quality through its ability to enhance patient autonomy and provide better treatment understanding. Improved patient autonomy and understanding potentially leads to better treatment adherence which in turn improve outcomes for patients (Epstein et al., 2010; Ulin et al., 2015).

Translation of PCC into practice requires the provider to be willing to put the patient at the forefront of the health care experience. However, for PCC to be most effective, patients also must be engaged in the process. For patients, choosing to participate in the process of care is an essential part of effectively managing health. Taking action to manage health is a multi-step process. Effectively managing their health requires many decision points resulting in the choice of several potential actions. These decisions include choosing to go to the doctor, choosing a plan of treatment or prevention with the doctor, adherence to treatment over time or following through on prevention, modification of treatment, and deciding whether an improvement in the desired outcome exists. Additionally, within this list of decisions, the patient must also choose whether or not to participate in shared decision making (SDM) during encounters with the physician. SDM is the open exchange of information between the patient and the doctor about health care decisions that incorporate the patient's values, beliefs, and preferences into the discussion (Institute of Medicine (U.S.) & Committee on Quality of Health Care in America, 2001; Mitchell et al., 2012). The result of effective shared decision making is a choice that has been deliberated by the patient and provider as a team and is mutually agreeable (Toupin-April et al., 2015). Evidence suggests patient engagement in shared decision making with their health care provider improves clinical outcomes (Rathert et al., 2013; Street et al., 2009). Patients that are fully engaged in making decision about their health care are considered to be activated patients (Hibbard & Greene, 2013). However, little is known about the factors that motivate patients to feel empowered to believe taking an active role in their health care is important.

Gaps in Current Knowledge

Many definitions of patient empowerment exist within medicine (Aujoulat et al., 2007; Barr et al., 2015; Bravo et al., 2015; Castro et al., 2016; Cerezo et al., 2016; Holmström & Röing, 2010; Johnson, 2011; McAllister et al., 2012), however only four take into account the perspective of the patient and do not focus on chronic pain conditions (Abrahams et al., 2019; Aujoulat et al., 2008; Johnsen et al., 2017; Small et al., 2013). Existing literature focuses on actions providers should take to empower patients to participate in shared decision making such as providing appropriate information (Aslani, 2013; Cerezo et al., 2016), learning how to communicate openly with patients (Evers, 2017; Teunis, 2018), and promoting patient centered interactions during encounters (Ubel et al., 2017). However, little is known about how these actions align with what patients believe is important and necessary for them to participate in making decisions regarding their health care. Understanding what patients need is important because physicians frequently underestimate how engaged patients would like to be in the process of care (Politi et al., 2013). Further, there is a paucity of literature examining the factors motivating patients to feel empowered to engage in shared decision making during the clinical encounters (Légaré et al., 2008; Légaré & Witteman, 2013). To design and implement effective interventions to improve the delivery of patient centered care, it is imperative to understand what patients believe is necessary to empower them to participate in shared decisions about chronic disease management.

Gaps in Knowledge for Patients with Fibromyalgia

Fibromyalgia syndrome is a non-curable, chronic pain condition affecting approximately 4 to 12 million in the United States (Centers for Disease Control and Prevention, 2017; Walitt et al., 2015). Treatment for FMS is often a combination of medication and non-pharmacologic treatment modalities (American College of Rheumatology, 2019; Centers for Disease Control and Prevention, 2017). The optimal combination of treatment modalities is different for each patient requiring frequent interactions between patients and providers to discover this combination. Due to the wide variety of treatment that may be effective for individual patients, FMS represents a condition in which it is important for patients to have confidence to participate in shared decisions regarding disease management. This participation is important because it allows for selection of a treatment aligned with the individual patient's values and preferences. Selecting a treatment that aligns with preferences has the potential to improve treatment adherence and desired patient outcomes. It is currently not known what motivates patients with FMS to participate in shared decision making with their physician to select optimal and mutually agreed upon treatment modalities. Additionally, there are associations reported in the literature between low socioeconomic status (SES) and FMS

(Fitzcharles et al., 2014; Kang et al., 2016). The factors empowering low SES populations with fibromyalgia to engage in share decisions with their providers may be different than those who are not of low SES.

Specific Aims

To create a patient-centered definition of patient empowerment, the specific aims for this study will be:

Specific Aim 1

Evaluate the body of literature related to patient empowerment since 2010 to identify existing conceptual definitions and conceptual domains and how those definitions and domains are translated within the context of clinical practice. This scoping review will be used to develop the interview guides probing patient perceptions of empowerment and their perceptions of how empowerment can be supported in clinical practice.

Specific Aim 2

Explore the major factors that constitute patient empowerment and participation in treatment decisions within the context of shared decision making for patients with fibromyalgia syndrome. The information gathered will be used to construct conceptual frameworks to describe concepts of empowerment and shared decision making.

Specific Aim 2a: Identify the major factors that constitute patient empowerment to participate in shared decision making for patients with fibromyalgia syndrome.

Specific Aim 2b: Describe patient perceptions of participation in shared decision making with their provider in patients with fibromyalgia syndrome.

Conclusion

This dissertation is outlined as follows. Chapter 2 evaluates the literature illustrating the state of evidence on the definitions and concepts related to patient empowerment published in the scientific literature since 2010. Then, after identifying the knowledge gap, Chapters 3 and 4 apply qualitative research methodology to elucidate major factors constituting perceptions of patient empowerment and how these perceptions translate into share decision making for patients with fibromyalgia. Conceptual frameworks will highlight what patients report as the major factors constituting patient empowerment and how those factors translate in shared decisions about disease management. Chapter 5 summarizes major insights gained in Chapters 2-4 and informs future research about the design and implementation of interventions seeking to improve shared decision making and the delivery of patient-centered care.

CHAPTER 2

REVIEW OF PATIENT EMPOWERMENT LITERATURE

Patient participation in decision-making with their provider and other activities focused on managing their health is a significant part of patient centered care (PCC) (Barry & Edgman-Levitan, 2012). PCC is an approach to patient care requiring open and honest communication between patients and providers incorporating the patient's priorities, values, and needs into the process of health care (Mitchell et al., 2012; Toupin-April et al., 2015). As part of PCC, shared decision making (SDM) occurs when patients and providers openly exchange information about the patient's values, beliefs, and preferences to make a mutually agreeable decision about health care treatments (Institute of Medicine (U.S.) & Committee on Quality of Health Care in America, 2001; Mitchell et al., 2012). For SDM to be effective, the patient needs to clearly express their preferences and priorities; and feel comfortable expressing this information to their doctor. The concept of patient empowerment is rooted in the ability of the patient to decide what is significant to them and take actions to communicate this information to their provider (Anderson & Funnell, 2010).

Patient empowerment is an important component for the success to ensure the delivery of patient centered care. Theoretical models of empowerment have been proposed to support increased levels of collaboration between patients and providers during the clinical encounter (Anderson & Funnell, 2010; The Lancet, 2012). Patients have expressed a desire to participate in their care through SDM (Gruman, 2011; Tzeng et al., 2015). Evidence suggests that patients participating in care leads to improvement in outcomes (Greene et al., 2015; Hibbard & Greene, 2013); however, there is limited evidence about what is effective when it comes to promoting patient empowerment to support SDM within clinical practice. In order to provide practical strategies for successful interventions aimed at translation of patient empowerment, there is a need to understand the current definitions of patient empowerment that exist in the literature since the enactment of the Affordable Care Act in 2010, which placed emphasis on patient centered care (Millenson & Macri, 2012).

Therefore, the objective of this chapter is to review the literature on patient empowerment since 2010 to identify existing conceptual definitions and how those definitions and domains that facilitate the translation of patient empowerment within the context of clinical practice.

Methods

To conduct this literature review, several databases were searched including PubMed/MEDLINE and Academic Search Complete. Search terms used to find applicable articles were " patient empowerment" and "patient empowerment AND chronic conditions." Search results in PubMed returned more than 55,000 articles. After applying filters for articles published in English within the past 10 years, the search yielded more than 24,000 articles. Due to the large volume of articles produced, the search was limited to articles using the words patient empowerment in the title, yielding a total of 429 articles. As described in Figure 2.1, this strategy resulted in 321 articles after duplicates were removed. Articles were screened by one reviewer by reviewing the study abstract. To be included in this scoping review, articles needed to address patient empowerment within clinical care between patients and physicians. Further review of the entire article yielded 56 relevant articles.

The relevant articles were reviewed for definitions created by the authors or definitions utilized by the authors in their respective study. The definitions were further sorted into categories of structure, process, or outcome based on the Donabedian model for health care quality (Berwick & Fox, 2016; Donabedian, 1988). Then the relevant articles were reviewed for various concepts of empowerment the authors were attempting to measure. These concepts were categorized into domains of empowerment. The definitions and domains are discussed further in this chapter.

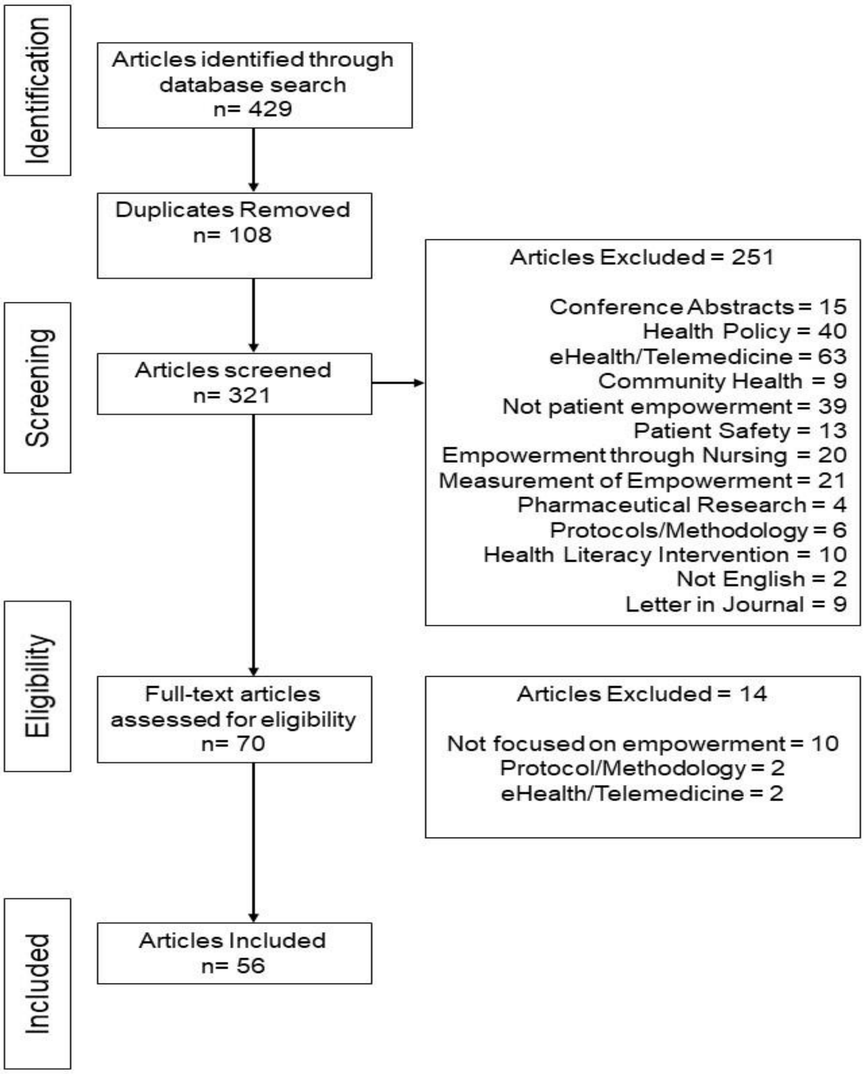

Figure 2.1. Study Flow Diagram

Results

The results of the literature search yielded 20 review articles describing definitions of patient empowerment and/or conceptual domains constituting empowerment; 20 studies using data try to measure empowerment or describe patient empowerment (13 quantitative methodology, 6 qualitative methodology, 1 mixed method); and 16 commentary articles where authors describe how empowerment should be viewed within clinical practice.

Definitions of Empowerment

In the published literature from 2010 to present, there are 12 definitions of patient empowerment noted (Table 2.1), with several of the definitions cited more than once as a theoretical basis. Few studies during this time frame focused on the patient perspectives and definitions of empowerment (Ramsay Wan et al., 2012; Renzi et al., 2017; Schneider-Kamp & Askegaard, 2019; Small et al., 2013). Several definitions explain that patient empowerment has to do with a change in patient behaviors. However, it is unclear what motivates this behavior change. The lack of a patient-defined definition of empowerment makes it difficult to assess how patients engage in care with their provider and facilitating strategies that translate it into action in clinical practice.

The Donabedian theory for evaluating health care suggests quality can be improved through changes in health care structure, process, or outcomes (Donabedian, 1988). In Table 2.1, definitions of empowerment are denoted as a process or an outcome, as defined by authors of the paper. In applying the Donabedian theory, patient empowerment may improve the delivery of PCC because it is considered to be a process that happens between doctors and patients (Aujoulat et al., 2007; Cerezo et al., 2016; Jørgensen et al., 2018) or an outcome where being empowered is the result (Anderson & Funnell, 2010; Holmström & Röing, 2010). In this context, patient empowerment is given to patients by the provider. In order for empowerment to occur as a process or an outcome both physicians and patients need to be actively involved (The Lancet, 2012). These views do not draw on the perspective of the patient and their role in empowerment. Furthermore, without a consistent and clear definition of patient empowerment, it is difficult to compare results across the literature to draw conclusions about how empowerment is applied to improve PCC within clinical practice. The empowerment literature is focused on interventions where either providers are stimulating patients to be empowered or patients are doing it for themselves (Bravo et al., 2015); rarely both perspectives are included (Bogaert & Petit, 2021; te Boveldt et al., 2014). Providers are tasked with taking actions such as providing information to patients (Aslani, 2013); eliciting information from the patient (Vinson, 2016); and helping patients achieve goals and overcome barriers (Anderson & Funnell, 2010). For these actions to be meaningful, patients need to be engage with their provider, be adherent to treatment plans, and able to self-manage their conditions (Funnell, 2016; Johnson, 2011). Further, patients and providers view empowerment differently. Patients define empowerment as personal change, while providers define empowerment as a process of communication (Aujoulat et al., 2007). Without taking into account the perspective of the patient, creating patient-centered interventions to boost empowerment for patients that can be implemented on a large scale is challenging.

Table 2.1 Definitions of Empowerment

Author of Definition	Definition	Process or Outcome	Cited by
Anderson & Funnell, 2010	"Empowerment is a process when the purpose of an educational intervention is to increase one's ability to think critically and act autonomously."	Process	
Aslani, 2013	"A process and outcome whereby patients' self-reliance, self efficacy, and active involvement in health related consultations ultimately impart treatment decision-making powers to patients."	Both	
Baars et al., 2010	"As a result of empowerment, patients may develop a greater sense of self-efficacy regarding various disease and treatment-related behaviors, and may express changes in life priorities and values."	Outcome	
Ballesta & EMPATHiE Consortium, 2016	"An empowered patient has control over the management of their condition in daily life. They take action to improve the quality of their life and have the necessary knowledge, skills, attitudes and self-awareness to adjust their behavior and to work in partnership with others where necessary, to achieve optimal well-being."	Outcome	Abrahams et al., 2019 Kayser et al., 2019
Bogaert & Petit, 2021	"The patient's capabilities to develop and make their choices with help as needed from their support network."	Outcome	

Feste & Anderson, 1995	"The empowerment philosophy is based on the assumption that to be health, people must be able to bring about changes, not only in their personal behavior, but also in their social situations and the organizations that influence their lives"	Process	Holmström & Röing, 2010
Johnson, 2011	"The notion of health care empowerment can be described as the process and state of participation in health care that is characterized as (1) engaged, (2) informed, (3) collaborative, (4) committed, and (5) tolerant of uncertainty."	Process	Johnson et al., 2012
The Lancet, 2012 (ENOPE)	"…a process to help people gain control, which includes people taking the initiative, solving problems, and making decisions and can be applied to different settings in health and social care, and self-management."	Process	Garattini & Padula, 2018 te Boveldt et al., 2014
McAllister et al., 2012	"Individual's capacity to make decisions about their health (behavior) and to have, or take control over aspects of their lives that relate to health."	Outcome	
Schulz & Nakamoto, 2013	"…patient empowerment is conceived as the patient's participation as an autonomous actor taking increased responsibility for and a more active role in decision making regarding his or her health."	Process	Bodolica & Spraggon, 2019 Náfrádi et al., 2017

Small et al., 2013	"An enabling process or outcome arising from communication with the health care professional and a mutual sharing of resources over information relating to illness, which enhances the patient's feelings of control, self-efficacy, coping abilities, and ability to achieve change over their condition."	Both	Acuña Mora et al., 2018 Acuña Mora et al., 2019
World Health Organization, 1998	"a process through which people gain greater control over decisions and actions affecting their health" and should be seen as both an individual and a community process."	Process	Kärner Köhler et al., 2018 Lejbkowicz et al., 2012 Wong et al., 2014

Domains of Empowerment

Within the many definitions of empowerment, many domains of empowerment explain the concepts encompassing the definitions of empowerment. The domains extracted from the empowerment literature are displayed in Table 2.2 (Agner & Braun, 2018; Barr et al., 2015; Castro et al., 2016; Cerezo et al., 2016; Johnson, 2011; Jørgensen et al., 2018; te Boveldt et al., 2014; Wakefield et al., 2018; Zhao et al., 2020). The review articles listed in the table each examine different aspects of patient empowerment. With so many domains of empowerment being discussed it is difficult to determine which are the most significant drivers of patient centered interactions between patients and providers. The number of identified domains can make translation to clinical practice difficulty because of the wide spread of concepts to cover. While there is overlap between articles with regard to several identified domains, it is not known if any carry more weight over others from the perspective of the patient within the concept of patient empowerment.

Table 2.2. Domains of Empowerment Identified in Systematic/Literature Review Studies

Authors	**Objective of Review Article**	**Empowerment Domains**
Agner & Braun, 2018	Patient views on empowerme0nt in qualitative research	Control Psychological Coping Legitimacy Support Knowledge Participation
Barr et al., 2015	Assess measures of patient empowerment	Patient states, experiences, and capacities Patient actions and behaviors

		Patient self-determination within the healthcare relationship Patient skills development
Castro et al., 2016	Explore concepts of patient empowerment, patient participation, and patient centered	Communication between provider and patient Patient centered approach Enhancing patient competency Active participation Sense of Meaning
Cerezo et al., 2016	Analyze definitions and dimensions of patient empowerment	Participating in decision making Gaining control Knowledge acquisition Coping skills Positive attitude Motivation Trust Sharing Capacity Building
Johnson, 2011	Explore how patient empowerment is influenced by external factors	Engagement Informed Collaborative Committed Tolerant of Uncertainty
Jørgenson et al., 2018	Barriers and facilitators to empowerment in patients with cancer	Empowerment is ongoing Knowledge is power Having an active role Patient-provider communication & interaction Support from being in a group Religion & spirituality Gender
te Boveldt et al., 2014	Define empowerment in the context of pain management for patients with cancer	Pain management Self-efficacy Active participation Coping Having resources
Wakefield et al., 2018	Define patient empowerment in the context of life limiting disease	Self-identity Personalized knowledge in theory & practice Acknowledgement of terminal illness Negotiating relationships Coping with continued loss

Zhao et al., 2020	Determine impacts of empowerment interventions for patients with hypertension	Self-management Lifestyle change

Further, the domains of empowerment can be combined into categories of relational concepts and personal concepts (Náfrádi et al., 2017). Relational concepts require interaction between two people such as being supportive or making decisions together. The relational interaction between patients and physicians is essential to the open and honest communication needed for shared decision making. Personal concepts are related to the patient themselves such as attitudes or self-efficacy. These differences are shown as a conceptual framework in Figure 2.2.

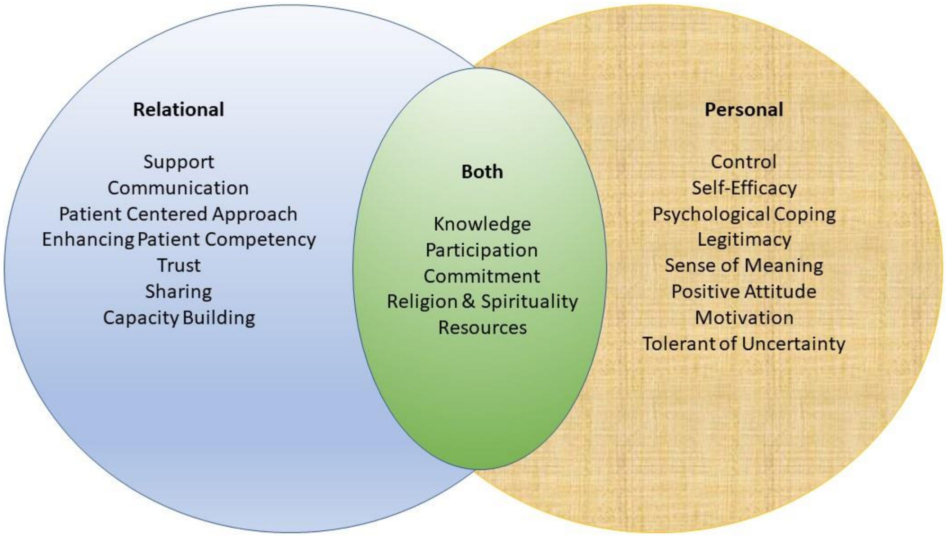

Figure 2.2. Conceptual Framework of Domains from Literature

Discussion and Conclusions

Patient empowerment is an essential part of PCC and SDM between patients and providers. However, there is little clarity and cohesion concerning the definition of empowerment or conceptual domains constituting patient empowerment. Within the existing literature, there are many definitions of empowerment being used in research and practice (Fumagalli et al., 2015; Garattini & Padula, 2018; Holmström & Röing, 2010; McAllister et al., 2012), with no clear definitive, standardized definition (Aujoulat et al., 2007; Barr et al., 2015; Johnson, 2011). A review article of patient empowerment and other related concepts by Castro et al in 2016 identified 20 definitions of patient empowerment (Castro et al., 2016). Similarly, a separate review article by Cerezo et al. analyzing definitions of patient empowerment identified 17 existing definitions (2016).

Within the context of patient centered care and shared decision making, both patients and providers have to take part in the interaction through communication. One of the main roles of the provider is to facilitate interactions that promote patient empowerment including openly exchanging information and enabling patients. First, providers discuss relevant information with patients in order to make decisions (Cerezo et al., 2016; Miller, 2009). In order for this decision making process to be effective, the information provided needs to be given at an appropriate level of health literacy (Aslani, 2013). Second, providers have to create an enabling relationship with their patients in order for empowerment to happen (Johnsen et al., 2017). However, physicians face several barriers to creating an environment of empowerment. Physicians are taught during medical school how to talk to patients and steer the patient toward treatment decisions picked by the doctor (Vinson, 2016). Although, medical students are increasingly being taught about how to implement shared decision making into their patient interactions (Yen et al., 2019). In practice, physicians are faced with changing treatment guidelines and challenges for patients, such as access to care that hinder enabling empowerment (Kambhampati et al., 2016). A paradigm shift is needed with an aim of creating an environment of empowerment.

For patient empowerment to lead to better patient-centered care, patients also have responsibilities within the patient-provider relationship. One action they need to take is to gather information about their condition and treatment options from reliable sources to have health care discussions with their provider (Miller, 2009). According to Jorgenson et al, empowerment is facilitated by patient having information, respect, and open communication with their provider (Jørgensen et al., 2018), which effectively makes patients a partner in their health care (Kayser et al., 2019). Being a partner in health care is part of shared decision making due to the relational nature of patients making decisions with their provider. However, little is known about what motivates patients to feel as if they can be a partner in their health care and how to translate information into action.

Given the lack of a single cohesive definition of empowerment, it is especially concerning that patients and providers have different perspectives on empowerment. Approaching empowerment from different perspectives creates a gap in communication that can lead to less effective SDM. Specifically, the breakdown in communication occurs because the knowledge from the provider is not accurately received and translated into actionable behavior change for the patient. Lack of actionable behavior change does not enable improvements in health outcomes.

Furthermore, ethical issues must be managed within the dynamic between the patient and physicians when considering patient empowerment. A principal-agent relationship exists between patients and physicians during a clinical encounter (Garattini & Padula, 2018). In a principal-agent relationship, the patient's need for information is reliant upon the knowledge possessed doctor because they have specialized experience and training in medicine creating a potential imbalance of power (Ludwig et al., 2010). Within this relationship, the provider is responsible for minimizing the power dynamic to ensure the patient is fully informed to make decisions that work for their situation (Anderson & Funnell, 2010). Additionally, information asymmetry exists as doctors hold information related to treatment and access to care (Dunn, 2019).

When patients visit the doctor and are empowered to participate in SDM health outcomes are improved through shared decisions. However, it is unclear whether the improved outcomes are patient defined or physician defined. Currently, the voice and perceptions of the patient are largely missing from the greater discussion about how patients feel empowered to participate in making shared medical decisions. Figure 2.3 shows a conceptual framework synthesizing how empowerment should impact SDM through the clinical decision making process between the patient and the provider. In this framework, patient empowerment to participate in shared decision making is a process through which the patient shares, up to their desired level of engagement, information, facts, and opinions of their experience with their condition to their health care provider in order to make mutually agreed upon decisions. After a treatment is selected, it is possible for the selection to change. Depending on the situation, the cycle may start again with a new clinical encounter, a new feeling of empowerment to make a change, or another discussion with the provider. The conceptual frameworks developed in Chapters 3 and 4 will show what happens during empowerment and shared decision making.

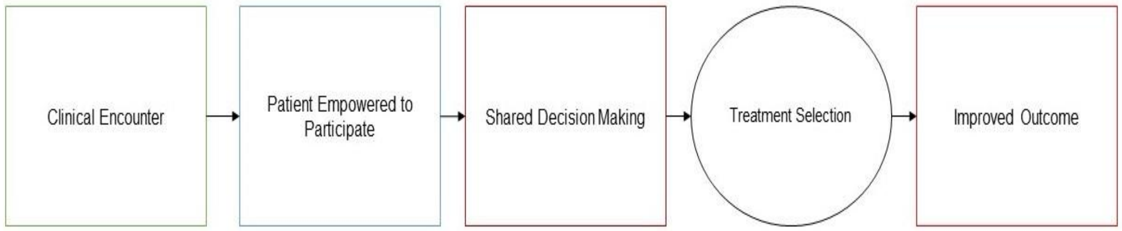

Figure 2.3. Conceptual Framework

CHAPTER 3

PERSPECTIVES ON EMPOWERMENT IN PATIENTS WITH FIBROMYALGIA SYNDROME[1]

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[1] Oostdyk, A.M. To be submitted to TBD.

Introduction

Fibromyalgia syndrome (FMS) is a chronic, multi-symptom condition affecting approximately 4 to 12 million people in the United States (Centers for Disease Control and Prevention, 2017; Walitt et al., 2015). Fibromyalgia syndrome disproportionately affects women with symptoms including widespread pain, fatigue, sleep problems, mood related symptoms (Borchers & Gershwin, 2015; Centers for Disease Control and Prevention, 2017; Walitt et al., 2015). Due to the complex symptoms experienced that are similar to other chronic conditions, fibromyalgia syndrome may take time to diagnose (American College of Rheumatology, 2019). Because there is no cure for fibromyalgia, patients must manage their symptoms, in conjunction with their treating physician, with an individualized combination of prescription and non-pharmacologic treatment modalities (American College of Rheumatology, 2019; Centers for Disease Control and Prevention, 2017; Rahman et al., 2014). However, treatment adherence is affected because patients report poor communication with their provider undermines adhering to recommended treatments (Bieber et al., 2008).

In order to adequately manage of fibromyalgia syndrome, patients need to be able to engage in shared decisions surrounding therapeutic options when making treatment decisions with their provider. Shared decision making (SDM) involves the patient and provider to openly and honestly exchange information to make mutually agreeable decisions for treatment that are congruous with the patient's preferences, beliefs, and values (Institute of Medicine (U.S.) & Committee on Quality of Health Care in America, 2001). For SDM to occur, patients need to feel comfortable expressing their preferences and goals to the doctor. Sharing goals and preferences empowers patient to participate in their therapy decisions, but patients’ must have the ability to actively discuss current therapeutic effectiveness with their doctor (Anderson & Funnell, 2010). Within shared decision making with the physician, patient empowerment is a process through which the patient shares, up to their desired level of engagement, information, facts, and opinions of their experience with their condition to their health care provider in order to make mutually agreed upon decisions.

Current research focuses on the role of the provider within SDM interactions and how providers can empower patients (Johnsen et al., 2017; Miller, 2009; Ubel et al., 2017). However, there is a paucity of evidence aimed at understanding how patients, such as those chronic conditions like FMS, feel empowered to discuss their condition and effectiveness of treatments with their provider (Légaré et al., 2012; Légaré & Witteman, 2013). Specifically, it remains unclear what actions or process patients take that lead to feeling empowered to participate in discussions about managing their fibromyalgia with their provider. The purpose of this study is to understand how patients with fibromyalgia syndrome feel empowered to actively participate discussions about treatments with their provider. Understanding how patient empowerment impacts care holds the potential to improve health communication between patients and providers by facilitating SDM and the selection of a therapy option better aligning with the patient's lifestyle and preference.

Methods

This study received exempt approval from the University of South Carolina Institutional Review Board prior to beginning recruitment activities.

Study Design

This study uses a cross-sectional, qualitative design to identify how patients with fibromyalgia syndrome feel empowered to participate in their healthcare. A purposive sample semi-structured, personal interviews were conducted. Using semi-structured interviews allows for the exploration of the patient's experiences and perceptions in their own words (DiCicco-Bloom & Crabtree, 2006). Through the interviews, patients were asked to describe their perspectives on empowerment and provide their perspectives on communicating with their physician about managing their condition. Due to COVID-19 precautions, participants were offered the option of participating in an interview via telephone, internet conferencing, or in person with social distancing. All participants in this study selected to complete the interview over the telephone. Interviews were conducted between November 2020 and May 2021. Participants were compensated with a $40 gift card for participation.

Study Participants

Participants were included in this study if they were over the age of 18 diagnosed with fibromyalgia syndrome. All subjects spoke fluent English. An informational script was read to each participant prior to beginning study activities. All participants were given an opportunity to ask questions or request additional information prior to participating.

Recruitment

Several methods of recruitment were used to identify and enroll participants in this study. Patients were recruited from the clinical population of the Rheumatology Subspecialty Clinic at Prisma Health in Greenville, South Carolina. Patients were identified via medical record review. Potentially eligible patients were sent an email invitation and a follow up phone call with information about the research study. Additional methods used to identify potentially eligible patients were via social media advertisement and through personal contacts. Interested potential participants were able to contact the investigators to schedule an appointment time for the interview. Patients were enrolled until information saturation was reached. When using qualitative interviews, the point of information saturation is reached when no new information is uncovered with additional interviews (Rowan & Huston, 1997).

Data Collection

Prior to recruiting for the interviews an interview guide was developed asking participants about their experiences as a patient with fibromyalgia, about interactions with their physician, and their preferences for participating in their health care. The core questions surrounding empowerment were developed during the conduct of a qualitative research study involving patients in a primary care setting. The main questions were developed to ask patients about feelings of empowerment. The questions were tested and refined based on responses from 18 patients in a primary care setting. Probing questions were conversational and based on responses of the participants. Interviews were planned to be at least

30 minutes in length. All interviews were conducted by a single interviewer. Interviews were audio recorded using an Olympus recorder and transcribed for data analysis.

Data Analysis

The initial codebook for data analysis was developed by reviewing the initial transcripts using a grounded theory approach (Bernard, 2011; Heath & Cowley, 2004). Three trained coders used an iterative process to code all interviews using open and axial coding (Vollstedt & Rezat, 2019). Interview coding was completed using N'Vivo 12 (QSR International) qualitative analysis software. Coders were in contact with each other to discuss codes that are questionable for inclusion in the codebook. Major and minor themes were identified and utilized to create a conceptual framework of patient empowerment to participation in shared decision making for patients with fibromyalgia (Humble & Radina, 2019; Maxwell, 2013).

Results

Participant Characteristics

A purposive sample of 16 participants were enrolled in this study. All participants had a diagnosis of fibromyalgia syndrome. The participants were primarily female (n=15), with a mean age of 51 years (range 32-74). Table 3.1 shows the participant demographic information.

Table 3.1. Participant Characteristics

Gender	
Female	15
Male	1

Age	Mean Age: 51.87 Range: 32-74 years old
32-39	4
40-49	3
50-59	5
60-69	2
70-74	2
Race	
Caucasian	11
African American/ Black	5

Themes and Subthemes

Taking an Active Role in Health Care and Communicating with the Doctor. Participants in this study were asked a series of questions regarding feelings of empowerment surrounding being an active participant in their healthcare and when communicating with their physician. In this study, we found that feelings of empowerment were based on four factors: personal actions of the patient actions of the physician during the clinical encounter relational actions between the patient and the physician and acquiring information. Table 3.2 shows the major themes and sub themes identified undertaking an active role in healthcare communicating with the doctor and sharing preferred outcomes.

Table 3.2 Themes and Subthemes of Empowerment to Take an Active Role in Health Care and Communicate with Doctor

Personal Actions Advocating for myself Having Insurance I know my body Personal Affirmation Choosing the right doctor	**Doctor Actions** Building Trust Doctor is accessible Includes me in decisions and asks opinion Giving clear information Listening Doctor knows patient Coordinator between doctors Checking-in with patient
Information Keeping track of my information Asking questions Having another person to gather information Acquiring information	**Relational Actions** Shared decisions with doctor On the same page as doctor Go through treatment options together

Personal Actions of the Patient. The first of four themes described by the participants is personal actions of the patients in order to feel like they are able to take an active role in their health care or communicating with their doctor. Participants described specific actions they do to manage their health care or discuss their health and symptoms with their provider. An important action of the patient was being an advocate for themselves and telling the doctor what was needed. One participant described advocating for themselves to stop taking a medication the doctor had prescribed due to the side effects. Being an advocate gave the participant a sense of control over the situation.

> *"And I called up Monday morning and I told him, told the nurse I need to come back in, this medicine's not working, matter of fact, it's doing this, and I walked in and he looked and he said, "Are you taking this medicine?" I said, "No, I had to quit, and this is why I had to quit," and he looked at me*

> *and he said, "Well, you can't do that," and I looked at him and said, "I certainly can, and I did." (#004)*

Patients with fibromyalgia experience symptoms such as pain and fatigue. They have learned to tune into the severity of the symptoms and feel they are the expert on their own body.

> "*The fact that I know what's going on with my body. I can tell when things are getting worse. I can tell when things are going okay. I can tell when there's a flare up and I can tell when there's definitely something that's not quite right." (#003).*

Sharing knowledge about her body made one participant feel empowered because she felt she was the expert about what was going on with her body. This feeling was enhanced when her physician listened to her experience.

> "*Because I know my body better than they do. Although they're the doctors, I know my body. When they listen to me about my body, that makes me feel more powerful because I've been to doctors that haven't." (#016)*

In addition to being the authority on their body and experiencing symptoms, participants discussed using personal affirmations and creating a positive environment to take control of their health. Patients with fibromyalgia often do not feel like they have control over they symptoms they experience, but using affirmation allowed one participant to look toward healing.

> *"Well number one, I believe in myself. I believe that this is not mean, I don't know. I'm spiritual, so I believe that nobody's body created to handle this much pain. Yeah. Yeah, I don't feel like this is the end. Some people want*

> *to accept it, accept fibromyalgia. But I still, in my heart, actually as a matter of fact, one of the things I say all day, all throughout the thing, especially when I'm feeling really bad. The first thing I say is, I'm whole, healed, and healthy. I just say that all the time. I'm whole, I'm healed, and I'm healthy. I keep saying that over and over again, even though sometimes I may not feel better, but it's just one of my favorite affirmations that I like to say." (#007)*

Another participant describes functioning in a positive environment to make her feel better, even when the tasks at hand may be difficult. Physical work may not improve her physical symptoms of fibromyalgia but being in a positive environment can help with mood symptoms and mental health. Being in good mental health helped the participant to feel more in control of her health.

> *"Personally, I like it in a bright lit room. I like sun, so when it's sunny, I make sure I'm outside, which makes me feel better. I can feel really horrible and go outside and start working in my yard, which is killing me. But at least I feel better mentally because I think when you get dragged down mentally, that really does you [ ] even more." (#015)*

Several participants described how having health insurance helps them take an active role in their health care by being able to pay for the different treatments to help try to improve symptoms of fibromyalgia syndrome. Additionally, health insurance allowed these patients to change a course of treatment if it was not working without worrying about the related costs. Health insurance also allowed participants to access care they need to manage fibromyalgia symptoms.

> *"The fact that I have insurance is huge because if I didn't have insurance then it would be one of those things that I would probably just try to deal with. The fact that I have insurance really does make it a lot easier to get the healthcare that I need to get." (#003)*

Actions of the Doctor. Within the clinical encounter with the doctor, participants described specific actions of the doctor that make them feel like they're able to take an active role in their health care and in communicating with the doctor. These items include building rapport and trust, the doctor being accessible, listening to the patient, checking in with the patient, making the patient feel known, and care coordination between doctors.

Participants described having trust as being an important part of the patient-physician relationship. Having a trusting relationship was essential to building a long-term relationship with the doctor. Part of building trust with the patient includes listening and understanding what the patient is going through.

> *"Knowing that she is open minded enough to listen to me and that she is as thorough as she is. Again, having that relationship with her that I trust her because I've been with her over 20 years." (#003)*

One participant described having a trusting relationship with the doctor led to more open communication about the symptoms and experiences of living with fibromyalgia. Patients described negative encounters with some physicians where trust was not part of the patient-physician relationship. These experiences left them feeling frustrated and unheard.

> *"You have to the trust your doctor. If you know your doctor cares about you, then you're going to be more open about telling he or her how you feel, that you're not going to be put down." (#004)*

When communicating, the action of listening by the doctor is very important to patients with fibromyalgia. The physical and emotional symptoms of fibromyalgia are unique to each individual patient, and they want to express their experience. Feeling like the physician is hearing what they are saying makes the patient feel like they are part of the conversation and that their experience with fibromyalgia matters.

> *"I like to be talked to like you're listening to me." (#016)*

> *"And so, I feel like he listens and kind of wants to talk to me about what I've been through and how that's helped or hurt." (#012)*

One participant described an experience adjusting medication doses with her doctor. The doctor listened to the patient's preferences, they were able to make a decision together, and the patient was satisfied with the outcome.

> *"Knowing that I'll be heard and listened to, knowing that my concern or ideas will be taken into account. I had in my mind a few months ago that I was like, "I am taking too much meds. I want to back off of something," and my doctor said, "Are you sure? Not sure if it's the best idea." And I said, "Well, if I wanted to get rid of one, what would be the best one?" He was like, "Again, I don't think that's a good idea, but this one, and titrate it." And I was like, "Okay." And he was right, and it took me about a month to deal with all*

> *of that, but he was like, "It's your body. It's your decision. I understand you don't want to take that many pills." (#014)*

Participants also described having access to the doctor outside of their clinical visits as being essential to building trust and feeling empowered. The severity of symptoms can vary day-to-day and being able to contact the doctor makes the patient feel empowered to actively manage their condition. Patients with long standing relationships with their physician build a partnership to manage fibromyalgia.

> *"…they've been my doctors for a long time, so I can talk to them outside of the office or I can email or text them, and I can say, "Listen, this is what's going on. I need you to call me," and it may be after hours or whatever, because they know that sometimes it may be a situation that I need to get some advice for something, and it's after hours." (#007)*

The idea of knowing their doctor is available to them builds confidence in managing living with fibromyalgia.

> *"And like I said, knowing that she listens and she's always available makes me feel confident." (#011)*

Additionally, participants described feeling empowered by being included in the discussion by the doctor to make health care decisions. The patients want their preferences and experiences to matter in the decision-making process, and not have actions dictated to them.

> *"I get to help them make decisions about what happens, whether it be, "Okay, am I going to take this medication or am I going to have this biopsy*

> *this year?" Because I decided not to…And they also ask me for my input, they don't just say, "We're going to do this this year." (#006)*

While the physicians have medical knowledge necessary to treat fibromyalgia, the patient brings the experience of living with the condition. Asking the patient their opinion on a potential treatment gives them a sense of control over their condition and a feeling of empowerment.

> *"She always asks me, "Is this okay?" Do you feel like that this will help you with the fibromyalgia?" She always gets my opinion of things. She always listens to me, and she always validates how I'm feeling." (#003)*

Relational Actions. The participants in this study discussed feeling empowered within the patient-physician relationship when they both worked together to make decisions for treatment. Working together allows the patient to discuss how a treatment may impact their life and allows the physician to inform the patient of potential options. The participants expressed a sense of satisfaction when they worked together with the physician to make the best choice for treatment.

When making decisions for treatment, one participant described making a shared decision with the doctor. Being part of the conversation lead to a feeling of empowerment.

> *"And we discussed options together, and we would go through the pros and cons of different things and make decisions that were in the best interest, I felt, for me. And just having that open conversation and discussion about, "Here are your options, and how does this work within your lifestyle or not*

> *work with in your lifestyle, or how feasible does this solution seem to you?" You have a conversation about the whole gamut of it, good, bad, and ugly, and then you make a decision based on that. And that's what makes me feel empowered, is when you're included in it." (#013)*

She went on to discuss feeling empowered when she and the doctor were working together and going through different treatment options to make the best choice for her.

> *"It's when you're on the same page with your physician…I felt empowered and understood that we were working towards a common goal, both of us."(#013)*

Information. The fourth theme related to empowerment is information. Information is the currency of empowerment. Participants described feeling empowered by acquiring information and learning everything they can about fibromyalgia and medications. Acquiring information allows the participants to weigh treatment options that work best within their lifestyle.

> *"So, for me if they diagnose me with... Well, they did with fibromyalgia, so I wanted to know everything about fibromyalgia down to how your connective tissues work. Okay? And how do those feed off of what nerves? I mean I literally I go all in. I had to know all that for us to be able to I guess figure out what the doctor and to know what medications I feel like would work for me better. And so yeah, I dived all into it. That's just what I do." (#002)*

Asking questions to the doctor is another way participants acquire information. Overall, the participants in this study said asking questions about symptoms and treatment was a vital part of communicating about fibromyalgia. The willingness of the participant to ask questions can change over time and is connected to advocating for oneself as a patient.

> *"I guess because I feel like I could ask the questions when I talk to the doctors, and I'm not shy about doing it. When I was younger ... I tend to be an introvert, and I wouldn't say anything. I'm not that person anymore." (#008*)

One participant felt empowered to participate in her care because the physician invited and entertained the questions asked.

> *"And she'll never think something's... I'm never asking a stupid question, and I think that helps a lot." (#011*)

Along with asking questions, one participant described having another person in the room during a doctor visit to help capture information as it is discussed. With so much information being exchanged, another person can help the participant remember the details of care and treatment.

> *"I have my husband come with me and I think that's important for all of us because particularly forget ... Not with most of these appointments but with some appointments you hear the first thing and you miss everything that came after it. You need somebody else there who maybe can hear it and not get so involved in it that they shut down." (#008)*

Several participants described keeping a detailed account of their own information related to symptoms or treatment. Having this information available allows the patient to track trends and also as a historical record of managing fibromyalgia. This information can later be shared with the health care provider to inform health care decisions at a later date.

> *"I would document every morning how I felt throughout the day, if there was anything different. I just kept a journal of how I felt each and every day, trying to figure out what I can do to turn this thing around without getting on medication." (#007)*

As symptom severity worsens with a flare up of symptoms, keeping a record allows the patient to remember what was happening at a specific point in time.

> *"The brain fog that I have because of fibromyalgia is very detrimental to what I try to look up and do. That's why I have to write everything down because it's really, really bad now." (#002)*

Another participant described feeling empowered by having all the information from the after-visit summary. All the new medical information is in front of her and can be used to make decisions. The power in information gives a fuller picture of the current status of her health.

> *"When I go to the doctor, my summary visit and I get all of my information there, and it's all I one place, and I can go and I visit, what we call it is MyChart, and I have everything there and I get all of my results, and I get them back so quickly. I feel empowered, because for once, I know what's going on. There's nobody there trying to hide anything. That makes me feel empowered." (#006)*

Sharing Outcomes That are Important. When participants were asked about feeling empowered to share what outcomes were important, there were several differences in the responses from taking an active role in health care and communicating with the doctor. First, the patient, physician, and relational actions described were based on communication and relationship. Sharing goals and outcomes were more personal than discussing symptoms.

Within an established patient-doctor relationship with trust, patients were more willing to be open to tell their physician what is important at that point in their care.

> *"Well, I'm very, like I said, I'm an open book. So, if I'm going to tell her, I really need to not feel the pain in my back, my lower back, let's say for example, so then I would just explain that to her" (#011)*

The actions of the doctor were very important to allowing the patient to feel comfortable to share important outcomes. Participants described empathetic behaviors as a key to allowing them to open up to the physician.

> *“I've developed a rapport with my doctors now. Because this team that I have now, they really seem to care. They really, really seem to care." (#007)*

Significant behaviors of the physician include caring, listening, and validating the patient’s feelings.

> *"Just knowing that my doctor does listen to me and that she validates what I say, and she knows that I'm not just coming in with something off the wall to talk to her about. She knows that if I do come in and want to discuss with her something new, that she will listen to it and actually take the time to decide with me if that's something that we want to do, if we want to take that as a course of action." (003)*

> *"I know that I have to receive one, but I just don't feel like back-to- back ones will be very beneficial to me right now, so I'll skip a year and do it. That was the conversation I had with my doctor, so we just moved forward, and he was like, "I already knew that you would say that, but I needed to ask." (#006)*

The participants in this study understood the time constraints of the visit to the doctor's office and also that health care providers manage the care of many patients. However, empathic behaviors from the physician helped the participants to have open communication with the physician. One participant described her experience with the doctor as being made to feel they were the only patient and that her concerns and preferences were valid.

> *"But if I had to guess, the way they've made me feel, I'm the only patient." (#007)*

Another important behavior is recognizing when to refer the patient to another physician if additional care or treatment is needed. The patient knowing they will be able to access needed care allows them to discuss what is important to them.

> *"…we should all be working together for the best course of treatment for your patient, whether that's sending them to a different department or another physician." (#013)*

Discussion

This study demonstrated the primary elements empowering patients with fibromyalgia to participate in making decisions with their doctor. The findings fill a critical gap within the literature by highlighting patient perspectives of empowerment rather than focusing on what providers believe is empowering for patients. The primary elements patients voiced as empowerment for making treatment decisions were: 1.) personal actions of the patient, 2.) the actions of the doctor, 3.) the patient-doctor relationship, and 4.) information. Actions related to trust and rapport building, as well as empathy carry the most weight in terms of empowerment. To make decisions, patients also desired to acquire information to inform the decision. Prior research found a similar relationship between knowledge and decision making in primary care settings (Small et al., 2013). Prior research has focused on the experience and identity of the patient in regard to symptoms and living with fibromyalgia (Ashe et al., 2017; Hallberg & Carlsson, 2000; Lempp et al., 2009; Raymond & Brown, 2000). This study differentiated itself because its findings focused on the patient experience of making treatment decisions within the clinical encounter.

The participants in this study described personal actions as being able to take control of their health care including advocating for themselves and knowing how their body functions. Figure 3.1 shows the relationships between the patient actions, physician actions, the patient-physician relationship, and information feeding into the process of empowerment. When talking about the actions of the doctor, the participants focused on ideas related to building trust and empathy. When the doctor and the patient come together to make a treatment decision the desired relationship for empowerment is a partnership between them working toward shared goals. Empowerment is a spectrum based on the preferences of participating the patient-physician relationship. Within this relationship, information is acquired from external sources or exchanged within the clinical encounter and used as a tool to make decision for treatment. When it comes to patients feeling empowered to share important outcomes with the doctor, the bottom part of Figure 3.1 involving information falls away and the relationship and empathy related actions become the important factors. Furthermore, this figure displays what is happening in the Patient Empowerment box contained within Figure 2.3.

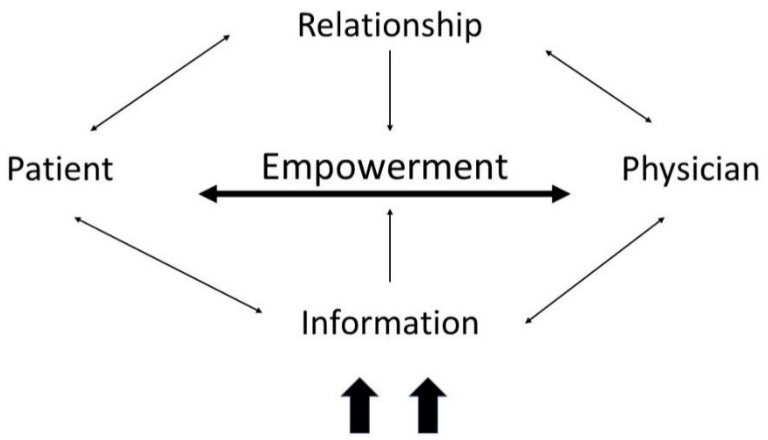

Figure 3.1: Conceptual Framework

Within the context of making decisions for treatments for patients with fibromyalgia, empowerment is not an action, but a process of building trust between the patient and provider using information to make decisions together. These findings are consistent with our working definition of empowerment - patient empowerment is a process through which the patient shares, up to their desired level of engagement, information, facts, and opinions of their experience with their condition to their health care provider in order to make mutually agreed upon decisions. For patients to feel empowered, the patient needs to feel confident and secure to share information and goals for treatment with the physicians. To foster sharing information, physicians can focus on rapport building and sharing empathy with patients with fibromyalgia.

Strengths and Limitations

This study highlighted the perspective of patients with fibromyalgia when making treatment decisions with a doctor. Although this study reached information saturation, the nature of qualitative research does not allow for wide generalizability of the results. The demographics of participants enrolled in this study aligned with what is known about fibromyalgia in the general population when examining racial factors; however, although more females than males are diagnosed with fibromyalgia, the study sample was heavily female (Walitt et al., 2015). Additional research is needed to determine differences in perspective between gender. A majority of the participants in this study experienced healthcare in the southeastern United States. The results of this study may not allow for generalizability to all regions of the country. Additionally, while this study focused on the perspective of the patient, the perspective of the provider was not included. Future research focused on the perspective of the provider may provide a fuller picture of the concept of empowerment.

Conclusions

The findings of this study suggest empowerment within shared decision making is a process of building trust and exchanging information between the patient and the doctor. Within the clinical encounter, the focus of the patient-physician relationship should focus on relationship building, exchanging information, and using information as a tool to make decisions for treatment for patients with fibromyalgia. Future research should focus on developing empowerment interventions that prepare the patient to feel comfortable communicating with their physician to improve trust with the physician to improve management of symptoms and care for fibromyalgia.

CHAPTER 4

PARTICIPATION IN SHARED DECISION MAKING IN PATIENTS WITH FIBROMYALGIA[2]

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[2] Oostdyk, A.M. To be submitted to TBD.

Introduction

Patient centered care encompasses health care that incorporates patient preferences, priorities, values, and needs into the process (Institute of Medicine (U.S.) & Committee on Quality of Health Care in America, 2001; Mitchell et al., 2012). To deliver patient centered care, effective shared decision making involves patients and physicians taking into account information about the patients goals and priorities to make best decision for treatment (Elwyn et al., 2012). This is especially important for patients with chronic conditions with multiple treatment modalities like fibromyalgia. Fibromyalgia is a chronic pain condition impacting millions of Americans (Centers for Disease Control and Prevention, 2017; Walitt et al., 2015). There is no cure for fibromyalgia and managing symptoms involve an individualized medicine approach to treatment involving both pharmacologic and non-pharmacologic modalities (Häuser et al., 2018; Rahman et al., 2014). With the multiple potential treatment choices available, shared decision making is an ideal mechanism for making a treatment choice aligning with the patient's preferences, priorities, and lifestyle. Patients with fibromyalgia reported better quality interactions with their doctor when shared decision making was part of their care (Bieber et al., 2008).

Much focus has been placed on the role of the provider and their needs as they promote shared decision making during the clinical encounter (Légaré & Witteman, 2013; Toupin-April et al., 2015; Ubel et al., 2017). However; few studies focus on the patient's role in shared decision making (Baars et al., 2010; Hopmans et al., 2015; Lin et al., 2020)., and no studies focus on how patients with fibromyalgia perceive and experience shared decision making. Specifically, it is not known how patients with fibromyalgia view the treatment decision making process. The aim of this study is to identify in patients with fibromyalgia syndrome the perspectives of their needs and actions when engaging in shared decision making with their provider.

Methods

Research Design

A cross-sectional, qualitative study was designed in order to explore how patients with fibromyalgia participate in and perceive shared decision making. This study employed individual, personal, semi-structured interviews with participants with fibromyalgia to collect perspectives on making treatment decisions with health care providers. An interview guide was developed with relevant questions to guide the discussions. Interviews were conducted by a single interviewer. Prior to beginning study activities, this study received exempt approval from the University of South Carolina Institutional Review Board.

Participant Recruitment

A purposive sample of patients was recruited to participate in this study. Women and men over the age of 18 with a diagnosis of fibromyalgia and fluent in English were eligible to participate in this study. There were no specific exclusion criteria.

To identify potential participants, several recruitment strategies were utilized. Potential participants were identified through a medical record search of patients being treated for fibromyalgia in one rheumatology practice in Greenville, South Carolina. Potential participants were contacted via email and then by telephone to gauge interest in participating in this study. Participants also were identified through personal contacts and social media advertisements. An informational e-flyer was posted to Facebook and Instagram. Any interested potential participants reaching out in response to the social media posts underwent a brief conversation to screen for eligibility. All patients completing the study were compensated with a $40 gift card for their time.

Data Collection

A purposive sample of patients with fibromyalgia were identified and recruited to participate in this study. Due to COVID-19 precautions, participants were given an option to participant in an interview over the telephone, via internet videoconferencing, or in person with social distancing. All participants opted to participate via telephone call. Interviews were conducted over the telephone by a single interviewer between November 2020 and May 2021. Prior to beginning the interview, consent was obtained from each participant using a script approved by the University of South Carolina IRB. Participants were given an opportunity to consider participation and ask any questions prior to beginning the interview. Interview questions were designed in the planning stages of the study to probe how patients communicate with their provider about their disease and make decisions about treatment. Based on the conversational nature of the interviews, probing questions were used to obtain additional information based on the responses of the participants. Interviews were audio-recorded using an Olympus digital recorder and transcribed for data analysis. Interviews were conducted until reaching the point of data saturation (Rowan & Huston, 1997). Data saturation is the point where no new information is uncovered when additional data is collected (Saunders et al., 2018).

Data Analysis

Interview transcripts were coded using a grounded theory approach for qualitative analysis (Bernard, 2011; Heath & Cowley, 2004). Coding was conducted by three coders using an iterative approach to coding. A codebook was developed, and new codes were added as themes and subthemes emerged from the data. Open and axial coding was completed (Vollstedt & Rezat, 2019). Coding was completed using N'VIVO 12 (QSR International). Themes and subthemes were sued to create a conceptual framework related to shared decision making for treatment decisions in patients with fibromyalgia.

Results

Participant Characteristics

A total of 16 participants were enrolled in this study. All participants had a diagnosis of fibromyalgia that was self-confirmed. A majority of the participants were female (n=15), with a mean age of 51 years (range 32-74). Table 4.1 displays demographic information of the participants.

Table 4.1. Participant Demographics

Gender	
Female	15
Male	1

Age	Mean age 51.87 Range: 32-74 years
Race	
Caucasian	11
African American/Black	5

Themes and Subthemes

Current State of Decision Making. Throughout the qualitative interview, participants in this study were asked questions regarding making decisions for treatment with their physician. Specifically, participants were asked about making a decision with their physician to try a new treatment for their fibromyalgia symptoms. The responses were grouped into four main themes: 1) decision style; 2) information; 3) choosing a new treatment; and 4) negative experiences. Table 4.2 displays the major themes and subthemes related to the current state of decision making for a new treatment for patients with fibromyalgia syndrome.

Table 4.2. Themes and Subthemes of the Current State of Making Decisions for Treatment

Theme: Decision Style	**Theme: Choosing a New Treatment**
Doctor works with me	Trial and Error
Let the doctor facilitate / Trusting doctor with decision	Hope it will work
Advocating for self	

Theme: Information	**Theme: Negative Experiences**
Doctor gives information	Being disregarded Doctor does not listen

Decision Style. Participants described the different styles of decision making they have encountered when making a decision for a new treatment. There were several decision-making styles encountered when making a decision to try a new treatment such as the doctor and patient working together, the doctor facilitating the decision and trusting the doctor to make the decision, and the patient advocating for themselves.

One participant described her experience of making a decision to try a new treatment as her and her doctor working together to make the best decision possible. The participant described the decision-making relationship as a meeting between the two parties to decide together.

> *"If you don't have that meeting of the minds type thing or relationship, then you can't work together when it comes to something like this."* (#004)

She went on to say that they have a collaborative relationship.

> *"…she just works with me."* (#004)

Another participant described a new doctor was willing to work with her to make a decision after several negative experiences. She felt the interaction was positive because there was give and take in the conversation as opposed to just being told what to do. This participant preferred making decisions together over someone else making the decision for her.

> *"Because I was having a conversation and talking with somebody, instead of being talked to."* (#001)

Another style of decision making encountered by participants was where they allowed the doctor to facilitate making the decision. In this situation, the physician is telling the patient what needs to be done based on the doctor's knowledge or experience. Within this decision style, the patient is placing trust in the physician to make the decision in the best interest of the patient. Frequently, the patient and the physician have a standing relationship or have built trust and rapport with each other.

One participant described the physician lowering the dose of one medication and starting her on another. The physician expressed concern about the medication she was taking and explained to the patient the risks and potential problems with continuing on this regimen. The patient placed trust in the physician to make the best decision for her at that time.

> *"I'll tell her what's been happening and then she'll suggest, for example…I was on such high, high dosages of Gabapentin, and she was worried about it, and she was like, "Oh my gosh, you cannot be on this, so such a high dosage." So, we brought it down and then she introduced another medication and she explained to me if there was going to be any side effects or of anything I needed to know, and it was super easy and it was great."* (#011)

The same participant went on to discuss having a longstanding relationship with the physician. Over time she had developed a significant amount of trust in the physician to facilitate and make decisions for medical treatment for the patient. This participant felt the physician would always act in the best interest of the patient.

> *"I trust her. So, I think that's that patient doctor trusts that is really, really important. And at the end of the day, obviously it's me and I just want to feel better. So, whatever she suggests, I'm all for it basically. No qualms, that's for sure." (#011)*

Another participant describes this trust as feeling comfortable with the doctor to *make the decisions for treatment.*

> *"Well, when you have a face-to-face conversation with your doctor, you feel comfortable with decisions they make, and being able to explain to them your feelings about your decisions, and the treatment they're prescribing for you."* (#010)

Another participant described her situation as the patient of making the decision to try a new treatment and the decision being best decision for her. To come to the best decision, the participant described letting the physician facilitate the discussion and bringing up the possible choices to be made.

> *"So, there is the reality that medicine, there is a business side of it, and so just you have to decide this is what I'm willing to do or not willing to do and how much you're willing to risk with newer things, because there's always something new coming out, but does it make it the right thing for you? So, figuring that out but letting the physician guide and facilitate, "Hey, maybe we should think about doing this or that."* (#014)

When making decisions for treatment, several participants noted the importance of advocating for what was the best decision for them. Participants felt they needed to be assertive in telling the physician about how certain treatments impact their daily life. Knowing how to be a self-advocate comes from the experience of talking to doctors and managing the symptoms of fibromyalgia over a period of years. One participant discussed how over time she was able to become a stronger advocate to discuss what she needed when discussing treatment options with the doctor.

> *"It's that same kind of feeling that I've gotten to where I know, I'm confident enough in what I've researched, and how long I've had this to know the good and bad and accept it, and know that I can go in there, have more confidence, and talk to the doctor."* (#001)

Another participant describes a time when she was not able to advocate for herself and underwent an expensive diagnostic test that did not help in the journey to find a solution for her health care issues. From this experience she learned the important of advocating for what is needed when making health care choices, and also from a financial standpoint.

> *And knowing how to ask the right questions, that's a huge thing…and because I hadn't done all my research, I went to a doctor just a kind of I think regular patient, without research, without anything, and I got a couple thousand-dollar CT scan that I didn't need. I didn't get my chief complaint even dealt with. So, I got a huge medical bill, told that, after I had all these tests done, there was nothing he could do for me, which he could have told*

> *me the first visit without all of the tests and the money, but I either wasn't strong enough or I didn't ... He didn't hear me, or he didn't care. I'm not really sure. But it was not beneficial to anyone at all.* (#014)

One participant described knowing she could go in with suggestions to advocate for what she needs for her health care. However, she experienced frustration because her needs were not heard by the physician and felt the encounter turned into a negotiation instead of a conversation.

> *"So just going in with suggestions, honestly it doesn't work. Usually, you end up reasoning with the doctor on what they want you to try."* (#009)

Information

Doctor gives information & listening. When making decisions for treatment, participants described wanting the doctor to provide them with information about their condition and possible treatments. One participant talked about wanting the physician to break down the information in ways she could understand. Having to research on her own what the doctor talked about led her to feeling frustrated.

> *"I really want him to sit there and listen to me and break things down to me. Don't just tell me what I got. Break things down for me, tell me how this works. How will it affect my body and things that I can do to prepare myself when it come on, instead of me had to research it on my own and see what this does."* (#005)

Similarly, another participant talked about finding the doctor that is the best fit for her, and who is able to provide high quality information. This patient wants to take the information and do more research based on the information given.

> *"And I think that's also a key to the processes, is finding the right doctor to listen to you and provide you with as much up-to-date information as well as good information. And doing some additional research on your own, and I've done some of that as well."* (#013)

Patients also look to the physician and the keeper of information. The patient shares information about their symptoms and will want the physician to provide them with information about what can be done to manage the symptoms.

> *"Then we'll get serious. and I'll tell him what my symptoms are and he'll say, "Well, what can I do for you?" And I'm like, "You tell me.""* (#016)

Trying a New Treatment. When trying out a new treatment participants described the process as trial and error. Treatments for fibromyalgia tend to be what works for the individual patient and are not universal across all patients with fibromyalgia. One participant described not having one treatment for all as a source of frustration.

> *"Right, all trial and error. And that's the biggest thing. The thing that works for me may do nothing for someone else, and that's the biggest frustration."* (#001)

Trying a new treatment, whether it is pharmacologic or non-pharmacologic, means the patient will not know how their body will react to the treatment. This is one of the biggest questions for the patients when choosing to try a new treatment modality.

> "*I guess the first thing that comes to mind is, how's it going to affect me after that treatment?* (#012)

Participants also described the feeling of hope when choosing a new treatment. They are hopeful the new treatment will help to soothe the symptoms they are experiencing. This sense of hope is especially urgent for patients who have not found much relief from other treatments they have tried.

> *"Well, of course, there's that I want to hope that it's going to work. Nothing really has ever really worked. You always have that, I wish I could take something that's going to do something for me, but everything I have tried has not done anything."* (#015)
>
> *"I guess hoping I'm going to get relief, relief from pain and from hurting. Getting relief from that."* (#012)

Negative Experiences

When discussing making decisions for treatment, several participants in this study described negative experiences they had when communicating with their physician. Patients with fibromyalgia will often research possible treatments on their own or connect with an online group of patients hoping to connect with others experiencing similar symptoms and trying different non-medication related treatments. When this participant brought these suggestions of treatments to the doctor, the participant was left feeling not heard and disregarded.

> *"Most of the time they're going to tell you what they're told to do instead of something you feel may work for you or certain tests and stuff. Like I would say, just looking through the group and seeing other people and they say*

> *"Oh, well my doctor told me I had this, but then I got tested for this and it ended up this and it wasn't that." So sometimes going in there and saying, "This is what I want to do." Or "Can I try this?" Usually, they don't want to hear what you want to do. It's more about what is typical treatment for you. And usually, it involves some pain medicine that does not work."* (#009)

Exchanging Information

A key component of shared decision making is the exchange of information between the patient and the physician. To discussion exchanging information, participants were asked what kinds of information they wanted to tell their doctor. The responses feel into three categories: symptoms, medication, and life events. Similarly, participants were asked about the kinds of information they wanted the doctor to share with them. Participants wanted the doctor to ask them questions about their condition, express empathy, and give them information about potential treatments. Table 4.3 displays the different themes found regarding exchanging information.

Table 4.3. Themes and Subthemes for Exchanging Information

Patient Giving Information to Doctor	Doctor Giving Information to Patient
Symptoms	Asking Questions
Medication	Expressing Empathy/Sympathy
Life Events	Information About Treatment
	Benefits
	Honest Information
	Alternatives

	Instructions

When sharing information with the physician, participants expressed the importance of being honest in sharing information about symptoms. Participants will use this information to make decisions for treatment in collaboration with their physician.

> *"Really I would like to be able to give them a more clear picture of how it affects me, because I think if they understood the day to day, if I can explain from the time I woke up to the time I went to bed, every symptom, without them feeling like "Oh, that's just to much, oh she's lying, oh she's exaggerating." I wish that I can get across to them how it really feels.* " (#009)

Participants also acknowledge their symptoms can change over time. Being able to explain symptoms occurring in the recent past helps the patient give the doctor a better picture of how the symptoms are impacting their life and guide treatment decisions.

> *"Well, I want to tell my doctor as much as I can tell him about every that is pertaining to my health, what has happened during the last few weeks when I had seen him or her, so that the doctor can have a snapshot in time as to how I've been feeling, what's been going on with my health and as to however it pertains to that appointment, so that he or she can make an informed decision as to what changes need to be made or not, if any. And so, we can move in the right direction as it pertains to my health, because*

> *if I don't tell him or her, then it could possibly... it can affect the way I'm being treated. Because if I lie and said, "Oh, it's been all great," then they can't help me. They can't help me, so I am very truthful and upfront with my doctors, so they can treat me to the best of their ability."* (#006)

One participant described sharing information about medications she has taken in the past and how the medications affected her. She was able to do this by keeping a detailed list of medications to share with the doctor.

> *"So, I just made lists of meds that I've been on, that and on the neurology front for the migraines, because the doctor would be like, "What about this? What about this? What about this?" and you need to be like, "No, I tried that. It did that. I tried that. It did that. I tried that. It did that," because the doctor sees you for a few minutes. I on the other hand live with myself." (#014)*

Another participant expressed feelings of satisfaction when she was able to tell her doctor about the events in her life in addition to her symptoms and reasons for visiting the office.

> "*The best doctor that I had would check in on not only my health, physically and mentally, but just about the ongoings of life."* (#013)

The participants in this study were asked about what kinds of information they wanted to doctor to share with them. Several participants wanted to doctor to ask them questions to guide the conversation.

> *"Yeah, I'd like for her to maybe ask me questions. I think that might help because like I said, when you're in it, it's just this is how it is. This is how I*

> *feel. And maybe if she asks questions or other doctors ask questions, it would help me a little bit more."* (#011)

Participants expressed wanting the doctors to better understand the symptoms of fibromyalgia. The symptoms of fibromyalgia can affect each patient differently. The doctor may not be able to know what the symptoms of fibromyalgia feel like to the patient, but the participants in this study expressed wanting the doctor to try to understand how the symptoms impact their lives.

> *"Just talking to somebody, a few people that have it and see how they can do better. It really to me is just listening and really trying not to brush a person off because you may know this is a symptom. To that person it can be something major or scary. So, I just think they need more... to really get in tune with their patients that has it and try to have more understanding beyond what the book teaches you it is, because we have so many symptoms that we feel is not a part of fibromyalgia, but then you go to the doctor and they're like "Well, that is a part." Well, this is what I'm worried about right now." (#009)*

One Participant described wanting the doctor to express sympathy about living with and managing fibromyalgia

> *Listen. And I don't expect empathy. I think that's something on the patient end that's a misconception. I don't expect you to empathize. Sympathy would be great if you could offer any of that, but I don't expect you to empathize with me. You probably don't know how I'm feeling, and for me to have that expectation is unfair. However, sympathy would be awesome. If*

> *I'm telling you my pain is on a seven and I barely got here today, you not really acknowledging that or asking how they can partner with me in that, that's not really good care." (#014)*

Finally, participants stated they want information regarding treatment from their physician. The types of information the patients wanted to have included benefits of treatment, instructions on what to do, and possible alternatives to traditional treatments. Participants talked about wanting the physician to be open and honest in the information they are providing.

> *Anything that they think is relevant to keeping me healthy and in the best condition possible.* (#013)
>
> *"I don't need them to lie to me and make everything like roses when it's not. If they think it's something that I need to know, they can call me on the phone, and they do, or they can tell me face to face, it doesn't really matter. Because I'm a patient that, I need it to be upfront at all times, because I can handle anything."* (#006)

One participant talked about wanting her physician to discuss the benefits of a new medication.

> *"Tell me what was new out there that she might think that would be good for me. Go through the benefits. Is there any concerns about the medication? Then I'd like to know as well." (#011)*

Another participant wanted to her doctor to share with her any new scientific findings on fibromyalgia. This participant discussed researching her symptoms and possible treatments, but also wanted to hear any new information the physician may have recently learned.

> *Has she come up with any new research or has she done any new research that would help with the fibromyalgia?* (#003)

Informed versus Shared Decisions

Participants were also asked their perspectives on what an informed decision is versus a shared decision. For the participants in this study, informed decisions were centered around gathering information to make a decision. However, shared decisions involved active participation, trust, and a decision made with another person. Table 4.4 shows the themes and subthemes regarding informed and shared decisions.

Table 4.4 Themes and Subthemes for Informed versus Shared Decisions

Informed Decision	**Shared Decision**
Theme: Gathering Information	**Theme: Active Participation**
Asking Questions	**Theme: Trust**
Doing Research / Being Informed	**Theme: Deciding Together**
Getting Information from Physician	Giving and Take Information
Discussing with Family/Spouse	Negotiation
	Including Family/Spouse

The information gathering involved in an informed decision involved specific actions by the patient including asking questions, doing research, and discussing options with physicians and/or family members. This information was then used to aid in the decision-making process. When gathering information, one participant described wanting all of her questions answered.

> "*I want to know all of the who, what, where, when, why. Right? So, am I a good candidate for it? How long has it been around?" (#014)*

The same participant felt being informed was a responsibility as a patient. Being informed about symptoms and treatment options allowed them to ask additional questions of their doctor and make the best treatment choice for them.

> *It's my responsibility to be as informed as I can before I walk in that office about whatever to where I can have a good dialogue with the doctor about whatever medication, procedure, whatever, whatever thing, and him not, I don't want to say forcing the hand, that's too strong of a word, but I'll say it this way, him not white-coating me, him not saying, "Here, I'm the doctor. I think you should do this. Go take this, go do that, and then you'll be better," but saying, "Okay. I hear that. I respect that," and then taking the time to walk through it with me as to why.* (#014)

Being an informed patient also involves gathering information from the physician. Participants believed physicians had knowledge to share to help them make a decision for treatment.

> *"That to me is they're telling you all the facts and you got to then narrow it down to what's going to be good for you."* (#015)
>
> "*That I know what's going on, and the ins and outs of that decision that we make toward my care. They let me know what's going on."* (#010)

Participants also described doing their own research to gather information about symptoms and possible treatments. The research was either done on their own, or to learn more about something the doctor had told them. One participant describes researching a medication the doctor had suggested and making a decision based on their own research.

> *"It means I know what I need or what the medicine does or what the treatment is. I'll look it up. I'll find out what he's wanting to do and then I decide whether or not I agree." (#015)*

Another participant described a similar situation about choosing a new medication based on conversations with the physician and their own research about the medication.

> *"I've researched it and I feel comfortable with going towards it, and I've made all the adjustments and changes that I need to make in order to go to that stronger drug…I'll meet him in the office, and they'll train me on how to use that medication." (#006)*

In contrast to gathering information for to make an informed decision, shared decisions involved taking more of an active role in the decision making process. One participant described making a shared decision for treatment as being actively involved in making the decision along with the physician.

> *"So, just doing my part, being a responsible patient, being an active participant in my own care rather than sitting back and just kind of letting a doctor, "Well, what about this? Try that. What about this? What about this?"*

> *I think shared decision-making would be the best word that we'd put there."* (#014)

Another patient described the trust needed between the patient and the physician to make a shared decision. Instead of the physician dictating a decision to the patient, the role of the physician is to guide the decision-making process.

> *"That I have enough trust in the person and the doctor that I'm working with, that I rely on her opinion and rely on her to help me process what it is that fibromyalgia is and how it is that I need to get better results from my fibromyalgia medicines or from the fibromyalgia itself."* (#003)

Several participants described a shared decision for treatment as a decision made together with the physician.

> *"We talk about it and then we decide whether or not it's something that we want to try."* (#003)

> *"Well, it means to me that you're trying to discuss something to see what the best option would be and then make a decision off of that. So, I guess it's, to me, it looks like you'd be talking it out, trying to figure out what the best course to do."* (#015)

One participant described the exchanging of information and making a decision with the physician as a negotiation. Even though the physician might recommend a treatment, there are factors in the life of the patient that may make restrict the decision to move forward with it.

> *"I think negotiation would be the best word, taking into ... It's not only me taking into account all of the things, but my doctor also knowing me,*

> *knowing me well, and him taking into account all of those things. So, yes, there might be this new, great test or drug or whatever, but, again, is it the right season? Insurance. If it's really expensive, it's probably better to do that test towards the end of the year, because I hit my out-of-pocket max every year. So, can we wait, and can we do that later?"* (#014)

Several participants also described involving their spouse or a family member in making decision. Decisions for treatment impact the patient and their family, and participants acknowledged those potential impacts.

> *"A shared decision would be something between either I would discuss with my doctor about it and then I would probably discuss with my husband and get his feedback and thoughts, and then come up with a game plan with my doctor."* (#011)
>
> *"I guess a shared decision, the way I would define it is it's our family now, so a shared decision would be discussing the best treatment course, like I said, for your lifestyle, your family. And I'm not necessarily just referring to your immediate family. I guess it could be immediate, but I talk with my parents a lot about how medical things, so it's not just my spouse. I guess that's my definition of a shared decision, bouncing all those ideas off them and then coming to a conclusion that you all somewhat agree with and understand, or agree to disagree."* (#013)

Discussion

This study elicited perspectives from patients with fibromyalgia on their perceptions of making shared treatment decisions with a physician. The study found in the current state of decision-making patients have a preference for certain decision-making styles where the provider has different amounts of input. However, participants frequently described having negative feelings about regarding treatment decisions with their physician because they feel their opinions or experiences were sometimes disregarded in the decision-making process.

Participants describe shared decision making where they had to become an active participant, have trust in their physician, and work collaboratively with the physician. In shared decision making, information was a key theme in the process as seen in Table 4.1. Informed decisions were primarily based on gathering information and using that information to make decisions as seen in the themes in Table 4.4. Participants described the information they wanted to share with their physician as being related to symptoms, side-effects of their medication, and their lifestyle. They also described the information they wanted to hear from the doctor as suggestions regarding the best potential treatments for them. Additionally, they needed expressions of empathy and sympathy related to their symptoms and side-effects.

This study was focused on the perspectives of patients with fibromyalgia on making decisions for treatment and shared decision making with the doctor. Previous studies of shared decision making have focused on patients with chronic conditions such as inflammatory bowel disease and cancer, but none specifically look at patients with fibromyalgia (Baars et al., 2010; Hopmans et al., 2015). Baars et al. (2010) studied preferences of shared decision making in patients with inflammatory bowel disease using a questionnaire to demonstrate patients thought shared decision making was an important part of clinical care. Similar to the results found in this study, Hopmans et al. (2015) asked patients with Stage I lung cancer to describe how decisions were made in their care, demonstrating that patients placed an emphasis on gathering information and being able to express their preferences.

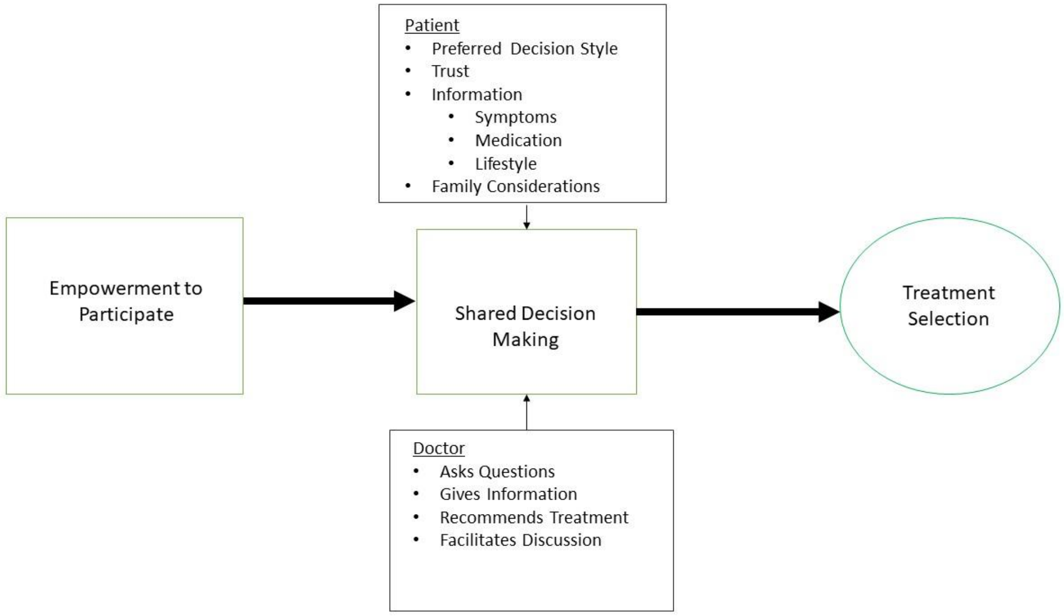

Figure 4.1 Conceptual Framework

As displayed in Figure 4.1, when considering the components required for successful shared decision making, from the perspective of the patient with fibromyalgia, there are several actions the patient must take and other actions the doctor should complete. Patients must be willing to be an active participant in the decision-making process and feel they trust their doctor. In addition, the patient needs to communicate to their doctor information about the current state of their condition and information about treatments that are or have tried to use in the past. The actions of the patients described in this study fit with previously stated patient actions in the working definition of patient empowerment to participate in shared decision making – patient empowerment is a process through which the patient shares, up to their desired level of engagement, information, facts, and opinions of their experience with their condition to their health care provider in order to make mutually agreed upon decisions. Further, the actions of the doctor are complementary to this. The doctor must be willing to give information, ask questions to gather more information, make recommendations, and facilitate the discussion for choosing a treatment. The information contained in Figure 4.1 presents a picture of the elements that feed into the Shared Decision Making box in Figure 2.3 in Chapter 2.

Strengths and Limitations

This study elicited perspectives on shared decision making for treatment with a physician specifically from the view of the patient with fibromyalgia. While this has been done in other chronic conditions, this study specifically targeted patients with fibromyalgia. Qualitative research does not lead to generalizability for all patients, the information learned from this study can lead to targeted interventions and future research that can be generalized to all patients. The participants in this study were primarily female. Additional research of men with fibromyalgia may reveal different preferences and needs in shared decision making. This study focused solely on shared decision making from the perspective of the patient. Additionally, research is needed to describe the perspective of the physician to gain a full picture of shared decision making in clinical practice.

Conclusions

The results of this study suggest shared decision making is understood by patients with fibromyalgia as a collaborative decision when choosing a treatment to manage symptoms. To actively participate in shared decision making, patients have to feel like they can openly communicate with the doctor. Conversely, physicians need to provide high quality information and willingly facilitate the discussion. Future research should examine how patients with fibromyalgia can communicate information to their doctor about their condition so doctors can utilize the information to make recommendations and facilitate discussion to make a choice for treatment.

CHAPTER 5

CONCLUSIONS AND FUTURE RESEARCH

The findings of the studies presented here confirm the working definition of empowerment in shared decision making in patients with fibromyalgia as a process through which the patient shares, up to their desired level of engagement, information, facts, and opinions of their experience with their condition to their health care provider to make mutually agreed upon decisions. Participants reported wanted to share information with their health care providers; however, successful experiences were varied across participants. Patients reporting having a trusting relationship with their health care provider reported feeling as if they could share more information than patients that did not feel they could trust the provider (Chapter 3). In the context of empowerment in shared decision making, information is the currency in the relationship between the patient and doctor when making decisions to choose a treatment as described in Chapters 3 and 4. For patients to feel empowered, patients need to feel confident and supported to share their information with their doctor. In order for patients to feel the confidence and support required to participate in shared decision making, a trusting relationship with their doctor must be built over time.

Shared decision making has been a goal of patient-doctor interactions for many years. However, participants reported having difficulty sharing information, at times, when navigating care for fibromyalgia. Participants reported health care providers they have encountered did not listen to or take into consideration the information they shared. Over time, as the participants became more experienced with their condition, they were able to find a doctor that provided the environment and trust to feel confident to share what is important and work collaboratively to decide on treatments that would work best for them. Participants reported a process of trial and error to discover the treatment modalities to best manage their symptoms. Working collaboratively with a doctor to make decisions to start or stop treatments left the patients feeling more satisfied with their health care.

To increase empowerment in shared decision making for patients with fibromyalgia, health care providers and health systems need to build a care environment where patients can openly share their experiences and preferences, and have those experience and preferences acknowledged and considered within the decision-making process. Fibromyalgia is a chronic pain condition with no known cure. As such, patients with this condition spend a considerable amount of time interacting with the health care system. From a provider perspective, focus should be placed on building an environment of trust and collaborative care. Patients with fibromyalgia do not need to be given empowerment, instead the need to be allowed a space to experience feeling empowered to share information about their condition.

Future research and interventions should be multi-modal and focus on communication between patients and health care providers. Future research should include patients with fibromyalgia in the design process to ensure what matters to the patient is truly being studied and interventions are being designed to meet the needs of this patient population. Interventions should focus on building rapport between patients and providers to allow open exchange of information to create an environment for shared decision making. Within the environment of shared decision making, standardized metrics need to be developed to determine improvement or decline of empowerment within each health care encounter and across patients. By improving empowerment in shared decision making, health care decisions will be made collaboratively leading to high patient satisfaction with their overall healthcare experience.

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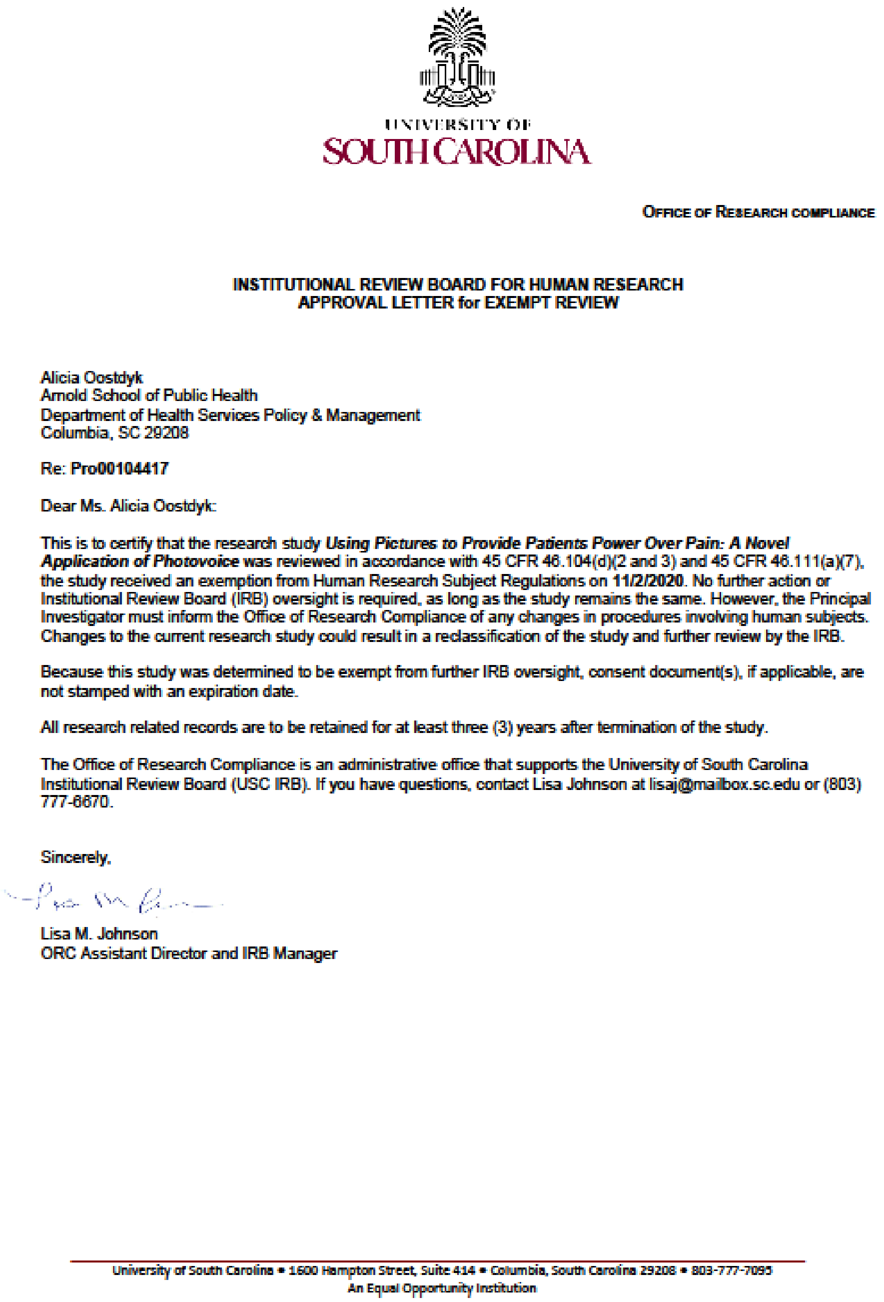
APPENDIX A - INSTITUTIONAL REVIEW BOARD APPROVAL



UNIVERSITY OF
SOUTH CAROLINA

OFFICE OF RESEARCH COMPLIANCE

INSTITUTIONAL REVIEW BOARD FOR HUMAN RESEARCH
APPROVAL LETTER for EXEMPT REVIEW

Alicia Oostdyk
Arnold School of Public Health
Department of Health Services Policy & Management
Columbia, SC 29208

Re: **Pro00104417**

Dear Ms. Alicia Oostdyk:

This is to certify that the research study ***Using Pictures to Provide Patients Power Over Pain: A Novel Application of Photovoice*** was reviewed in accordance with 45 CFR 46.104(d)(2 and 3) and 45 CFR 46.111(a)(7), the study received an exemption from Human Research Subject Regulations on **11/2/2020**. No further action or Institutional Review Board (IRB) oversight is required, as long as the study remains the same. However, the Principal Investigator must inform the Office of Research Compliance of any changes in procedures involving human subjects. Changes to the current research study could result in a reclassification of the study and further review by the IRB.

Because this study was determined to be exempt from further IRB oversight, consent document(s), if applicable, are not stamped with an expiration date.

All research related records are to be retained for at least three (3) years after termination of the study.

The Office of Research Compliance is an administrative office that supports the University of South Carolina Institutional Review Board (USC IRB). If you have questions, contact Lisa Johnson at lisaj@mailbox.sc.edu or (803) 777-6670.

Sincerely,

Lisa M. Johnson
ORC Assistant Director and IRB Manager

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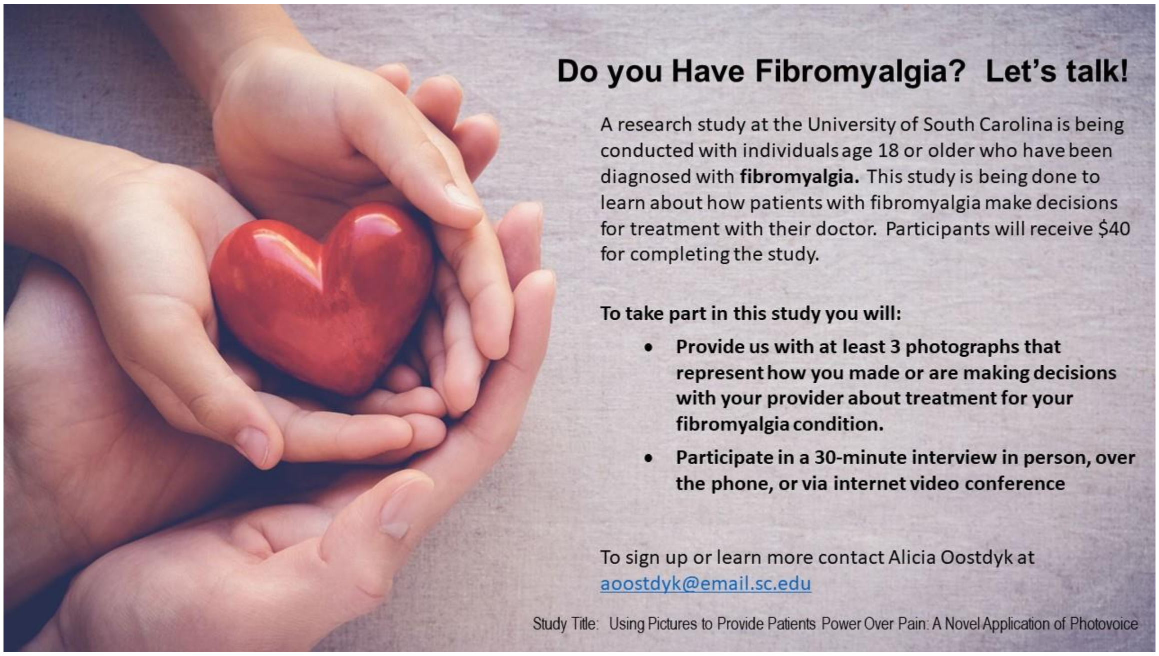
APPENDIX B - RECRUITMENT FLYER



Do you Have Fibromyalgia? Let's talk!

A research study at the University of South Carolina is being conducted with individuals age 18 or older who have been diagnosed with **fibromyalgia.** This study is being done to learn about how patients with fibromyalgia make decisions for treatment with their doctor. Participants will receive $40 for completing the study.

To take part in this study you will:

- **Provide us with at least 3 photographs that represent how you made or are making decisions with your provider about treatment for your fibromyalgia condition.**
- **Participate in a 30-minute interview in person, over the phone, or via internet video conference**

To sign up or learn more contact Alicia Oostdyk at aoostdyk@email.sc.edu

Study Title: Using Pictures to Provide Patients Power Over Pain: A Novel Application of Photovoice

Figure Appendix B.1 Recruitment Flyer

APPENDIX C - INTERVIEW GUIDE

The following questions were used to guide the qualitative interviews.

Decisions

- Tell me about your last visit with the doctor…
    - Did you prepare for your visit? What did you do?
    - How did your doctor discuss your treatment options?
    - How did you discuss your treatment options with the doctor?
- When thinking about your treatment for fibromyalgia, who is responsible for making the decision for treatment? Why?
- What does making a decision about treatment look like?
- What does making a shared decision look like?
- What does making an informed decision look like?
- What is the process you go through when deciding on a treatment for fibromyalgia?
    - What types of things do you think about when making a decision about treatment?
    - What information do you want to have in order to make a decision?
    - Who do you talk to anyone else besides your doctor when making decisions?
    - What does your doctor play in making these decisions?

Preference

- During your visit with your doctor, what information do you want share with your doctor?
    - How do you share this information?
    - What questions does the doctor ask you?
    - What questions do you want the doctor to ask you?
    - What questions do you ask your doctor?
- *<<Mirror this question based on question above – what information do you want to share>>* What do you want your doctor to consider when making a recommendation for treatment?
    - How do you feel when your doctor makes a treatment recommendation?
    - How do you react?
- How do you share your choice of treatment you decide to have with your doctor?
- When you need to see a doctor, what does in an ideal visit look like?
    - What information is shared by you?
    - What questions does the doctor ask?
    - What does this interaction look like?
    - Or was there anything that wasn't ideal at your last visit?
- Have you been in a situation where you wanted a different treatment than what your physician suggested?
    - What did you do?

    - How did it make you feel?

Empowerment

- What actions during your visit make you feel involved in making decisions about your health care?
    - Actions of provider? -- What did you do/how do you react/How did this lead you to share?
    - Actions of patient?
- What makes you feel [empowered] like you are able to take an active role in your health care?
- What makes you feel [empowered] like you are able to discuss with your doctor what you want to do regarding treatment?
- What makes you feel [empowered] like you are able to share what outcomes is important to you?
- What makes you feel confident to take an active role in your health care?
- What makes you feel confident to tell your doctor what you want to do regarding treatment?
- What makes you feel confident to share what goals or priorities are important to you?