

**SOCIAL SUPPORT AND COMMUNICATIVE DISENFRANCHISEMENT:  
EXTENDING THE THEORY OF MOTIVATED INFORMATION  
MANAGEMENT WITHIN A CONTESTED ILLNESS CONTEXT**

by  
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A dissertation submitted to the Faculty of the University of Delaware in partial  
fulfillment of the  
requirements for the degree of Doctor of Philosophy in Communication

Spring 2025

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## ACKNOWLEDGEMENTS

I would like to thank my committee members for their guidance and advice throughout this entire process.

I would also like to thank my hand surgeon and physical therapists for helping me be able to type again.

This manuscript is dedicated to

My wife, Karissa, for her love and understanding. I could not have achieved this goal without her. I am so proud of both of us for becoming doctors.

My cats, Amelia and Tenzin, for keeping me company during long days of writing.

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## ABSTRACT

The way that individuals with contested illnesses seek out information about their illness plays a major role in determining their quality of life. This study used the Theory of Motivated Information Management to examine how individuals with contested illnesses deal with uncertainty and the factors that influence the usage of information-seeking strategies and how that influences their quality of life. The results reveal that there is a negative relationship between avoiding information and quality of life for individuals with contested illnesses. The results also demonstrate that for individuals with low perceived social support, there is a negative relationship between direct information-seeking and quality of life whereas for individuals with high perceived social support, this relationship is positive. The results also show that for individuals with low perceived communicative disenfranchisement, there is a positive relationship between direct information-seeking and quality of life, whereas for individuals with high perceived communicative disenfranchisement, this relationship is negative.

## CHAPTER 1

### INTRODUCTION

According to the CDC, approximately 60% of the United States' population has a chronic illness (Elflein, 2023). Living with a chronic illness can drastically decrease the quality and length of life, especially when the condition is not managed properly (Pereira et al., 2021). Whereas many chronic health conditions have viable treatment plans and clear steps patients can take to manage their conditions, there are some that have neither.

When a chronic illness is disputed on a cultural, medical, or legal level, has unclear treatment options, has an ambiguous etiology, and the status of the illness as legitimate is controversial, it is described as a contested illness (Swoboda, 2008). Some contested illnesses include fibromyalgia (Armentor, 2017) and chronic fatigue syndrome (Conrad & Barker, 2008). Given that those with contested illnesses experience skepticism surrounding the legitimacy of their illness from healthcare providers (Armentor, 2017), and friends and family members (Barker, 2008), it is likely that individuals who have such illnesses will experience considerable and even a novel uncertainty. Uncertainty can be defined as “existing when details of situations are ambiguous, complex, unpredictable or probabilistic, when information is unavailable or inconsistent, and when people feel insecure in their own state of knowledge or the state of knowledge in general” (Brashers,

2001, p. 478). Uncertainty is linked with feelings of anxiety and distress (Phillips-Wren & Adya, 2020; Rimal & Turner, 2009).

The Theory of Motivated Information Management (TMIM) proffers that when an individual's desired level of uncertainty and actual level of uncertainty deviate from one another, that they are likely to both influence anxiety and a desire to manage such anxiety by engaging in information seeking activities (Kuang & Wilson, 2021).

Individuals with contested illnesses are likely to experience a mismatch between their desired level of uncertainty and actual level of uncertainty. For example, those with contested illnesses experience skepticism and stigma (Swoboda, 2008) that may make the presence of non-support or support that is neutral, unhelpful, or undermining (Crowley, 2016; Crowley et al., 2025) more available within the context of their social networks. Further contributing to this problem is the adversarial relationship individuals with contested illnesses have with healthcare providers, which limits the assistance they can receive in coping with uncertainty related to their illness. This adversarial relationship may manifest through a phenomenon known as communication disenfranchisement (Hintz et al., 2023). Communication disenfranchisement refers to the ways in which communication underlies the denial of power, rights, and privileges for individuals, classes, or groups (Hintz et al., 2023). Based on previous research into the stigma and skepticism experienced by individuals with contested illnesses within a healthcare setting (Armentor, 2017), it is likely that such individuals would experience the denial of power, rights, and privileges associated with communication disenfranchisement.

The primary goal of the current study is to extend TMIM's model meaningfully by applying it to an understanding how individuals manage uncertainty with contested illnesses and how this influences their quality of life. As noted, receiving quality support is likely challenging for individuals with contested illnesses. Therefore, a secondary goal of the study is to identify how individuals attempt to manage the complexities of support in their social networks and its impact on information seeking and reports of quality of life. Lastly, because individuals with contested illnesses often experience adversarial relationships with healthcare providers, which can lead to negative outcomes, a third goal of this study is to examine the role of communicative disenfranchisement on information seeking and reports of quality of life.

### **1.1 Contested Illnesses**

A contested illness refers to an illness where an individual claims they have a disease that is not recognized or acknowledged as being strictly medical (Conrad & Barker, 2010). Contested illnesses have a variety of characteristics, such as their status of being a legitimate illness being controversial and being disputed on a cultural, medical, or legal level (Swoboda, 2008). Such illnesses are often thought of being medically invisible because there does not seem to be any known cause for the illness (Conrad & Barker, 2010).

An additional reason why contested illnesses are considered medically invisible is because of the way symptoms typically manifest (Murphy et al., 2016). The symptoms of many of these illnesses, such as fibromyalgia or chronic fatigue syndrome, are often general, such as fatigue or pain (Armentor, 2017). Such symptoms are not always visible

and additionally, many of these illnesses are diagnosed by healthcare providers based on self-reported symptoms rather than through diagnostic testing or imaging (Swoboda, 2008). Furthermore, many contested illnesses do not respond well to established modes of treatment (Murphy et al., 2016). As such, there remains a lot of skepticism from the public (Barker, 2008) and healthcare providers (Au et al., 2022) about these diagnoses. As a result, there is a high probability that individuals with contested illnesses will experience a considerable amount of uncertainty.

Prior studies have identified that individuals with contested illnesses have difficulty maintaining the social relationships and roles they had before their illness (Armentor, 2017; Arnold et al., 2008; Crooks, 2007; Sim & Madden, 2008; Wuytack & Miller, 2011). These studies also highlighted the belief of many individuals with contested illnesses that both their friends and family members did not truly understand what they were going through (Armentor, 2017; Sim & Madden, 2008; Wuytack & Miller, 2011). These studies are beneficial in the sense that they raise awareness about the obstacles and challenges of having a contested illness for both patients and potentially supportive people in their social networks.

The current study, however, aims to expand prior research in the contested illness realm in four distinct ways. One area of expansion involves using a theoretical framework to inform our understanding of how individuals with contested illnesses make decisions on when to seek out or avoid information surrounding their illness. TMIM has been applied to a variety of health contexts but has not been studied in conjunction with contested illnesses. A second area of expansion is examining factors (i.e., social support

and communicative disenfranchisement) that play a role in either decreasing or increasing the obstacles and challenges associated with contested illnesses. Communicative disenfranchisement has been studied in the context of women's interactions with healthcare providers (Hintz & Wilson, 2021; Thompson et al., 2023) and chronic pain (Hintz et al., 2024) but is yet to be applied to individuals with contested illnesses. The final area of expansion is examining how either seeking out information directly or avoiding it impacts the quality of life of individuals with contested illnesses, which is a novel area of research. A few studies have expanded on TMIM by looking at the outcomes of different information-seeking strategies, but this is the first study to examine how different information-seeking strategies impact reports on quality of life.

## **1.2 Uncertainty**

Many individuals with illnesses encounter a period of uncertainty surrounding their symptoms and what illness they might have, but individuals with contested illnesses often wonder if their symptoms are even real (Armentor, 2017), which likely fosters a novel and particularly insidious type of uncertainty. At its core, uncertainty is about self-perception and individuals' ability to make predictions about their futures and make sense of the world around them (Brashers, 2001). Because information about contested illness may be inconsistent or altogether unavailable, those with contested illnesses are likely to feel insecure about how much they know about their illnesses or even how much is known about their illnesses by the healthcare system broadly (Barker, 2008; Swoboda, 2008).

For many individuals, when they are uncertain about what might be causing their symptoms, receiving a diagnosis can be a positive thing because it provides an explanation (Avery & Braunack-Mayer, 2007) and validation (Rowlands et al., 2016) of their symptoms. However, for those with contested illnesses, this may not be the case because the stigma associated with their illness may lead to patients still being questioned by healthcare providers and social network members even after receiving a diagnosis (Conrad & Barker, 2010). The nonsupport from these close social network members may lead to uncertainty (Armentor, 2017; Murphy et al., 2016), anxiety (Phillips-Wren & Adya, 2020; Rimal & Turner, 2009), and feeling disenfranchised (Hintz et al., 2023; Thompson et al., 2023), further contributing to exacerbating their illness and/or disease symptoms due to the impacts of chronic stress on physiological systems in the body (Leschak & Eisenberger, 2019). As uncertainty can lead to many negative consequences, and is generally uncomfortable to experience, individuals are typically motivated to manage their uncertainty in some way.

## CHAPTER 2

### THEORY OF MOTIVATED INFORMATION MANAGEMENT

One approach to describing how individuals manage their uncertainty is the Theory of Motivated Information Management (TMIM, Afifi, 2009). TMIM is applied broadly to investigate uncertainty among both critically ill and chronically ill patients. This work has shown that TMIM is an effective framework in predicting uncertainty associated with illness and attempts to adapt it. Some of these studies include examining the role of online support groups for individuals with chronic illnesses (Kanter et al., 2019), factors driving information seeking or avoidance during the COVID-19 pandemic (Crowley et al., 2021; Je et al., 2022; Link, 2023), and information seeking surrounding family health history (Hovick, 2014; Kuang & Gettings, 2020; Rauscher & Hesse, 2014;). Given that TMIM has often been studied in relation to health and information-seeking behaviors related to challenging topics (Kuang & Gettings, 2020), it makes sense to apply it to a contested illness context.

TMIM provides an explanation for the process individuals go through when deciding if they should seek information about an important topic from others (Afifi, 2016). This process is made up of three distinct phases that explain how individuals make this decision. The three phases are interpretation, evaluation, and decision (Kanter et al., 2019).

## **2.1 Interpretation**

The interpretation phase involves an individual becoming aware that there is a discrepancy between how much uncertainty they want to have about a topic or issue and how much uncertainty they have about it (Afifi & Weiner, 2004). Once the individual identifies that there is an uncertainty discrepancy, this is typically followed by an emotional response (Kanter et al., 2019). A variety of studies have identified a relationship between uncertainty discrepancy and feelings of anxiety within a health context (Fowler et al., 2018; Kanter et al., 2019; Kuang & Wilson, 2021; Rauscher & Hesse, 2014). Once anxiety is experienced as a result of an uncertainty discrepancy, the individual moves into the evaluation phase (Afifi & Weiner, 2004).

## **2.2 Evaluation**

The evaluation phase consists of both outcome expectancies and efficacy assessments. Outcome expectancies refer to the individual's evaluation of the costs and benefits that might arise from a search for information. This evaluation may influence whether the individual decides to seek out information or avoid it. If the individual has a positive expectancy, they will likely be encouraged to directly seek out information whereas a negative expectancy would likely discourage direct seeking efforts (Afifi & Weiner, 2004; Afifi, 2016; Kanter et al., 2019; Kuang & Gettings, 2020).

On the other hand, efficacy assessments involve the extent to which an individual feels like they can enact a certain behavior or the extent to which they feel like a target individual can take action to achieve a desired outcome (Afifi & Weiner, 2004; Kanter et al., 2019). In relation to TMIM, this refers to an individual seeking out information from

a specific source and the desired outcome is reducing the anxiety associated with the uncertainty discrepancy (Kuang & Gettings, 2020). Efficacy assessments are broken down into three distinct types, including communication efficacy, coping efficacy, and target efficacy (Ju et al., 2022).

Communication efficacy involves an individual's belief that they can successfully communicate about the issue at hand (Kanter et al., 2019). Being able to communicate successfully is a skill and for an individual to obtain information, the individual needs to believe they possess enough skill to complete the necessary communication tasks (Kuang & Gettings, 2020). Prior research in this area has primarily centered around an individual's ability to acquire information from individuals in their social network (Fowler & Afifi, 2011; Fowler et al., 2018; Kuang & Wilson, 2021).

Coping efficacy involves whether the individual believes they have the social, instrumental, or emotional resources to manage the outcomes from seeking out information (Afifi & Weiner, 2004; Crowley et al., 2021; Link, 2023). Individuals can choose to use a more direct or avoidant strategy and they need to identify whether they can live with the results of their choice (Kuang & Gettings, 2020). If the individual decides they cannot cope with the results of a strategy, they may decide to choose a different one.

Whereas communication and coping efficacy focus on the individual's beliefs about themselves and their abilities, target efficacy is focused on the capabilities of others. Target efficacy is further broken down into target ability and target honesty (Afifi, 2016; Crowley et al., 2021; Kuang & Gettings, 2020). Target ability involves whether the

person an individual is seeking information from (the target) is capable of answering the individual's questions, whereas target honesty involves whether the individual believes the target will answer truthfully (Ju et al., 2022).

For example, in the context of family health history (Kuang & Gettings, 2020), an individual may want to know about their partner's family health history, but their partner may either not know this information or they may be unwilling to share it. Other studies in this area found that there was a belief among participants that seeking out information about family health information from their partner may lead to tension or relational changes (McAllister et al., 2007; Van Oostrom et al., 2007). These types of efficacy beliefs may be a contributor to the finding that whereas 96% of Americans felt like obtaining a family health history was important, only 30% actively sought out this information (Yoon et al., 2004).

Talking about health-related information can be difficult. Within the context of contested illnesses, this may be particularly challenging given the stigma and bias associated with such illnesses (Au et al., 2022; Barker, 2008). Combined with the lack of knowledge that exists about the causes and treatments of contested illnesses, individuals with such illnesses may have limited efficacy.

### **2.3 Decision Making Phase**

Once the evaluation phase is complete, the individual moves to the decision phase. In this phase, the individual decides whether they want to seek out information from the target or avoid seeking out information (Afifi & Afifi, 2009). If an individual expects a positive outcome and has high efficacy assessments across the three efficacy

domains (communication, coping, and target), they are more likely to seek out information (Kanter et al., 2019). This has been demonstrated across a variety of contexts, such as in a study by Chung and Kim (2008) that showed individuals were more likely to apply the knowledge they learned from a cancer blog if they found the blog to be credible. Additionally, Dillow and LaBelle (2014) found that when an individual experienced uncertainty surrounding a partner's sexually transmitted infection testing status, they were more likely to seek information from their partner when they were high in efficacy.

#### **2.4 Information Seeking and Avoidance**

The extent to which the individual has positive or negative outcome expectancies and efficacy assessments can also influence whether they choose to seek out information (Kuang & Gettings, 2020). Direct information seeking involves strategies like reaching out to members of their social network, searching online for information, or talking to people outside of their network (Crowley et al., 2020). A study by Hovick (2014) demonstrated that when a partner felt they were capable of getting the family health history information they wanted from their partner and expected they would have a positive conversation, they were more likely to seek out the information in a direct way.

On the other hand, if an individual has reason to doubt they will achieve a positive outcome or they doubt either their own efficacy or the efficacy of the target, they are more likely to avoid seeking out information (Kuang & Gettings, 2020). Within the context of family health history, a study by Cox & McKellin (1999) found that some individuals choose to not seek out information about their partner's family health history

because they feared information pertaining to an increased risk of disease. Additional studies have shown that if the individual felt that seeking out family health history information could cause tension in the relationship with their partner, they may choose to avoid seeking out the information even if they thought it was important to know such information (McAllister et al., 2007; Van Oostrom et al., 2007; Yoon et al., 2004).

Prior research has demonstrated that avoiding information, particularly within a health context, can be harmful. For example, research into the COVID-19 pandemic revealed that avoiding health information surrounding vaccines led to a lack of knowledge gain, inhibited decision making, and lower compliance with receiving a vaccine (Crowley et al., 2025; Latkin et al., 2021; Pomares et al., 2020; Siebenhaar et al., 2020; Wong, 2014). As such, it is expected that individuals would achieve better health outcomes by seeking out information rather than avoiding it in most contexts.

## CHAPTER 3

### TMIM RELATIONSHIPS

#### **3.1 Uncertainty Discrepancy and Anxiety**

TMIM proposes that when an individual recognizes that there is a discrepancy between how much uncertainty they want to have and how much uncertainty they have, they experience anxiety (Kuang & Wilson, 2019). This experience of uncertainty-related anxiety is demonstrated in a variety of health contexts, including family health history (Hovick, 2014; Kuang & Gettings, 2020;), the COVID-19 pandemic (Crowley et al., 2021; Ju et al., 2022) sexually transmitted infections (Dillow & LaBelle, 2014), and negative life events (Tian et al., 2016). Whereas most studies found a significant relationship between uncertainty discrepancy and anxiety, a study by Kanter et al. (2019) found that there was not a significant relationship between uncertainty discrepancy and anxiety among their participants with chronic illnesses.

The proposed explanation for this is that the participants of this study did not experience much uncertainty discrepancy about their illness. This was likely the result of several factors, including that most of the participants were not newly diagnosed with their illness, the participants were receiving regular treatment from a healthcare provider, and that many participants reported taking medication for treatment. As such, these participants had likely already collected a lot of information about their illness, which

reduced most of their uncertainty discrepancy. As individuals with contested illnesses often have limited treatment options (Barker, 2008) and contentious relationships with healthcare providers (Armentor, 2017), it may be unlikely that they would be able to reduce their uncertainty discrepancy as much as the participants in Kanter et al's (2019) study. Therefore, it is proposed that the uncertainty discrepancy people with contested illnesses experience will be positively associated with reports of anxiety about such a discrepancy.

H<sup>1</sup>: Uncertainty discrepancy will be positively associated with uncertainty discrepancy anxiety for individuals with contested illnesses.

### **3.2 Anxiety and Outcome Expectancies**

Afifi & Weiner (2004) propose that when a discrepancy between how much one knows and how much one wants to know is recognized, individuals are motivated to manage the physiological reaction they experience because of the anxiety they encounter. As stated previously, TMIM proposes that when this takes place, individual's first go through a process called outcome expectancies, which is defined as an individual's assessment of the costs and benefits associated with a particular information-seeking strategy (Kanter et al., 2019). When an individual is anxious about a difference in their desired and actual level of uncertainty, they are likely to have a negative evaluation of the costs and benefits associated with seeking out information as demonstrated in the context of family health history (Hovick, 2014; Rauscher & Hesse, 2014), sexual health information (Afifi & Weiner, 2006; Chang, 2014), and caregiving for parents (Fowler & Afifi, 2011). Given that individuals will experience considerable uncertainty discrepancy

about their contested illnesses, it is proposed they will report outcome expectancies similar to what is shown in the similar other studies noted above.

H<sup>2</sup>: Uncertainty discrepancy anxiety will be negatively associated with outcome expectancies for individuals with contested illnesses.

### **3.3 Anxiety and Efficacy Assessments**

The anxiety associated with uncertainty discrepancy is likely to influence efficacy assessments as well (Afifi & Weiner, 2004). Efficacy in this context refers to an individual's perceptions of either their own ability or the ability of a target object to effectively perform a behavior (Bandura, 1997). As mentioned previously, TMIM explains efficacy assessments in terms of three distinct types, including communication efficacy, coping efficacy and target efficacy (Kanter et al., 2019). TMIM proposes that when an individual experiences anxiety due to uncertainty discrepancy, they are likely to have low efficacy across all three types (Afifi & Weiner, 2004). The relationship between anxiety and both communication and coping efficacy has been demonstrated across a variety of health contexts (Afifi & Weiner, 2006; Chang, 2014; Fowler & Afifi, 2011; Hovick, 2014; Rauscher & Hesse, 2014).

Based on the extensive support for the inverse relationship between anxiety and communication and coping efficacy assessments, it is proposed that this relationship will persist for individuals with contested illnesses. The stigma and bias surrounding contested illnesses (Barker, 2008) may lead to the individuals who have such illnesses to feel like they do not have the ability to communicate with others about their illness in an effective way (Armentor, 2017; Sim & Madden, 2008; Wuytack & Miller, 2011).

Furthermore, the often-contentious relationship between individuals with contested illnesses and healthcare providers (Au et al., 2022) and the lack of viable treatment options (Murphy et al., 2016) may make individuals with contested illnesses feel as if they cannot cope with the information they receive.

H<sup>3</sup>: Uncertainty discrepancy anxiety will be negatively associated with coping efficacy and communication efficacy for individuals with contested illnesses.

### **3.4 Efficacy Assessments and Outcome Expectancies**

TMIM proposes that, in addition to there being two separate parts of the evaluation phase, there is also a directional connection between the two parts (Afifi & Weiner, 2004), meaning that outcome expectancies always comes before efficacy assessments in the model. As mentioned previously, outcome expectancies involve the costs and benefits individuals believe will occur as a result of an action, whereas efficacy beliefs refer to the reflections on the likelihood of someone or something performing that action (Hovick, 2014). TMIM proposes that these assessments are related, but not the same thing. For example, an individual can assess the costs and benefits of seeking out family health history information, but this is not the same as believing one is capable of obtaining such information from a partner (McAllister et al., 2007; Van Oostrom et al., 2007; Yoon et al., 2004).

TMIM posits that outcome expectations is the first part of the model because an individual makes predictions about what they think the outcome of a particular action will be before determining whether they can cope with the results (Afifi & Weiner, 2004). Additionally, the individual will make such predictions (i.e., outcome expectancies)

before they determine whether they have the ability to effectively enact a communication strategy to receive the information they are seeking (i.e., efficacy assessments) (Kanter et al., 2019). A meta-analysis conducted by Kuang and Wilson (2019) identified that there was strong support for the relationship between outcome expectancies and efficacy assessments across a variety of studies.

In terms of contested illness, it is expected that the results of the present study will emerge in a manner consistent with prior studies regarding the relationship between outcome expectancies and the efficacy assessments. If an individual feels like they will not be able to cope with the information they receive about their illness (i.e., coping efficacy) or if they feel like they do not have the ability to obtain the information they want (i.e., communication efficacy), they will likely decide to not seek out information. Given prior work in this area, it is proposed that:

H<sup>4</sup>: Outcome expectancies will be positively associated with coping efficacy and communication efficacy assessments for individuals with contested illnesses.

### **3.5 Efficacy and Information Seeking**

Historically, it was assumed that when an individual experienced uncertainty, they would inevitably manage this uncertainty by seeking out information (Afifi & Weiner, 2004). However, more recent research has identified that there is also the possibility that uncertain individuals may decide to avoid seeking out information entirely. As Babrow (2001) argues, there are some uncertainties that simply cannot be resolved by obtaining more information. In such situations, the individual may decide they are going to incur more benefits in avoiding relevant information (Kuang & Wilson, 2019). For instance, if

an individual thinks they will be stigmatized for being diagnosed with a particular illness, they may decide they are better off not receiving a diagnosis.

TMIM proposes that the efficacy an individual experiences during the evaluation phase influences their decision to either seek out or avoid information (Afifi & Weiner, 2004). When individuals are higher in communication and coping efficacy, they are more likely to seek out information. Alternatively, individuals reporting lower levels of each type of efficacy are shown to be more likely to avoid information (Kuang & Wilson, 2019; Link, 2023). This has been demonstrated within a variety of contexts, including COVID-19 (Crowley et al., 2021; Ju et al., 2022), chronic illness (Kanter et al., 2019), and family health history (Hovick, 2014; Kuang & Gettings, 2020). The Kanter et al. (2019) study in particular found that individuals with chronic illness were more likely to seek out information from an online support group than a healthcare provider because they felt more comfortable with and trusting of people who had gone through similar experiences and believed they were more likely to obtain the information they sought. Within the context of family health history, Hovick (2014) found that when an individual felt they had the ability to obtain the information they wanted, they were more likely to choose a more direct information strategy with their romantic partner.

Within the context of contested illness, it is anticipated that there will be a similar connection between efficacy assessments and the strategy used for information seeking. If an individual feels they have the capability of communicating or obtaining the information they want and the ability to cope with the results of what they might find, they are more likely to use a direct strategy. However, if they do not feel efficacious in

either area, they are likely to avoid seeking information altogether (Kuang & Wilson, 2019).

Furthermore, prior studies have shown that many individuals with contested illnesses have challenges with maintaining the social relationships they had prior to their illness (Armentor, 2017; Arnold et al., 2008; Crooks, 2007; Sim & Madden, 2008; Wuytack & Miller, 2011). Additionally, individuals with contested illnesses often report feeling as if those close to them and their healthcare providers did not really understand their experience with their illness (Armentor, 2017; Sim & Madden, 2008; Wuytack & Miller, 2011). This may lead to individuals with contested illnesses being selective in who they decide to seek information from. As such, this may even heighten the connection between communication and coping efficacy and direct information-seeking because the individual may want to be even more sure that they have the necessary communication and coping skills before reaching out to others in a direct way. Overall, it is likely that individuals with contested illnesses will seek out information in a direct way from those they have positive efficacy assessments with and will avoid seeking out information from those they have more negative efficacy assessments with.

H<sup>5</sup>: Coping efficacy and communication efficacy will be positively associated with direct information-seeking for individuals with contested illnesses

H<sup>6</sup>: Coping efficacy and communication efficacy will be negatively associated with avoidance for individuals with contested illnesses.

TMIM does not hypothesize a direct pathway between outcome expectancies and information-seeking. However, several recent studies have examined TMIM within the

context of the COVID-19 pandemic and proposed that such a path exists (Aisha et al., 2022; Crowley et al., 2021). Both studies found that there was a significant positive relationship between outcome expectancies and information-seeking. Given that the current study is also occurring within a health context and participants, as noted above are likely negotiating considerable uncertainty, a direct pathway between the variables is hypothesized.

H<sup>7</sup>: Outcome expectancies will be positively associated with direct information-seeking for individuals with contested illnesses.

H<sup>8</sup>: Outcome expectancies will be negatively associated with avoidance for individuals with contested illnesses.

### **3.6 Information Seeking and Quality of Life**

The decision to either directly seek out information or avoid it can have an impact on an individual's health, especially in the context of interacting with a healthcare provider. When an individual avoids seeking out information about their health in interactions with a healthcare provider, they may be less likely to get the answers they want (Brashers et al., 2002; Crowley et al., 2025). The patient receiving minimal answers about their illness may contribute to poorer health, both because they do not have the information they need to treat their illness and because their frustration may lead to them choosing not to seek out information in the future (Sanoff et al., 2015). As mentioned previously, research into the COVID-19 pandemic revealed a variety of areas where avoiding health information led to a host of potential negative health outcomes (Crowley et al., 2025; Latkin et al., 2021; Pomares et al., 2020; Siebenhaar et al., 2020, Wong,

2014). As pointed out previously, receiving a diagnosis for a contested illness can be challenging (Armentor, 2017). There are also no known cures for such illnesses and treatment options can be limited (Barker, 2008). However, there are options for decreasing the severity of symptoms (Au et al., 2022). Therefore, using more direct information-seeking strategies, which are more likely to lead to obtaining the sought after information (Kuang & Wilson, 2019), is more likely to lead to higher quality of life than avoiding information.

H<sup>9</sup>: Direct information-seeking will be positively associated with quality of life for individuals with contested illnesses.

H<sup>10</sup>: Avoidance will be negatively associated with quality of life for individuals with contested illnesses.

## CHAPTER 4

### MODERATORS

#### **4.1 Communicative Disenfranchisement**

The skepticism surrounding contested illnesses often leads to stigmatization (Armentor, 2017; Au et al., 2022; Barker, 2008; Conrad & Barker, 2010, Murphy et al., 2016). There is also the possibility that a healthcare provider will offer a psychiatric issue as a potential explanation in the absence of laboratory findings (Swoboda, 2008). Based on the stigmatization of contested illnesses and how patients are often treated, there is potential for individuals with such illnesses to experience a concept known as communicative disenfranchisement (Hintz et al., 2023).

Communicative disenfranchisement refers to the ways in which communication underlies the denial of power, rights, and privileges for individuals, classes, or groups (Hintz et al., 2023). The theory of communicative disenfranchisement (TCD) offers a framework for examining communicative messages that question and dismiss patients' health concerns and the consequences of such messages (Hintz et al., 2023). The source of such messages traditionally comes from healthcare providers (Hildenbrand et al., 2021).

The theoretical model of disenfranchisement suits the experience of those with contested illnesses (Thompson et al., 2023). TCD offers three constructs that can be

utilized to better understand experiences for those with contested illnesses: disenfranchising talk, proximal consequences, and negative goal inferences (Hintz et al., 2023). Disenfranchising talk includes messages that are designed to discredit someone (Thompson et al., 2023) and lead to material or social consequences. For instance, a healthcare provider may challenge whether an individual is experiencing symptoms as claimed (Hintz et al., 2023), which may lead to them not receiving pain medication. Existing research supports the idea that disenfranchising talk occurs for those with contested illnesses. Indeed, individuals with contested illnesses report experiencing messages that discredit whether their illness exists or whether their experiences of symptoms are legitimate (Armentor, 2017; Au et al., 2022; Barker, 2008; Murphy et al., 2016; Swoboda, 2008).

The second construct of TCD underlying communicative disenfranchisement is proximal consequences (Hintz et al., 2023). Proximal consequences refer to the immediate consequences that occur because of being subjected to disenfranchising talk (Hintz et al., 2023). These consequences can involve a lack of credibility and/or a lack of access to resources, support, and medical care (Thompson et al., 2023). As a disenfranchised group, those with contested illnesses experience such proximal consequences as experiencing a lack of credibility (Barker, 2008) and having their sources of support removed, whether with members of their own social network or their healthcare providers (Armentor, 2017; Duerringer, 2020).

Finally, TCD identifies that disenfranchisement involves negative goal inferences (Hintz et al., 2023). Negative goal inference occurs when individuals who have

experienced disenfranchising talk and proximal consequences anticipate that their future interactions with network members or healthcare providers will also be negative (Hintz et al., 2023). Negative goal inference is reflected in the lived experiences of people navigating contested illnesses. For instance, individuals with contested illnesses often have adversarial relationships with healthcare providers (Armentor, 2017; Swoboda, 2008). This type of relationship may lead to mistrust in the medical system, which can shape future interactions (Benkert et al., 2019; Jaiswal & Halkitis, 2019).

The present study proposes that for individuals with contested illnesses, communicative disenfranchisement will act as a moderator for the entire TMIM model. Given that individuals with contested illnesses are often discredited by healthcare providers (Au et al., 2020; Murphy et al., 2016) and are at risk of having sources of support removed (Armentor, 2017; Thompson & Duerringer, 2020), it is likely that individuals who experience higher levels of communicative disenfranchisement will experience more uncertainty discrepancy, resulting in uncertainty-related anxiety, than individuals who experience lower levels of communicative disenfranchisement. Additionally, the struggles contested illness patients often have with healthcare providers (Armentor, 2017; Swoboda, 2008), which tend to lead to mistrust in the medical system (Benkert et al., 2019; Jaiswal & Halkitis, 2019) will likely lead to more negative outcome expectancies and efficacy assessments (Hovick, 2014; Kanter et al., 2019; Kuang & Gettings, 2020) for individuals with higher levels of communicative disenfranchisement than for those with lower levels. In turn, these negative outcome expectancies and efficacy assessments will lead to a decreased chance of individuals seeking out

information in a direct way (Kuang & Wilson, 2019) for those with higher levels of communicative disenfranchisement. Finally, given our understanding of how avoiding or not obtaining information related to health can negatively impact well-being in other contexts (Latkin et al., 2021; Link, 2023; Pomares et al., 2020; Wong, 2014), it is likely that this will occur for individuals with contested illnesses who have higher levels of communicative disenfranchisement as well.

H<sup>11</sup>: There will be group differences in communicative disenfranchisement such that individuals with high perceived communicative disenfranchisement will demonstrate stronger relationships across the hypothesized model than individuals with low perceived communicative disenfranchisement.

## **4.2 Social Support**

The current study also proposes that social support will act as a moderator for the entire TMIM model for individuals with contested illnesses. Social support can be defined as the “material and emotional resources that are available to a person through interpersonal contacts (Aslund et al., 2014, p. 3). It is often thought of as a buffer for stress (Cohen and Wills, 1985) and has been demonstrated to enhance health (Burlerson, 2009). Additionally, one of social support’s main functions is to manage or reduce uncertainty (Ford et al., 1996).

In the context of contested illnesses, it is often necessary for both the individual and their social network to engage in ongoing adaptation (Primomo et al., 1990). Put simply, this means that when someone is unable to deal with uncertainty, social support can act as a buffer to help them feel an increase sense of ability and control (Ford et al.,

1996). As such, in this perspective, individuals who have the highest levels of stress receive the greatest benefits from social support (Laquidara & Lincoln, 2024).

A second perspective on social support, known as the main effects model, states that social support can provide benefits regardless of whether a person is experiencing stress or not (Cohen & Wills, 1985). This is thought to occur through mechanisms like positive emotions and improved self-esteem. Prior research has shown that the stress-buffering and main effects model are likely not mutually exclusive and work together (Laquidara & Lincoln, 2024).

Prior work has shown that social support is beneficial in managing uncertainty (Barker, 2008; Bulow, 2004; Murphy et al., 2016). Given the role social support has played in reducing uncertainty in other contexts, it is proposed that individuals with contested illnesses who perceive they are receiving more social support will experience lower uncertainty discrepancy and lower levels of anxiety. Additionally, prior research into social support for individuals with chronic illnesses has found that being able to communicate with others about their health problems improves an individual's ability to cope with their illness (Kim & Lee, 2014; Rains et al, 2015). Social support will also likely make an individual feel as if they are capable of communicating with others about their illness (i.e., communication efficacy) and that seeking out information will lead to positive results (i.e., outcome expectancies). Also, receiving social support is shown to be connected to decreases in stress, loneliness, pain, and depression for individuals with chronic illnesses as well as an increase in feelings of self-efficacy when interacting with a healthcare provider (Wright, 2016). Given this, it is expected that those with high levels

of social support, compared to those with low levels, will experience lower levels of uncertainty anxiety, higher levels of efficacy assessments and outcome expectancies, higher usage of direct information-seeking strategies, lower usage of indirect information-seeking strategies, and higher quality of life.

H<sup>12</sup>: There will be group differences in social support such that individuals with high perceived social support will demonstrate lower levels of uncertainty anxiety, higher levels of efficacy assessments and outcome expectancies, higher usage of direct information-seeking strategies, lower usage of avoidance strategies, and higher quality of life.

## CHAPTER 5

### METHODS

#### **5.1 Procedures**

The participants for this study were recruited using Prolific Academic, which is an online research platform ([www.prolific.co](http://www.prolific.co)). Prolific was specifically developed for cognitive and behavioral researchers and has been shown to perform better than its competitors in regard to data quality (Douglas et al., 2023; Peer et al., 2022). The inclusion criteria required participants to be over the age of 18, fluent in English, and have a contested illness. Participants were presented with a commitment check question – “We care about the quality of our survey data. For us to get the most accurate measures of your opinions, it is important that you provide thoughtful answers to each question in this survey. Do you commit to providing thoughtful answers to the questions in this survey.” Prior work has suggested that this type of commitment check is related to lower rates of data quality issues than other types of attention checks (Clifford & Jarit, 2016). All of the participants reported that they were committed to providing thoughtful answers.

#### **5.2 Sample and Data Analysis**

A power analysis was conducted based on an effect size of .08 (Aisha et al., 2022), a power of .80, an alpha of .05, and the 12 variables included in the current model. This suggested that the estimated sample size needed was 211. The resulting sample

included 228 participants. 64.4% ( $n = 147$ ) of the participants were female, 32.4% ( $n = 74$ ) of participants were male, and 3% ( $n = 7$ ) reported being non-binary. Additionally, 78.1% ( $n = 178$ ) of participants were White, 8.3% ( $n = 19$ ) were Black of African American, 5.7% ( $n = 13$ ), 3.5% ( $n = 8$ ) were Asian, 1.3% ( $n = 3$ ) were Middle Eastern, 1.3% were American Indian or Alaskan Natives, and 1.7% ( $n = 4$ ) reported being a race other than these options. The ages of the participants ranged from 19 to 83 ( $SD = 12.86$ ). The majority of participants in the sample completed a high school degree or GED or higher 97% ( $n = 221$ ). Additionally, approximately 47.8% ( $n = 109$ ) of participants had previously visited an online support group associated with their illness, whereas 51.3% ( $n = 117$ ) had not previously visited an online support group associated with their illness. The length of time since diagnosis for the participants ranged from two months to 33 years.

Many of the participants were diagnosed recently with 44.3% ( $n = 86$ ) of participants being diagnosed in the last 3 years. Additionally, the number of illnesses reported by participants ranged in number between 1 and 5 with the majority of participants reporting 1 illness (85.8%,  $n = 194$ ). The most common contested illnesses reported were chronic fatigue syndrome (31.1%,  $n = 71$ ), fibromyalgia (26.3%,  $n = 60$ ), long COVID (18.8%,  $n = 43$ ), and IBS (4.8%,  $n = 11$ ).

### **5.3 Measures**

Participants completed a series of scaled items to measure the variables of interest in this study. Negatively keyed items were reverse coded so that higher values indicated greater endorsement of each variable. Each scale was also tested for reliability. Means

and standard deviations for all scales are listed in Table 1. For each scale, the higher number indicates a greater intensity of the variable.

### **Uncertainty Discrepancy**

Consistent with prior research (see Crowley et al., 2021), uncertainty discrepancy was measured by subtracting the item “how much information do you know about your illness” from “how much information do you want to know about your illness” where positive numbers indicated a desire to know less about their illness. The scale item was anchored from 1 = nothing to 7 = everything.

### **Anxiety About Uncertainty Discrepancy**

Anxiety about uncertainty discrepancy was measured using three items and was measured on a 7-point Likert-type scale anchored from 1 = strongly disagree to 7 = strongly agree. Sample items included “I experience anxiety when I think about how little I know about my illness” and “It makes me anxious to think about the difference between how much I want to know about my illness and how much I know.” This approach to measuring anxiety about uncertainty discrepancy is in line with prior research (Crowley et al., 2021) and was reliable ( $\alpha = .92$ ).

### **Social Support**

Social support was measured using the Online Social Support Scale (OSSS) (Nick et al., 2018). The scale consists of 10 items and was measured using a Likert-type scale anchored from 1 = strongly disagree to 7 = strongly agree. Sample items included “the people who are close to me show me they care about me” and “the people who are close to me are interested in me as a person.” The scale was reliable ( $\alpha = .95$ ).

## **Communicative Disenfranchisement**

Communicative disenfranchisement was measured using modified versions of three subscales (Hintz et al., 2023). The original subscales were 23, 30, and 15 items respectively so the decision was made to shorten each of them. This decision was made because there was concern that given that many of the participants have illnesses that come with symptoms of fatigue, an especially lengthy survey would lead to burnout. The items that were chosen were picked based on the items that seemed the most relevant to this population and by eliminating items that appeared to be redundant. For example, the items “Said or implied that the pain is normal,” “Said or implied that everyone experiences pain,” “Said or implied that the pain is just part of being human,” and “Said or implied that everyone has to cope with pain” are very similar to each other. As such, the decision was made to only measure one of these items as they appeared redundant because as a study by Haroz et al. (2020) notes, lengthy scales with very similar items can increase respondent fatigue and reduce accuracy in the study. Additionally, items like “Assumed I was just trying to get pain medication” and “Assumed that I was a drug seeker” may have been relevant for some participants based on their specific illness, but it would not fit for others. As such, items like “Ignored me when I brought up my symptoms” and “Suggested my symptoms are not really as bad I as I say they are” were deemed to be more relevant for all of the participants. As Stanton et al. (2002) state, eliminating items that appear to lack relevance is an acceptable practice.

The first subscale is known as the Disenfranchising Talk scale. The scale is made up of eight items and is measured on a 7-point Likert-type scale anchored from 1 = never

to 7 = always. Sample items included “How often has your doctor suggested that your symptoms are not really as bad as you say they are” and “How often has your doctor said or implied that your symptoms were not real.” This subscale was found to be reliable ( $\alpha = .91$ ).

The proximal consequences subscale consists of eight items and is measured on a 7-point Likert-type scale anchored from 1 = strongly disagree to 7 = strongly agree. Sample items included “Negative interactions in the past with my doctors in which we talked about my symptoms have made me hesitant to bring my symptoms up in future conversations” and “Negative interactions in the past with my doctors in which we talked about my symptoms have made me more selective about who I talk to about my symptoms in the future.” This scale was also found to be reliable ( $\alpha = .96$ ).

The Negative Goal Inferences subscale is made up of seven items and is measured on a 7-point Likert-type scale anchored from 1 = strongly disagree to 7 = strongly agree. Sample items included “If/when I talk to doctors about my symptoms in the future, I realistically expect that they will treat me with respect” and “If/when I talk to doctors about my symptoms in the future, I realistically expect that they will treat me like my symptoms really exist.” was found to be reliable ( $\alpha = .97$ ). The full scale was also reliable ( $\alpha = .96$ ).

### **Outcome Expectancies**

Outcome expectancies was measured using five items borrowed from Crowley et al., 2021 and was measured on a 7-point Likert-type scale anchored from 1 = a lot more negatives than positives to 7 = a lot more positives than negatives. Sample items included

“Learning about my illness through my healthcare provider would lead to” and “Learning about my illness from my friends and family would lead to.” The scale was reliable ( $\alpha = .75$ ).

### **Efficacy Assessments**

Efficacy assessments was measured using three subscales borrowed from (Crowley et al., 2021). The first subscale is coping efficacy. This subscale is made up of three items and is measured on a 7-point Likert-type scale anchored from 1 = strongly disagree to 7 = strongly agree. Sample items included “I would be able to handle whatever I might find out about my illness” and “I can cope with whatever I learn about my illness.” The scale was reliable ( $\alpha = .78$ ).

The second subscale is communication efficacy. It is made up of three items borrowed from (Crowley et al., 2021) and is measured using a 7-point Likert-type scale anchored from 1 = strongly disagree to 7 = strongly agree. Sample items include “I feel I have the ability to find credible information about my illness” and “I can find any information I need to find about my illness.” The scale was reliable ( $\alpha = .74$ ).

The third subscale is target efficacy. It is made up of three items borrowed from (Crowley et al., 2021) and is measured on a 7-point Likert-type scale anchored from 1 = strongly disagree to 7 = strongly agree. Given the low reliability of this subscale ( $\alpha = .44$ ), the decision was made to drop it.

### **Information Seeking**

Information seeking was measured using three subscales, all of which were borrowed from Crowley et al., (2021). The first subscale is direct information-seeking. It

is made up of five items and is measured on a 7-point Likert-type scale anchored from 1 = strongly disagree to 7 = strongly agree. The reliability for this scale was relatively low ( $\alpha = .51$ ). Given this, the decision was made to use a single measure of “When it comes to seeking out information about my illness, I engage in conversations with others about my illness.” This decision was made because it was the one item in this scale that was borrowed directly from Crowley et al.’s scale (2021) without modification.

The second subscale was indirect information-seeking. It is made up of five items borrowed from Crowley et al. (2021) and is measured on a 7-point Likert-type scale anchored from 1 = strongly disagree to 7 = strongly agree. The scale reliability was low ( $\alpha = .51$ ). As a result, the decision was made to drop this scale.

The third subscale was avoidance. It is made up of two items borrowed from Crowley et al. (2021) and is measured on a 7-point Likert-type scale anchored from 1 = strongly disagree to 7 = strongly agree. Sample items include “When it comes to seeking out information about my illness, I avoid information about my illness” and “When it comes to seeking out information about my illness, I try and prevent the topic of my illness from coming up in conversation.” The scale was reliable ( $\alpha = .72$ ).

### **Quality of Life**

Quality of life was measured using the Pain Disability Index (Tait, 1990). It is made up of six items and is measured on a 10-point Likert-type scale where 1 = no disability and 10 = worst disability. Sample items included recreation activities such as hobbies and social activities such as participation with friends. The scale was reliable ( $\alpha = .88$ ).

## Statistical Analysis

Descriptive statistics were calculated for all variables included in the model. The means, standard deviations, and correlations for all of the variables are located in Table 1. Path analyses were conducted to test the study hypotheses as shown in Figure 1-3. Unstandardized regression coefficients and standard errors are reported. Group analyses were conducted to test differences based on perceived communicative disenfranchisement ( $M = 4.00$ ,  $SD = 1.48$ , low  $n = 119$ , high  $n = 109$ ) and perceived social support ( $M = 4.79$ ,  $SD = 1.33$ , low  $n = 109$ , high  $n = 119$ ). The groups were divided by high and low levels of each variable, which was determined by looking at the mean for each variable. Participants below the mean were considered to be low in that variable and participants above the mean were considered to be high in each variable. Wald tests compared coefficients among the different groups.

## CHAPTER 6

### RESULTS

The initial data analysis involved a probe for deviation from normality for the dependent and independent variables. Transformations were not performed as no significant skewness or kurtosis emerged among the measured variables (skewness and kurtosis  $< 3$  and  $< 10$ , Kline, 1998). Additionally, bivariate correlations were assessed to determine if there was evidence of multicollinearity. All VIF variables were  $< 2.43$ , which indicates that there were no problematic variables in these analyses. The correlations among the variables are identified in Table 1.

#### **6.1 Preliminary Analyses**

The average number of years since the participants received a diagnosis for their illness was 5.92 years ( $SD = 6.93$ ). Interestingly, there was a significant negative correlation between the number of years since diagnosis and uncertainty anxiety ( $\alpha = -.19, p < .01$ ) and a significant positive relationship between the number of years since diagnosis and both coping efficacy ( $\alpha = .17, p < .05$ ) and communication efficacy ( $\alpha = .22, p < .01$ ). Although speculative, this suggests that the longer an individual has a contested illness, the less anxious they are about the difference between what they know and what they want to know about their illness. This may be because they have learned more about their illness the longer they have had it or because they have had the illness

long enough that this discrepancy no longer bothers them as much. The relationship between the number of years since diagnosis and both types of efficacy suggests that the longer an individual lives with their illness, the more they might believe in their ability to communicate with others about their illness and the more they believe they can handle whatever information comes their way.

## 6.2 Hypotheses Testing

Table 2 offers a summary of the hypotheses testing, including whether they hypothesis was supported, and a brief explanation of the finding. The results of the path analysis testing H1-H10 (main effect model) and model fit statistics are available in Table 3. As expected, (H1) there was a significant positive relationship between uncertainty discrepancy and uncertainty anxiety [ $b = .45 (.10), p < .001$ ]. Moreover, H2 was not supported, as there was a negative relationship between uncertainty anxiety and outcome expectancies, but not a significant one [ $b = -.07 (.04), p = .10$ ]. Additionally, there was support for H3 in that there was a significant negative relationship between both coping efficacy [ $b = -.18 (.95), p < .001$ ] and communication efficacy [ $b = -.29 (.04), p < .001$ ] with uncertainty anxiety. As predicted, H4 was supported indicating a significantly positive relationship between outcome expectancies and both coping efficacy [ $b = .17 (.07), p < .05$ ] and communication efficacy [ $b = .22 (.06), p < .01$ ].

The predicted significant positive relationship between coping efficacy [ $b = -.07 (.09), p = .44$ ] and communication efficacy [ $b = .10 (.09), p = .27$ ] with direct information-seeking (H5) was not supported. However, H6, which predicted a significant negative relationship between coping efficacy [ $b = -.22 (.09), p < .05$ ] and

communication efficacy [ $b = -.02 (.09), p = .80$ ] with avoidance was partially supported. Additionally, the predicted relationship between outcome expectancies and direct information-seeking (H7) was supported [ $b = .41 (.09), p < .001$ ]. Furthermore, in support of H8, there was a significantly negative relationship between outcome expectancies and avoidance as predicted [ $b = -.40 (.09), p < .001$ ]. Finally, H9, which predicted a significant positive relationship between direct information-seeking and quality of life was not supported [ $b = -.02 (.09), p = .84$ ], whereas H10 was supported, which predicted a negative association between avoidance and quality of life [ $b = -.18 (.09), p < .05$ ].

### **6.3 Group Differences in Communicative Disenfranchisement**

The results of the path analysis testing group differences in perceived communicative disenfranchisement and the model fit statistics are available in Table 4. There was a significant difference in the relationship between direct information-seeking and quality of life [ $\chi^2(1) = 5.57, p = .03$ ] for individuals with low perceived communicative disenfranchisement [ $b = .18 (.14), p = .19$ ] and high perceived communicative disenfranchisement [ $b = -.24 (.11), p < .05$ ]. As such, H11 is partially supported.

An additional interesting finding is that for individuals with high perceived communicative disenfranchisement, using an avoidance strategy [ $b = -.10 (.12), p = .41$ ] has a less negative influence on quality of life than it does for individuals with low perceived communicative disenfranchisement [ $b = -.18 (.13), p = .19$ ]. This suggests that for individuals who are high in communicative disenfranchisement, it may be less harmful for them to avoid information related to their illness altogether than to seek it out

from healthcare providers and social network members who are unsupportive. As such, for this population it may be better to avoid seeking out information than seeking it out from the wrong source.

#### **6.4 Group Differences in Social Support**

The results of the path analysis testing for groups differences in perceived social support and the model fit statistics are presented in Table 5. There was a significant difference in the relationship between direct information-seeking and quality of life [ $X^2(1) = 7.27, p = .01$ ] for individuals with low perceived social support [ $b = -.27 (.11), p < .05$ ] and individuals with high perceived social support [ $b = .21 (.14), p = .14$ ]. Given this, H12 is partially supported.

## CHAPTER 7

### DISCUSSION

In an effort to better understand the role of uncertainty and information-seeking strategy usage for individuals with contested illnesses, this study achieved four significant goals. First, the present study successfully applied the TMIM model to the novel context of contested illnesses. As mentioned previously, due to the often-invisible symptoms (Armentor, 2017; Swoboda, 2008), lack of established modes of treatment (Murphy et al., 2016), and skepticism from the public and healthcare providers (Barker, 2008; Au et al., 2022) make it likely that individuals with contested illnesses will experience a considerable amount of uncertainty surrounding their illness. Additionally, given that individuals with contested illnesses often feel as if their support networks and healthcare providers do not understand their illness experience (Armentor, 2017; Sim & Madden, 2008; Wuytack & Miller, 2011), decision making surrounding whether to seek out information or avoid it may be particularly salient for this population.

Second, the present study helps to extend the TMIM model, along with other recent research (see Crowley et al., 2021; Tian et al., 2016; Droser, 2020) by showcasing its applicability to health outcomes beyond information-seeking or avoidance such as with reports of quality of life in the current study. Third, the current study highlights the

essential role of social support in the TMIM model for this population. Specifically, it reveals the role of direct information-seeking in quality of life for individuals with contested illnesses. Finally, the findings of this study demonstrate that communicative disenfranchisement may play a role in the TMIM process for individuals with contested illnesses, particularly in the relationship between direct information-seeking and quality of life.

### **7.1 TMIM in Contested Illnesses**

The first implication of this study is that TMIM was successfully applied to the novel context of individuals with contested illnesses. The results broadly reveal that the TMIM model works mostly as it does in other contexts for individuals with contested illnesses with a few notable exceptions. One specific finding is that uncertainty discrepancy had a positive relationship with uncertainty anxiety. As mentioned previously, prior studies have identified a relationship between uncertainty and uncertainty anxiety across a variety of health contexts (Fowler et al., 2018; Kanter et al., 2019; Kuang & Wilson, 2021; Rauscher & Hesse, 2014).

Additionally, there was a negative relationship between uncertainty anxiety and both coping and communication efficacy. Prior work has revealed that when an individual experiences uncertainty anxiety, they are likely to have low coping efficacy and communication efficacy (Afifi & Weiner, 2004). This relationship has been demonstrated across other health contexts (Fowler & Afifi, 2011; Chang, 2014; Afifi & Weiner, 2006; Rauscher & Hesse, 2014; Hovick, 2014). It therefore makes sense that, given the stigma and bias that often surround contested illnesses (Barker, 2008) coupled with a lack of

solid treatment options (Murphy et al., 2016) and feelings of being misunderstood (Armentor, 2017; Sim & Madden, 2008; Wuytack & Miller, 2011) that the results would show consistency in the relationship between experiencing anxiety due to uncertainty and one's belief that they may not be able to communicate about their illness effectively or cope with the information they receive about their illness.

Furthermore, there was a positive relationship between both coping and communication efficacy and outcome expectations. As mentioned previously, a meta-analysis conducted by Kuang & Wilson (2019) demonstrated strong support for this relationship. The consistency in results in the current study confirms that, if an individual with a contested illness feels they will achieve positive results by seeking out information, they will also be more likely to feel as if they have the ability to communicate with others effectively and cope with any information they might receive. For example, if an individual believes seeking out information about their symptoms from a healthcare provider will lead to positive results (i.e., receiving a diagnosis, receiving a treatment plan), they likely believe in their ability to communicate effectively to achieve their desired result and believe in their ability to cope with the information they receive. On the other hand, if the individual believes that seeking out information about their symptoms from a healthcare provider will lead to negative results (i.e., having their symptoms dismissed), they likely do not believe in their ability to achieve a positive result and may not correspondingly believe in their ability to cope with such dismissals.

The results also demonstrated a negative relationship between coping efficacy and avoidance. As shown in a meta-analysis by Kuang & Wilson (2019), when an individual

feels efficacious in their ability to cope with the information they seek, they are less likely to avoid seeking out information. If an individual with a contested illness feels as if they can cope with any information they receive from their healthcare provider or support network regarding their illness, there is little reason for them to attempt to avoid seeking out this information.

Finally, the results revealed a positive relationship between outcome expectancies and direct information-seeking and a negative relationship between outcome expectancies and avoidance. Prior studies have found a similar relationship (Aisha et al., 2022; Crowley et al., 2021) between these variables. It makes sense that this relationship would exist within this population because the belief in a positive outcome is likely to drive a willingness to seek out information in a more direct way. As the consequences of receiving a negative outcome can be severe for individuals with contested illnesses (Armentor, 2017; Sim & Madden, 2008; Wuytack & Miller, 2011) the positive relationship between outcome expectancies and direct information-seeking is a logical one.

Given the stigma and skepticism surrounding many contested illnesses (Barker, 2008; Au et al., 2022) individuals with contested illnesses may have significant concerns regarding the outcome of seeking out information from either members of their social support network or healthcare providers. For example, some patients who present to a healthcare provider with symptoms like generalized pain and fatigue may be told that what they are experiencing is a result of a psychiatric disorder (Conrad & Barker, 2010; Gibson et al., 2016) or be labeled as drug-seeking (Dassieu et al., 2021). Being labeled as

such creates additional barriers to receiving care in subsequent encounters with healthcare providers as this increases the likelihood of having one's claims dismissed (Gibson et al., 2016). As such, an individual with a contested illness would want to make sure that they had a high probability of achieving a positive outcome (i.e., high outcome expectations) before deciding to use a direct information-seeking strategy. Additionally, as avoiding information has been linked to being less likely to receive answers (Brashers et al., 2002; Crowley et al., 2025) it makes sense for an individual who is confident in achieving a positive outcome to reject this strategy in favor of a direct one that is more likely to be successful.

## **7.2 Quality of Life Extension**

The second major implication of this study is the successful extension of TMIM. Much as Crowley et al.'s (2021) study on TMIM within a COVID-19 context does, the current study extends the TMIM model by highlighting how it can be applied to actual outcomes. The results show that there is a negative relationship between avoidance and quality of life for individuals with contested illnesses. As mentioned previously, when individuals avoid seeking out information, they are less likely to receive the answers they seek (Brashers et al., 2002; Crowley et al., 2025). Additionally, when an individual does not receive the answers they want in a medical context, this may lead to poorer health (Sanoff et al., 2015). As such, this relationship highlights the dangers of using an avoidance strategy under certain conditions for this population.

### **7.3 Group Differences in Social Support**

The third major implication of the findings reveal that there are group differences in perceived social support among individuals who reported either high or low levels of social support. Prior work on TMIM has not emphasized the role of social support with some exceptions. In the current study, social support moderates the relationship between direct information-seeking and quality of life for individuals with contested illnesses. The model fit statistics show that a model with the addition of social support is a better fit for individuals with contested illnesses.

As mentioned above, there was a significant difference in the relationship between direct information-seeking and quality of life for individuals with low and high perceived social support. For individuals with low social support, the relationship between direct information-seeking and quality of life is actually negative, which indicates that when direct information-seeking usage increases, quality of life decreases. One possible explanation for this is that if an individual feels as if they are not receiving adequate social support, they may not receive the benefits of seeking out information in a direct way. This finding may also be partially explained by the concept of support marshaling (see Crowley, 2016). Support marshaling argues that individuals engage in efforts to gather the resource of support by actively structuring their social networks in ways that optimize their potential for achieving goals. If a network is comprised of low support potential already by extension of the support providers, the individual needing support is disadvantaged even if they seek support through direct strategies that are typically identified as being the most skillful and healthy (Crowley et al., 2025).

Additionally, this finding can be partially explained through the lens of the main effects model. As mentioned previously, the main effects model states that social support leads to positive outcomes regardless of whether an individual is experiencing stress (Cohen & Wills, 1985). Specifically, the main effects model argues that social support can have direct effects on well-being through positive emotions and a boost in self-esteem (Laquidara et al., 2024). The inverse would then indicate that a lack of a psychological sense of available social support can also have direct effects on well-being in a negative way through negative emotions and a decrease in self-esteem. The results indicate that for individuals with low perceived social support, they may be better off avoiding information than directly seeking it out from unsupportive social network members.

Conversely, the results showed that there was a positive relationship between direct information-seeking and quality of life for individuals with high perceived social support. Individuals who perceive that they are getting the support they need from their friends and family likely feel confident in seeking out information in a direct way, which would then boost their quality of life. Such individuals would likely be more inclined to seek out support in direct ways (Crowley et al., 2025) and also be able to take advantage of the benefits described in the main effects model (Cohen & Wills, 1985). This finding is consistent with substantial research identifying the benefits of direct information-seeking (Crowley et al., 2025; Crowley J.L. & High, A.C., 2022; Morrison, 2006) but helps explain conditions under which engaging in such communication might not be

advantageous; that is, it might not be helpful to engage in direct strategies when a support network is comprised of mostly non-supportive providers.

#### **7.4 The Role of Communicative Disenfranchisement**

The final implication of the current study is the potential role of disenfranchisement in explaining outcomes within the TMIM model. Prior research has yet to explore communicative disenfranchisement in the context of TMIM. The results show that there was a significant difference in the relationship between direct information-seeking and quality of life for individuals with low perceived communicative disenfranchisement and high perceived communicative disenfranchisement. For individuals with low communicative disenfranchisement (i.e., individuals who do not feel disenfranchised by healthcare providers), the relationship between direct information-seeking and quality of life is positive. This indicates that when an individual does not feel disenfranchised, seeking out information in a direct way boosts their perceptions of their quality of life.

However, when an individual is high in communicative disenfranchisement (i.e., individuals who do feel disenfranchised by healthcare providers) the relationship between direct information-seeking and quality of life is negative. As highlighted earlier, the stigma and skepticism surrounding contested illnesses (Au et al., 2022; Barker, 2008; Armentor, 2017) can lead to negative consequences for individuals who seek out information from an unsympathetic healthcare provider in a direct way. Seeking a diagnosis or treatment options from a healthcare provider who disenfranchises the patient

can lead to a lack of credibility, a lack of resources, and a lack of support and medical care (Thompson et al., 2023) as outlined by the concept of proximal consequences.

Looking at some of the individual measures within the communicative disenfranchisement scale can provide some insight into the consequences of experiencing negative interactions with a healthcare provider related to the participants' contested illnesses. A majority of participants agreed that prior negative interactions with healthcare providers made them hesitant to bring up their symptoms to others (71%,  $n = 162$ ), made them stop talking about their symptoms with some people they knew (62%,  $n = 141$ ), made them distrustful of others they might talk to about their symptoms (64%,  $n = 146$ ), and made it harder for them to find support from others (63%,  $n = 144$ ). This indicates that individuals with contested illnesses may feel that negative experiences with healthcare providers can make them feel more hesitant to reach out to others and make it more difficult for them to get the support they need. Given the relationship between social support and quality of life (See Table 1), it could be that seeking out information from a healthcare provider and receiving negative feedback (i.e., disenfranchisement) limits essential sources of support that may boost quality of life. For example, if an individual with a contested illness is labeled as a drug-seeker or as someone who is either suffering from a mental health condition or making up their symptoms by their healthcare provider, this could lead to other people in the individual's network also not being supportive.

An additional explanation also emerged as a result of examining individual measures within the communicative disenfranchisement scale. A majority of participants

agreed that prior negative interactions with healthcare providers made it harder for them to receive a diagnosis (68%,  $n = 155$ ), to seek out future care for their symptoms (69%,  $n = 157$ ), to get treatment for their symptoms (68%  $n = 155$ ), and made it less likely they would seek out care for other issues moving forward (64%,  $n = 146$ ). As such, it may be that seeking out information from a healthcare provider in a direct way and receiving negative feedback (i.e., disenfranchisement) limits a contested illness patients' ability to receive a diagnosis and their ability to receive proper care for both their contested illness symptoms and any other health issues they may have in the future, resulting in poorer quality of life.

A major implication for both variables is that whereas direct information-seeking is thought to lead to better outcomes in a variety of contexts, this may not be the case for individuals with contested illnesses under certain conditions. If an individual with a contested illness is not receiving adequate support from either members of their social network or from their healthcare provider, seeking out information in a direct way may not be beneficial. In fact, under such conditions, they may be better off avoiding information altogether.

### **7.5 Practical Implications**

There are several practical implications of this study in terms of how it can benefit individuals with contested illnesses. The study demonstrates the role of information-seeking on quality of life for this population in that the use of more indirect information-seeking strategies is associated with lower quality of life. This highlights the importance of understanding the factors that lead to individuals with contested illnesses choosing

either a direct or indirect strategy. As high perceived social support is associated with direct information-seeking strategy usage, individuals with contested illnesses should be encouraged to seek out help and information from their support networks and healthcare providers in direct ways. But perhaps even more importantly, the support networks of individuals with contested illnesses should be encouraged to be open and willing to provide help and information when possible. As stated previously, individuals with contested illnesses often feel isolated from their friends and family because they feel like they do not understand what they are going through. Given that individuals who perceive receiving low social support do not appear to receive the quality-of-life benefits associated with direct information-seeking, it is vitally important for the friends and family members of individuals with contested illnesses to learn more about their illness to facilitate understanding and be able to provide adequate support.

Additionally, as there is a negative association between direct information-seeking and quality of life for individuals who perceive high communicative disenfranchisement, healthcare providers should be encouraged to learn more about contested illnesses and provide patient-centered care for all patients. When an individual has a negative experience with a healthcare provider, it is likely to influence their health in negative ways as it makes them less likely to seek out care in the future. Healthcare providers should be reminded that disenfranchising contested illness patients in this way goes against their directive of “do no harm” as doing so can negatively impact quality of life for this population.

One way this could be applied is by creating an action plan to address patients feeling disenfranchised by their healthcare providers. For example, medical professionals are required to complete a certain number of Continuing Medical Education (CME) credits to maintain their license (NIH, 2017). One option could be creating a CME course to teach medical professionals more about contested illnesses and how to make sure these patients do not feel disenfranchised. This could then lead to future studies that examine the efficacy of these training programs to see if they make an improvement in quality of life or other outcomes for individuals with contested illnesses.

Furthermore, contested illness patients should be encouraged to take advantage of resources such as online support groups that can shed light on whether other contested illness patients have had a positive or negative experience with a given healthcare provider. Given that seeking out information from an unsupportive healthcare provider can negatively influence a contested illness patient's ability to receive a diagnosis and their ability to receive treatment for their symptoms in the future (Armentor, 2017; Au et al., 2022; Barker, 2008) it is imperative that individuals with contested illnesses have a better understanding of whether a healthcare provider will be supportive or not before seeking out information from them. This is particularly salient for this population as the results of the current study indicate that contested illness patients may be better off avoiding information than seeking out information from an unsupportive source.

### **7.7 Limitations and Future Directions**

The findings of the current study identify important pathways regarding uncertainty, information-seeking strategies, and quality of life for individuals with

contested illnesses. However, this research is not without limitations. First, the scale for direct information-seeking was relatively low and was shortened to a reduced scale. This may have influenced the model fit and/or may have affected how other variables relate to each other.

Additionally, the cross-sectional nature of the study limited the ability to make causal claims. Future studies should seek to conduct a longitudinal study. A large part of the contested illness experience is informed by the journey an individual has to go on to receive a diagnosis. A longitudinal study would be able to track this journey over time and see how participants' thoughts on concepts like efficacy, outcome expectancies, and information-seeking strategies may change over time. Over the course of receiving a diagnosis and beyond, individuals with contested illnesses may encounter healthcare providers and social network members that are more or less supportive. Conducting a longitudinal study could provide additional information on how these encounters influence these individuals' information-seeking strategies and their quality of life.

Furthermore, the result of both the main effect and moderation models resulted in only marginally acceptable fits. The sample size was small, which likely contributed to the low CFI and TLI. Future studies could replicate these results with an increased sample size to establish greater confidence in the findings.

Additionally, the current study only examined information-seeking and avoidance. The original TMIM model also utilizes the concept of reappraisal. Future studies could study the role of reappraisal to see if this process plays a role in how individuals with contested illnesses deal with uncertainty. Also, whereas the original TMIM model only

looks at how uncertainty leads to anxiety, more recent studies have examined other emotional responses to uncertainty. Future studies could look at whether uncertainty impacts other types of emotion and how this may influence information-seeking strategies.

Given that communicative disenfranchisement is a relatively new theory, future studies could examine it further in the context of contested illness both using TMIM and other similar theories. Furthermore, the current study employed an abridged version of the communicative disenfranchisement scale. Future studies could use the entire scale to see if this would make a difference in the results. Additional concepts like medical mistrust, both on an individual and institutional level, could also be examined to see if they relate to information-seeking for individuals with contested illnesses. The current study also looked at a variety of contested illnesses. It may be that communicative disenfranchisement has more of an impact on some types of contested illnesses than others. Future studies could examine one particular contested illness (i.e., fibromyalgia) to see if the results are similar.

Finally, there have been relatively few studies that have examined the outcomes of information-seeking or avoidance. Future studies could utilize quality of life measures in other health-related contexts within the TMIM framework. Additionally, future studies could examine other outcome variables within a contested illness context. Potential outcome variables could include examining both the specific physical and mental health symptoms the participants may experience. This could include levels of fatigue and pain, depression, and anxiety, among others.

## **7.8 Conclusion**

These findings have important implications for individuals with contested illnesses. Results from this national sample investigated predictors of quality of life for this population and further extended our understanding of TMIM. It identified that avoiding information negatively influenced reports of quality of life for individuals with contested illnesses. Social support and communicative disenfranchisement were both identified as factors in how using direct information-seeking influences quality of life. Individuals with high perceived social support reported receiving quality of life benefits for choosing a direct strategy whereas individuals with high perceived communicative disenfranchisement did not receive these benefits.

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Figure 1: TMIM Model

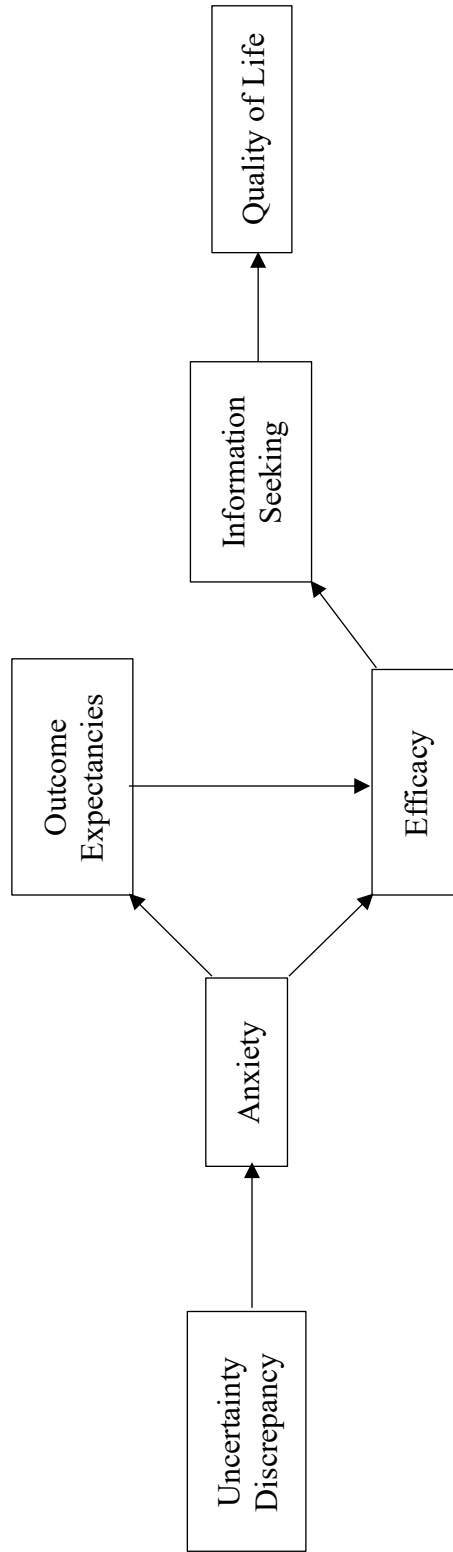


Table 1: Descriptives and correlations

Variable	n	M	SD	1	2	3	4	5	6	7	8	9	10	11	12
1. Years Since Diagnosis	228	5.92	6.93	-											
2. Age	228	42.11	12.86	.36**	-										
3. Uncertainty Discrepancy	228	1.62	1.25	-.12	-.14*	-									
4. Uncertainty Anxiety	228	4.22	1.65	-.19**	-.21**	.35**	-								
5. Outcome Expectancies	228	4.55	1.09	-.05	.05	-.02	-.11	-							
6. Coping Efficacy	228	4.95	1.19	.17*	.18*	.03	-.30**	.20**	-						
7. Communication Efficacy	228	5.02	1.20	.22**	.22**	-.29**	-.47**	.25**	.35**	-					
8. Direct Information-Seeking	228	4.59	1.12	.04	.03	-.11	-.09	.36**	.16*	.26**	-				
9. Avoidance	228	3.13	1.36	-.03	-.11	-.13*	.20**	-.32**	-.35**	-.22**	-.31**	-			
10. Social Support	228	4.79	1.33	-.13	-.01	-.05	-.02	.39**	.05	.17*	.27**	-.12	-		
11. Communicative Disenfranchisement	228	4.68	1.75	-.04	-.12	.21**	.29**	-.38**	-.05	-.24**	-.15*	.24**	-.32**	-	
12. Quality of Life	228	5.56	2.02	-.15*	-.01	.05	-.06	.12	.06	.15*	.08	-.15*	.28**	-.20**	-

\* = < .05, \*\* = < .01

Table 2: Summary of hypothesis testing

Hypothesis	Significance Testing	Summary of Finding
H1: Uncertainty discrepancy will be positively associated with uncertainty anxiety	Supported	Uncertainty discrepancy is significantly positively associated with uncertainty anxiety
H2: Uncertainty anxiety will be negatively associated with outcome expectancies	Not supported	
H3: Uncertainty anxiety will be negatively associated with efficacy assessments	Supported	Uncertainty anxiety is significantly negatively associated with efficacy assessments
H4: Outcome expectancies will be positively associated with efficacy assessments	Supported	Outcome expectancies are significantly positively associated with efficacy assessments
H5: Efficacy assessments will be positively associated with direct information-seeking	Not Supported	Efficacy assessments are significantly positively associated with direct information-seeking
H6: Efficacy assessments will be negatively associated with avoidance	Supported	Efficacy assessments are significantly negatively associated with avoidance
H7: Outcome expectancies will be positively associated with direct information-seeking	Supported	Outcome expectancies are significantly positively associated with direct information-seeking
H8: Outcome expectancies will be negatively associated with avoidance	Not supported	
H9: Direct information-seeking will be positively associated with quality of life	Not supported	
H10: Avoidance will be negatively associated with quality of life	Supported	Avoidance is negatively associated with quality of life
H11: Communicative disenfranchisement is a moderator of the hypothesized relationships	Partially supported	Communicative disenfranchisement moderates the relationship between direct information-seeking and quality of life
H12: Social support is a moderator of the hypothesized relationships	Partially supported	Social support moderates the relationship between direct information-seeking and quality of life

Table 3: TMIM original model

Independent Variables	Dependent Variables						
	Uncertainty Anxiety	Outcome Expectancies	Coping Efficacy	Communication Efficacy	Direct Information-Seeking	Indirect Information-Seeking	Quality of Life
	b(se)	b(se)	b(se)		b(se)	b(se)	b(se)
Uncertainty discrepancy	<b>.45(.09)</b>	-	-	-	-	-	-
Uncertainty anxiety	-	-.07(.04)	<b>-.17(.03)</b>	-	-	-	-
Outcome expectancies	-	-	<b>.25(.04)</b>	-	<b>.37(.06)</b>	-.07(.06)	-
Coping efficacy	-	-	-	-	<b>.26(.09)</b>	<b>-.27(.09)</b>	-
Communication efficacy	-	-	-	-	-	-	-
Direct information seeking	-	-	-	-	-	-	.22(.15)
Indirect information seeking	-	-	-	-	-	-	<b>-.33(.15)</b>

Model fit: RMSEA = .074 (.05, .10); CFI = .84; TLI = .73 Chi-square = 71.52, p < .00. Bolded coefficients indicate statistical significance of at least p < .05.

Table 4: Group differences by perceived communicative disenfranchisement category (n = 228)

Independent variable	Path Dependent variable	Main effect coefficient	Group coefficients	Wald statistics
		b(sc)	b(sc)	
Uncertainty Anxiety	Uncertainty Discrepancy	<b>.45 (.09)</b>	(1) <b>.36 (.12)</b> (2) <b>.42 (.11)</b>	$\chi^2 = .12, p = .73$
Outcome Expectancies	Uncertainty Anxiety	-.07 (.05)	(1) .01 (.06) (2) -.02 (.07)	$\chi^2 = .17, p = .68$
Coping Efficacy	Uncertainty Anxiety	<b>-.18 (.05)</b>	(1) <b>-.18 (.06)</b> (2) <b>-.21 (.07)</b>	$\chi^2 = .07, p = .80$
Coping Efficacy	Outcome Expectancies	<b>.17 (.07)</b>	(1) <b>.22 (.09)</b> (2) <b>.16 (.12)</b>	$\chi^2 = .16, p = .69$
Communication Efficacy	Uncertainty Anxiety	<b>-.29 (.04)</b>	(1) <b>-.24 (.06)</b> (2) <b>-.33 (.07)</b>	$\chi^2 = 1.19, p = .27$
Communication Efficacy	Outcome Expectancies	<b>.22 (.06)</b>	(1) .16 (.09) (2) .23 (.11)	$\chi^2 = .24, p = .63$
Direct Information-Seeking	Outcome Expectancies	<b>.41 (.09)</b>	(1) <b>.40 (.14)</b> (2) <b>.43 (.14)</b>	$\chi^2 = .02, p = .28$
Direct Information-Seeking	Coping Efficacy	.07 (.09)	(1) .02 (.14) (2) -.13 (.12)	$\chi^2 = .67, p = .41$
Direct Information-Seeking	Communication Efficacy	.10 (.09)	(1) .13 (.15) (2) .04 (.12)	$\chi^2 = .21, p = .65$
Avoidance	Outcome Expectancies	<b>-.40 (.09)</b>	(1) -.28 (.14) (2) <b>-.43 (.13)</b>	$\chi^2 = .57, p = .45$
Avoidance	Coping Efficacy	<b>-.21 (.09)</b>	(1) -.27 (.14) (2) -.12 (.11)	$\chi^2 = .76, p = .38$
Avoidance	Communication Efficacy	-.02 (.09)	(1) -.24 (.15) (2) .13 (.12)	$\chi^2 = 3.68, p = .05$
Quality of Life	Direct Information-Seeking	-.02 (.09)	(1) .18 (.20) (2) <b>-.24 (.11)</b>	$\chi^2 = 5.57, p = .02$
Quality of Life	Avoidance	-.18 (.09)	(1) -.18 (.14) (2) -.10 (.12)	$\chi^2 = .19, p = .67$

Model fit: RMSEA = .081 (.05, .11); CFI = .84; TLI = .71 Chi-square = 91.81,  $p < .001$ . Bolded coefficients indicate statistical significance of at least  $p < .05$ . 1 = low communicative disenfranchisement, 2 = high communicative disenfranchisement.

Table 5: Group differences by perceived social support category (n = 228)

Independent variable	Path	Main effect coefficient	Group coefficients	Wald statistics
	Dependent variable	b(se)	b(se)	
Uncertainty Anxiety	Uncertainty	<b>.45 (.09)</b>	(1) <b>.60 (.12)</b>	$\chi^2 = 2.37, p = .12$
	Discrepancy		(2) <b>.34 (.12)</b>	
Outcome Expectancies	Uncertainty Anxiety	-.07 (.04)	(1) -.11 (.06) (2) -.04 (.06)	$\chi^2 = .74, p = .21$
Coping Efficacy	Uncertainty Anxiety	<b>-.18 (.05)</b>	(1) -.11 (.07) (2) <b>-.23 (.06)</b>	$\chi^2 = 1.51, p = .21$
Coping Efficacy	Outcome Expectancies	<b>.17 (.07)</b>	(1) <b>.32 (.11)</b> (2) .08 (.09)	$\chi^2 = 2.85, p = .09$
Communication Efficacy	Uncertainty Anxiety	<b>-.29 (.04)</b>	(1) <b>-.33 (.07)</b> (2) <b>-.27 (.06)</b>	$\chi^2 = .59, p = .44$
Communication Efficacy	Outcome Expectancies	<b>.22 (.06)</b>	(1) .11 (.10) (2) <b>.25 (.09)</b>	$\chi^2 = 1.22, p = .27$
Direct Information-Seeking	Outcome Expectancies	<b>.41 (.09)</b>	(1) .29 (.15) (2) <b>.50 (.13)</b>	$\chi^2 = 1.19, p = .28$
Direct Information-Seeking	Coping Efficacy	-.07 (.09)	(1) -.09 (.13) (2) .01 (.13)	$\chi^2 = .29, p = .59$
Direct Information-Seeking	Communication Efficacy	.10 (.09)	(1) -.06 (.13) (2) .18 (.13)	$\chi^2 = 1.70, p = .19$
Avoidance	Outcome Expectancies	<b>-.40 (.09)</b>	(1) <b>-.47 (.14)</b> (2) <b>-.32 (.14)</b>	$\chi^2 = .59, p = .44$
Avoidance	Coping Efficacy	<b>-.21 (.09)</b>	(1) -.07 (.12) (2) <b>-.42 (.14)</b>	$\chi^2 = 3.62, p = .06$
Avoidance	Communication Efficacy	-.02 (.09)	(1) -.08 (.11) (2) .07 (.14)	$\chi^2 = .71, p = .40$
Quality of Life	Direct Information-Seeking	-.02 (.09)	(1) <b>-.27 (.11)</b> (2) .21 (.14)	$\chi^2 = 7.27, p = .01$
Quality of Life	Avoidance	<b>-.18 (.09)</b>	(1) -.08 (.12) (2) -.17 (.13)	$\chi^2 = .27, p = .61$

Model fit: RMSEA = .067 (.03, .10); CFI = .89; TLI = .80 Chi-square = 80.31, p = .01. Bolded coefficients indicate statistical significance of at least  $p < .05$ . 1 = Low perceived social support, 2 = high perceived social support.

## APPENDIX

### Communicative Disenfranchisement Scale

#### Disenfranchising Talk Subscale

- 1. Suggested that the pain is not really as bad as I say it is**
2. Expressed skepticism about how bad the pain really is
3. Suggested that the pain doesn't affect me as much as I say it does
4. Suggested that my description of the pain is exaggerated
- 5. Said or implied that the pain was not real**
- 6. Said or implied that the pain was all in my head**
7. Said or implied that the pain is not really happening to me
8. Said or implied that I wasn't actually in pain
- 9. Said or implied that the pain is normal**
10. Said or implied that everyone experiences pain
11. Said or implied that the pain is just a part of being human
12. Said or implied that everyone has to cope with pain
- 13. Tried to get me to stop talking about the pain**
- 14. Changed the subject when I tried to talk about the pain**
- 15. Interrupted me when I tried to talk about the pain**
- 16. Ignored me when I brought the pain up**
17. Did not give me an opportunity to talk about the pain
18. Prevented me from talking about the pain
19. Made it impossible for me to talk about the pain
20. Assumed that I had an ulterior motive for talking about the pain
21. Assumed that I was just trying to get pain medication
22. Assumed that I was a drug seeker
23. Assumed that I was up to no good

\*Items that are bolded were selected for this study

## Proximal Consequences Subscale

- 1. Made me hesitant to bring the pain up in future conversations**
2. Made me talk less about the pain moving forward
3. Made it harder for me to talk about the pain with others after that
4. Made it less likely that I will talk about the pain from now on
5. Made me think twice before talking about my pain in the future
6. Made me isolate myself from others to avoid talking about my pain
7. Made me choose carefully who to talk to about the pain in the future
- 8. Made me distrustful of others who I might talk to about the pain**
9. Made me selective about who I talk to about the pain in the future
10. Made me change what I said to others about my pain moving forward
- 11. Made me stop talking about the pain with some people I know**
12. Made me hesitant to talk about the pain with someone new in the future
13. Made me appear to be a dishonest person to others
14. Made me appear to be unworthy of sympathy to others
15. Made me seem untrustworthy to others
16. Made me appear to be a person of low character to others
17. Made me look like a bad person to others
18. Made me look unintelligent to others
19. Made me appear to be uninformed to others
20. Made me appear to be stupid to others
21. Made me seem incompetent to others
22. Made me look irrational to others
23. Made it harder for me to receive what I needed to get by
24. Made it harder for me to get help when I needed it
- 25. Made it harder for me to find support from others**
- 26. Made it harder for me to receive a diagnosis**
- 27. Made it harder for me to be treated for my pain**
- 28. Made it harder for me to seek future care for my pain**
- 29. Made me less likely to seek care for other physical health issues moving forward**
30. Made me hesitant to seek care for any mental health concerns which may arise in the future

\*Items that are bolded were selected for this study

## Negative Goal Inference Subscale

1. **Talk to me as though I am really in pain**
2. **Treat me like my pain really exists**
3. **Talk to me as if they are really trying to understand my pain**
4. Talk to me as though they believe that I am as limited by my pain as I say that I am
5. Try to get me to talk about my pain as much as I want or need to
6. Try to help me to get or find what I need to get by
7. **Genuinely try to figure out what is going on regarding my pain**
8. Partner with me in trying to manage my condition
9. Treat me like an equal partner during our interaction
10. **Treat me with respect**
11. **Listen to me in a way that shows they care**
12. Treat me the same as they would treat someone without chronic pain
13. **Make things better for me by the end of our interaction than before we talked**
14. Assume that my motivations for talking about my pain are honest
15. View me as a person who knows what they are talking about regarding my pain

\*Items that are bolded were selected for this study