May 2021

# Explicating the Process of Communicative Disenfranchisement for Women with Chronic Overlapping Pain Conditions (COPCs)

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# Explicating the Process of Communicative Disenfranchisement for Women with Chronic Overlapping Pain Conditions (COPCs)

by

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A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
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College of Arts and Sciences
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Date of Approval:
May 21, 2021

Keywords: critical interpersonal and family communication, health communication, communication theory, normative rhetorical theory, scale development

# DEDICATION

For those held captive by pain and those with the courage to fight.

# ACKNOWLEDGMENTS

This dissertation would not have been possible without the support of many. I first acknowledge Steven R. Wilson for his unwavering support and mentorship over the past three years. To date, he has overseen the publication of nearly 20 articles, essays, and book chapters and has responded to well over 2 million emails. Further, he deserves recognition for his openness to multiple ways of knowing and for his patience during times where these new ideas challenged me. My work would not have garnered the recognition it has (to date) if the types of questions I could ask had been limited. Finally, he has always seen me as a person first. Excellent mentorship is a gift which I will pay forward in my position as a faculty member.

I next acknowledge members of the committee. Patrice Buzzanell is acknowledged for expanding my understanding of (and challenging my assumptions about) communication research. I am better able to engage in conversations with scholars in other subfields as a result of our joint endeavors. Marleah Dean Kruzel is acknowledged for involving me from (literally) the first day I arrived at USF in her program of health communication research. Her dedication to addressing pragmatic social health problems through research and unfettered commitment to giving back to the communities she studies are two practices which I will carry forward. Maria Koskan Venetis is acknowledged for equipping me with the confidence to explore the communication contexts that have interested me for the past five years. Even when others questioned the ideas of a 21-year-old master's student, she never discouraged me. The product of her support and friendship is evidenced by the subsequent successes of these research efforts.

Kai Kuang is also acknowledged for her consulting assistance with the statistical analyses in study two and assistance in the wrangling of SPSS AMOS.

I next acknowledge several additional friends and mentors for their contributions to my growth as a scholar and person. Eileen Berlin Ray is acknowledged for her willingness to speak with me about communicative disenfranchisement, research, and life. She served as an expert rater and has provided thoughts and recommendations throughout the writing process. I am grateful to know her and call her a friend. Mark Peterson, Professor of Philosophy, is acknowledged for his unmatched understanding of philosophical concepts. His ability to demystify them was vital as I integrated them in this project. Timothy Betts and Jonathan Baker are acknowledged for teaching me to better argue for and defend my ideas, and for pushing me to think critically about the impact of my research. Mike McDowell is acknowledged for spending hours helping me to grasp and apply critical theory in my research. These three have been my sources of support during trying times over the past three years.

Finally, I acknowledge my family members for their support. My parents, Steven and Cheryl Hintz, are acknowledged for always reminding me to have fun in my pursuit of knowledge. I am indebted to you and work each day to make you proud. My brother, Charlie Hintz is acknowledged for his instrumental role in my intellectual growth and development. Thank you for teaching me to embrace difference and to always continue learning. Finally, my husband Pádraig Lawlor is acknowledged for working with me to create a life that values knowledge, exploration, and passion. These are the bedrock principles upon which our careers and lives will continue to flourish. I share my present and future successes with you and our fur children, Keaton and Lionel.

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# ABSTRACT

This dissertation builds upon the extant literature in fields such as medicine, psychology, sociology, women and gender studies, and communication studies to theoretically explicate and develop a measure of the process of communicative disenfranchisement (CD). This dissertation refers to CD in two capacities: (a) as the *phenomenon of CD* (i.e., a communication construct and process unfolding over time), and (b) as a *theoretical framework* (i.e., that builds on CIFC tenets and elucidates the phenomenon of CD) which is abbreviated *TCD* (i.e., theory of communicative disenfranchisement). TCD enables scholars to assess how talk may disempower and empower again individuals and communities over time. This dissertation explores how CD unfolds for female patients who experience one or more chronic overlapping pain conditions (COPCs) and experience the communicated denial or contestation of symptoms or illness effects by important others. Such interactions inhere notions of power, are affected by material public sphere actants (such as discourses about women in pain and health policies) and require grappling with the relational and identity implications of talk. Existing measures of tangential constructs do not account for these dimensions. Hence, a mid-range theoretical explication of TCD, developed in the context of COPCs, is produced to enable future researchers to examine CD across diverse communication contexts.

Guided by assumptions derived from the critical interpersonal and family communication (CIFC) framework and multiple goals frameworks, two studies comprise this dissertation project. Study one consisted of a systematic qualitative meta-synthesis of publications (e.g., interview studies) about the interactions and experiences of COPC patients as well as patient accounts of these interactions posted to Reddit. Study one accomplished three aims: (a) explicating the dimensions and conceptual boundaries of CD by exploring how women with COPCs themselves talk about CD, (b) facilitating initial item generation for a measure of CD, and (c) suggesting possible outcomes of CD (after which specific hypotheses were proposed).

Study two facilitated the development and validation of a measure of CD. Following guidance by DeVellis (2017) and foregrounded by the theoretical explication completed in the first study, study two consisted of the initial development and validation of a multidimensional measure of CD in the context of COPCs with 400 patients who have spoken to a medical provider at least once about at least one of the 10 COPCs. Participants for study two were recruited through: (a) my personal social network, (b) participants with COPCs from past studies who indicated a continued interest in study participation, (c) snowball sampling from these participants via email, and (d) online/social media advertisements.

This dissertation produced measures of three CD constructs as well as a mid-range theoretical explication of the dimensions and effects of TCD in the context of COPCs. These findings may enable researchers to assess the features, prevalence, and outcomes of CD across diverse contexts and populations, and may affect positive social changes in the relations which constitute CD. The theoretical and practical implications of these findings are discussed as well as limitations and directions for future research (e.g., conducting a second validation study).

# CHAPTER ONE: INTRODUCTION

## Statement of the Problem

Three central problems together form the warrant for this dissertation: (a) the need to theorize and measure the process of communicative disenfranchisement (CD), (b) the need to examine disenfranchising talk in the context of chronic overlapping pain conditions (COPCs), and (c) the need for critical interpersonal theories to advance the field.

To illustrate these problems, consider the following examples. A woman experiencing persistent unexplained pain is told by a medical provider that her pain is "all in her head," catalyzing an extended search for psychological treatment that delays her diagnosis of vulvodynia, a chronic genital pain condition, by more than 10 years. A college student reporting a sexual assault to investigators is treated insensitively and callously which leads to her suicide. An elderly man being institutionalized in a nursing home is not consulted regarding his preferences; questions instead are directed to his adult children, beginning a process which minimizes his independence and maximizes conformity and control (Ray, 1996a). Although these interactions appear disparate, they illustrate a communicative phenomenon presently underexplored in communication studies. I conceptualize the process underlying these examples as *communicative disenfranchisement* (CD). These interactions are characterized by many terms within existing literature and, despite growing interest in understanding this process, no consensus, formal conceptual explication, or means of measurement has been offered.

This communicative process unfolds in interactions that female patients with COPCs have with a variety of important others (e.g., medical providers). COPCs are poorly understood, and patients with COPCs often report being disbelieved, having reports of symptoms and illness effects dismissed or contested, and being perceived as malingerers by medical providers, friends, and family members. Such talk is disempowering, may damage patient credibility or legitimacy, and can result in a diminished capacity to participate meaningfully in future health conversations with others. However, no measure of CD in this context exists. Measures of related constructs do not capture the effects of this talk across health, relational, and identity domains. Consequently, the features, prevalence, and outcomes of CD are unknown.

Further, exploring this context requires grappling with fundamental questions about what counts as knowledge and whose knowledge counts, questions often addressed through the analytical lens of power employed by critical scholars (Ono, 2009). The disenfranchising interactions explored in this dissertation are interpersonal interactions. However, despite the groundswell of interest in CIFC research (e.g., Moore, 2017a; Moore & Manning, 2019; Suter, 2016, 2018), the production of such research remains hampered by the existence of few critical interpersonal and family communication theories (Suter & Norwood, 2017). Hence, the development of a mid-range theoretical framework to explain the process of CD creates heuristic value and, in part, contribute to efforts to rectify the dearth of CIFC theoretical frameworks. To enhance clarity, this dissertation uses the abbreviation *CD* when referring to the *phenomenon of CD* (i.e., a communication construct and process unfolding over time), and *TCD* (i.e., theory of communicative disenfranchisement) when referring to the creation of a *theoretical framework* that builds on CIFC and multiple goals theoretical tenets and elucidates the phenomenon of CD.

## Overview and Purpose of the Research

To address these gaps, this dissertation explicates and measures the process of CD in the context of COPCs. Measuring CD could help to explain why patients with COPCs experience such lengthy diagnostic delays and experience such severe negative pain-related and well-being outcomes. A measure of CD must be grounded in a theoretical explication of the concept of CD (Chaffee, 1991) for its potential relationship to outcomes of relevance to stakeholders to become elucidated. Hence, two primary outcomes evidence the success of this project. Specifically, this dissertation has produced (a) a working measure of CD which has initial evidence for its validity, and (b) a theoretical explication of the dimensions and effects of CD in the context of COPCs which is supported by a validated scale (DeVellis, 2017).

## Preview of Subsequent Chapters

Chapter two first introduces the concept and history of CD, explores assumptions of TCD, introduces the context of COPCs, and reviews the interdisciplinary literature about disenfranchising interactions experienced by patients with COPCs. The assumptions of the critical perspective are next described, followed by an explication of the assumptions of the CIFC and multiple goals frameworks which provide a theoretical foundation for the subsequent dissertation studies. Next, related concepts in the field of communication to which TCD is both related and distinct are overviewed to identify gaps in the existing literature. Chapter three details the rationale and methodology for study one, including guiding the research questions, an explanation of the meta-synthesis procedure, and sampling procedures which have been conducted thus far. The purpose of study one is to produce an explication of CD as a construct and process. Chapter four includes the findings and interpretations for each research question in study one. Chapter five details the rationale, research questions, and methodology for study two, conducted to create and test a measure of CD which is based upon the theoretical explication of the construct produced in study one. Chapter six contains the findings and interpretations for each hypothesis in study two. Chapter seven concludes with a discussion of research findings across all studies, theoretical and practical implications, and limitations of each study.

# CHAPTER TWO: LITERATURE REVIEW

> "Assisted with a post-mortem [autopsy] when I was a student. Female patient died in her 40s. Her medical history had extensive complaints of abdominal pains, one Dr. even referred to her as a 'hypochondriac' and others commented on apparent anxiety. Opened her abdomen and she had extensive scar tissue, she was absolutely massacred inside from endometriosis. She suffered for decades and never got referred for a laparoscopy. She didn't have fucking anxiety, she had a medical condition." -Medical provider on Reddit

This literature review first defines TCD and overviews its history, then introduces COPCs and the disenfranchising interactions experienced by female patients. The chapter then discusses some assumptions of the critical metatheoretical perspective, after which it describes the CIFC and multiple goals frameworks as well as lines of research which are related to TCD.

## Communicative Disenfranchisement: Discreditation, Silencing, and Perpetuation

*Disenfranchisement* is "the state of being deprived of a right or privilege, especially the right to vote" (Oxford Dictionary, 2020a). Although disenfranchisement is most often described in relation to voting (e.g., in reference to the "widespread disenfranchisement of minority voters"), it can be conceived of as the deprivation of one's rights more generally. A next task is then defining disenfranchisement in the context of communication. *CD* is described by Ray (1996a) as the denial of "full privileges, rights, and power within the existing societal structure" accomplished by keeping "people, groups, and classes" who are or become vulnerable (whether by birth or by circumstance) invisible through "silencing them, discrediting their claims…or by perpetuating the structure that enables disenfranchisement in the first place" (Ray, 1996a, p. xv).

This silencing, discrediting, and perpetuation of structure occurs in an effort to control the production of discourses which exist at odds with what is sanctioned by the regime of truth (i.e., the status quo, what is normalized; Foucault, 1972). This definition assumes that language is a social actor which constructs meaning and which has consequences (Gergen, 1985).

All individuals are likely to belong to a disenfranchised group at some point during their lives, and thus they are only “temporarily enfranchised” (Ray, 1996b, p. xv). The *communication-disenfranchisement relationship* is described as a “communicative process” which is “accomplished, managed, and overcome” across various social health contexts through interactions with “family, friends, institutions, and mass media” (Ray, 1996a, p. xvi). Therefore, disenfranchising messages may be received from or directed to *specific others* (e.g., family members, friends, romantic partners, medical providers), *members of organizations or institutions* (e.g., insurance company representatives, nursing home employees), or *generalized others* (e.g., social media audiences, the mass media). Thus, TCD analyzes disenfranchisement at multiple levels, consisting of the “interpersonal and societal messages [which] marginalize or empower the disenfranchised” (Ray, 1996a, p. xvii). These individuals, organizations, and institutions establish social standards which make clear who “fits” in society and who does not.

Ray’s (1996a, 1996b) edited collections about communication and disenfranchisement in social health contexts were assembled to further fuel the critical turn occurring at that time in the subfield of health communication by including research topics and contexts which had otherwise been stigmatized and marginalized. Thus, TCD was created to examine social health issues, the communicative process which constitutes them, and the concordant implications. Despite lacking a formal conceptual explication, a rich line of inquiry in the mid-1990s (Ray, 1996a, 1996b) explicitly examined the process of communication disenfranchisement for a variety of groups in a multitude of contexts. These included issues related (but not limited) to: (a) *socioeconomic status* such as homelessness (Miller, 1996); (b) *family life* such as infertility (Geist et al., 1996), divorce (Rudd, 1996), and the institutionalization of the elderly (Nussbaum et al., 1996); (c) *abuse* such as sexual violence (Eckman & Mastronardi, 1996) and sexual harassment (Clair, 1996); and (d) *health concerns* such as HIV/AIDS (e.g., Metts & Manns, 1996), patient-provider communication for gay men (Corey, 1996), dignity in death and dying (Thompson, 1996), and disability studies (Braithwaite, 1996; Johnson & Albrecht, 1996). Importantly, in social health contexts the disenfranchised are not viewed as being "deprived of healthcare" altogether, which would constitute an access issue, but rather as being "victims of the franchise" through their experiences with healthcare systems (Scharf & Kahler, 1996, p. 96). This distinction enables us to differentiate disenfranchisement from other social processes (described below) such as stigma and marginalization, which operate from a locus of social differentiation and exclusion (e.g., Dorrance Hall, 2017; Meisenbach, 2010; Smith, 2007).

Although references to the communication-disenfranchisement relationship are not made explicitly today, due to the lack of a formal framework for its study and the time elapsed since the publications of these works, the critical turn in interpersonal and family studies is ushering in a revived interest in examining the interpersonal interactions which I argue characterize CD. Some research has begun to uncover the communication disenfranchisement relationship. For example, three special issues of the *Journal of Family Communication* have been published in the last decade which have highlighted research on families marginalized due to demographic categories (e.g., race/ethnicity), national culture, and issues of diversity and inclusion (Turner & West, 2003, 2011; Turner, 2019). The most recent special issue includes a number of communication contexts which may embody CD, including the rhetoric of immigration espoused by the Trump administration toward Central American refugees (Chattopadhyay, 2019), strain experienced by interracial couples in communication with family members (Brummett & Afifi, 2019), and conflict between incarcerated mothers and their children (Rudd et al., 2019).

Other examples include recent publications by Thompson (i.e., Thompson & Duerringer, 2020; Thompson et al., 2018; Thompson & Parsloe, 2019) which have examined why (i.e., for what purpose) and how (i.e., with what rationale) individuals contest or express disbelief about a sick family member's or romantic partner's health complaint(s). Interactions in which skepticism or disbelief are expressed about an ill family member's symptoms constitute CD, as these publications are fundamentally concerned with understanding how those family members are: denied citizenship to the "sick" group through knowledge claims and the invocation of discourses about what could or could not be a "real" illness (Mokros & Deetz, 1996), and are thus denied support and resources. It is important to note here that examining issues of CD experienced by specific populations does not necessarily presume that one group or discourse is necessarily correct, better, or on higher moral footing. This is because a discourse "does not reflect an objective world as much as it subjectively creates one" (Meisenbach, 2010, p. 272). Rather, examining CD means understanding the operations of discursive power which make those evaluations possible and their effects real (i.e., communication is constitutive of reality).

For instance, patients with one of two poorly understood chronic pain conditions (myalgic encephalomyelitis, also called chronic fatigue syndrome [CFS], and multiple chemical sensitivity [MCS]) often reported being told that they are "just plain crazy" by providers due to lacking biological facts or evidence which could account for their symptoms (Dumit, 2006, p. 585). As a result, they are often denied medical care and access to disability; this in turn further fuels perceptions that symptoms were not real, results in widespread underdiagnosis, and limits the impetus for funding medical research to discover otherwise. The communication of denial can be viewed as knowledge claims which are sanctioned by the regime of truth (described below), dually connecting disenfranchisement to recursive operations of discursive power and precipitating into material consequences for the target of disenfranchising talk.

### Communicative Disenfranchisement as Constitutive

The assumption that CD is also *constitutive* should be discussed. Two perspectives on CD as a constitutive process are offered by Mokros and Deetz (1996). A first view, most common in communication scholarship, sees *communication as a process of information exchange*, where it is assumed that knowledge is discovered through language. With this view, we may come to create "natural" categories with which to observe ongoing phenomena, such as "communication, the disenfranchised, and health" (p. 43). Examples of this view within health communication are studies which take communication as the site of investigation, such as studies seeking to maximize compliance, satisfaction, or attitude change (Mokros & Deetz, 1996). Communicative issues, then, are perceived as personal deficits (i.e., as personal failings or shortcomings) for interactants. Attempts to rectify such deficits come at personal costs for the disenfranchised, for example, attempting to reclaim agency and seek care may require making hidden a part of oneself deemed "deficient" (Afifi & Steuber, 2009).

For instance, efforts to address issues of teenage pregnancy in the early-1990s painted teen pregnancy as a moral and acultural issue which stemmed from an informational deficit. Women who were not on birth control were said to "trust to luck alone" (New York Times, 1991) and were thus disenfranchised on moral grounds for living irrational lives uncontrolled by the available scientific advancements in reproductive technology. To challenge this first view, TCD would highlight the classist social structure which separates those rational individuals who “ought” to be able to exert control from those who cannot control themselves is reified (Ray, 1996a). Discourses reproduce this classism, whereby unwanted teenage pregnancies are attributed to the personal failings of the uneducated, uninformed women who exist in contrast with the rational and educated women who utilize scientific advancements to avoid unwanted pregnancies. This view perpetuates paternalistic beliefs about reproduction and decreases the chance that those who are disenfranchised will attempt to rectify these “personal failings” (Mokros & Deetz, 1996). However, while this example usefully illustrates how public sphere discourses may offer the conditions for disenfranchisement to occur, this first view is restrictive as it inadequately explains health phenomena. Hence a second view is offered, in which communication is regarded as being *constitutive*, not merely an episode of information exchange but instead the means through which our experience of reality is formed. The central goal of this view is to answer the question “what is real?” The constitutive view acknowledges that past interactions and knowledge make possible the present interaction. Specifically, persons and things are said to be communicatively constituted, pointing to the importance of considering both discursive and material realities. The constitutive view of persons and things represents a Foucauldian (1972) approach to understanding discourse and structure, which “define[s] and restrict[s] what we perceive to be real and of value” (Mokros & Deetz, 1996, p. 33) and becomes shared in interactions and naturalized across time.

Consequently, recognizing disenfranchisement as a constitutive communicative process allows us to view “the disenfranchised” not as a group or set of individuals who are different from us, but as a mutually determined perspective about who is (dis)enfranchised. When examining disenfranchisement, we must also always examine enfranchisement, as one does not exist without the other. Similarly, as critical approaches offer critique in an effort to promote change, deconstructive efforts must also be accompanied by reconstructive efforts (Hall, 1998). In examining disenfranchisement in health and illness, we must question the assumptions upon which these categories rest and view them as being constituted through communication. These socially constructed categories then come to be accepted as “real.” Communicatively constituted persons and things are political and ideological, then, because they are “products of a continuously amended and contested world view grounded in human relations” (Mokros & Deetz, 1996, p. 33). It is this constitutive view that makes possible the critical appraisal of communication practices by comparing those practices to plausible alternatives.

### Communicative Disenfranchisement as a Process

TCD views disenfranchisement as a *communication process*, meaning that the events and relationships which constitute it are continually changing and dynamic (Berlo, 1960). An explanation of a communication process always involves three features: (a) an overall description of the pattern of the process, (b) a description of how events are related and influence one another over time, and (c) a description of how transitions between events are connected to the pattern of the process (Poole, 2013). Given these explanatory features, one must study a process which is complete, as one cannot determine whether a pattern applies without all of its events having occurred. Explanatory factors that punctuate the process may include “critical events and turning points, contextual influence at various points in the process, formative patterns that give overall direction to the change, and causal factors that influence the sequencing of events” (Poole, 2007, p. 185). Common issues in process approaches include managing the complexities of events and their temporal connections, accounting for differing time scales within the process, and explaining how processes themselves change across time. Methodologies suitable for the process approach are those which are able to identify and test relationships between events and overall patterns over time, and cope with multiple time scales (Poole, 2007).

### Process v. Variance Approaches

What is a communication process? The process approach to communication research exists at odds with *variance approaches,* which examine relationships among variables to explain change (Mohr, 1982). Variance approaches are characterized by causal statements which describe interrelationships among variables in an effort to produce reliable and valid measures and models. Specifically, variance approaches are concerned with *efficient causation,* which concerns the factors at play at the present moment within an immediate event (Poole, 2007). The unit of analysis within the variance approach is the variable. Those measures and models are then evaluated according to the extent to which they are generalizable, able to be applied to other contexts and situations (Poole, 2007). Generalizability is a criterion for variance approaches because it is assumed that there is an "underlying generative mechanism that specifies the causal relationship" which can be extended across similar/dissimilar cases and contexts (Poole, 2007, p. 187). Variance approaches are inadequate for the study of process for a number of reasons. As variance approaches are concerned with efficient causation and variables, it is difficult to capture change over time through a variance approach. Processes also vary, meaning that they may manifest in multiple forms. Variance approaches which rely on statistical methods assume that factors operate in a homogeneous, uniform manner within the same time scale (Abbott, 1988). Thus, variance approaches are not well suited for the study of process.

Conversely, conceptualizing communication as a process means explaining "how a sequence of events leads to some outcome" (Poole, 2007, p. 182). Research on communication processes is lacking given the complexity of the models and methods required to identify and test them (Poole, 2013). Multiple methodologies are typically utilized to identify communication processes, including but limited to direct observation, archival analysis, or multiple case studies (Poole, 2007). Both qualitative and quantitative approaches are employed in process research, as a mixture of approaches is suitable for the variety of methods used to capture communication processes. This study utilizes a "retroduction" approach, where an initial theoretical framework guides the observation of collection and additional data which then modify that same framework (Poole et al., 2000, p. 115-117).

This definition of the process approach necessarily implies that some form of temporal ordering will be present within a process model. The ordering of events means that events occurring later depend upon the events which precede them. Each event then shapes the events which follow it. Put differently, process approaches are designed to account for change occurring over time through the identification of the events and patterns that create change. Process approaches are characterized by theoretical narratives which draw connections across events unfolding over time. The unit of analysis, then, is the "evolving central subject that makes events happen and to which events occur" and the unit of observation is the event (Poole, 2007, 184). Theories such as Knapp's (1978) interpersonal relationship dissolution model, the transtheoretical model (Prochaska et al., 2008), diffusion of innovations (Rogers, 2003), action assembly theory (Greene, 1984), and relational turbulence theory (Solomon et al., 2016) all embody elements of the process approach to communication research. Further, Greene (1984) and Solomon et al. (2016) illustrate programs of research which rely primarily on variance methods but have done so to develop and test process theories. This dissertation proceeds similarly by developing a process model and testing that model via variance methods.

In terms of generalizability, process approaches derive strength from the *versatility* of the produced models (as opposed to the uniformity and consistency of theories produced through variance approaches). Versatility refers to “the degree to which…a generative mechanism for a process…can encompass a broad domain of developmental patterns without modifying its essential character” (Poole, 2007, p. 187). Put differently, the essential difference between the variance approach and the process approach lies in the ability of the latter to adapt to many often-disparate events and sequences by “stretching” or “shrinking” the explanation to fit specific cases according to: (a) the length of the process, (b) the rate at which the process unfolds, and (c) inconsistencies in the lengths of stages or process phases (Poole, 2013). The generalizability of a variance theory depends upon whether the proposed interrelationships between variables hold uniformly across a variety of contexts in which disclosure occurs. However, generalizability for a process theory of CD would be evaluated according to how well it encompasses processes unfolding in disparate contexts in which CD may occur, as this is the “common generative mechanism” of interest (Poole, 2007, p. 187).

Although generalizability is based on efficient causality, a suitable criterion for variance approaches, it fails to explain such changes across time as it remains fundamentally concerned with the present. As such, *final and formal causality* are additional informants for theorizing communication process as they are related to versatility. *Final causality* refers to the end state or goal which determines how the events individuals experience unfold across time. For instance, the end state or goal of reaching a decision moves a provider through a decision-making process. Poole (2013) explains that final causality is “any end state that attracts a process to itself” (p. 382). *Formal causation* refers to a template (whether discursive or material) that dictates how change will occur. For instance, a provider engaging in a decision-making process may follow a process specified within a diagnostic algorithm, or a researcher may be required to fulfill a list of requirements to write and submit a grant application. These examples of formal causation point to the interrelationships between individual behavior and the institutional and cultural guidance which may inform processes as they unfold.

### Four Motors of Communication Processes

As process theorists often encounter difficulty defining the boundaries of the process in question, it is next necessary to detail four distinct generative mechanisms which define process types. *Generative mechanisms (i.e., motors)* are those logics from which causal relationships are specified (in the variance approach) and which order the phases of a process (in the process approach). For instance, in Poole's (1983) multiple sequence model of decision development, the "sequence of experience" is the generative mechanism that moves those solving a problem through phases of encountering an issue, brainstorming solutions, and solving the problem.

A first (and most common) generative mechanism is the *life cycle*, which is a process that occurs in an established and unwavering sequence of stages. Knapp's (1978) model of relationship dissolution is one example of a life cycle process. The ordering of those stages can be either inherent (e.g., the life cycle of a human being) or defined by an external entity (e.g., an institution, the media). The life cycle motor is present in a communication process when a single entity (e.g., family, person, organization, decision, etc.) is centralized, the process proceeds in a series of stages which cohere to a "program, routine, institution, or logic" that determines the ordering of stages (Poole, 2013, p. 393). An example of a motor might include the maintenance of relational interdependence within relational turbulence theory (Solomon et al., 2016). Life cycle models necessarily end with a fixed termination point, such as the dissolution of a relationship (e.g., Knapp, 1978) or death.

A second generative mechanism is the *teleological* process, a term which refers broadly to the explanation of a phenomenon according to its purpose and not what causes it (Oxford Dictionary, 2020b). Within the process approach, the teleological process is one which "views processes as a sequence of goal formulation, implementation, evaluation, and modification of actions or of goals based on deviation of expected outcomes from actual outcomes" (Poole, 2013, p. 387). For a teleological motor to be present, an individual or group should be centralized and be working toward a goal/end state, as signified by the clear actions necessary to attain the goal and the accomplishment of those actions by the individual or group. Finally, there should be stages that do not necessarily occur in a predetermined order. An example of a teleological process is the model of blended family development (Baxter et al., 1999), where a longitudinal study of family development over four years resulted in five trajectories (mapping the degree of "feeling like a family"). Contemporary examples would include work about the process of family member marginalization by Dorrance Hall (2017), and the disclosure decision-making model (DD-MM; Greene, 2009), where a discloser evaluates the outcome of a disclosure decision and uses this outcome to reassess future disclosures. The termination point of a teleological process is the attainment of a goal and maintenance of this steady state (Poole, 2013).

A third generative mechanism is the *dialectical* process, which is a process "driven by conflicts or tensions" which "elicit reactions from actors, groups, or organizations" and then "shape how the dialectic unfolds" (Poole, 2013, p. 389). Two traditions of dialectical theory exist. The first is a Hegelian dialectical process of thesis, antithesis and synthesis. For instance, much corporate social responsibility literature denotes a struggle between profitability (the thesis) and obligations to social responsibility (the antithesis), which decrease profitability when organizations act in service to society (e.g., Meyers & Garrett, 1993). Synthesis may occur if the organization is publicly owned and profits dedicated to a charitable cause, or the existing contradiction could be reproduced and thus synthesis not reached. A second tradition is the Bakhtinian idea of dialectical tensions, where a series of these tensions play out across time and interact but are not resolved. A rich line of theoretical inquiry has sprung from the Bakhtinian dialectical tradition via relational dialectics theory (Baxter & Montgomery, 1996; Baxter, 2011). For example, Hintz and Brown (2020) denoted a tension between discourses of reproductive normativity and autonomy which played out discursively in interactions in which differences in views about childbearing were discussed. A dialectical motor is present in communication research if tension/conflict occurs between two or more actors, evidence of the tension exists and actors attempt to manage it, and the outcomes of the tension/conflict influence the subsequent development of the process (Poole, 2013).

A final generative mechanism is the *evolutionary* process, least explored, which is theorized to occur through the variation-selection-retention (VSR) sequence at the individual member level, and through ecological processes operating at the macro level. The evolutionary model proposes that variations in existing entities (e.g., individuals, organizations, technologies, texts, etc.) occur by chance or by design, and those not optimally suited for the environment are selected out. This evolutionary motor has been applied to the study of communication networks (Monge et al., 2008), where individuals attempt *linkages* to others to seek “information, advice, or exchange” (Poole, 2013, p. 391) through various modalities. Some linkages become selected out as they are less rewarding to the individual or organization seeking them, while others become formalized as norms governing communication behaviors. For instance, women with endometriosis form linkages between their patient community, the knowledge claims they produce, and the means of resisting competing knowledge claims made by others (Whelan, 2007). Thus, the evolutionary motor pertains to these *links*. Forces act on links which make organizations and individuals more or less desirable and possible (i.e., the capacity of individuals and organizations to support new members and relationships; Poole, 2013). An evolutionary motor exists if a relatively unified population of entities is competing for scarce resources and there are mechanisms which support VSR (Poole, 2013).

### Multiple Motor Processes and Interrelationships

Processes may also have multiple motors that operate at multiple levels. For instance, a study by Bryant and Monge (2008) which produced a developmental model of the children's television community included an evolutionary motor for linkages at the micro level and a life cycle motor at the macro level. Motors can have three types of interlevel relationships. *Hierarchical* motor organization occurs where "the process at any given level is dependent on changes in units at higher and lower levels" (Poole, 2013, p. 392). The previous example of the developmental model represents the hierarchical interlevel relationship among motors. This notion of hierarchical motors holds promise for addressing the functions of the public and private sphere bidirectionality (Suter, 2016, 2018) and also of the hierarchized discourses present within the Foucauldian approach to power (Moore, 2017a). Next, motors may also be *entangled*, meaning that they affect one another without being attached to a single process. For instance, action assembly theory (Greene, 1984) represents entangled motors, as the process exists in no particular order at four somewhat autonomous levels which still influence one another. Finally, motors may also be *aggregated*, meaning that a higher-level process is constituted by the processes at lower levels (Poole, 2013). Poole's (1983) multiple sequence model described earlier embodies this organization of motors.

Multiple motors may also be related directly or indirectly. Direct relationships include "*reinforcing* (positive), *dampening* (negative), and *complex* (nonlinear)" (Poole, 2013, p. 393, emphasis in original). Two forms of indirect relationships among motors exist. *Entrainment* happens when "motors synchronize their operation due to an external pacing factor (an entrainer)" (Poole, 2013, p. 393). Examples of entrainers include process deadlines and external events. A second indirect relationship, a *cyclical* relationship, can be found in processes where multiple motors take turns affecting a process over time. For instance, Baxter (2011) describes diachronic separation as a form of discursive interplay in which discourses differentially affect meaning creation either over time (called cyclic alternation or spiraling inversion) or depending on the setting in which or topic about which the conversation occurs (segmentation). In sum, a researcher who seeks to produce a process theory must be interested in elucidating how a series of unique or disparate cases are united by a common process which unfolds across time.

### Chronic Overlapping Pain Conditions (COPCs)

This dissertation examines communicative interactions in which women with poorly understood chronic pain conditions experience the questioning, contestation, etc. of their account of pain by various others, such as a spouse or significant other, friend, family member, medical provider, and/or employer.[1] Relevant interactions with medical providers could be pursued by patients for the purposes of seeking diagnosis or treatment for symptoms or seeking pain relief or the continuation of an existing treatment regimen (e.g., opioid use), and could occur in general practice or pain management clinics specifically. Mokros and Deetz (1996) note that potential

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[1] Throughout this response, the term "women" encompasses those assigned the sex of "female" at birth. However, this term should be read to include those individuals who were assigned female at birth but who now do not identify with this gender identity.

relations among communication and disenfranchisement includes how "certain groups of people are listened to and responded to" and necessarily consider questions about what "counts as real" in issues of health (p. 29). I select this context not in an effort to determine what "causes" these conditions, but to argue that public and private discourses about women in pain together constitute the reality in which these women must negotiate for power (Corey, 1996; Suter, 2016). Mokros and Deetz (1996) further argue that "illness itself…is a form of alienation, loss of control, and disenfranchisement" (p. 42).

TCD is also takes a processual view insofar as an affirmative diagnosis by a new provider or new discovery which enables the identification of a biomechanism which explains symptoms would enable the enfranchisement these patients. For example, Dumit (2006) discussed how the denials of health insurance and disability claims experienced by patients with chronic fatigue syndrome had been facilitated by the lack of a biomarker which could objectively identify its presence. In 2019, a biomarker was discovered which could correctly detect CFS, a condition which had previously been largely considered "imaginary" by medical providers (Sanidou, 2019), through a blood test with perfect accuracy (Esfandyarpour et al., 2019). Such a discovery changes the nature of talk about this issue and within these interactions, highlighting the bidirectional nature of health research and policy (the public sphere) and interactions with providers (the private sphere; Suter, 2018). Patients with CFS who had been disenfranchised, through this communicative process, may now be enfranchised again through talk.

I am selecting these poorly understood chronic pain conditions because many of these female-dominant (or exclusively female) pain syndromes can be conceptualized as "contested," where patients' pain symptoms are "medically suspect because they are not associated with any known physical abnormality" (Conrad & Barker, 2010, p. 70), symptoms which are referred to as being “idiopathic” (Maixner et al., 2016). To reflect this, a new working definition of pain has been proposed by the International Association for the Study of Pain (IASP), who now define *pain* as “an aversive sensory and emotional experience typically caused by, or resembling that caused by, actual or potential tissue injury” (2019, n.p.). This points to the social forces that privilege some systems of inquiry over others (e.g., causal evidence over patient experiences) across time (Gergen, 1985). Consequently, others (e.g., providers, family members, friends) may be reluctant to validate or believe reports about the existence or severity of pain and other symptoms, referred to as *subjectivity challenges* in pain management (Miller et al., 2017). Yet, it is not sufficient to point to abuses of individual power or instances of talk which may constitute hurtful communication (Vangelisti at al., 2007). Conflict between patients and providers stems not only from demands by patients for better/more information, but rather from challenges by patients about what knowledge is granted credence and who produces that knowledge (Whelan, 2007). Even if a provider, partner, or family member cannot move the patient closer to diagnosis or treatment (e.g., through having better/more information), interactions need not be disenfranchising (Hintz & Venetis, 2019). Further rationale exists for viewing CD as a process by examining the effects of these communicated evaluations, which have been linked to delayed help seeking, symptom underreporting, and undertreatment (e.g., American Pain Society, 2011; Donaldson & Meana, 2011; Newton et al., 2013).

Poorly understood conditions are operationalized as those which are classified by the National Institutes of Health (NIH) as chronic overlapping pain conditions (COPCs; Maixner et al., 2016), where a patient often suffers from two or more of the 10 conditions in the following list: interstitial cystitis (also called painful bladder syndrome), irritable bowel syndrome, vulvodynia, endometriosis, temporomandibular disorders, chronic low back pain, headache (with two subcategories of chronic tension type headache and chronic migraine), myalgic encephalomyelitis (also called CFS), and fibromyalgia. Although these conditions are poorly understood, it should be noted that they are not uncommon. According to prevalence estimates, the least common COPCs (CFS, vulvodynia, and fibromyalgia) each affect between four and six million women in the United States, and the most common COPCs (temporomandibular disorders and irritable bowel syndrome) each affect an estimated 35 and 44 million individuals in the U.S. respectively (Chronic Pain Research Alliance [CPRA], 2015). Estimates about the U.S. economic impact of these conditions, when accounting for direct and indirect medical expenses and lost productivity, range between 17 billion dollars (chronic migraine) and 380 billion dollars (irritable bowel syndrome) annually (CPRA, 2015).

Although a definition of COPCs would normally be included here, there is no existing consensus about how COPCs overlap, how they develop, nor how to classify or diagnose them, and thus no formal definition exists (Maixner et al., 2016). The status of COPCs today can be compared historically to early research on the experiences of those living with HIV/AIDS in which medical professionals were perceived as being “not uniformly knowledgeable about the disease nor uniformly unbiased in their attitudes toward those who need care” (Metts & Manns, 1996, p. 362). COPCs can further be called “poorly understood” as the issues affecting the majority female patient population are multi-level. Specifically, the extant scientific evidence available to physicians is insufficient due to underfunding, few treatments are approved by the Food and Drug Administration (FDA) to treat them, and patients are frequently misdiagnosed due to inadequate medical training (CPRA, 2015). Although a recent allocation of 500 million dollars by the NIH, the first of its kind, has been provisioned to address issues associated with chronic pain and opioid use disorders (Collins et al., 2018), change is slow. In the interim, patients are left confused about the onset of pain and begin an often-fruitless search for causal attributions in which personal pain management strategies may be employed to varying degrees of success (Donaldson & Meana, 2011). The numerous barriers to help-seeking and often unhelpful interactions contribute to diagnostic and treatment delays, which then fuel mistrust and disillusionment and further contribute to a patient's poorer quality of life and heightened disability status (CPRA, 2015).

## Disenfranchising Interactions Experienced by Women with COPCs

Although these interactions are not so termed "disenfranchising," many terms are used to describe interactions in which women are dismissed and disbelieved. It is first necessary to connect COPCs to CD before the literature discussing COPC patient experiences is reviewed.

### Assumptions: Illness as Socially Constructed

To better understand the role of CD in COPCs, this dissertation operates from a view that illness is socially constructed (Conrad & Barker, 2010), which has three defining assumptions.

A first implication is that "some illnesses are particularly embedded with cultural meaning – which is not directly derived from the nature of the condition – that shapes how society responds to those afflicted and influences the experience of that illness" (Conrad & Barker, 2010, p. S67). These cultural meanings refer to the taken-for-granted assumptions about an illness. For instance, taken-for-granted cultural meanings associated with contested illnesses (which are distinct from stigmatized illnesses) include that such illnesses (many of which are also COPCs) are not widely recognized or acknowledged, such that the public, providers, and patients may question reported symptoms or the credibility of the complainants (Birk, 2013; Conrad & Barker, 2010). These conditions are described as being "burdened by the cultural meaning of a medically invisible condition in an era of high-tech biomedicine" (Conrad &

Barker, 2010, p. S70), where mistreatment toward individuals with COPCs stems not from something inherent to the condition, but the cultural meanings about what "counts" as an illness. It is because of this perspective that research which aims to change the negative cultural and social meanings related to contested illness may prove fruitful.

A second implication is that the lived individual experiences of illness form the basis for its construction. Viewing illness experience as being socially constructed enables us to highlight aspects of patienthood that medical research cannot (Conrad & Barker, 2010). For example, we might examine the efforts by lay women with COPCs to generate and share local illness knowledge through self-made communities. Doing so illustrates the value of understanding the experiences and meanings of subjective illness experiences and their social management. A social constructionist view of disenfranchisement, then, would suggest that COPCs are not inherently disenfranchising. Disenfranchisement is constructed through the reactions of others to illness and its symptoms or to the "type" of individuals with the illness (Conrad & Barker, 2010).

A third closely related implication is that "medical knowledge about illness and disease is not necessarily given by nature but is constructed and developed by claims-makers and interested parties" (Conrad & Barker, 2010, p. S67). For instance, efforts to include women in clinical trials to better understand gender disparities in health outcomes arose as a result of social pressure from feminist and advocacy groups, rather than as product of those disparities being natural Truths. This coheres to the Foucauldian (1972) approach to power/knowledge described in greater detail below, where individuals make knowledge claims sanctioned by the regime of truth. Producers of knowledge claims about health who hold interests in their operations include scientists, providers, insurance companies, pharmaceutical companies, patients, and advocacy organizations (Conrad & Barker, 2010). Parties such as insurance companies are incentivized to dismiss or deny claims of chronic illness in the aim of producing profits (Dumit, 2006). This relates to the idea of *medicalization*, the process of redefining human experiences (e.g., menopause, erectile dysfunction) as medical issues (often for profit; Conrad, 2007). In sum, understanding the relationship between COPCs and TCD means recognizing the capacity of social forces to construct illness experience.

### COPCs and Negative Interactions

Communication scholarship has begun to explore the negative interactions experienced by chronic pain patients, including by focusing on communication in relationships between chronic pain patients and romantic partners, friends, and family members (e.g., Thompson & Duerringer, 2020; Thompson et al., 2018; Thompson & Parsloe, 2019). However, a majority of such scholarship remains focused solely on patient-provider interactions.

For the past ten years, a program of communication research by Marianne Matthias has examined shared decision making and opioid use negotiation among chronic pain patients and their providers. Among other findings, her research has underscored the lack of gratification experienced by providers who treat chronic pain patients (particularly “difficult” patients), the tension surrounding the negotiation of opioid use, and the importance of positive patient-provider relationships for ensuring optimal pain care outcomes (e.g., Matthias et al., 2010, 2019; Matthias, 2020). Such interactions are characterized by mutual feelings of frustration and helplessness by both patients and providers (Johansen & Risor, 2017). Recent work by Agarwal (2018, 2019) has further explored how patients with chronic pain interface with complementary and alternative medicine (CAM) practitioners, particularly how patients conceptualize pain and how specific functions of the therapeutic relationship supported patient healing goals. Many additional intradisciplinary publications represent a recent surge of interest in understanding such interactions (e.g., Chapman & Beach, 2019; Hall & Miller-Ott, 2019; Hook, 2019; Riquelme et al., 2018; Ruben et al., 2017; Ruben & Hall, 2016; Rubinsky et al., 2020; Wright, 2019).

Outside of the discipline, a wealth of (largely atheoretical) studies have examined negative interactions had by women with COPCs. A general process emerges across studies of the experiences of women with COPCs. Female patients first struggle to be believed by important others, and this disbelief is then expressed in interactions with them. Many other terms are used to describe the communicative functions of this interaction, including normalization (Ballard et al., 2006; Denny, 2004; Markovic et al., 2008), trivializing (Cox et al., 2003; Denny, 2004), dismissal (Cox et al., 2003; Shapiro-Baruch, 1995), diminishment (Shapiro-Baruch, 1995), and ignoring (Gundström et al., 2017) among others. The most widely used term is invalidation, defined below (Kool et al., 2009, 2011). These interactions are complicated by challenges in dealing with subjective patient experiences (Markovic et al., 2008) and contribute to diagnostic delays (Markovic et al., 2008; Wuytack & Miller, 2011). If patients are able to and can afford to continue to seek a diagnosis, receiving the diagnosis often brings relief to patients (Ballard et al., 2006; Wutyack & Miller, 2011). These patients who receive a diagnosis are then enfranchised with the ability to call themselves "sick" again (Dumit, 2006). However, diagnosis only marks the beginning of a journey. As one patient described, "it's either suicide or fight" (Huntington & Gilmour, 2005, p. 1129). Patients may then experience fear spurred by ineffective treatments and/or recurrence of pain (Denny, 2004).

### Assumptions of the Critical Perspective

Building on the assumptions (e.g., process perspective, social construction of health) outlined so far, this dissertation is grounded specifically in the CIFC as well as multiple goal frameworks. Before the CIFC and multiple goals frameworks are overviewed, the assumptions of the critical intellectual tradition are first offered. To understand the critical meta-theoretical perspective and its assumptions, *theory* must first be defined. Littlejohn et al. (2017) note that theories “help [to] explain and understand phenomena; they provide a conceptual framework or foundation from which scholars develop knowledge” (p. 6). *Metatheory*, then, can be viewed as a theory of theories useful for grouping approaches with shared assumptions (Craig, 1999). Three paradigms (i.e., post-positivism, interpretivism, and critical) comprise much of communication research (Craig, 1989). Although variation exists within each approach (described below for the critical paradigm; Ono, 2009), each carries a relatively stable series of guiding and conceptually distinct epistemological, ontological, and axiological assumptions (Littlejohn et al., 2017). *Epistemology* questions how knowledge is created (e.g., “What counts as knowledge? Whose knowledge counts?”), *axiology* questions the role of values within research (e.g., “What role do my values play a role in the research process?”) and *ontology* questions what we know about the nature of being (e.g., “What is real?”; Littlejohn et al., 2017). I next offer an overview of critical metatheoretical approaches and discuss some epistemological, axiological, and ontological assumptions of critical perspectives.

*Critical approaches* seek to “excavate political underpinnings” (Conquergood, 1991, p. 179) by producing critiques of the status quo, capturing inequities, and spurring social change. The product of critical scholarship is a socio-political critique of taken-for-granted assumptions constructed in an effort to affect social change (Moore, 2017a), or as Wiegman (2002) states, to “diagnose and to heal” (p. 128). Epistemologically, then, critical approaches assume that our social locations (e.g., gender, sexuality, class, race) situate and constrain our understanding of the world (Sotirin & Ellingson, 2018) and that there are multiple subjective and political realities. Mumby (1997) calls this the “discourse of suspicion,” which attends to issues of “power and ideology" and other limiting structural factors that affect social constructions of reality (p. 9). Individuals themselves are the sites of understanding, and critical scholarship is said to be concerned with "*discursive reflection*," in which communicators must question assumptions held about their own understanding of the world (Craig, 1999, p. 133). Such reflection is both affected by and comes to affect the production of knowledge, as the researcher's self-knowledge comes to be "counted" as such. Communication within this approach functions to "focus on the significance of meanings, stories, cognitive schema, ideologies, and cultural norms in creating, maintaining, and transforming social life" (Craig, 1999, p. 114).

Ontologically, critical approaches take a variety of perspectives. *Social constructionism* represents one example of an ontological assumption of the critical approach, where the "constitutive role of communication in creating meaning and identity" is recognized (Mumby, 1997, p. 18). Unlike some interpretive approaches, critical social constructionism (a) attends to issues of power in the construction of reality and (b) examines whose realities are privileged (Mumby, 1997). Another clear ontological distinction within the critical project can be made between critical *modernism* and critical *postmodernism* (although others have argued that this distinction represents a dated binary which fails to account for the contemporary diversity of critical metatheoretical commitments; Moore & Manning, 2019). These represent two major critical approaches to the study of power (the first tenet of the CIFC heuristic, see below) in communication scholarship (Baxter & Asbury, 2015; Suter, 2018), the major distinction being that modernism presumes the existence of universal Truths while postmodernism presumes the existence of multiple truths. Postmodernism also seeks to interrogate the relationship between knowledge and power by examining the everyday micropractices which constitute it (Deetz, 2001; Zoller & Kline, 2008). Although both critical modernism and postmodernism are useful for critiquing the communicative operations of power, they do so differently (Baxter & Asbury, 2015). Critical modernism views power as being “embedded within ubiquitous, oppressive, structural, ideological systems,” while critical postmodernism views power as being dispersed, constructed through discourses which are “unfinalizable, unstable, and local” (Suter, 2018, p. 5-6). The modernist and postmodernist perspectives are two ontological commitments: the former holding an assumption that the world is fixed and stable while the latter assumes the opposite.

Axiologically, critical approaches embrace values as being essential to the research process, where research is said to be “thoroughly contaminated” by them (Ellingson, 1998, p. 494). As Behar (1997) has noted, some worry that “anything goes,” (p. 14) when values and personal information become viable for inclusion within published studies. Although the sharing of personal experiences and values within research had once been viewed as an indication of bias, Behar contends that *vulnerability*, or disclosed information about the researcher, is useful (indeed, powerful) so long as it forwards the contention of the manuscript. Given that the aims of the critical project include affecting social change, the role of the researcher is one of advocacy and activism and hence inexplicably involves consideration of the role of values. Further, given that our social locations are thought to situate our understanding of reality (Sotirin & Ellingson, 2018), critical scholars often employ *reflexivity*, “an active ongoing process of critical reflection both on the kind of knowledge produced from research and how that knowledge is generated” (Guillemin & Gillam, 2004, p. 274) to account for the influence of the researcher’s own values on the research process and product.

Critical theorizing fundamentally challenges “hegemonic” (i.e., dominant) ideology, the positioning of order as a natural state, the subject-object dualism, and the upholding of objectivity as a regulatory ideal (Craig, 1999). *Praxis*, the use of critical theorizing for social change, is an important feature of critical research, as it frees (or "emancipates"; Miller, 2005) individuals from binding structural constraints (Sotirin & Ellingson, 2018). Building knowledge within the critical tradition, then, requires addressing, problematizing, or challenging these taken-for-granted assumptions and structures. For instance, some family communication scholars have problematized taken-for-granted disciplinary assumptions about metatheoretical perspectives, arguing that our trichotomized and segmented views are inherently constraining obstructions which inhibit the production of knowledge (Droser, 2017). Critical theorizing is undertaken in an effort to avoid reinscribing the dominant structures and practices which contribute to inequities (Chevrette, 2013; Mumby, 1997).

In contrast to other metatheoretical approaches, critical approaches are decidedly *political*, meaning that they "are concerned with advancing beliefs, principles, and practices related to progressive social justice goals" (Moore & Manning, 2019, p. 48). Critical approaches also center *dissensus research* by positioning conflict as a natural state (Suter, 2018). Contrasting with *consensus research*, which works within dominant knowledge structures, existing social arrangements, and identities aiming to reveal or reflect underlying natural or social worlds, dissensus research works to reexamine recurrent, dominant structurings (Deetz, 2001). Conducting dissensus communication research means examining the struggles which plague competing systems of meaning given voice by interactants. The emancipatory potential of critical scholarship is realized when research discovers how individuals free themselves from previously invisible practices which have been injurious to them.

What is meant by *discourse* is often ambiguous in IFC scholarship and requires clarification (Allen, 2019). A *discourse* is a "cultural system of meaning that circulates among a group's members and which makes our talk sensical" (Baxter & Braithwaite, 2008, p. 349). A majority of IFC scholarship views discourse as an instrument to be utilized by individuals to achieve goals (Allen, 2019), reflecting a reluctance to decenter the individual within IFC analyses (Lannamann, 1991, 1992). A helpful distinction can be made then between big “D” discourse, and little “d” discourse (Alvesson & Karreman, 2000), where the former serves the purposes of the “social construction, maintenance, and validation of reality” and the latter of “local communicative acts” (Allen, 2019, p. 109). Baxter’s (2011) RDT 2.0. and discussion of distal discourses reflects big “D” Discourse, as it views discourses as systems of meaning, while Baxter’s (2011) discussion of proximal discourses and Galvin’s (2006) discussion of the discourse dependent family embodies little “d” discourse, as they are concerned with the use of language in particular relationships or families (Allen, 2019). Allen (2019) continues to note that combinations of conceptualizations of D/discourse are rare (with some exceptions, e.g., Gettings, 2019), and IFC scholars often fail to address assumptions about discourse explicitly or describe discourse in multiple ways within the study.

Hence, in an effort to be explicit about the role of D/discourse within CIFC scholarship (and given that formal articulations of the role of discourse within the CIFC heuristic are not explicit), I argue that the tenets of the CIFC heuristic (particularly tenet #2, described below) necessitate utilizing both conceptualizations of D/discourse. Big “D” Discourse is utilized when Discourses are described as systems of meaning which circulate within the public sphere, and little “d” discourse is utilized to discuss how discourses and practices are employed in response to the status quo. Examining discourse in particular is useful because discourses existing at the level of culture become “localized in a given relationship or family” in an effort to “[make] interaction and relational life intelligible to those inside and outside of the relationship” (Galvin & Braithwaite, 2014). A variety of theoretical frameworks such as relational dialectics theory 2.0

(Baxter, 2011) and methodologies such as contrapuntal analysis (Baxter, 2011), intersectional analysis (Crenshaw, 1991; Suter, 2018), and discourse tracing (LeGreco & Tracy, 2009) have been developed to examine multiplicities of these often-conflicting perspectives.

## Critical Interpersonal and Family Communication Framework

I next overview the four key "shifts" advocated for in interpersonal/family communication scholarship by the critical interpersonal and family communication (CIFC) framework. To provide context prior to describing the CIFC heuristic, it would be helpful to further explicate the features of "critical perspectives" in interpersonal and family communication (IFC) scholarship. Moore and Manning (2019) argue that there are several important distinctions between CIFC and IFC scholarship more broadly. First, CIFC is not limited to particular topics of study, but is rather characterized by *how* any particular topic is studied. For instance, although studies which examine military families are most often conducted within postpositivist and interpretive paradigms, Moore and Manning (2019) note that such scholarship could benefit from a critical vantage point to examine issues such as classism, racism, capitalism, and/or sexism. Second, the CIFC heuristic centralizes a particular series of metatheoretical commitments within the critical perspective (as described above).

Although the CIFC heuristic was formally explicated by Suter (2016, 2018), it is a contemporary response to longstanding calls within the field of interpersonal and family communication to integrate critical perspectives (cf., Fitch, 1994; Lannamann, 1991, 1992; Moore & Manning, 2019; Parks, 1995). Specific major lines of neglected interpersonal inquiry include *queer studies* (e.g., Abdi, 2014; Elia, 2003; Manning & Stern, 2018), *gender/feminist studies* (e.g., Denker, 2013; Manning & Denker, 2015; Norwood, 2012, 2013), *race studies* (e.g., Davis, 2018, 2019; Soliz & Phillips, 2018), *autoethnography* (e.g., Adams & Manning, 2015), and *performance studies/performativity* (e.g., Moore, 2017b). In fact, Moore and Manning (2019) argue that interpersonal communication is the last communication sub-discipline to integrate critical approaches, despite recurrent criticisms over time regarding its emphasis on individualism, subjectivity, and ahistoricism (Lannamann, 1991). In what follows, I describe and overview the four tenets of the CIFC heuristic.

### Four Tenets of the CIFC Heuristic

The CIFC heuristic is *critical* as it embodies this approach, operationalizing *critical* interpersonal and family communication research as that which: (a) attends to issues of power, (b) collapses the public-private binary, (c) concerns the resistance (or perpetuation; Medved, 2016), critique, and/or transformation of the status quo to serve social justice ends, and (d) incorporates author reflexivity (Suter, 2016, 2018). In each of the four sections that follow, I integrate canonical and contemporary CIFC literature as well as relevant examples and definitions to illustrate each tenet.

**Tenet #1: Examining Power**. The first tenet of the CIFC heuristic is an explicit research focus on issues associated with *power*, the "larger sociocultural systems and discourses impacting individuals, relationships, and family" (Suter, 2018, p. 5). As not all systems of meaning are deemed equally legitimate, natural, or normative (Baxter, 2011), critical approaches substantially center issues of power. For instance, Hintz and Brown (2020) examined how the non-normative discourse of voluntary childlessness and normative discourse of pronatalism exist in tension with one another. Further, examining power is useful as it serves to "emancipate and empower [the] disenfranchised" (Suter & Norwood, 2017, p. 4). In contrast to traditional IFC scholarship which often views power as an individual-level variable (i.e., as a beneficial inequality which awards social influence or as a matter of self-perception or status and dominance in an unequal relationship between individuals; Dunbar, 2015), the CIFC heuristic expands this view of power as *also* being external to the individual. The traditional view of power is largely individualistic (Lannamann, 1992), neglecting to consider the social conditions which underly and permeate the interaction (Moore, 2017a).

Critical modernists and postmodernists disagree about the location of power that is external to the individual, the former locating it in structures and systems and the latter in discourse (Suter, 2016). Regardless of one's particular modern or postmodern commitments, fruitfully examining power within the CIFC heuristic means examining the friction experienced by individuals who encounter these structures or discourses (Suter, 2016). For instance, a CIFC analysis by Hintz (2019b) revealed that heterosexual women who experience painful intercourse reported disempowerment upon encountering discourses concerning the role of sex in their relationships (i.e., that penetrative intercourse is a heterosexual relational prerequisite) and what it means to be a "good" female partner (i.e., that failing to have sex means failing as a woman), among others. Baxter (2011) offers an example of the postmodern tradition, theorizing power as existing within discursive struggle which results in discursive centralization or marginalization.

*A Foucauldian approach to power*. I accept Moore's (2017) contention that integrating a Foucauldian (1980) approach to our operationalization of power may prove fruitful in advancing critical theorizing in interpersonal communication scholarship. Specifically, moving away from an individual-level view of power enables the researcher to attribute particular communicative practices not only to the individuals who employ them, but to the larger operations of power which make those practices possible or deem them acceptable. Foucault explains that power is "exercised rather than possessed; it is not the 'privilege', acquired or preserved, of the dominant class, but the overall effect of its strategic positions — an effect that is manifested and sometimes extended by the position of those who are dominated" (1975, p. 25-26). To further explore this idea and its implications, I first overview the Foucauldian approach generally (including its assumptions) and discuss several specific benefits of integrating this perspective.

A Foucauldian approach to power assumes that power is a "dispersed, unstable, and plural" force operating through "interacting and hierarchized discourses" (Moore, 2017a, p. 6) in which claims are made about what is true and real (or comes to be "recognized as true"; Feder, 2011, p. 56). Foucault (1975) suggests that power is exercised in interpersonal and familial interactions, what he describes as "micro-physics of power" (p. 26). From this view, power is seen as occurring through the struggle of human interaction. In interpersonal health contexts, examining power matters for understanding how individuals accomplish tasks such as encouraging others to believe health concerns (Thompson & Duerringer, 2020). Foucault (1972) defines a *discourse* as "a group of statements and conceptual configurations brought together in a discursive formation" (p. 116-117). A *discursive formation* refers to "the total set of relations that unite, at a given period, the discursive practices that give rise to epistemological figures, sciences and possible formalized systems" (Foucault, 1972, p. 211).

Put differently, Foucault argues that the *discursive practices* employed by individuals and institutions comprise those discursive formations. Discourses are related to discursive practices in a bi-directional, recursive capacity whereby discursive practices are theorized both to create knowledge and be defined by that created knowledge (Foucault, 1972). Discourses are connected to power through *discursive fields*, theorized by Foucualt (1972) as the practices employed by institutions that dictate who and under which conditions individuals may speak. Discursive fields are "strategies" (de Certeau, 1984) created and maintained to control relations of power and knowledge production. For instance, individuals are classified by the psychological community according to whether the traits they exhibit fall within normative limits (West, 1996). Those outside of these limits may be deemed “mentally ill” by providers, who are attributed credibility and given the ability to speak on issues of mental illness through the satisfaction of conditions established by the discursive field (e.g., medical licensure requirements). Thus, discourse is knowledge, and knowledge is produced to establish and maintain relations of power.

This approach of viewing discourse as the site of knowledge production in the service of power is useful because it allows for the analysis of a wide array of social practices as opposed to viewing power as being enacted through the state (e.g., structures, systems, etc.). In this way, power is a productive (not repressive) process (not an object) which is sustained by making knowledge claims (i.e., discourses) about what is true while silencing other claims. Foucault (1980) calls this idea “*power/knowledge*,” again reiterating the idea that knowledge cannot exist without power. This is characterized by Suter (2018) as the critical postmodern tradition which views power external to the individual as existing within discourse. Individuals are located within power as bearers of knowledge and as *subjects* produced by discourse, in that the “self” is not one’s soul or mind, but instead “a complicated amalgamation of social forces and political structures,” a *subjectivity* (Moore, 2017a, p. 7). Regarding the study of communication, then, Foucault would argue that people enact social scripts which are determined not by individual agency, but by discourses of power.

The power dynamics at play in patient-provider contexts exist irrespective of and prior to particular interactions with patients. Specific patient-provider interactions always occur in relation to these pre-determined and power-laden discourses, and although interactants may affirm, reject, or attempt to change their own relationship with a given discourse, they are always constrained by it. For instance, attempts to institute standards of “patient-centered care” inherently acknowledge that the dominant form of care is not patient-centered. Thus, attempts to alter the status quo must first legitimize its dominance. This constitutes what Suter and Norwood (2017) describe as the relationship between interpersonal/family communication and power, whereby power is "embedded in, enforced by, and intertwined to" family life (Suter & Norwood, 2017, p. 292). In what follows next, I turn to outlining several specific benefits gained by taking a Foucauldian perspective to theorizing power.

First, adopting a Foucauldian approach to understanding the role of power that is external to the individual holds promise within health contexts specifically. Foucault proposed the concept of *bio-power*, defined as "a set of mechanisms through which the basic biological features of the human species became the object of political strategy, our general strategy of power…" (2007, p. 16). Bio-power is conceptualized as both knowledge about the human body and knowledge about groups of individuals which is used to regulate those individuals and populations. For instance, the political nature of female reproductive rights and the restrictions placed upon those rights is an example of bio-power. These mechanisms of bio-power operate recursively through *relations* (i.e., interactions) with others, "the set of procedures whose role is to establish, maintain, and transform mechanisms of power" (Foucault, 2007, p. 17), where power is conceptualized as being both the cause and effects of those relations. In another example, the experience of a female patient who reports symptoms to a medical provider and then experiences the dismissal of those symptoms is illustrative of bio-power insofar as bio-power is what makes that dismissal possible. Bio-power is a discourse that grants legitimacy through citizenship, a process of determining how and whose bodies receive treatment, whereby the dismissal is a barrier to citizenship within the realm of "medically recognized." Put differently, we legitimize and constitute power relations through discourse, and discourse is also the means through which power is maintained and disrupted.

Analyses of such relations naturally lead to connections with analyses of their historical development (Foucault, 2007), addressing ongoing criticisms that interpersonal communication scholarship is too often ahistorical (Fitch, 1994; Lannamann, 1992; Moore, 2017a). This represents an implicit assumption that communication is constitutive of relationships (CCR; Manning, 2020), as opposed to only occurring within them (often called the "container" model; Baxter, 2011). Through a CCR approach, we must consider past interactions and communication within that given relationship as opposed to only talk occurring at a particular time. Manning (2014) continues to argue that we must also consider larger cultural discourses which affect how the relationship is understood. Discourses which are reified through relations with others as dominant can be conceptualized as constituting the status quo. As the interaction is the mechanism through which power is "established, maintained, and transformed" (Foucault, 2007, p. 17), it is also the site for possible critique, resistance, and transformation (Suter, 2016, 2018).

Second, adopting a Foucauldian approach enables the theorizing of power as a process. Over time individuals may alter a dominant discourse sufficiently enough that an otherwise alternative perspective then becomes subsumed into and modifies a dominant discourse. For example, if a sufficiently large number of providers adopt and integrate proposed standards of "patient-centered care," the term will become indistinct from "care" in general, which would then come to constitute the dominant discourse. Through this process of power-laden discursive transformation, the qualifier "patient-centered" is lost as it becomes the dominant mode of operation. Further, the dominance of any discourse is fleeting, continually renegotiated under changing sociocultural contexts. For instance, an alternative discourse may arise which questions whether our new dominant discourse of “care” (i.e., formerly “patient-centered care” in our example) adequately meets the challenges of all patients, particularly minority groups or LGBT+ patients (e.g., Venetis et al., 2017). This processual (and continual) renegotiation of power comes to reflect prevailing consensus over time.

This process of discursive transformation over time is possible because, as Foucault suggests (Ormiston & Schrift, 1990), individuals possess the capacity to recognize power structures and selectively critique some and *reify* others, meaning “to treat an abstract concept as a thing” (Chafee, 1991, p. 39). For example, Spitzack (1998) called on communication scholars to avoid reproducing (and to begin to problematize) masculinity through their research practices, and Chevrette (2013) made similar calls regarding the reification of heteronormativity. Thus, through relating (or interacting) individuals possess the capacity to both perpetuate (i.e., be “complicit” in; Buzzanell & Liu, 2005) and/or resist or transform the status quo.

Third, adopting a Foucauldian approach to power allows for the theorizing of power at multiple levels (i.e., micro, meso, macro). For instance, a traditional approach to understanding power might suggest that providers exert power in patient-provider relationships by dismissing reports of symptoms by female patients as a form of dominance. A Foucauldian approach, however, might additionally examine how power operates through a series of hierarchically organized discourses at multiple levels (e.g., the medical education system, the media, etc.; Hayward, 1998). The product of this multi-level approach to power operations is an understanding of the “regime of truth,” where the word *truth* itself refers to “a system of ordered procedures for the production, regulation, distribution, circulation, and operation of statements” (Foucault, 1975, p. 133). A *regime of truth* is the successful outcome of a battle for truth in which “the rules according to which the true and false are separated” are established and "specific effects of power are attached to the true" (p. 132). For instance, a regime of truth about female pain might dictate which types of pain are deemed "normal" (i.e., something to be endured silently) versus abnormal and worthy of medical attention, or which knowledge claims about pain are taken seriously and which are dismissed. Commonplace beliefs such as "all young women want to have children" are illustrative of these regimes of truth as they are taken for granted/naturalized. Individuals (from this perspective) are able to exert power in communicative interactions not because of some status they possess; rather, they produce power by making knowledge claims which are legitimized by the regime of truth within which the interaction occurs. This is not to say that discourse hides the truth, but rather that discourse privileges some truths over others.

The regime of truth is also sustained through relations (i.e., interactions) with others, as it dictates the means by which claims of truth are to be investigated. This multitude of competing discourses (i.e., "truths") create differences in power which construct particular meanings and values for social actors (Mumby, 1997). Thus, to examine power as a multi-level process within critical research, we must view power both through its "official" manifestations (e.g., policy, laws) and its "informal" (i.e., localized, interpersonal) manifestations in the communication micro-practices that constitute daily interactions (Foucault, 1980; Wood, 2015). Hayward (1998) theorizes that these specific effects of the regime of truth are the boundaries formed by power which constrain and enable individual agency. In the language of TCD, then, individuals are not disempowered as a result of CD because they lose something intrinsic to them, but because they *are rendered less able to participate in the discourses to which they are subjected*.

For instance, when considering potential causes of racially disparate enactments of police brutality, some may adopt racist views which function to silence and discredit the experiences of

Black, Indigenous and people of color (BIPOC) by blaming stereotypical personality or behavioral characteristics (e.g., aggressiveness) for catalyzing such brutality. Efforts toward resistance (e.g., protests) by victimized individuals and communities are then often reinterpreted as further evidence for the conditions (e.g., aggressiveness) which are argued to have caused the issue, perpetuating the status quo social constructions which initially made disenfranchisement possible. Here, BIPOC may be less able to participate in the discourses to which they are subjected because attempts at resistance are weaponized to ossify the regime of truth and the power relations which sustain it. This example also illustrates how disenfranchisement is recursive, as power relations both make the CD possible and are sustained through it.

The preceding example also calls into question notions of individual and community agency. *Agency* refers to "a repeated process, an iterable procedure…That the subject is that which must be constituted again and again implies that it is open to formations that are not fully constrained in advance" where individuals may "[rework] the very conventions by which we are enabled" through discourses and related practices (Butler, 1995, p. 135). Regimes of truth make invisible these boundaries for those who reproduce the regime of truth such that individuals may have a limited capacity to know and shape them. However, those existing at the boundaries of a discourse (i.e., the vulnerable) are better able to recognize such boundaries. As Lannamann (1991) writes, "when we see the constraints that limit our choices we are aware of power relations; when we see only choices we live in and reproduce power" (p. 198).

For instance, childfree women are constrained by a regime of truth which suggests that women should have children. However, childfree women must always orient the communication work (Donovan, 2019) of childfreedom in relation to this prevailing discourse while also critiquing the very paradigm which constrains them. Moore (2017b) takes a Foucauldian approach to understanding the functions of power in her analysis of formerly childfree mothers tasked with renegotiating face upon having children. She explains that power/knowledge sustains the "never mother/(future) mother" binary unless formerly childfree mothers engage in everyday communication practices, "facework strategies," to transform and subvert the status quo (where a woman can both be a "never mother" and a "mother" at different points in time; Moore, 2017b). Discourses and practices of resistance enacted by individuals, then, operate *within* power relations (as opposed to outside of them; Foucault, 1972). Put differently, those who are on the margins and who render the fault lines in discourse visible to those who are centralized have the power to alter social relations, even if one must be complicit in legitimizing the dominant discourse to make incremental shifts in its conceptualization.

In sum, the first tenet of the CIFC heuristic requires researchers to centralize discussions of power. In addition to viewing power in an individual-level capacity, power is also viewed as being external to the individual. However, disagreement exists about where to locate that power (i.e., whether within structures or discourses). I argue that taking a Foucauldian approach to understanding this external power as situated within discourse has several explicit benefits, including: (a) theorizing about bio-power, (b) viewing power as a discursive process, and (c) examining the functions of power through discourse at multiple levels. This perspective holds promise for advancing analyses of the communicative operations of power. I next describe the second tenet of the CIFC heuristic: the bidirectionality of the private and public spheres.

**Tenet #2: Bidirectionality of the Private and Public.** The second tenet of the CIFC heuristic is the collapse of the binary between the public and private spheres, where they are to be viewed as indistinct (Suter, 2016, 2018). Notions of these spheres as being separate emerged from the work of Habermas (1991), who sought to distinguish between the *public sphere*, an "institutionalized arena of discursive interaction" (Fraser, 1990, p. 57) in which the free deliberation of ideas occurs (where possible in an effort to create consensus; Hauser, 1998); and the *private sphere*, fundamentally concerned with "civil society" and the maintenance of the family through the exchange of social labor (Habermas, 1991, p. 30). Interpersonal and family communication scholarship has often viewed communicative relationships as existing without influence from these broader systems, structures, and discourses (Suter & Norwood, 2017).

However, individuals and families remain connected to the public sphere insofar as they must interface with institutions (e.g., the healthcare system, the government) and are affected by public policy and normative expectations for their lives and behavior. Thus, defining interpersonal and family communication in terms of "levels of practice" such as daily *micropractices* (which may be ordinary/mundane), *mesopractices* within families or groups, and the *macropractices* (e.g., discourses) of institutions creates space for critical perspectives (Moore & Manning, 2019). For instance, Hintz (2019b) described three ways in which the media reify norms governing heterosexual sex which are problematic for women with chronic genital pain and their romantic partners. As opposed to viewing these romantic relationships as existing without influence from the public sphere, such knowledge is integrated as an explanatory mechanism for the issues experienced by this population when discussing sex.

Further, the CIFC heuristic advocates not only for the collapse of this false binary between the public and private spheres, but for consideration of their *bidirectional* interpenetration, where "larger social institutions/discourses are viewed as mutually structuring and restructuring one another" (Suter, 2018, p. 7). As opposed to only examining the effects of the public sphere on interpersonal relationships, the CIFC heuristic argues that these relationships themselves may be entities which in turn hold the capacity to influence the public sphere. An example of the private interpenetrating to affect the public could be Medved's (2016) analysis of the experiences of stay-at-home-fathers (SAHFs) who had been denigrated by the enforcement of this gendered bifurcation between the public and private spheres (i.e., that domestic affairs are to be handled by women). Through this private resistance, SAHFs draw attention to, and alter, taken-for-granted perceptions of stay-at-home parenthood. The temporal nature of this interpenetration connects to the Foucauldian approach to power described earlier, whereby power is processual and individuals can affect discourses of power across time.

The feminist mantra, "the personal is political" (Sotirin & Ellingson, 2018) further embodies this idea, having sought to dismantle the false binary between the patriarchal public sphere and matriarchal private sphere which excluded women from meaningful political participation. Suter (2018) acknowledges her own feminist commitments which guided the development of the CIFC heuristic, reflecting other recent calls to integrate feminist and gender perspectives into CIFC theorizing (e.g., Manning & Denker, 2015; Sotirin & Ellingson, 2018). Moore and Manning (2019) outline six particular politics which could extend future CIFC inquiry. Among these are identity politics, deconstructive politics, economic politics, technological politics, politics of affect, and material politics. While these politics all hold promise for advancing CIFC research, the politics of materialism (Harris, 2016) holds particular promise for fruitful cross-fertilization with multiple goals frameworks, described later.

In the same way that the CIFC framework calls for analysis of public and private sphere bidirectionality, I argue that CIFC scholars should also consider the bidirectionality between discursive practices and material conditions. A politics of new *materialism* advocates for some consideration of "how objects and other non-human actants are constitutive of relationship and families" (Moore & Manning, 2019, p. 51), in other words, "how matter comes to matter"

(Barad, 2003, p. 801). For example, the available facts about a particular illness might be considered non-human actants insofar as they are *forces* employed by interactants to craft judgements a person’s sickness and need for care (Dumit, 2006). Materialism is useful in CIFC research because it subverts the subject-object dualism and enables us to understand the “explanatory role of generative structures and mechanisms” in ways otherwise not possible (Reed, 2004, p. 415). As subjectivist approaches alone fail to acknowledge “the powerful influences of the material conditions beyond the interpretive and rational control of the subject,” a materialist approach instead encourages a movement away from only individual perception as a means of examining communicative processes (Lannamann, 1991, p. 190).

Materialist approaches view reality as being constituted through the human practices which intentionally transform the status quo (see tenet #3 below) and are constrained by circumstances beyond their immediate control (Held, 1980; Marx 1852/1978). For instance, Gatlin (1977) examined the effects of farm-to-city migration on the interpersonal relationships of early Americans. In a more contemporary example, McAlister (2011) analyzed the functions of the physical layout of the American family home in promoting heteronormativity. Dean et al. (2016) similarly considered how physical space within an emergency department both enabled and constrained various communicative practices. All of these examples embody the relationship between material resources and relationships.

Applying this politics of materialism within CIFC research means exploring the relationship between objects and other non-human actants and discourse and “critiquing the material-discursive practices that constitute unjust operations of power” (Allen & Allen, 2019, p. 297). Allen and Allen (2019) call for an examination of how, in addition to discourse, texts and objects can participate actively in the constitution of relationships and reality. For instance, legislation and media coverage pertaining to the treatment of patients with chronic pain, as well as prescription opioid medications which offer pain relief are texts and objects which could well affect how interpersonal relationships (and reality) are constituted by patients. Such actants also constrain patient agency, and thus scholars have called for an examination of what Carpentier (2017) calls the "*discursive-material knot*," comprised of agency, material structure, and discourse (p. 14). Specifically, this "knot" suggests that the material may actively participate within discourse, able both to dislocate dominant discourses and invite the ascription of meaning. Hence discourse and material conditions both constrain and enable agency (Carpentier, 2017).

In sum, the second tenet of the CIFC heuristic asks that researchers consider the ways in which interpersonal relationships are both influenced by and come to influence the material conditions, ideologies, social institutions, and discourses which comprise the public sphere.

**Tenet #3: Critique, Resistance, and Transformation of the Status Quo.** The third tenet of the CIFC heuristic suggests that individuals enact discourses and practices (Medved, 2016) of critique, resistance, and transformation of the status quo to promote social justice ends (Suter, 2016, 2018). This tenet can be connected to our Foucauldian view of power described earlier, whereby interaction is the mechanism through which power is established and maintained, and therefore it is also the means of resistance. Drawing upon a dissensus approach to research which reclaims conflict as the natural state, the CIFC heuristic views the *status quo* as an oppressive, unnatural deviation from conflict (Deetz, 2001; Sotirin & Ellingson, 2018). Thus, we examine the discourses and practices that broadly challenge the status quo.

For instance, Hintz (2019b) examined how women with chronic genital pain resisted status quo expectations which governed heterosexual sexual relationships by developing a self-advocating orientation and demanding increased engagement from their partners in managing pain. They enacted discourses and practices to transform the status quo by adopting a conditional view of romantic relationships (refusing to enter relationships which required they engage in painful intercourse) and negotiating a new sexual normal to change black-and-white views about what sex and intimacy constituted. For Medved's (2016) examination of stay-at-home fathers, discourses and practices of resistance included claiming the SAHF label and refining career ambitions to accommodate the demands of caregiving (among others). Discourses and practices of transformation included negotiating unconventional roles early in the marriage and transforming stay-at-home parenthood and career tasks to be gender neutral.

In addition to resistance and transformation, and given that the CIFC heuristic "promotes examinations of calcified communicative practices and processes that suppress more marginalized and/or muted individuals" (Suter, 2018, p. 10), I elect to carry forward Medved's (2016) notion that we not only centralize an analysis of practices of *critique*, but also the ways in which interactants *perpetuate* the status quo (what might be called the reification of dominant power structures from a Foucauldian perspective). Thus, this dissertation examines the discursive practices which serve to perpetuate, critique, resist, and transform the status quo for social justice ends. Discourses and practices which perpetuated status quo notions about the role of sex in heterosexual relationships (Hintz, 2019a) included stereotyping all men as being sex-driven and offering to open the relationship to permit a male partner to seek sexual gratification elsewhere. Examples of discourses and practices which perpetuated status quo notions about stay-at-home-fatherhood included engaging in building and outdoor labor tasks (e.g., building sheds, doing handyman work) and engaging in masculine protective behaviors (Medved, 2016).

Examining the ways in which individuals enact discourses and practices of perpetuation, resistance, and transformation is useful because such research can serve *social justice* ends

(Suter, 2018). Researchers striving for these ends must collapse the presumed boundary between themselves and the participants, instead working alongside participants to encourage critical reflection about their own lives and create partnerships with participant communities to affect change. Such change is possible not only for participants and the communities they represent, but also at the level of policy and/or institution (e.g., the healthcare system), whereby such findings could improve the interactions had by community members with those institutions (Suter, 2018). Hence, this tent represents the "practical" arm of the CIFC heuristic, through which praxis can be accomplished (Sotirin & Ellingson, 2018).

In sum, the third tenet of the CIFC heuristic requires researchers to examine the discourses and related practices which perpetuate, resist, and transform the status quo. Doing so enables an understanding of the ways in which dominant discourses are challenged through interactions, and the product of this understanding can be utilized to affect positive change.

**Tenet #4: Reflexivity.** The fourth tenet of the CIFC heuristic is *reflexivity*, defined earlier as "an active ongoing process of critical reflection both on the kind of knowledge produced from research and how that knowledge is generated" (Guillemin & Gillam, 2004, p. 274). Although Suter and Norwood (2017) suggest in a footnote that author reflexivity is least relevant for discussions of theory, it remains a part of the theoretical framework and will thus be described. Reflexivity is employed within CIFC scholarship to account for the influence of the researcher's own values on the research process and product. For instance, Davis considered her own position as a Black woman when positing a theoretical framework for understanding the collective communication practices of Black women (Davis, 2015; Davis & Afifi, 2019). Building upon calls for interpersonal communication scholarship to move away from ahistorical, value-neutral perspectives, the CIFC heuristic (Lannamann, 1991) requires self-reflexivity by the researcher throughout the research process. This tenet also requires that the researcher explicitly position themselves within written reports and allot space for doing so (Suter, 2018). This tenet guides this dissertation project as I am a woman living with multiple COPCs. My status as a patient offers me unique insight into the issues faced by this population as well as the need for theoretical development which can explain this communicative phenomenon and its effects.

### Gender and a Feminist Approach to CIFC

Gender bias about women and their experiences of pain is an integral part of the context explored in this dissertation (CECPW, 2010; Samulowitz et al., 2018). The CIFC heuristic also lends itself to critical feminist theorizing, as although it is not an explicit tenet of the theory, Suter (2018) does acknowledge her own feminist commitments which undergird her articulation of the CIFC heuristic. Hintz (2019b) applied tenets of critical feminist theorizing as a sensitizing framework in her application of the CIFC heuristic to examine a similar gendered pain context. Given that integrating a critical feminist perspective would likely prove useful in illuminating the experiences of women with COPCs, it may be useful to discuss some assumptions and potential applications of such a perspective as a sensitizing framework with which to approach our CIFC/multiple goals integration.

Critical feminist theories (CFTs) offer a novel mode of explanation for understanding how interactions where pain is discussed are invariably affected by, and intertwined to, larger power structures which perpetuate the status quo (Sotirin & Ellingson, 2018; Suter, 2018). While many critical feminist theories abound (e.g., standpoint, socialist feminist, and poststructuralist theories), a series of assumptions undergird CFTs. Sotirin and Ellingson (2018) describe these assumptions of critical feminist theorizing as a continual process. Three central assumptions are overviewed and connected to possibilities for development in the area of pain communication:

(a) power, (b) subordination of knowledge and experiences, and (c) equal representation and voice. Many methodologies are suitable for exploring these assumptions as they affect micro and macro-level policies and interactions in less studied realms of gendered life (Wood, 2015).

First, CFTs center issues of power, “structured relations of dominance and control” (Sotirin & Ellingson, 2018, p. 111), in an effort to understand how our social locations (e.g., gender, SES, race) situate our understanding of the world. We must also consider intersections of gender and race, as both gender and racial disparities abound in pain treatment and the discursive management of pain (Pryma, 2017). *Gender* is assumed to be a “critical site of power, identity, and experience” (Sotirin & Ellingson, 2018, p. 111), and must be examined in an effort to uncover gender inequities and enact social change (Wood, 2015). The experience of having pain is gendered. In a national epidemiological survey, women overall were found to be approximately two times more likely than men to report having a chronic pain syndrome (Munce & Stewart, 2007). Women are more likely to report experiencing chronic pain, of heightened severity, which persists longer than pain reported by men (Pieretti et al., 2016). Some pain syndromes are more gendered than others, presumed to be caused by “an interaction of genetic, anatomical, physiological, neuronal, hormonal, psychological and social factors which modulate pain differently in the sexes” (Pieretti et al., 2016, p. 144). For example, women were six times more likely to report having fibromyalgia than men, but only 1.6 times more likely to report arthritic pain (Munce & Stewart, 2007). Many other poorly understood pain syndromes such as irritable bowel syndrome (Thakur et al., 2015) and vulvodynia (Lusher & Murray, 2018) affect a majority or exclusively female patients.

Second, women are theorized to belong to a subordinate group for whom society was not developed. Consequently, the experiences and knowledge of women are often absent or misrepresented (Wood, 2015). This is apparent when examining gendered perceptions of reports of pain. Many female-dominant pain syndromes can be conceptualized as “contested,” where patients’ pain symptoms are “medically suspect because they are not associated with any known physical abnormality” (Conrad & Barker, 2010, p. 70). As a result, providers may be reluctant to validate or believe reports of pain, contributing to underreporting and undertreatment (APS, 2011; Newton et al., 2013). Although women (when compared to men) experience pain more severely and frequently and as lasting longer, they are treated less aggressively (i.e., more likely to be sent home, given less pain medication, etc.; Kaul et al., 2007). Poorly understood health conditions suffer from a legitimacy deficit (Dumit, 2006; Kempner, 2014) as causal biological attribution often cannot be ascertained in these cases, leaving room for the questioning of the credibility of patients and their symptoms. Concerns about being disbelieved are particularly salient for female patients, as conceptualizations of gender and femininity provide a lens through which female patients and their pain may be viewed by providers. This underscores the necessity of examining the historical conditions which precede interaction (Moore, 2017a).

Reports of female pain may be filtered through a “histrionic” lens, whereby the symptoms of women are viewed as “not real” and as the result of a melodramatic, attention-seeking, and theatrical effort to receive a secondary benefit of some sort from being ill such as seeking attention, shirking one’s ascribed duties, or receiving medication (CECPW, 2010; Ussher, 2013). Differences in perceptions of patient pain by the gender of the patient also result from different specific communicative practices employed by female patients. An extensive body of research has explored such differences, determining that in general men tend to report pain in less descriptive, less emotion-focused ways (which are perceived as being more tangible and objective), while women tend to use more descriptive, emotion and sensory-focused language than men and report more symptoms at once (e.g., Strong et al., 2009). Men are viewed as stoic while women are viewed as hysterical (Samulowitz et al., 2018). Providers are also least confident in diagnosing and treating women's health conditions (Maserejian et al., 2009). For example, experimental studies have demonstrated that female (relative to male) patients who report pain are perceived as being less trustworthy, as having less pain, and as being more likely to exaggerate pain (Schäfer et al., 2016). Consequently, providers were less likely to offer analgesics and more likely to recommend psychological treatment to these patients (Schäfer et al., 2016). Foucualt (1972) would explain this phenomenon through the discursive field maintained by the medical establishment. Such a discursive field dictates who is able to speak about health and healthcare, where patients not viewed as legitimately "ill" may therefore not be seen as satisfying the conditions for engaging in discourse about it.

These views are then often communicated to women by providers, family members, romantic partners, and friends, serving in effect to silence complaints of pain, discredit self-beliefs about pain and the legitimacy of complaints made to others, and reinforce the beliefs and stereotypes about sick women more broadly which make those claims possible, hence embodying TCD. These communicative acts, for instance attributing reports of pain to an underlying psychological issue (i.e., what Krebs and Schoenbauer (2019) call the "discourse of psycho-abnormality," in which women receive message such as "it's all in your head"), also remove the impetus and means for discovering otherwise (e.g., research funds are not often dedicated to ascertain possible underlying biomechanisms for perceived psychological disorders; Dusenbery, 2018). This represents one way in which power is recursive and comes to be reinforced/sustained via interactions with others (Foucault, 2007), such that "knowledge" about whether an individual's health complaints (i.e., knowledge claims) are legitimate become deindividualized, evaluated through a person’s own beliefs about what criteria separate truth from falsity and are sustained through relations which communicate those evaluations.

Third, CFTs argue that the voices of women are deserving of respect and full inclusion and giving voice to women means providing the ability to define phenomena (Wood, 2015). Due to a historical reluctance to include women in clinical trials, understanding of female-dominant pain conditions is lacking (Liu & Dipietro Mager, 2016). However, communication scholarship can help by offering recommendations to ensure that interactions with providers, romantic partners, and family members are not perpetuating status quo discourses and practices regarding the treatment of women with COPCs in the absence of effective treatment/science. Patients communicating about their own pain must be acutely aware of the role of gender. Kempner (2014) argues that “for a disease to be fully legitimated, the people who have it must be viewed as deserving of care and resources,” but the credibility of female patients is suspect in these cases. For instance, a female patient’s appearance (i.e., looking/acting too sick or too weak), level of knowledge and preparedness for the interaction, and level of assertiveness during the interaction are all considerations female patients must make when attempting to make reports of pain believable to others (Werner & Malterud, 2003). Feeling misunderstood, rejected, ignored, belittled, blamed for their condition, and assigned psychological explanation models, women often encounter difficulty establishing credibility, leading to systemic stigmatization and invalidation – disenfranchisement (Newton et al., 2013; Werner & Malterud, 2003). Female patients are then in danger of being marginalized from further care (Cowley et al., 2009). The importance of such issues also extends beyond patient-provider contexts. Female patients must ensure that partners, family members, and friends trust their pain accounts.

To affect social change through a feminist CIFC sensitization, this study explicates features of the status quo for female pain patients, to better understand the everyday realities of women navigating these issues of power, representation, and subordination. An analysis of the ways in which female pain patients enact discourses and practices (Medved, 2016) to critique, resist, and transform this status quo, has occured (Suter, 2016). Such findings could have implications for future critical feminist theorizing, but also for practice, as studies could explicate barriers at both micro and macro levels which limit access to care, harm relationships, affect patient identities, and implicate larger organizational structures in experiences of pain management (Donaldson & Meana, 2011).

In sum, four tenets of the CIFC heuristic together form a roadmap for future critically inflected interpersonal and family communication research. Through the examination of power, public and private sphere bidirectionality, discourses, materialities, and related practices which perpetuate, resist, and transform the status quo, and considerations of author reflexivity, this dissertation contributes to this burgeoning area of scholarship. Having explicated CFIC, I turn to the other theoretical framework that informs this dissertation.

## Multiple Goals Frameworks

Existing conceptualizations of concepts related to CD such as illness invalidation (Kool et al., 2010) focus exclusively on issues such as diagnostic errors and symptom invalidation. Thus, such issues are presently characterized as being related primarily to the task of pursuing diagnosis and treatment. However, multiple goals theoretical perspectives instead suggest that such interactions contain multiple conversational purposes to which interactants must attend and in doing so implicate relational and identity meanings (Clark & Delia, 1979). Generally, multiple goals perspectives share some common assumptions, including that communication is undertaken for a particular purpose, that this purpose often makes other objectives also relevant to pursue, and that these purposes can conflict with one another (Caughlin, 2010; Wilson & Caughlin, 2017). Although variation exists across multiple goals perspectives, some perspectives, particularly Goldsmith's (2004, 2019) NRT and some tenets of Caughlin's (2010) multiple goals theory of personal relationships, are best suited to guide this dissertation project.

### Normative Rhetorical Theory

Formerly known as the normative model of social support (NMSS; Goldsmith, 2004), Goldsmith's (2019) NRT is a framework useful for understanding how interactions in which multiple conversational purposes exist, conflict, and are evaluated by others.

To begin, a definition and general overview of NRT is offered. NRT is *normative*, meaning that it attempts to assess the quality of communicative interactions by connecting message features with evaluations (i.e., better or worse) as determined by one's sociocultural community. Hence, NRT is useful for "document[ing] common meanings and practices for a social group" such as patients with COPCs (Goldsmith, 2019, p. 217). NRT is *rhetorical*, acknowledging that messages both define and are defined by the situation for which they are produced. For example, patient-provider interactions experienced by women with COPCs both attend to a commonly understood conversational purpose and also constitute the outcome of the consultation. NRT is also a mid-range *theory*, meaning that the results of an NRT analysis in a particular context are not intended to be generalizable in their present form but can be used to better understand the same phenomena in other contexts. Given that the goal of an NRT analysis is to understand why some forms of talk are evaluated to be better or worse than others, the findings from this dissertation hold promise for practitioners interacting with women with COPCs, as well as patients entering consultations.

Next, the three guiding assumptions of NRT, which together form its heuristic framework, are explicated. First, NRT posits that we attend to *multiple meanings* or *purposes* in talk, specifically that we attempt to accomplish communicative tasks while also managing implications for our identities and relationships (Clark & Delia, 1979). Therefore, NRT is appropriate for situations in which "pursuing [a] task poses problems for enacting desired identities and relational definitions" (Goldsmith, 2019, p. 217). For instance, disenfranchising interactions which occur when patients with COPCs pursue the "task" of seeking diagnosis and treatment are imbued with meanings about a patient's identity (e.g., they are fabricating or malingering) and relationship (e.g., they are exploiting the patient-provider relationship for some gain or challenging the authority of the provider) which shape meanings and evaluations of talk. Existing research about interactions experienced by patients with COPCs focus primarily on the tasks of pursuing diagnosis or evaluating patient symptom descriptions, neglecting to consider these additional conversational implications for their identities and relationships.

The *desired identities* of relating parties may also be inhered in talk (Goldsmith, 2019). For example, women with vulvodynia report feeling like "bad" or "broken women" and that, by extension, talking about vulvodynia made them feel like "bad partners" due to their inability to fulfill sexual expectations within their relationships (Hintz, 2019b). Particular *relational definitions*, defining features of relationships such as the organization of power, may also become implicated (Goldsmith, 2019). For instance, a patient who argues for the legitimacy of their pain despite a provider's insistence to the contrary challenges notions about the patient-provider relationship (e.g., that provider is in charge). In another example, women with vulvodynia sometimes withheld or modified potentially negative information about the severity or expected longevity of painful symptoms because they perceived that this information would jeopardize the continuation of their heterosexual romantic relationships (Hintz, 2019b).

Second, NRT asserts that in order to understand the effects of activities on participants, the *meanings* of the activities themselves for participants must be themselves understood (Goldsmith, 2019). While some meanings are specific to a given individual or relationship, sociocultural *speech communities*, groups of individuals who utilize a shared meaning system to act and interpret others' actions, also limit the plausible range of evaluations of talk. Women with endometriosis, for example, who report that "no one agrees except for those of us who have it," have been referred to as an "epistemological community" (Whelan, 2007, p. 957). NRT, then, enables us to better understand the meanings and communicative practices held by patients with COPCs as it "provides a set of guiding assumptions that direct attention to the relevant aspects of a type of communication to document common meanings and practices for a social group" (Goldsmith, 2019, p. 217). Here we can also see linkages to power/knowledge. In this way, examining the communicative practices of a particular community enables us to understand both how talk is understood and which logics connect communicative features to these evaluations. By examining accounts of interactions from a particular sociocultural community (e.g., women with COPCs), common practices, a range of plausible meanings, and the rationale for the connection between practices and meanings can be proposed.

Third, NRT assumes that interactions are contextually situated at both the sociocultural and interactional levels. The *broad sociocultural context* first affects the interpretation of talk (Goldsmith, 2019). For example, pressing concern about the opioid epidemic likely shapes discussions about the treatment of COPCs and affects providers' evaluations of the talk produced by patients (e.g., viewing all patients with COPCs who request opioids as potential addicts).

Another layer of context includes the *communicative context of the interaction*. For example, talk about childfree sterilization would hold different meaning depending upon whether a patient was a post-menopausal woman with several children or a fertile childfree person. Participants are assumed to be knowledgeable reporters about their meanings and practices (Goldsmith, 2019).

Finally, three key theoretical advancements from NMSS (Goldsmith, 2004) to NRT (Goldsmith, 2019) are described. First, NRT remains a framework useful for understanding how conversations with multiple situationally relevant purposes create communicative *dilemmas*, where those purposes must be simultaneously interpreted and managed (Goldsmith, 2004, 2019). In moving forward, NRT questions whether and how these multiple purposes can be interrelated. While NMSS (Goldsmith, 2004) suggested that multiple "goals" or conversational purposes could be *in competition* with one another in a given interaction, NRT asserts that dilemmas can also be *paradoxical*, where multiple purposes are mutually exclusive or contradictory and create a "double bind" for interactants. For example, Wilson and colleagues (2015) reported that the family members of military service members felt that they should "push, but not be pushy" when encouraging service members to seek mental health treatment. Wilson et al. (2015) called for future work to continue to examine paradoxical dilemmas, where multiple relevant conversational purposes remain and must be attended to.

Second, NRT also continues to explicate how such dilemmas are managed, how the management of dilemmas is evaluated by others (e.g., as better or worse), and the meanings driving such evaluations (Goldsmith, 2019). However, NRT moves away from using language such as "goals" and "strategies," instead opting for "purposes" and "practices" to better reflect the socially defined nature of talk. Put differently, "goals" and "strategies" may incorrectly imply that an individual has the sole capacity to manage dilemmas. In moving away from the "strategy-selection-centric view" of responding to dilemmas, NRT places additional emphasis on the role of the social environment for shaping our own talk and our interpretation of the meaning of that talk (Goldsmith, 2019, p. 223).

In an example of how the social environment shapes the interpretation and meanings of talk, patients with COPCs grow communication networks with fellow patients to educate themselves about the condition in order to be able to evaluate new claims about themselves or their illness. It is because of the uncertainty of these conditions and negative encounters when attempts to seek help are made that women feel compelled to become personally responsible for their own care (Rebman et al., 2017). This education allows for women to see themselves as having agency regarding caring for themselves, and operations of power can be seen through the use of claims about acquired knowledge made by patients (Whelan, 2007). This process of education is described as the "collective counter-emplotment of facts" where individuals "draw upon the collected experiences of others in order to navigate these sites of struggle, including courts, insurance agencies, mass media, and government" (Dumit, 2006, p. 585). This functions as a form of discursive resistance to power (i.e., discursive practices of enfranchisement) derived through the gathering of knowledge claims which are not sanctioned by the regime of truth. This collective coming together of patients highlights how these conditions happen to *communities* (i.e., networks) of women (Whelan, 2007), and where "reactions against medical mismanagement and struggles to obtain help and information…emerge from and, in turn, help to constitute specific views about what actually counts as knowledge and how to adjudicate competing claims" (Whelan, 2007, p. 977). These points of connection make clear the utility of examining the CIFC and multiple goals frameworks as a theoretical basis for explicating TCD.

Third, in moving away from this “strategy-selection-centric view,” NRT suggests three potential responses to dilemmas. First, *interpretive lenses* are decisions about how to understand a situation that shape how talk is decoded and understood. For example, Goldsmith et al. (2012) noted that patients and partners managing recovery from a cardiac event adopted *legitimacy* as an interpretive lens to reinterpret potentially bothersome reminders as functions of the caregiving role. Second, *environmental resources* are routines and interactions existing outside of the immediate conversation which are utilized to shift context. For example, in the same study, Goldsmith et al. (2012) found that partners drew upon members of their *social networks* such as medical providers to contextualize reminders about dietary and lifestyle alterations. Third, *communicative practices* (Wilson & Caughlin, 2017; Goldsmith, 2019) are specific features of talk enacted to respond to dilemmas. For instance, Goldsmith et al. (2012) found that couples *rationed talk* about dietary and lifestyle changes following a cardiac event to respect patient autonomy. This advancement recognizes that all interactants do not necessarily have the same “strategies” at their disposal in a given interaction. Although interpretive lenses and environmental resources appeared in NMSS (Goldsmith, 2004), NRT conceptualizes these potential responses as controllable parameters, meaning that they can be utilized at will by participants to connect message features to plausible meanings.

Although all assumptions of NRT are described above, two are most salient for guiding this dissertation: (a) that interactions always contain multiple relevant conversational purposes and meanings, specifically that the pursuance of conversational tasks always inheres meanings about our relationships and identities, and (b) that interactants and interactions are always embedded within sociocultural speech communities which constrain the plausible range of potential meanings and evaluations of talk.

### Multiple Goals Theory of Personal Relationships

In addition to tenets of NRT, this dissertation integrates Caughlin's (2010) multiple goals theory of personal relationships (MGTPR). MGTPR was developed to extend message production and relationship research by importing a multiple goals perspective. Specific (and traditionally separate) varieties of multiple goals research include: (a) multiple goals research aiming to understand how goals shape message production, (b) multiple goals research attempting to evaluate communication quality or sophistication through examinations of communication context (Goldsmith, 2004) or logics employed by individuals to manage multiple goals (O'Keefe, 1988); and (c) multiple goals research which explores how beliefs and inferences about communication goals (i.e., goals which we ascribe to ourselves and others) shape conversational meanings. This tripartite explanation of multiple goals research as a field of study is later used as a framework to illustrate the utility of MGTPR.

To provide a more nuanced explanation for the connection between communication interactions and outcomes, Caughlin (2010) builds upon extant multiple goals research by positing a conceptual model which links communication goals to interaction and to outcomes for each episode. Assuming that message goals and messages are interdependent among interactants, MGTPR further asserts that messages produced by one interactant shape perceptions of own and partner goals and result in subjective evaluations of interactions. These perceptions of goal and communication tendencies (e.g., communication patterns such as topic avoidance) in particular encounters are then theorized to, in aggregate and across time and additional interactions, coalesce into relational-level constructs (e.g., communication satisfaction; Caughlin, 2010).

Guntzviller (2017) used MGTPR as a lens for studying *language brokering*, or situations in which bilingual children help translate when their Spanish-speaking mothers interact with adults who only speak English. These interactions occur in a variety of settings, such as at the doctor's office or at school. During any individual interaction, children have a sense of what goals they and their mother are pursuing, and likewise mothers have a sense of what goals they and their child are pursuing. Over time and across situations, MGTPR argues that children and mothers gain a sense of the goals they *typically* have during language brokering episodes, as well as what goals they perceive the other person typically pursues. Guntzviller's findings suggest that, for both parties, perceptions of their own typical interaction goals as well as their perceptions of the other party's typical goals, shaped how satisfied they were with their relationship generally. For example, children reported greater satisfaction when they pursued the goal of "acting Latino/a" while translating for their mother as well as when they perceived that their mother pursued the goal of supporting them in such situations.

This dissertation adopts Caughlin's (2010) assertion that concepts from multiple goals perspectives may be useful beyond only discrete interactions. Specifically, this dissertation adopts MGTPR's assertion that specific interactions, over time and in aggregate, may coalesce into relational-level constructs, including perceptions of communication tendencies and the goals that others tend to pursue. This assertion suggests that particular encounters experienced by women with COPCs, in aggregate, my coalesce into more global evaluations of perceived CD and attune female patients to goals others tend to pursue in conversations about illness symptoms or effects (e.g., that important others will tend pursue the goal of evaluating the credibility of their pain complaint). We can infer that a global perception of disenfranchisement may emerge from these goal assessments.

Adopting this assertion from MGTPR assists us in clarifying the connections between talk, disenfranchisement, and agency, as it specifies a mechanism by and through which specific interactions with important others may result in disempowerment by constraining individuals' ability to participate meaningfully in the discourses to which they are subjected which are sustained and repeated in future similar conversations with others. In the context of COPCs, a global perception of disenfranchisement precipitates over time given both patients' history of interactions in which COPCs are discussed and their attenuation to the perceived goals of others (e.g., assessing the credibility of pain complaints). In response, women with COPCs may *self-constrain* by, for example, no longer pursuing diagnosis and treatment, or *experience the imposition of constraint* when, for example, a psychological explanation for pain becomes written into a patient's electronic health record – a material actant – which inhibits future unbiased assessments of symptoms by providers.

This latter example also suggests that important others (e.g., medical providers) also become attuned to the perceived goals of women reporting chronic pain and which may result in global assessments (e.g., women who report chronic pain are exaggerating or feigning to escape work). This example suggests multi-level operations of these mechanisms, such that discrete specific interactions between women with COPCs and an important other over time may result in global assessments by women of disenfranchisement, but also that important others (e.g., medical providers), through regular interactions with women with COPCs, may develop and refine goal assessments which create the conditions for disenfranchising talk to occur. Although MGTPR has focused primarily on a specific interaction or a number of discrete interactions across time between the same individuals, this dissertation may illuminate how the same process may operate at this third higher level of abstraction (Caughlin, 2010). By moving beyond a focus on only individuals in a specific interaction, MGTPR allows clear connections between concepts of discourse (e.g., discrete assessments that women who report chronic pain are malingering become subsumed into broader discourses about women in pain which are available to evaluate future patients' health complaints) and power/knowledge (e.g., discourses come to dictate the means by and through which accounts of female pain are evaluated). In this way, women with COPCs may become disenfranchised through talk as they are disempowered (i.e., constrained in their ability to participate in the discourses to which they are subjected) and disempowerment precipitates into material consequences which ossify it.

In sum, CD is well-suited for examination through an integration of the CIFC and multiple goals frameworks. Examining disenfranchisement necessarily means studying "the relations of power that give them form and substance" (West, 1996, p. 310). The multi-level nature of CD is underscored by the ways in which discourses circulating in the public sphere come to affect private interactions. As power is established and sustained through relations with others, opportunities to both perpetuate and potentially resist and transform the status quo are also possible through such relations. To finish building a rationale for specific research questions posed in this dissertation, this chapter concludes by comparing CD to several existing constructs.

## Related Lines of Research

Ray (1996a) notes that many of the chapters appearing in her edited collection represented existing research agendas at the time about social issues which had been refocused for inclusion in the collection to center disenfranchisement. A process view of disenfranchisement, then, is useful because it highlights commonalities across a wide range of prior work that have not necessarily been noticed before. This suggests that both traditional interpersonal, family, and health communication scholarship as well as current and future arcs of CIFC scholarship could be augmented by a formal articulation of TCD and its properties. To create pathways for understanding how TCD fits within and could augment existing lines of traditional IFC research, and to differentiate CD from similar concepts, I next overview similarities and differences between these related lines of research and TCD. A summary of the comparisons drawn in this section is presented in Table 1.

### Marginalization Perspectives and Estrangement

Many programs of communication research are foregrounded by a locus of distancing, including many of those pertaining to marginalization, alienation, and estrangement (Scharp & Dorrance Hall, 2017). Although these programs of research differ in their topical foci, they are united by a locus of exclusion. Among other ways, CD differs from these areas of research as CD instead operates from a locus of disempowerment, assuming rather that communication constitutes disenfranchisement – not that "the disenfranchised" are a distinct group.

**Marginalization as Difference and Exclusion.** A first related line of research is to that of marginalization, divided here to differentiate conceptualizations of the construct: (a) marginalization as difference and exclusion, and (b) marginalization as social identity.

Marginalization presumes a locus of (or is a framework suited to explain the process of) *social exclusion* (i.e., outcasting, rejection, ignoring, ostracizing, bullying; Dorrance Hall, 2017). Within IFC scholarship specifically, *marginalization* typically refers to the ways in which individuals can be pushed to the margins of their families or groups, for example, through communicative behaviors which are intended to promote distancing and estrangement (Scharp, 2019). Marginalization is theorized to result from an evaluation (e.g., disapproval) about some aspect of those individuals and communities (e.g., areas of difference; Dorrance Hall, 2017). Specifically, Dorrance Hall (2017) argues that marginalization results from and/or represents a mix of dimensions of *similarity/difference* (e.g., marginalized family members are often different from their families), *inclusion/exclusion* (e.g., marginalized family members may be more or less connected to their families), and *approval/disapproval* (e.g., marginalized family members are negatively evaluated by their families). While a process view of marginalization is implicit in Dorrance Hall's (2017) work, a formal process theory has not been articulated.

CD is connected to this view of marginalization as individuals who are marginalized because they are excluded, disconnected from important others, and/or disapproved of (Dorrance Hall, 2017) are also often disenfranchised. However, TCD also presumes a locus of (or is a framework suited to explain the process of) *disempowerment* (i.e., through the denial or contestation of one's agency, credibility/legitimacy, rights and privileges, etc.) through sanctioned knowledge claims which hampers a person's meaningful participation in society, and offers a larger process view which accounts for changing operations of power over time. Further, CD often involves contexts in which an individual's "differences" are the site of contestation. For example, Hintz and Brown (2020) examined how childfree women who express desires not to have children to others often experience these communicated contestations (e.g., "You'll change your mind someday and have children") which function to deny the childfree person's different parental status. Women with COPCs who complain of severe menstrual pain and who are told that such pain is normal represent another example of this phenomenon (Denny, 2009). Such an interaction is disenfranchising insofar as the contestation of abnormality requires the reinterpretation of a patient's symptoms through available regimes of truth and the conclusion that such symptoms must be fabricated or exaggerated for some secondary gain. In sum, this view posits that marginalization is the vehicle by and through which the social exclusion of individuals or communities occurs, while TCD instead asserts that disenfranchisement is the process by which individuals, communities, and groups are disempowered through talk.

**Table 1.** Overview of Related Lines of Research.

| **Line of Research** | **Connection to CD** | **How Extended by CD** |
|---|---|---|
| **Marginalization as Difference and Exclusion** | • Marginalized individuals (i.e., individuals excluded along loci of exclusion, disconnection, and disapproval) are also often disenfranchised. | • TCD operates from a locus of disempowerment, not social exclusion.<br>• TCD is a larger process theory which accounts for changing operations of power over time.<br>• CD sometimes involves the *denial* of one's difference. |
| **Marginalization as Social Identity** | • Individuals experiencing disenfranchisement may occupy marginalized social identities/identity categories. | • Individuals need not be marginalized first to be disenfranchised later, because TCD is constitutive – the "disenfranchised" are not a defined group but rather are constituted as such through talk.<br>• TCD operates from a locus of disempowerment, not social exclusion. |
| **Estrangement** | • Individuals experiencing disenfranchisement may also be estranged from close others. | • TCD operates from a locus of disempowerment, not social exclusion.<br>• Estrangement typically refers to family relationships, CD is experienced across many relationship types. |
| **Hurtful Communication** | • CD can involve talk which causes emotional hurt. | • This literature lacks a larger "macro" focus (e.g., the role of discourses) and does not have a process focus.<br>• Centers individual relationships without also examining the contexts in which relationships are embedded. |
| **(Dis)confirmation** | • Disconfirming messages are a component of the hurtful talk that shapes the process of CD.<br>• Disconfirmation also has an implied process – it looks at how messages support and/or challenge projected identities. | • Disconfirmation refers to the specific communicative behaviors, while TCD additionally refers to the overall process in which such behaviors become embedded.<br>• Lacks a larger macro focus and connections to discourse and power. |
| **Attribution** | • Attributions are made both about the targets of and the producers of disenfranchising talk (by the other party). | • Often lacks a larger macro focus and connections to discourse and power. |
| **Uncertainty Perspectives** | • Uncertainty may be a catalyst for or make possible CD. | • Remains concerned primarily with uncertainty management and behavioral responses to uncertainty.<br>• Lacks connections between micro and macro levels (e.g., poor funding, inadequate training, poor attitudes toward patients) that create the conditions for uncertainty and precede interactions in which uncertainty is managed. |

**Table 1 (Continued)**

| | | |
|---|---|---|
| **Stigma Perspectives** | - SMC (Meisenbach, 2010): Stigma may either cause, result from, or be worsened by disenfranchising talk.<br>- SC (Smith, 2007): Individuals experiencing CD may also be marked, labeled, assigned responsibility for the disenfranchisement. | - SC is post-positivist and SMC is primarily interpretive. TCD offers a critical take by highlighting and theorizing power in ways that stigma scholars outside of the field (e.g., SFC) have done.<br>- SC: CD often means that others *contest* a potentially stigmatizing mark or label (i.e., being diagnosed with a COPC). However, TCD views communication as constituting disenfranchisement, thus the idea of marks and labels are excessively deterministic.<br>- SMC: Discourses not only affect constructions of stigma, but are hierarchical, interlocking, and (through power) they make possible the conditions for stigma to occur in the first place.<br>- SFC: TCD takes a communicative approach to understanding stigma and power. |
| **Disenfranchised Grief** | - Disenfranchised grief (Doka, 1999) refers to the denial of a "right to grieve" caused by a lack of social recognition and support for that loss. | - Describes the operations of TCD in a particular context, but TCD will offer a more general heuristic process of disenfranchisement and centralize the role of communication in disenfranchisement. |

**Marginalization as Social Identity.** A second view of marginalization is that of marginalization as a (or some combination of a) social identity(ies) or identity category(ies). CD is connected to this view, as individuals experiencing disenfranchisement may occupy marginalized social identity categories. However, individuals need not first be marginalized to be disenfranchised later because TCD assumes that communication constitutes disenfranchisement. A view of marginalization as a social identity, from a CD perspective, is excessively deterministic, as all of us are only temporarily enfranchised and could become disenfranchised at any point (Ray, 1996a), whereas we cannot say that we are only temporarily non-marginalized. Thus, disenfranchisement can result from a person's marginalized status. For example, Ray (1996a) describes marginalization in terms of "vulnerable populations" who are either born vulnerable or become vulnerable by circumstance. However, vulnerability to disenfranchisement and marginalization are not necessarily synonymous. For instance, it is possible to be vulnerable to becoming disenfranchised without first being marginalized. Educated affluent and middle-class White women who become ill with a poorly understood chronic pain condition for example, may experience CD through interactions with family members, medical providers, and romantic partners. Yet, these women are not typically considered a marginalized population.

The utility of this shift in thinking enables us to consider intersections of "marked" categories of identity which are typically viewed as being marginalized, and "unmarked" categories of identity which are not (Suter, 2018; Yep, 2010). Although much debate exists as to whether non-multiply marginalized groups can be the considered intersectional, Zack (2005) has argued that all women are multiply oppressed, citing physical ableness, among others, as additional sites of oppression. Zack continues to argue that women (inherently occupying a socially disadvantaged position) who are privileged in some ways (e.g., I am White) are not immune to intersections with other disadvantaged positions (e.g., restrictions on bodily ability), and thus should not be excluded from this line of inquiry (2005). Furthermore, recent critical scholarship has underscored a need for "thicker" intersectional research, seeking to include categories such as bodily functionality as an important element of identity (Yep, 2016).

Relational dialectics theory 2.0. (Baxter, 2011), one of the few IFC theories which deals explicitly with marginalization, views marginalization as resulting from an individual, group, or feature of one's identity being labeled as "non-normative, off-center, unnatural, and somehow deviant" accomplished through the voicing of a more dominant discourse (p. 123). A similar view was espoused in the introduction to the recent special issue of the *Journal of Family Communication* (Turner, 2019) dedicated to "families on the margins," which sought to "bring those on the margins to the center" through research and activism (p. 175). This view of families as being "on the margins" seems to embody a determinism that is antithetical to the constitutive view of CD. As opposed to viewing populations of interest in critical scholarship only in terms of the perceived "margins" of increasing sociodemographic diversity and form (e.g., the move over time from heterosexual marital communication to communication in non-monogamous and polyamorous relationships), we can also examine the ways in which individuals not necessarily belonging to a marginalized group may experience disenfranchisement. The marginalized can experience CD but it is not necessary that a person first be marginalized for this to occur because, unlike the marginalized, the disenfranchised are not presumed to be inherently different.

**Estrangement.** Estrangement is one form of family distancing (Scharp, 2019), typically discussed in parent-child relationships and occurring when "at least one family member…no longer wants to have a relationship and/or seeks to limit the interaction…because of a negative relationship" (Scharp & Dorrance Hall, 2019, p. 35). For example, Scharp (2019) articulated a grounded theory of family distancing which outlines mechanisms by and through which adult children estrange themselves from their parents (e.g., legal action). CD is related to estrangement, as those individuals experiencing disenfranchisement may be estranged from the important others who produce such talk. Traditionally interpretive in nature, Scharp and Dorrance Hall (2019) note multiple critical future directions for estrangement research to understand how individuals in relationships "resist the stigma and *disenfranchisement* that often accompany their [estrangement] experiences" (p. 38, emphasis added). However, TCD extends beyond only family relationships to implicate interactions with a variety of important specific and generalized others in medical, mediated, private, and workplace contexts (Ray, 1996a).

### Hurtful Communication

While CD may involve talk which causes emotional hurt, the literature on hurtful communication lacks a larger macro focus (aside from some discussions of habituation) and does not have a process focus. *Hurtful communication*, defined simply as the emotional hurt caused by an interaction (Vangelisti & Young, 2000), represents another line of IFC scholarship which is potentially related to TCD. Communication is thought to be most hurtful when it is perceived to be intentional, represents a pattern of similar behavior, and is perceived to be uncontrollable (Bernhold et al., 2018; Young & Bippus, 2001) and can result in relational distancing for friends or romantic partners (McLaren & Solomon, 2008). Attempts to model responses to hurtful communication include propositions for: (a) a *sensitization model*, where the recipient of a hurtful message becomes increasingly sensitive to hurt which feels increasingly intense over time (Vangelisti & Hample, 2010) and (b) a *habituation model*, which suggests that individuals become numb to future hurtful communication (Vangelisti et al., 2007).

It is certainly plausible that disenfranchising interactions cause emotional hurt. However, the degree to which hurtful communication contributes to disenfranchisement is unknown. Further, most research on hurtful communication examines hurtful messages or interactions in relationships with friends, family members, or romantic partners without analyzing the larger macro-contexts in which those relationships are embedded which this dissertation explores. Research centering “hurtful” communication in patient-provider contexts is scant (e.g., “disrespectful” messages received by obese women from providers; Entwistle, 2008). Such scholarship instead tends to focus on communication which does not adhere to tenets of patient-centeredness or other specific keywords such as invalidation. Thus, to understand how patients respond to such talk, exploring the emotional effects of CD could prove fruitful.

### (Dis)confirmation

Another IFC framework with ties to CD is confirmation theory, specifically the notion of disconfirming communication. Disconfirming messages are likely a component of the hurtful talk that shapes the process of CD. Disconfirmation also has an implied process – it looks at how messages support and/or challenge individuals' projected identities. However, disconfirmation refers to specific communicative behaviors, and TCD additionally refers to the overall process in which such behaviors become embedded. Hence, confirmation literature lacks a larger macro focus and connections to discourse and power; TCD may complement the literature in this sense.

Confirmation theory posits that, as individuals communicate, they require validation to sustain personal growth (Buber, 1965). *Confirmation* itself refers to the degree to which a message validates that the other person is respectable and valuable (i.e., positive regard), while *disconfirmation* conversely refers to messages which convey rejection and dismissal (i.e., negative regard; Dailey, 2006, p. 436). What is being confirmed or not is a person's *self-definition* as conveyed within and through communication, comprised of numerous aspects of oneself such as attitudes, beliefs, and feelings (Dailey, 2006). Confirming responses make a person feel good about themselves, while disconfirming responses make a person feel badly about themselves. In healthcare contexts, a confirming response is said to be achieved when "a patient receives external evidence that either strengthens their positive self-assessment or weakens their negative self-assessment" (Stenberg et al., 2012, p. 168). Disconfirming responses therefore may seem warm or responsive but actually be disconfirming. For instance, a student who is preparing for a highly consequential examination may say, "I'm anxious about starting my exams next week" and receive a response from a friend saying, "You'll be fine." At face value, such a response seems confirming. However, this response may be heard as disconfirming because it implies that the person need not be experiencing the anxiety they feel. Opportunities to manage feelings of anxiety through talk are also removed, a process which is theorized to hinder personal development (Dailey, 2006).

In a typology of the confirmation-disconfirmation message continuum created by Sieburg (1985), confirming messages are those which recognize, acknowledge, and endorse the other, while disconfirming messages are those which convey indifference, disqualification, and imperviousness. Given that CD in health contexts necessarily includes disconfirming messages, these three types are explored in further depth. *Indifference* embodies total disconfirmation. People who experience indifference may be interrupted, avoided, or ignored (Sieburg, 1985). *Disqualification* embodies partial disconfirmation (Sieburg, 1973). People who are disqualified may experience behaviors such as question evasion or changing the subject which make them feel neither heard nor important. *Imperviousness* also embodies partial disconfirmation to a lesser degree, as the specific communicative attempts made are recognized and built upon by the receiver. People who experience imperviousness have their experiences and feelings denied, analyzed, and/or misinterpreted by the listener (whose interpretations are added to the meaning).

Disconfirming messages are likely a component of the hurtful talk that shapes the process of CD. In healthcare interactions, disconfirming responses go by a variety of terms (e.g., invalidation, dismissal, disbelief, etc.) but most often characterize imperviousness (experiences of denial and discreditation which address communication attempts by patients; Sieburg, 1985). One of these terms used most commonly, *invalidation*, refers to a complex and multifaceted structure of communicative behaviors (Kool et al., 2009). *Invalidation* is defined as the "cognitive, affective, and behavioral responses of others that are perceived as denying, lecturing, overprotecting, not supporting, and not acknowledging with respect to the condition of the patient" which then may act to "deprive the patient [of] help" (Kool et al., 2011, p. 63). Invalidation refers to the specific communicative behaviors, and disenfranchisement refers to the overall process in which such behaviors become embedded. For example, disenfranchising psychological explanations for pain were experienced so often by women with autoimmune disorders in the early 2000s, poorly understood at the time, that they were more likely to be correctly diagnosed by the psychologists to whom they were referred than by the providers who made the referrals (Dusenbery, 2018).

Instances of invalidating responses from medical providers experienced by pain patients have also been linked to heightened reports of pain interference and increased negative affect (Edlund et al., 2017). This definition of invalidation closely aligns with Sieburg's (1985) conceptualization of imperviousness. For instance, a patient with fibromyalgia, a poorly understood chronic pain condition, remarked that she was told by her provider that, "'Oh nothing's wrong. You're depressed.' I kept getting, 'You're depressed. You're depressed.' I was like, 'No'" (Armentor, 2017, p. 467). In another example, a female patient reporting symptoms of endometriosis, a chronic pelvic pain condition worsened by hormonal fluctuations associated with menstruation, reported that she was told by a provider that "it's what girls go through, it's what happens, it's period pain" (Denny, 2009, p. 989). These examples describe disconfirming messages which discredit and reinterpret complaints about pain as being normative or as resulting from psychological symptoms (a face threatening conversation which often results in denial by the patient; Burbaum et al., 2010).

Although evidence does not exist to directly link disconfirming responses to disenfranchisement, knowledge of the potential for these disconfirming interactions with providers has been found to discourage help-seeking behaviors by women with vulvodynia (Donaldson & Meana, 2011). Further, in another study of patients with back and neck pain, "getting confirmation" was the most important factor across the entire diagnostic and treatment period, even more so than recovering or being "cured" from the injury or illness causing the pain

(Stenberg et al., 2012). Getting confirmation for these patients meant, in part, being taken seriously and not being “brushed aside” (p. 165). These patients who felt that interactions with their physiotherapist had been disconfirming encountered difficulty creating a plan to move forward with recovery and often lost motivation to do so (Stenberg et al., 2012).

### Attribution

CD is connected to attribution theory because disenfranchising talk involves attributions made both about the targets of and producers of such talk. Although some attribution scholarship has examined the macro-social context of attributions (cf. linking attribution to intergroup processes, Hewstone, 1989; linking attributions and accounts, Orbuch, 1997; attribution as a means of constructing reality with implications for power, Buttny, 1985, 1993; Gergen, 1985), much of the U.S. attribution literature (e.g., Heider, 1958; Weiner,1972) has centered attributional micro-processes (e.g., models of attributional dimensions, attributional biases, etc.) without much attention to larger macro-social contexts nor connections to discourse and power. To better understand the motivations for CD and motivations for interpreting disenfranchising talk from others, attribution theory should be discussed.

Attribution theory posits that *attributions* are inferences are made about others in an effort to interpret their actions or determine the causes of an event or behavior (Heider, 1958; Weiner, 1972). Heider (1958) first argued that we tend to attribute the behavior of others to either external (situational) causes or internal (dispositional) causes. Weiner (1986) then expanded upon these initial conceptions to produce a general attributional model comprised of several phases, where internal and external causes became renamed as *antecedent conditions*. External (situational) causes became renamed as *environmental factors,* which included specific information about the situation and social norms. Internal (dispositional) causes became renamed *personal factors*, which included the causal schemas employed by individuals, *attributional biases* (e.g., self-serving bias, where we attribute successes to ourselves but failures to other factors), and the *fundamental attribution error* (i.e., where we attribute the failures of others to individual characteristics and successes to other situational factors).

As opposed to only including a limited number of *perceived causes* for the behavior or event, a multitude of perceived causes were then articulated, constituting the next phase of the model. Perceived causes of issues in health and illness specifically included heredity, personality, family history, life stress, fatigue, good/poor habits, weather, exposure to germs, and luck (Weiner, 1986). Next, a triad of *causal dimensions* are offered, which connect attributions to their potential to motivate behavior. This triad includes dimensions of: (a) *stability*, whether a cause is fixed or varies over time; (b) *locus*, whether a cause is internal or external to the individual, and (c) *controllability*, whether the cause is within a person's control. Psychological outcomes of this attributional process include the expectations held by a person for succeeding, self-efficacy, and affect. The behavioral consequences which follow include changes in one's level of effort, achievement, decision-making, and persistence (Weiner, 1986).

Although attribution theory is inadequate to explain the entire process of CD, we might consider attributions a catalyst for CD (both in terms of motivations for producing disenfranchising messages and the attributions made about those messages which serve to further disenfranchise the recipient). In particular, attributions do appear in several capacities when considering CD. Attributions are made both about the targets of and the producers of disenfranchising talk (by the other party). For instance, studies by Thompson and colleagues (e.g., Thompson & Duerringer, 2020) described earlier seek to understand which attributions are made by the family members of patients who question health complaints, and which schemas are employed to interpret those complaints. Attributions are made in knowledge claims about patients. For example, a patient who reports pain and is denied pain medication may have had such pain attributed to their being labeled a “drug-seeker,” the consequences of which often include being unable to access future pain care and treatment (Campaign to End Chronic Pain in Women [CECPW], 2010). Several of the disconfirming interactions described in the previous section, where attributions were made about symptoms reported by female patients as being psychological in origin or a normal feature of female anatomy (and therefore an overreaction), are also examples of attributions in action. Attributions made about patients with fibromyalgia may result from skepticism about the validity of complaints of pain in the absence of visible physical symptoms (i.e., “evidence” of the “real pain” which would render a patient eligible to receive help; Kool et al., 2011). Thus, patients lacking such evidence in the presentation of physical symptoms experience isolation, stigma, and emotional distress following statements which express disbelief (Newton et al., 2013).

Attributions about the causes of a patient’s own symptoms may also be affected by disenfranchising talk. For instance, scholars examining vulvodynia (e.g., Jodoin et al., 2008) and fibromyalgia (e.g., Kool et al., 2011) have examined how self-attributions for pain and partner attributions for pain affect health and relational outcomes for both patient and partner. Women suffering from conditions like vulvodynia undertake an often-fruitless personal search for “causal attributions” for unexplainable pain upon its onset, and this period of searching is a known barrier to diagnosis and treatment (Donaldson & Meana, 2011, p. 817). Many poorly understood pain conditions such as endometriosis could likely be described as unstable (i.e., fluctuating over time) with an external locus of control (Denny, 2009). Thus, after disconfirming interactions, these women may causally attribute pain to their own actions (e.g., attributing pain to a psychological disorder, an overreaction to something normal, or a personal mistake or shortcoming as communicated to them by others through knowledge claims; Shallcross et al., 2018) and consequently withdraw and become isolated (Newton et al., 2013). This represents findings about attributions made by women generally, where women are more likely than men to attribute failings to internal factors (Scott, 1997). However, given that such pain is often considered by the patient to be unstable, internally caused, and out of one's immediate control, possibilities for meaningful action are thereby removed. The chronic pelvic pain community refers to this phenomenon as "the breaking of optimism" (Tight Lipped, 2020). Examining attributions present in the process of CD can help us to understand motivations for considering patient reports of pain and for patients in interpreting and later acting (or not) consequently.

### Uncertainty Perspectives

*Uncertainty* is a multidimensional construct (Kuang, 2018) which occurs 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). Perceptions of uncertainty are then an inherent part of human communication, as communication is conceptualized as the vehicle through which uncertainty is managed (Brashers, 2001). Many approaches to the study of uncertainty in communication exist within a variety of theoretical frameworks (cf., Afifi & Weiner, 2004; Babrow, 2001; Berger & Calabrese, 1975; Brashers, 2001; Solomon et al., 2016). Many of these frameworks would prove useful for examining the functions of CD, as uncertainty (e.g., uncertainties about health complaints) is likely a catalyst for CD. However, despite some exceptions which advocate for interpretive approaches to uncertainty (e.g., Babrow et al., 2006; Goldsmith, 2001) uncertainty perspectives remain primarily concerned with information management and behavioral responses to uncertainty. Thus, the extant literature lacks connections between micro and macro levels to understand conditions which create uncertainty.

For example, we could examine what Babrow (2001) refers to as *epistemological uncertainty* within problematic integration theory, meaning uncertainty about what it means to know something. Epistemological uncertainty may occur, for example, when individuals encountering difficulty integrating new beliefs (e.g., my family member is fabricating or exaggerating) with existing beliefs (e.g., my family member is a trustworthy person) experience uncertainty about the sufficiency and validity of information and encounter difficulty organizing it (p. 558). Again, a process view of CD is useful for highlighting connections across multiple concepts in ways which have not been discussed before. Women with vulvodynia sometimes reported that treatment by family members, friends, and romantic partners in particular worsened after providers offered disenfranchising explanations for pain (Hintz, 2019a). For instance, after one woman was told by a provider that there was no visible cause for her pain (e.g., infection, sores, irritation), her partner began to accuse her of lacking sexual interest in him. More specifically, then, epistemological uncertainty may motivate a change in what it means to know whether a person is sick (formerly through knowledge claims produced by that person; Thompson & Duerringer, 2020) in light of evidence sought out from a perceivably trustworthy source which casts doubt. However, another view of uncertainty has developed which addresses the unique circumstances of health contexts.

*Illness uncertainty* (cf., Clayton et al., 2018; Kuang, 2018; Kuang & Wilson, 2017; Mishel, 1990) relates to the inability of a person to "determine the meaning of illness-related events" as a result of having a dissatisfactory amount or quality of information about a health issue (Mishel, 1988, p. 225). The tripartite model of illness uncertainty includes: (a) *medical*, uncertainty associated with the diagnosis, prognosis, and treatment of an illness or symptoms; (b) *social*, uncertainty about private and professional relationships; and (c) *personal*, uncertainty associated with identities, roles, financial standing, and future plans (Brashers et al., 2003). For instance, adolescents and young adults (AYA) with cancer may experience medical uncertainty about how curable a specific cancer is, personal uncertainty about the ability to continue to work or afford treatment, and social uncertainty about the impact of cancer on their partner or family members (Dean & Davidson, 2018; Donovan et al., 2015).

Uncertainty is another key factor which makes disenfranchising communication possible for poorly understood chronic pain conditions. Poor funding to research the origins of and treatments for chronic pain, coupled with inadequate medical training and limited general social awareness of these conditions create the "perfect storm" of uncertainty (CECPW, 2010, p. 13). This example illustrates the potential utility of exploring micro and macro linkages present in uncertainty in illness contexts. Feelings of uncertainty are greater when limited sensemaking resources (e.g., support, information, education) are unavailable (Mishel, 1988). Thus, women suffering from poorly understood pain conditions experience illness uncertainty from the onset of symptoms through diagnosis and treatment, as even if a diagnosis can be reached, treatment options and the underlying etiology of the condition may remain unknown (CECPW, 2010).

Groopman (2008) writes that medical students are increasingly trained to rely on diagnostic algorithms as a means of cohering to standards of evidence-based medicine. Patients not fitting into these diagnostic schemas may have symptoms normalized and be sent home (Hartman et al., 2009), may be told to seek psychiatric care, perpetuating the stereotype of the "crazy, lazy, illness-fixed or weak woman" (Werner et al., 2004, p. 1035), or may be diagnosed with "medically unexplained symptoms" (MUS) often with the presumption that symptoms are really "psychologically explained" (Newton et al., 2013). This represents a reliance primarily on the *biomedical* frame as opposed to the *biopsychosocial* frame (Engel, 1977), where providers emphasize "lack of objective evidence, problematized subjective patient testimony, and manifested feelings of *uncertainty*, doubt and powerlessness" (Rasmussen & Rø, 2018, p. 1, emphasis added). These examples illustrate how uncertainty makes possible disenfranchising talk about poorly understood chronic pain conditions.

### Stigma Perspectives

Stigma is generally considered to be an adverse reaction to some negative evaluation of difference (Link & Phelan, 2001). Three central perspectives on the study of stigma exist and are reviewed: (a) stigma communication model (Smith, 2007), (b) stigma management communication (Meisenbach, 2010), and (c) stigma as a fundamental cause (Hatzenbuehler et al., 2013). Stigma and CD are connected such that stigma may either cause, result from, or be worsened by disenfranchising talk, and individuals who are experiencing disenfranchisement may be marked, labeled, or assigned responsibility for the disenfranchisement. However, existing perspectives are either primarily post-positivist or interpretive, whereas TCD offers a critical take by taking a communicative approach to understanding power and drawing connections to stigma perspectives in other fields. CD also sometimes involves the *contestation* of the stigmatizing mark or label (e.g., having a poorly understood chronic pain condition), and views discourse not only as constructing stigma, but also creating the precedent conditions for stigma to occur.

*Stigma* refers to "an attribute that is deeply discrediting" (Goffman, 1963, p. 3). Uncertainty creates room for stigma, as conditions which are "shrouded in great uncertainty" are more susceptible to stigmatization (CECPW, 2010). For chronic pain patients, stigma manifests in disbelief and skepticism about the presence, severity, and effects of one’s pain and appears in interactions with romantic partners, relatives, friends, and medical providers (Cohen et al., 2011; De Ruddere & Craig, 2016). These experiences are heightened for individuals with poorly understood, contested, or otherwise medically unexplained pain syndromes (Joachim & Acorn, 2000; Slade et al., 2009). Stigmatized pain patients evoke less sympathy (Cohen et al., 2011), are more disliked, and arouse suspicion in the absence of a biological explanation for pain (De Ruddere et al., 2014). Perceptions of stigma also negatively affect patient physical and psychological well-being (Kool et al., 2013). Recent calls within medical chronic pain literature have noted the need for theoretical development in the area of stigma, specifically to understand processes by which perceptions of self-stigma and public stigma are formed and come to affect patient health outcomes (De Ruddere & Craig, 2016). Thus, some discussion of the predominant intradisciplinary and transdisciplinary perspectives on stigma is necessary.

**Stigma Communication Model.** Smith’s (2007) stigma communication model is one theoretical framework with the capacity to respond to this call. Stigma communication posits that individuals first become *marked* as belonging to a stigmatized group, where cues are utilized which “evoke automatic reactions for quick recognition, learning potential, and suggested social response” (p. 468). *Labels* are then ascribed to groups of marked individuals which function to highlight stigma and separate those labeled from those who are not, contributing to depersonalization and the use of stereotypes (Smith, 2007). The connection between marks and labels can be clearly seen in the following example. In a study of women with chronic pelvic pain who experienced disbelief in interactions with general care practitioners (GPs), one interviewed GP remarked that “if women are fat and tearful then there’s likely to be a psychological component” (McGowan et al., 1999, p. 132). Here “fat” and “tearful” are cues which mark the patient and suggest a social response, a label of “psychological” issues. This label sets those patients presumed to be presenting with psychological issues apart from those presenting with verifiable physical illnesses. As was previewed above, stigmatized individuals and groups are often viewed as being *responsible* for the stigma (either through choosing the stigmatized condition or having control over it; Smith, 2007). Such a choice is thought to result from a moral failing or personality issue (Goffman, 1963). For instance, complaints of pain in the absence of some physical evidence (i.e., “proof”) which accounts for pain calls into question the personal integrity of the patient (Newton et al., 2013). Expressions of disbelief by others about reports of pain reinforce stigma and may serve to suggest that pain is fabricated, assigning the responsibility for that pain to the patient.

Smith’s (2007) final attribute of stigma is the idea that the stigmatized group may cause *peril* (i.e., danger or harm) to the larger community and that others must be warned against this peril. These four attributes (i.e., marks, labels, responsibility, and peril) together are theorized to create responses in others and form attitudes about the stigmatized. Such attitudes are then theorized to encourage individuals to act to protect themselves, “the normals,” from the stigmatized and share stigma messages with others (Smith, 2007, p. 469). Our example earlier of a patient being labeled a “drug-seeker” within a medical chart illustrates this point. Relatedly, an infamous chronic pain quotation sees a provider remarking that “women with genital pain often make us feel that we do not know what we are doing” (Binik et al., 2007, p. 141).

One possible source of peril held by patients for providers, then, is the perceived undermining of their authority and knowledgeability. Providers often view patients with chronic pain as attempting to manipulate them during the interaction (Miller et al., 2017). Hahn et al. (1996) argue that female chronic pain patients are often viewed as attempting to procure power or coercion over the physician by reporting subjective “difficult” symptoms. This is theorized to occur as a contest of authority (Salmon, 2007, p. 246), when patients assert their direct illness account as being infallible in contrast to a provider’s indirect, fallible explanation (Peters et al., 1998). This is referred to as the “chasm between medical and personal discourses” (Thompson & Duerringer, 2020, p. 4). Thus, women with chronic pain must often undertake communication work (Donovan, 2019; Hintz & Scott, 2020) by attempting to avoid looking “too smart,” or “too strong” as so to threaten the provider (Werner & Malterud, 2003). Women with chronic pain who incite these feelings of peril in providers must overcome them to receive adequate care.

**Stigma Management Communication.** Meisenbach’s (2010) stigma management communication (SMC) model is another framework with the capacity to respond to this call. In response to Smith’s (2007) stigma communication model, Meisenbach (2010) addresses a number of additional strategies employed by recipients of stigmatized messages (other than merely acceptance). Specifically, according to SMC, approaching stigma from a communicative perspective means “focusing on how individuals encounter and discursively react to perceived stigmas” (Meisenbach, 2010, p. 269). In particular, the SMC model first asserts that stigmas (e.g., physical, social, moral) are *discursively constructed*, where perceptions about stigmas are created through talk. These perceptions can be held only by publics, only by stigmatized individuals, or by both parties. The SMC model also asserts that stigmas affect and are affected by discourses and material conditions and change over time. *Materiality* or the *material conditions* include those which are related to one’s body and the physical environment (e.g., a disability/condition). Next, the SMC model also asserts that stigmas vary in *breadth*, referring to the scope of the stigma, and *depth*, referring to the intensity of the stigma and the closeness of the association between the stigma and the context or identity.

The SMC model builds upon Smith's (2007) contention that a message is stigmatizing when it marks an individual, labels them, assigns responsibility for the mark, and associates the mark with a level of danger. The SMC model adds some consideration of the individual's internal attitude toward the applicability of a stigma and the degree to which individuals desire to uphold or change perceptions of a stigma. These attitudes are then theorized to influence selections of stigma management strategies (e.g., accepting, avoiding) and the outcomes (e.g., health, self-esteem) which result (Meisenbach, 2010). Four appraisal combinations are possible within SMC. The individual can either: (a) accept public perception of a stigma and that it applies to them, resulting in acceptance stigma management strategies (e.g., passivity, silence, isolation); (b) accept public perception of a stigma and denying that it applies to the self, resulting in avoidance stigma management strategies (e.g., avoidance of stigma situations, hiding stigma attribute); (c) challenge public perception of a stigma and accept that it applies to them, resulting in the evasion of responsibility for the stigma or attempts to reduce the offensiveness of the stigma; or (d) challenge public perception of a stigma and deny that it applies to the self, resulting in denial or ignoring behaviors. Several studies have found similar clusters using in-depth interviews on health topics (e.g., Noltensmeyer & Meisenbach, 2016; O'Shay-Wallace, 2019). The effects of perceptions of internalized (self) stigma (Waugh et al., 2014) and public stigma (De Ruddere & Craig, 2016) are well documented within chronic pain populations. Such a distinction between the acceptance and challenging of public and self-stigmas may explain why some members of the same population, affected by the same stigmas, may experience negative effects while others do not (De Rudderre & Craig, 2016).

**Stigma as a Fundamental Cause.** Conceptualizations of stigma in other disciplines share similarities with and differ from the process described here (e.g., Link & Phelan, 2001) and should be discussed. Link and Phelan's (2001) seminal publication about the relationship between stigma and health outcomes proposes that individuals and groups are labeled, stereotyped, separated (much like Smith's (2007) model), lose status and experience discrimination as a function of power within interactions. Importantly, this definition brings to bear the idea of *discrimination*, which is theorized to occur at both the individual level (i.e., through inequitable treatment as a result of stigmatized group membership) and at a structural level (i.e., through the "societal conditions that constrain an individual's opportunities, resources, and well-being;" Hatzenbuehler et al., 2013, p. 813). Discussions of stigma must include discrimination, but stigma extends beyond discrimination to include how individuals and groups are labeled and stereotyped (Phelan et al., 2008).

Stigma is considered to be a *fundamental cause* of health inequities (between the stigmatized and non-stigmatized), meaning that it remains associated with such inequalities over time despite improvements which may otherwise have rectified disparities (e.g., disease changes, reductions in risk factors, implemented health interventions) through the evolution of new mechanisms which reproduce them (Hatzenbuehler et al., 2013). For instance, inequalities between those with and without mental illness were first maintained through the mechanism of institutionalization, and then later through deinstitutionalization via the mechanism of withholding access to a person's own money and other resources unless prescription medications were taken as ordered (Monahan, 2008). Stigma is complex, as it is theorized to influence multiple outcomes through multiple mechanisms and "disrupts or inhibits access to multiple resources –structural, interpersonal, and psychological – that could otherwise be used to avoid or minimize poor health" (p. 819). Outcomes of stigma include a reduction in these available resources, isolation (due to fear of the discovery of the stigma and judgement; Pachankis, 2007), a plethora of psychological and behavioral outcomes, and stress (Hatzenbuehler et al., 2013).

**Comparisons Between Stigma and Communicative Disenfranchisement.** These perspectives on stigma suggest ways in which stigma may be intimately linked (e.g., Mendible, 2019) with disenfranchisement as outlined above. Meisenbach (2010) proposes that stigma is discursively constructed, meaning that talk can produce stigma (CECPW, 2010). For instance, Thompson and Duerringer (2020) describe how "processes of power…reinforce dominant discourses of health and serve to further marginalize and stigmatize some of the most vulnerably ill" (p. 2). Therefore, we can connect the idea that stigma exists on public/private axes to the public and private sphere bidirectionality described by Suter (2016). The notion that perceptions of stigma are mutually created through talk by multiple parties connects to the argument by Mokros and Deetz (1996) about CD being mutually determined. However, several important differences are also present.

Stigma results from social forces (e.g., attitudes, cultural taboos, etc.) constituting a "negative response to difference" by one group about another group (Meisenbach, 2010, p. 270), which can include discriminatory practices (Hatzenbuehler et al., 2013). In the disenfranchisement literature, stigma is typically described as either being the cause for, resulting from, or being worsened by disenfranchising talk. For instance, Welch Cline and McKenzie (1996) describe the disenfranchisement of women with HIV/AIDS as consisting of specific communicative behaviors such as "misdiagnoses, delayed diagnoses, inadequate treatment" which are conceptualized as being "rooted in" the stigma of HIV/AIDS and as being "magnified" in interactions with female patients (e.g., Welch Cline & McKenzie, 1996, p. 367). Differences in the process of CD in relation to stigma, then, can be viewed as including not only examining how discourses affect constructions of stigma, but how those discourses are hierarchical, how they interlock, and how (through power) they make possible the conditions for stigma to occur in the first place (Foucault, 1972; Moore & Manning, 2019).

Smith's (2007) stigma communication model detailed the process by which stigma unfolds communicatively. Meisenbach's SMC (2010) model built upon this earlier work to encourage us to understand how individuals perceive and respond to stigma communication. Further, SMC (Meisenbach, 2010) notes the need to integrate critical perspectives to better understand lived experiences of stigma and the role of power in shaping interactions in which stigma communication occurs. However, this retains the locus of social exclusion noted in the earlier discussion about marginalization. On the other hand, disenfranchisement represents the more formalized processes (which are accomplished communicatively) through which individuals experience communicated denial or contestation. Dumit (2006) refers to this experience of denial and contestation in the context of poorly understood pain conditions as "illness[es] you have to fight to get" (p. 578). Examining disenfranchisement also enables some understanding of the ways in which the disenfranchised may be enfranchised again. Thus, stigma may certainly be a part of the process of CD, but it is possible to be disenfranchised without first being stigmatized. For example, women with chronic overlapping pain conditions may actually attempt to label or mark themselves sick and experience the contestation of the ascription of this label. Despite these connections, the process of CD differs in the capacities described above.

**Disenfranchised Grief.** *Disenfranchised grief* (herein DG; Doka, 1999), refers to "grief experienced by those who incur a loss that is not, or cannot be, openly acknowledged, publicly mourned or socially supported" (p. 37). For instance, the grief and loss experienced by medical providers (e.g., closing a private practice and beginning work at a large medical complex) is often disenfranchised due to, for example, high-stress working environments which limit the collegial exchange of experiences, and concerns about career implications if they are perceived as complaining (Lathrop, 2017). Various aspects of grief can be disenfranchised, including *bereavement*, operationalized through *structural elements* of relationships, losses, and grievers; *grief* (reactions to losses, where individuals and/or their expressions of emotions and symptoms "are not recognized, legitimated, or supported by society;" Corr, 1999, p. 8); *mourning* (a means of coping with loss and with grief, where those means are not understood or socially supported; Corr, 1999). More generally, then, individuals, relationships, identities, experiences, and our reactions to those experiences may be disenfranchised. These are expanded upon below.

Particularly interested in disenfranchisement related to grief resulting from a loss, Doka (1999) asserts that individuals may experience DG when: (a) a given *relationship is not recognized* (e.g., when a loss is extra-familial such as a lover, stepparent, caregiver, or coworker), (b) when the *loss itself is not recognized* (e.g., the death of a pet, individuals who are institutionalized or incarcerated), (c) when *the griever is not recognized* (e.g., very young and very old individuals are viewed as lacking the capacity to comprehend death), or (d) when *the death itself is disenfranchising* (e.g., the stigma caused by deaths from suicide, drug overdose, and drunk driving prevents the meaningful social acknowledgement of the loss). CD may occur, then, in a variety of interpersonal, familial, and health contexts. Familial forms may be questioned (e.g., childfree families; Hintz & Brown, 2020), the severity and effect(s) of the experience may be questioned, individuals may be told that they inherently cannot experience what they have experienced (e.g., due to racial and gender biases in pain management; Hoffman et al., 2016), and the nature of the target of the disenfranchisement itself may be questioned (e.g., the existence and nature of COPCs is contested; Maixner et al., 2016). Imbued within these potential motivators for disenfranchisement are assessments about what is or is not a “real” family, relationship, and experience and whose experiences are counted as “real.” Such ideas are informed by salient cultural discourses which dictate the means by and through which such assessments and competing claims about reality are to be adjudicated.

Further, *the way that an individual grieves* may not be validated (e.g., women are expected to be more emotive than men) and thus contribute to DG. Hence ideas about what is “appropriate” grieving are informed by cultural norms and conventions which prescribe individual behavior. The *outcomes of grieving* can also be disenfranchised (Corr, 2002) when others respond negatively to mourners for not embodying cultural prescriptions about overcoming loss (e.g., when mourners “take too long with their mourning, fail to return to ‘normal’ or move on, persistently hurt, are slow to take up new relationships, or maintain a relationship with the deceased;” Attig, 2004, p. 200). In the context of this dissertation, a robust body of literature explores how female patients with COPCs are viewed as failing to achieve the “sick role,” where one’s suffering is socially recognized and legitimated, which often requires a doctor’s affirmative diagnosis of a biological explanation for the illness (Glenton, 2003). Reckoning with the “sick role,” female patients who strive for medical diagnoses to legitimate their suffering are sanctioned when visible and consistent symptoms are unable to be ascertained, psychological diagnoses instead offered which delegitimate suffering, subsequent attempts to achieve a diagnosis (which would legitimate the illness) are in turn interpreted as further evidence for the psychological diagnosis, and any benefits received (e.g., leave from work, pain medications) become interpreted as motivations for reporting symptoms to begin with (Glenton, 2003). Female patients with COPCs managing the potential outcomes of living with COPCs (e.g., reduced capacity to work) may find that those outcomes are disenfranchised (e.g., that they are trying to receive disability benefits).

These contributors to DG result in the denial of a “right to grieve” (Doka, 2002, p. 5), which Attig (2004) defines as “entitlements…to non-interference from others” in the pursuit of actions or experiences (p. 197). Individuals retain agency regarding whether to pursue particular entitlements (like “ticketholders”), as one is not required to exercise a right. However, like tickets when they are used, others must honor the exercise of particular rights without interfering or prohibiting its use (Attig, 2004). The right to grieve, then, “entitles a bereaved person to grieve in a manner and when [they] need or choose to, free of interference from others” (Attig, 2004, p. 198) and disenfranchisement violates that right through interference. In this way, DG involves not only the denial of rights through interference, but also through the imposition of social and material sanctions. DG is a failure of communication at multiple levels, including a *failure to empathize* with those who are suffering; *failures of the exercise of power in relationships*, where additional suffering is imposed upon disenfranchised individuals and constrains their ability to exercise their right to grieve; and *ethical failures* in respecting the experiences of the bereaved (Attig, 2004).

DG has been critiqued for forwarding binary assumptions about “enfranchised” versus “disenfranchised” experiences of loss, and for suggesting that the experience of grief “should not be socially regulated” (Robson & Walter, 2013, p. 97). Instead, disenfranchisement has been proposed as a hierarchy, such that interrelationships among dimensions of loss are elucidated (e.g., our immediate family members such as parents and children “count” more than secondary family members such as grandparents and cousins; Robson & Walter, 2013). CD likely similarly operates through discursive operations of power, whereby discourses constitute regimes of truth which dictate how truth and falsity are separated and the act of deeming some experiences, relationships, identities, and families more “real” than others in turn reifies that discourse. For example, illnesses which have a verifiable biological basis are considered to be more “real” than those which do not, and when illnesses considered to be less legitimate are constituted as such through talk, the impetus for discovering otherwise becomes moot, reifying that discourse. Further, it is these systems of meaning about COPCs which mandate that illness experiences are socially regulated, even when this reliance on social regulation creates the conditions for disenfranchisement to occur and thus social regulation is less desirable. For instance, if claims about a person’s chronic pain did not have to be socially validated because the negative consequences of not seeking that social validation would not occur, opportunities for disenfranchisement to occur would be fewer.

In sum, TCD draws and builds upon a number of rich lines of inquiry. This section has helped to clarify the ways in which disenfranchising communication may potentially occur for some individuals/groups as a result of the process marginalization (i.e., that marginalized groups may then be additionally vulnerable to becoming disenfranchised). Describing these related lines of research further illuminates the nature of the (often emotionally hurtful) messages made possible by stigma and uncertainty. Such messages may be disconfirming insofar as they increase negative patient self-assessments and make attributions about patient symptoms such that symptoms are attributed to an internal locus which may be uncontrollable (e.g., a personality characteristic or psychological disorder). The methodology for study one is next overviewed.

# CHAPTER THREE: META-SYNTHESIS METHOD AND RESULTS

Three interrelated studies for this IRB-approved (See Appendix I) dissertation are conducted to develop and validate a measure of CD grounded in a theoretical explication of this communication process. This dissertation explicates and measures the construct of CD to make the disenfranchising experiences of women with COPCs visible and draw connections to health, relational, and identity outcomes. See Table 2 for a dissertation completion timeline. In what follows, I overview the method and results for the meta-synthesis, which comprises half of the first of three studies comprising this dissertation.

## Study One: Explicating Communicative Disenfranchisement (CD)

Guided by an integration of multiple goals frameworks (Caughlin, 2010; Goldsmith, 2004, 2019) and CIFC heuristic (Suter, 2016, 2018), study one is substantively concerned with explicating CD (Chaffee, 1991). Given that the idea of CD was developed to examine social health issues broadly termed (Ray, 1996a, 1996b), this dissertation remains within these boundaries and offers a mid-range theory of the construct of CD, its assumptions, and its dimensions. As shown in the previous chapter, these interactions have been characterized by a variety of terms within the academic literature and, despite growing interest in understanding this process (i.e., what Burke (2019) in the *Journal of the American Medical Association* called "medicine's silent epidemic") no consensus or formal conceptual explication of CD has been offered. I argue that this *negative communicative interaction* (i.e., an interaction which is unhelpful or malicious), and the keywords which approximate it, is best embodied by CD.

**Table 2.** Timeline for the Completion of the Dissertation.

<table>
<tr><th rowspan="2">Study Item</th><th colspan="5">Time Schedule (▓ Projected | ░ Actual)</th></tr>
<tr><th>7/20<br>(M0)</th><th>8/20-10/20</th><th>11/20-1/21</th><th>2/21- 4/21</th><th>5/21-7/21</th></tr>
<tr><td>IRB Appoval (Exempt Determination, 07/09/20)</td><td>▓</td><td></td><td></td><td></td><td></td></tr>
<tr><td>Proposal Drafting</td><td>▓</td><td></td><td></td><td></td><td></td></tr>
<tr><td>Study One: Data Collection</td><td>▓</td><td></td><td></td><td></td><td></td></tr>
<tr><td>Proposal Defense</td><td>▓</td><td>░</td><td></td><td></td><td></td></tr>
<tr><td>Study One: Data Collection/Analysis/Writing</td><td></td><td>▓</td><td>▓</td><td></td><td></td></tr>
<tr><td>Study Two: Drafting Survey</td><td></td><td></td><td>▓</td><td>░</td><td></td></tr>
<tr><td>Study Two: Raters and First Sample</td><td></td><td></td><td></td><td>▓</td><td></td></tr>
<tr><td>Study Two: Data Analysis and Writing</td><td></td><td></td><td></td><td>▓</td><td>▓</td></tr>
<tr><td>Final Defense</td><td></td><td></td><td></td><td></td><td>▓</td></tr>
<tr><td>Deposit Dissertation</td><td></td><td></td><td></td><td></td><td>▓</td></tr>
</table>

I also argue that some of these particular terms (those which are not synonyms), refer to distinct subdimensions of the CD process. Chafee (1991) might argue that terms such as dismissed, disbelieved, and invalidated are *primitive terms*, meaning that they are easily understood and accepted, while the idea of CD might be a *derived term*, which is built upon and comprised of primitive terms. Or, it may be argued that there are lower order concepts, which are closer to the world of observation, and higher order concepts which subsume them (Chafee, 1991), pointing to the utility of modeling such a process. For instance, to have an account of pain not acknowledged and to have an account of pain attributed to a psychological cause are both potential features of disenfranchising interactions but refer to specific communicative acts.

### Study One Aims and Research Questions

Study one consists of a qualitative meta-synthesis (described below) of the extant literature on the experiences of patients with COPCs which I argue constitute CD as well as accounts of such interactions posted to Reddit forums. These data sources were selected because they are illustrative of private (interview studies) and public (Reddit) sphere representations COPC patient experiences respectively. Study one accomplishes three aims: (a) defining the dimensions and boundaries of CD as a construct (Aim 1), (b) facilitating initial item generation (Aim 2), and (c) suggesting possible outcomes of CD (after which specific hypotheses are proposed; Aim 3). Reddit data are used primarily to address Aims 2 and 3. Corresponding research questions (RQs) ask: What dimensions of negative talk are reported by female patients with one or more COPCs in scholarly publications about their experiences when communicating about their COPC(s) with others? (RQ1), What potential outcomes of CD are described by patients and publications (RQ2), and What pool of initial items could comprise a measure of CD? (RQ3)? A meta-synthesis produces a line of argument which lays foundation for the further construct explication described in chapter four. See Table 3.

**Table 3.** Summary of Study One Aims, RQs, and Methods

| Study Aim | Research Question | Methods Employed to Address |
|---|---|---|
| Defining the dimensions and boundaries of CD as a construct. (Aim 1) | How do patients and scholarly publications about their experiences characterize the dimensions of CD? (RQ1) | • Meta-synthesis to determine what "counts" as CD and utilizing tenets of construct explication to lay out TCD.<br>• Analysis of Reddit data using same sensitizing concepts. |
| Suggesting possible outcomes of CD. (Aim 2) | What potential outcomes of CD are described by patients and publications? (RQ2) | • Coding for outcomes noted in studies included in meta-synthesis (e.g., "depression has known correlates with chronic pain") and those mentioned by Reddit users (e.g., "I became depressed"). |
| Facilitating initial item generation. (Aim 3) | What pool of initial items could comprise a measure of CD? (RQ3) | • In vivo codes from qualitative data in meta-synthesis and Reddit data of patients' experiences. |

See Figure 1 for a summary of study one methods, relationship with study aims, and contributions to outcomes required for setting up study two.

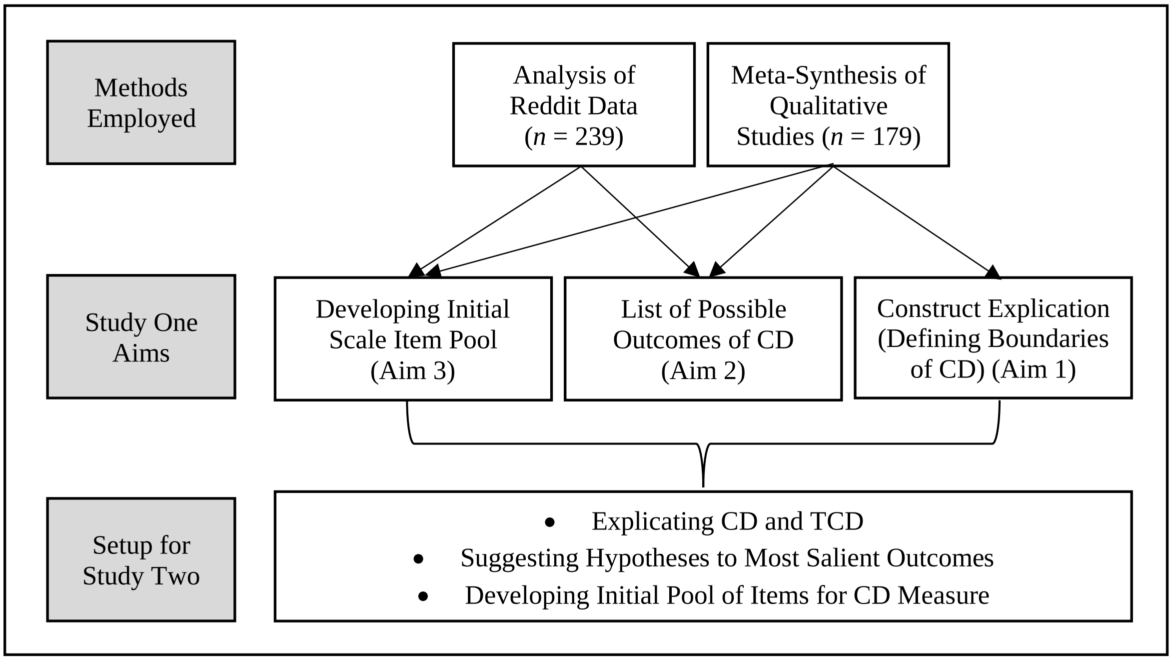

**Figure 1.** Summary of Study One Procedures, Aims, Outcomes Toward Study Two Setup.

### Meta-Synthesis: About the Method and Seven Procedural Phases

To partially address RQ1, RQ2, and RQ3, study one will first consist of a meta-synthesis. *Meta-synthesis* (also called *meta-ethnography*) is the most prevalent qualitative synthesis method in health research (Cahill et al., 2018). Meta-synthesis, first articulated by Noblit and Hare (1988), is a rigorous data analytic technique useful for uniting the contributions of findings across qualitative studies about a particular health topic in an effort to elucidate patient experiences and inform salient policy (Atkins et al., 2008; Cahill et al., 2018). Meta-synthesis is particularly useful for utilizing existing research knowledge to understand patients' experiences of chronic pain (Toye et al., 2013a). Similar to *meta-analyses* of quantitative research, a meta-synthesis involves identifying the scope of the review, developing criteria for including/excluding studies, identifying studies systematically, and then appraising and synthesizing the findings of those studies (Cahill et al., 2018). For instance, meta-synthesis has been used to examine the role of the patient-provider relationship in decision and meaning-making processes regarding antidepressant use (Malpass et al., 2009)

Conducting a meta-synthesis involves seven phases (Noblit & Hare, 1988), and meta-syntheses are evaluated according to the extent to which they adhere to and accurately report the data analysis process in each phase (France et al., 2014). Although each of the seven phases are described below and presented as being conceptually distinct, they are iterative and interlinked and refer to one analytic process (Noblit & Hare, 1988). Next, each phase is described, criteria for its evaluation explained, and a description of how that phase was executed. See Table 4.

**Phase one.** First, the aims of the review must be determined to assess whether a meta-synthesis is necessary. Meta-syntheses are evaluated according to whether the synthesis is motivated by a conceptual question for which interpretive methodologies are suitable, and whether the aim of the synthesis is explicitly stated (France et al., 2014). In this study, the aim of the review is to understand the experiences of patients with COPCs related to communicating with important others (most of whom are medical providers) about COPCs when seeking treatment/diagnosis and/or living with these conditions. A meta-synthesis is necessary as no reviews of the extant qualitative research about the experiences of patients with COPCs exist while at the same time a great interest in understanding this process exists (e.g., Burke, 2019). Further, this meta-synthesis will seek commonalities and connections across a range of topics and COPCs to help to explicate CD.

**Table 4.** Summary of Meta-Synthesis (MS) Phases, Procedures, Evaluation Criteria

| MS Phase | Procedures Enacted | Evaluation Criteria (France et al., 2014) |
|---|---|---|
| Phase One: Getting Started | • Assess whether a MS is necessary.<br>• Determine the aims of the MS. | • Is the MS motivated by a conceptual question for which interpretive methods are suitable?<br>• Is the aim of the MS explicitly stated? |
| Phase Two: Deciding What is Relevant to the Initial Interest | • Develop inclusionary and exclusionary criteria.<br>• Search for and sample studies. | • Are the methods for searching and selecting studies for inclusion fully described?<br>• Is the search technique exhaustive?<br>• Is the approach to searching explicitly stated? |
| Phase Three: Reading the Studies | • Data immersion<br>• Identify first, second, and third-order constructs.<br>• Record memos | • In what order were studies read and synthesized (e.g., chronologically)?<br>• Are the procedures for identifying key concepts from primary studies explicit?<br>• Is the number of key concepts initially identified stated? |
| Phase Four: Determining How the Studies are Related | • Determine how studies in MS are related. | • Is the process through which the relation among studies is determined clear? |
| Phase Five: Translating Studies into One Another | • Reinterpret concepts from primary studies arising from second-order constructs.<br>• Identify similarities and differences among studies. | • Are all translational procedures clearly explained?<br>• Are key concepts reinterpreted to compare key concepts across (rather than only within) studies? |
| Phase Six: Synthesizing Translations | • Produce a synthesis which either develops a line of argument or a novel concept/theory. | • Is the process of developing third-order constructs is clearly explained?<br>• Are the specific studies which contributed to the development of the new constructs listed?<br>• Are third-order constructs (i.e., a line of argument or a conceptual model or theory) presented? |
| Phase Seven: Expressing the Synthesis | • Report the results of the MS. | • Is it clear whether the selected exemplars are from study participants or authors? |

**Phase two.** Second, articles must be sampled, guided by theoretical tenets, to select studies for inclusion and exclusion which meet the aims of initial interest (Cahill et al., 2018). In this phase, meta-syntheses are evaluated according to whether the methods for searching and selecting studies for inclusion and exclusion are described fully, the search technique is exhaustive, and the approach to searching for studies is explicitly stated (France et al., 2014). It is recommended that two individuals work together to assess study relevance (Atkins et al., 2008; France et al., 2014). Hence, another coder was included in the study selection process and reliability was calculated using Krippendorff's SPSS KALPHA macro (Hayes & Krippendorff, 2007). Procedures for achieving reliability are described below. While disagreement exists about the number of studies appropriate for a meta-synthesis, one review found that 21 studies, on average, were included (with a range of 3 to 77 articles; France et al., 2014), although the possibility and utility of conducting meta-syntheses of greater than 77 articles has been noted if aided by qualitative data analysis (QDA) computerized software (Toye et al., 2013b). In this dissertation, MAXQDA (2020) was used to facilitate the analysis and synthesis of 82 articles.

The importance of assessing the quality of included articles is contested among proponents of meta-synthesis, as disagreement exists about what unified concepts could constitute “quality” for qualitative studies (Toye et al., 2013b). France et al. (2014) note that the purpose of quality appraisal is to “exclude biased studies” from the review (p. 8), going on to note that quality appraisals of qualitative data are “time consuming, judging the quality is subjective” and that a “poor description of the methods (which is a key focus of QA [quality appraisal] tools)” does not indicate the quality of that study (p. 8). For the purpose of this dissertation, the quality of included studies will not be assessed given that included studies span several decades and cross disciplinary and meta-theoretical boundaries which each have (often disparate) norms for the reporting and analysis of qualitative research. Hence, any attempt to ascertain cross-study comparisons of “quality” when comparing two articles, one employing a qualitative content analysis and the other interpretive phenomenological analysis, for example, are challenging (Cahill et al., 2018). Sampling procedures for this phase are described below.

*SCOPUS sampling procedures.* To sample qualitative articles about patient experiences for the meta-synthesis, SCOPUS was searched using a series of Boolean operators (See Figure 2) for each of the 10 COPCs. If a COPC had an alternative name(s) to which it is (or was) referred as medical terminology changes over time (e.g., fibromyalgia is also sometimes called fibrositis;

vulvodynia has alternative names of vulvar vestibulitis, vestibulodynia, provoked vestibulitis, primary vulvodynia, etc.), all possible alternative names were included in these Boolean operators to ensure that all relevant articles would be captured in the search. A total of 10 searches were performed, each time using all possible names for specific COPCs. Boolean operators were adopted from Shallcross et al.'s (2018) meta-synthesis and review of qualitative research about female patients' experiences living with and seeking treatment for vulvodynia. Specifically, the selected Boolean operators limited the search to qualitative interview studies conducted to assess lived experiences of COPCs. SCOPUS was selected as it is among the largest databases and has relatively unrestricted search functionality which allows for long strings of Boolean operators. The search for all 10 COPCs produced an initial sample of 616 articles. SCOPUS search parameters initially were applied to exclude 123 articles which were either: (a) not written in English, (b) in press but not yet published as of May 2020, (c) not journal articles, or (d) not published in academic journals, leaving a sample of 493 articles.

Reliability coding then commenced to code the remaining sample of 493 articles for relevance. At this time, a codebook was developed (see Appendix C) to further refine the sample by excluding articles which (in order of consideration): (a) were not primarily qualitative, (b) did not primarily concern patient experiences of seeking diagnosis or treatment for/living with the condition, or (c) were not studies about the COPC identified in the search term. Specific examples of coding decisions are included in the following paragraph. Another coder was involved to facilitate relevance coding using this codebook. Following procedures described by Neuendorf (2011), coder training occurred during one long in-person meeting at which time a sample of 11 articles (6% of the total dataset) was utilized to practice using the codebook. After the additional coder had been walked through these eleven examples with the author, they participated in two additional rounds of reliability coding to achieve acceptable levels of reliability on all codes (KALPHA > .80 for all codes), coding 11 articles in each round such that 33 total articles were utilized for coder training and reliability sampling (18% of the final sample, less than 20% as recommended; Krippendorff, 2018). KALPHAs by code are reported below.

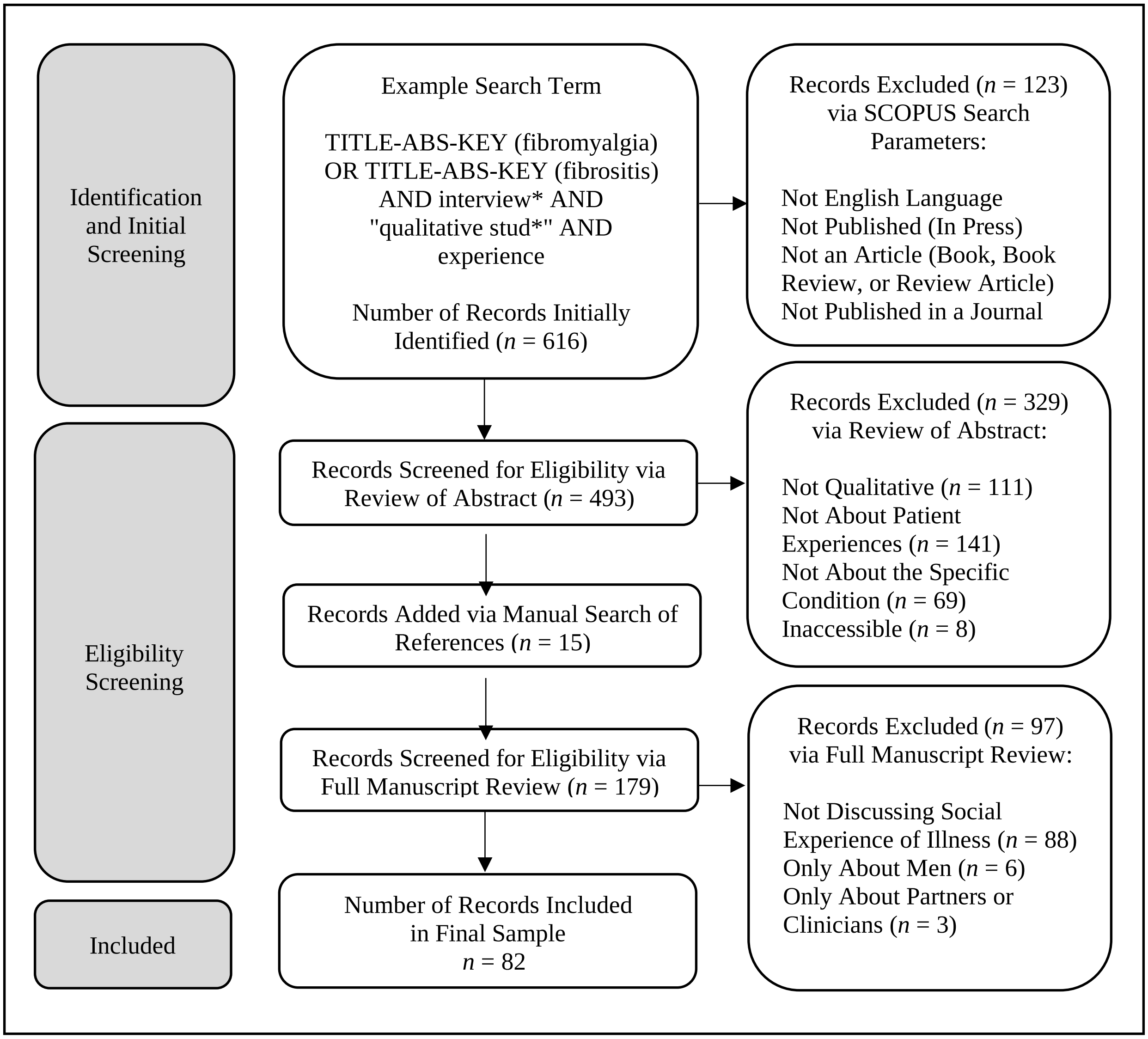

**Figure 2.** Decision Tree for Identification of Published Studies for Meta-Synthesis.

Throughout the relevance coding process, 326 total articles were excluded from the final sample for the following reasons. First, eight articles were inaccessible. Second, 111 articles were excluded because the aims of the study were not primarily qualitative (KALPHA = 1.00). For instance, studies assessing the efficacy of various treatments or reporting findings from experimental trials were excluded. Further, studies reporting quantitative survey data which also included some data from an open-ended response question were excluded, as were studies reporting data gathered from highly structured interviews conducted for the purposes of gathering data for statistical analyses. Another 141 qualitative articles were excluded because they did not primarily concern patient experiences of seeking diagnosis/treatment for or living with the condition (KALPHA = 1.00). For example, evaluation studies, qualitative analyses intended to help validate measures, and qualitative studies conducted to account for participants' lack of interest in clinical trials were all excluded from further review.

An additional 69 articles were excluded from the sample because they were not qualitative studies about patients' experiences living with the condition identified in the search term (KALPHA = 1.00). For instance, searches for irritable bowel syndrome (IBS) sometimes also included participants with a similar condition, inflammatory bowel disease (IBD). However, given that IBD has an unambiguous etiology which can be visually confirmed via colonoscopy, and hence that IBD is not a COPC, these studies were excluded. Studies were retained if more than one COPC was included in the analysis. For instance, a study about how female patients with fibromyalgia and chronic back pain represent symptoms to their medical providers was retained. This left a final sample of 164 articles included from SCOPUS. To ensure that the search was exhaustive, reference lists for each of the 164 included studies were then reviewed to locate additional studies meeting the inclusionary and exclusionary criteria and were coded via the same process and relevance criteria as outlined above, resulting in the addition of 15 articles

(KALPHA = .91) and a total of 179 included. Throughout this process, only 1 article was sampled using search terms for "interstitial cystitis," and this article was not coded as relevant.

Next, the same coders manually reviewed this sample of 179 articles to further assess relevance and arrive at a final sample. As this dissertation is primarily interested in the experiences of female patients with COPCs, articles discussing only the experiences of male patients with COPCs (*n* = 6) were excluded from further analysis, as were articles which only discussed the experiences of partners and medical providers (*n* = 3). Relevance was further assessed to separate qualitative articles which were interview studies, and which discussed patients' experiences of pain and illness broadly from articles relevant for the purposes of this analysis which discussed the social experience of COPCs. In particular, a need arose to distinguish between the implications of pain and the implications of talk about pain.

As coder training had already occurred, at this stage, another coder and I began by coding 18 full articles (10% of the sample) for relevance to retain only articles which at any point mentioned interactions in which patients with COPCs discussed their pain with others and/or the effects of those interactions (rather than only the effects of living with the condition). For example, a seminal publication by Kaler (2006) about vulvodynia was not retained because it only discussed the implications of having vulvodynia for the heterosexual relationships and identities of patients rather than also describing the effects of interactions in which vulvodynia was discussed. As this article only generally discussed the strain of *living with chronic pain* on these relationships, they (i.e., this article and others like it) were not of interest for this meta-synthesis. Articles discussing the relational implications which arose when important others (i.e., medical providers) expressed disbelief (for example) about the COPC, however, were retained, as they had a greater focus on talk and CD. In another example, articles which discussed only the identity implications of living with chronic pain were not retained, however articles which discussed the identity implications of talk about COPCs in which accounts of symptoms were discredited (for example) were retained. As coder training had already occurred, reliability for this step was achieved after 1 total round of coding (18 total articles; KALPHA = .89). Using these criteria, I reviewed the full texts of the remaining articles for relevance (*n* = 161) and an additional 88 articles were excluded from the final sample (*n* = 82) at this stage.

The final sample included 82 studies published between 1998 and 2020 representing 2,524 patients' (number of participants range 0 – 464; *M* = 31, *SD* = 56) experiences of communicating with important others (i.e., mostly medical providers) about COPCs. The dates for the included studies were a result of the sampling and not an *a priori* decision. Three studies did not include interviews or focus groups (i.e., were analyses of observational data). The number of studies included by COPC ranged from 0 (interstitial cystitis) to 25 (fibromyalgia; *M* = 8.3, *SD* = 7.7). This meant that there were no studies included in the final sample which discussed patients' experiences of talking with others about interstitial cystitis. Such studies span diverse international contexts including the aboriginal tribes of Australia, Punjabi Indians living in the United Kingdom, and female patients in South Africa and across South America, in addition to numerous studies conducted in Scandinavian countries (i.e., Denmark, Norway, and Sweden), Western Europe, Canada, and the United States. See Appendix D for a list of studies. I also recorded the following information about each article in the final sample (*n* = 82): (a) which COPC was represented in the final sample, (b) the field represented by each article as determined by the disciplinary affiliation of the first author, (c) the journals represented, and (d) the year each article was published. See Table 5 for summary descriptive statistics.

**Table 5.** Frequencies for characteristics of included studies (*n* = 82).

| Characteristic | *N* (%) |
|---|---|
| COPC Represented | |
| Chronic Fatigue Syndrome | 9 (11%) |
| Chronic Low Back Pain | 15 (18.3%) |
| Chronic Migraine | 1 (1.2%) |
| Chronic Tension Type Headache | 2 (2.4%) |
| Endometriosis | 11 (13.4%) |
| Fibromyalgia | 25 (30.5%) |
| Interstitial Cystitis | 0 (0%) |
| Irritable Bowel Syndrome | 4 (4.9%) |
| Temporomandibular Joint Disorders | 5 (6.1%) |
| Vulvodynia | 10 (12.2%) |
| Fields Represented (by >1 article) | |
| Medicine | 23 (28%) |
| Psychology | 11 (13.4%) |
| Nursing | 10 (12.2%) |
| Health Sciences | 7 (8.5%) |
| Sociology | 7 (8.5%) |
| Physical Therapy | 5 (6.1%) |
| Public Health | 3 (3.7%) |
| Dental Sciences | 3 (3.7%) |
| Health Studies | 3 (3.7%) |
| Communication | 2 (2.4%) |
| Journals Represented (by >2 articles) | |
| Disability and Rehabilitation | 5 (6.1%) |
| Social Science & Medicine | 5 (6.1%) |
| Sociology of Health & Illness | 3 (3.7%) |
| Psychology and Health | 3 (3.7%) |
| Journal of Clinical Nursing | 3 (3.7%) |
| Health Care for Women International | 3 (3.7%) |
| Family Practice | 3 (3.7%) |
| Chronic Illness | 3 (3.7%) |
| Year of Publication (Range 1998 – 2020) | |
| 2017 – 2020 | 26 (31.7%) |
| 2013 – 2016 | 17 (20.7%) |
| 2009 – 2012 | 13 (15.9%) |
| 2005 – 2008 | 16 (19.5%) |
| 2001 – 2004 | 5 (6.1%) |
| 1998 – 2000 | 5 (6.1%) |

**Phase three.** Third, articles in the final sample must be read repeatedly, and memos should be recorded to capture the authors’ initial thoughts and interpretations regarding key concepts from each study (Toye et al., 2013b), a process which can be facilitated by computerized QDA software. This represents the “reading” phase of conducting a meta-synthesis, where the researcher must work to read not only *within* studies, but *across* them. This step is followed by a second one, “conceptual innovation” (Lee et al., 2015), in which a translation and reinterpretation of the data occurs. Hence, meta-synthesis facilitates both an analysis of qualitative study findings in aggregate, but also enables a researcher to abstract from those findings insight about some novel concept or phenomenon which transcends the summation of concepts from the original sampled studies. The “data” which are extracted for the purposes of synthesizing are divided into first, second, and third-order constructs (Britten et al., 2002; Toye et al., 2014; see below). In this phase, meta-syntheses are evaluated according to whether the order in which studies were read and synthesized are clearly explained (the most common method being chronologically), whether procedures for identifying concepts from primary studies are explicit, and whether the number of concepts initially identified during this phase is stated (France et al., 2014).

*First-order constructs* are the words used by participants quoted in the sampled qualitative studies. For instance, first-order constructs in Malpass et al.’s (2009) study of patient-provider communication about antidepressant use included patients’ experiences of conversations about antidepressant use in the form of quotations. *Second-order constructs* are the study authors’ interpretations of those first-order constructs. For Malpass et al. (2009), second-order constructs included the themes and concepts which emerged from authors’ interpretations of patient experiences. *Third-order constructs* refer to the researchers’ interpretations of the second-order constructs, which enable the researcher to glean novel insight about the aims of the meta-synthesis (i.e., the phenomenon or theoretical tenet(s) in question; Schutz, 2012) and to produce a conceptual model/theory (France et al., 2014). Malpass et al. (2009) described how first and second-order constructs illustrated third-order constructs, or two meaning-making processes which characterized antidepressant use: a “moral” side whereby patients prioritized understanding the effects of antidepressant use on their own identities, and a "medication" side where patients focused on managing depression through treatment with antidepressants. At this point, during the conceptual innovation phase, which consists of "employ[ing] concepts not found in the included studies" (Cahill et al., 2018, p. 134), theoretical tenets sensitize the analysis (Blaikie, 2000), whereby *sensitized concepts* (Blaikie, 2000; Blumer, 1969) direct the researcher to engage in data analysis with "an open, but not empty mind" (Flemmen, 2018, p. 85).

Here, all sampled articles were first reviewed in depth and memos recorded in MAXQDA 2020 to capture initial thoughts and impressions. Studies were reviewed chronologically by COPC in alphabetical order (i.e., beginning with the earliest dated article in the CFS folder and ending with the most recently dated article in the vulvodynia folder, as displayed in Appendix D). Again, using MAXQDA 2020, first and second-order constructs (i.e., participants' quotations and authors' interpretations of those quotations) were first coded. These first ($n$ = 210) and second order ($n$ = 177) constructs were coded in the results section of the sampled manuscripts. One example of a first-order construct coded was the participant quotation "Another doctor told me the illness was all in my mind when I came to him to find out what was causing widespread diffuse pain" (CFS; McManimen et al., 2017, p. 247), while an example of a second-order construct coded in reference to this quotation was "These types of interactions were viewed as harmful because the participant believed the physician was dismissing their physical symptoms in favor of a stigmatizing psychological etiology…" (CFS; McManimen et al., 2017, p. 247).

In these examples, the first-order constructs are participants' quotations as included in the sampled articles, while the second-order constructs interpret those quotations within the goals of each particular study (e.g., to assess the relationship between negative patient experiences and perceptions of trust in the patient-provider relationship). Consistent with the sampling parameters and relevance criteria outlined above, only first and second-order constructs which were related to the social experience of illness (i.e., talking about COPCs, interactions in which COPCs were discussed, the effects of those interactions on patients) were coded. The findings of the meta-synthesis below will provide quotations from both first- and second-order constructs. This is done to draw comparisons between second-order constructs and utilize first-order constructs to illustrate those constructs in relation to third-order constructs.

In addition, to facilitate the synthesizing of first and second-order constructs into third-order constructs and to identify themes emerging among first and second-order constructs, sensitized concepts from multiple goals theories and CIFC were also coded. These sensitizing concepts included: (a) the task, relational, and identity implications of disenfranchising talk about COPCs (Clark & Delia, 1979); (b) discrete (i.e., interaction-specific) and global communication goal inferences (Caughlin, 2010), as well as (c) knowledge claims made by interactants (i.e., which evidence discursive operations of power), (d) interpenetration of private interactions by the public sphere (e.g., references to media and policy and the material consequences of the interaction which extend beyond it), and (e) practices which perpetuate, resist, and transform the status quo. Two additional codes were included. First, outcomes described in sampled articles and/or described by participants were coded to be considered as outcome measures in the final theoretical model. Second, *in vivo* quotations and phrases which could constitute scale items were coded to expedite the initial generation of a pool of scale items.

After first and second-order constructs are coded, a next task is to identify themes among these coded first and second-order constructs. The overall goal of this step is to identify the key concepts (i.e., ideas, themes, interpretations) which comprise the “data” for the meta-synthesis and to record how they appear across studies. In this case, the key concepts are provided by our sensitizing concepts. To facilitate this aim, a matrix table was created which lists each study as well as whether key sensitizing concepts appear in each study and if so, what conceptualization of that concept is offered in each study (France et al., 2014). Recording how key concepts are conceptualized across studies is necessary for completing phases four through six of the meta-synthesis, where those conceptualizations are compared and juxtaposed to create a line of argument with novel third-order interpretations about CD. See Appendix E.

**Phases four, five, and six.** In phase four, concepts identified in phase three are compared and juxtaposed across studies to help to eventually identify themes (i.e., "patterned response[s] or meaning[s] within the data set," Braun & Clarke, 2006, p. 82) which explain the data and are identified in phase five. This fourth phase is evaluated according to whether the process for assessing the relationship between primary studies (usually done by comparing concepts across studies) is explicit and clear (France et al., 2014). In phase five, studies are "translated into one another" (Cahill et al., 2018, p. 134) to identify themes by taking each concept identified in phase four (i.e., concepts emerging from second-order constructs) and comparing that concept to findings in all other studies to determine similarities and differences across the sample (Toye et al., 2013b). Phase five of meta-syntheses is evaluated according to whether the reporting of procedures is clear and whether the researcher sufficiently reinterprets these concepts to draw meaningful comparisons across studies (rather than only within them; France et al., 2014).

In phase six, translations are synthesized, whereby either points of similarity across studies are highlighted (i.e., a reciprocal synthesis) for analyses in which findings substantially converge, or points of difference are highlighted (i.e., a refutational synthesis) for analyses in which findings are substantially different, a process which can again be accomplished through QDA software (Toye et al., 2014). This phase of the analysis enables the researcher to develop a line of argument (Atkins et al., 2008) in which synthesized findings together form a coherent narrative toward the aims of the synthesis, which may be developing a new concept or theory (France et al., 2014). The sixth phase is evaluated according to whether the process of developing third-order constructs is clearly explained, the specific studies which contributed to the development of the new constructs are listed, and whether third-order constructs (i.e., a line of argument or a conceptual model or theory) are presented (France et al., 2014).

In this study, using the data matrix created in phase three, conceptualizations of concepts were compared across studies. I reviewed and compared these conceptualizations by each column (which lists each sensitizing concept and conceptualizations by each study of that concept). As findings substantively converged, a reciprocal synthesis is produced which formed a coherent narrative about the concepts which constitute CD. Across studies, various domains of each concept (e.g., knowledge claims) emerged through comparison. This process represents the translation of second-order constructs (e.g., providers question the existence of female patients' pain) into third-order constructs (e.g., the discrediting of the existence of the target of disenfranchising talk). The specific studies which contributed to each third-order construct are reflected in Appendix E.

**Phase seven.** Phase seven involves writing synthesis findings. There is no consensus about whether participants' quotations or authors' interpretations should be used as exemplars in meta-syntheses (France et al., 2014), but it should be clear whether included quotations are from participants or authors. In sum, performing a meta-synthesis produces an aggregated analysis of findings from the extant qualitative literature about patients' experiences of living with (and managing) COPCs and the reinterpretation of those data toward the aim of defining the dimensions and boundaries of CD as a construct (RQ1). During the process of conducting the meta-analysis, I also kept a coded list in MAXQDA of any outcomes mentioned by participants (e.g., "I became depressed") or by study authors (e.g., "There is a known association between chronic pain and depression") to consider as outcome measures for studies two and three (RQ2).

## Results: Meta-Synthesis of Qualitative Studies

The purpose of this meta-synthesis is to map concepts identified in the extant qualitative literature regarding patients' experiences of speaking with others about COPCs onto extant theoretical sensitizing concepts from multiple goals theorizing and the CIFC framework. The product of this meta-synthesis takes findings from the extant literature about these experiences and draws higher-order inferences about the phenomenon of CD which forms the basis of the construct explication of TCD which follows the presentation of findings of this meta-synthesis.

### Results: Meta-Synthesis of Qualitative Studies

This meta-synthesis maps concepts identified in the extant qualitative literature regarding patients' experiences of speaking with others about COPCs onto the extant theoretical sensitizing concepts from multiple goals theorizing and the CIFC framework. The product of this meta-synthesis takes findings from the extant literature about these experiences and draws higher-order inferences (i.e., third-order concepts) about the phenomenon of CD which forms the basis of the construct explication of TCD which follows the presentation of these findings.

In the presentation of findings below, there are some instances in which first and second-order constructs are presented interchangeably. This is because of space constraints within many medical and health-focused journals which often do not allow room for exemplars. Take for instance this example of a sentence in the text below, "Other patients reported being told that there was nothing wrong (Grogan et al., 2018, p. 1370; Holloway et al., 2007, p. 1459) by their doctors, expressing doubt about the existence of pain." Here a second-order interpretation of those data are included (i.e., authors' interpretations of participants' quotations) because there are not quotations from participants (i.e., first-order constructs) in these published articles. Direct quotations of text below which come from study participants are signaled accordingly in the text which precedes the quotation (e.g., "one participant noted").

Four interrelated key concepts were identified which map onto (but also build upon) sensitizing concepts from multiple goals and CIFC frameworks and which characterize the negative experiences of patients with COPCs when communicating about their pain and the effects of their illness with others. These include the: (a) dimensions of disenfranchising talk (DT), (b) more immediate (or proximal) consequences (PCs) of disenfranchising talk, (c) negative inferences female patients with COPCs make about others' goal tendencies (NGIs), and (d) communication practices employed toward enfranchisement and reification.

These key concepts represent the conceptual innovation from the first and second-order constructs coded in MAXQDA to third-order constructs which aid in the explication of TCD. As one example, a patient in McManimen et al.'s (2019) study reported being told that "There is no such thing as CFS/Fibromyalgia" (p. 249; a first-order construct), which was interpreted by McManimen et al. (2019) as this provider contesting the existence of these illnesses (a second-order construct). These first and second-order constructs became a part of the "discrediting" dimension of the third-order construct (i.e., key concept) of disenfranchising talk (DT). See Table 6 for a summary and examples of all first, second, and third-order constructs.

**Table 6.** Summary of Constructs from the Meta-Synthesis.

| **Example First-Order Constructs** | **Second-Order Constructs (Authors' Interpretations as Appearing in Sampled Studies)** | **Third-Order Constructs (Toward Explicating TCD)** |
|---|---|---|
| • ‘‘They (the doctors) **do not think that it hurts as much as one says**” (Hellström et al., 1999, p. 17).<br>• “Who hasn't heard them say…'Oh yes, **she can paint** (or mow the lawn, hang up the clothes) **so she can't be that ill**!” (Glenton, 2003, p. 2248)<br>• “A rheumatologist said, “**There is no such thing as CFS/Fibromyalgia**” (McManimen et al., 2019, p. 249)<br>• “She [my gynecologist] accused me of lying about the condition …**every time I tried to say something about it, she cut me off and wouldn't let me speak**” (Young et al., 2019, p. 129).<br>• **“I was told [by physicians] either that I'm frigid or that I don't like sex; just learn to accept it...”** (Sadownik et al., 2012, p. 26)<br>• “And he [my doctor] says, **‘You present like a drug addict.'”** (Buchman et al., 2016, p. 1399) | • Contesting the existence of the COPC or illness itself.<br>• Contesting the seriousness and severity of the illness COPC.<br>• Contesting patients' experiences of the COPC and how the COPC is experienced by them in comparison to others.<br>• Downplaying the seriousness and severity of the COPC.<br>• Discouraging the patient from discussing the COPC now and in the future with others.<br>• Pain argued to be feigned for an ulterior motive (e.g., malingering, drug seeking, secondary benefits).<br>• Invoking stereotypical ideas about female patients and chronic pain patients and using them to evaluate patients' COPCs.<br>• Existence of pain or condition is denied. | Dimensions of Disenfranchising Talk: Discrediting, Silencing, Stereotyping.<br>(Knowledge Claims and Reification of Invoked Discourses) |
| • “**I had negative interactions talking about my low back pain with others…I don't want to talk to anyone. I don't think anyone would understand**” (Glenton, 2003, p. 2247).<br>• “When I was in [hospital]…it was, like—, ‘**Oh, she's just a junkie looking to get stoned.'** They **didn't believe that I was actually suffering and in pain.** They thought I was faking it completely...” (Buchman et al., 2016, p. 1398).<br>• “…if I pulled a muscle **I would probably be unwilling to go to the doctors** because you know they'll just say…‘It's part of your Fibro …'” (Ashe et al., 2017, p. 4). | • Hesitancy to talk with others and seek future care.<br>• Isolation, withdrawal, and heightened selectivity about who to interact with.<br>• Pain is viewed as a personal and moral failing.<br>• Loss of perceived credibility for reporting of health complaints.<br>• Diagnosis as a barrier to future care.<br>• Denial of support, benefits, and accommodations.<br>• Medical records follow patients between appointments. | Implications of Disenfranchisement: Proximal Consequences of DT. |

**Table 6 (Continued)**

| | | |
|---|---|---|
| • "I have one document from one of the doctors that said that I have psychological problems…**The medical profession does not take [fibromyalgia] seriously**" (Cunningham & Jillings, 2006, p. 260)<br>• "**They think that you exaggerate**, and you need to try hard so that they believe you, because they don't. You experience that immediately, that **they don't believe you**" (Gundström et al., 2018, p. 209).<br>• "**I felt like [my doctor] was making fun of me**…It's like she was saying 'Oh, you're just a hypochondriac'…**Doctors are supposed to be understanding, open-minded, sympathetic**" (Dickson et al., 2007, p. 857). | • Others will try to evaluate my credibility, the legitimacy of my health complaints, and my motivations for talking about them.<br>• My doctor did XYZ → loss of faith in the medical system/profession.<br>• My doctor couldn't help me → no one can help me.<br>• Specific person didn't understand my condition → no one will understand my condition. | Negative Inferences about Others' Goal Tendencies |
| • **Perpetuation:** "They described the need to be **obedient** ("Whatever anybody tells me to do, I do it" (Liz)), **not challenging** incorrect hypotheses of doctors…and continuing to be "**nice**" (Liz)" (Shallcross et al., 2018, p. 970).<br>• **Critique:** "And [doctor] asked if I wanted to go on sick leave. I got angry at him. I said that I don't run here because I want to go on sick leave; I come because I want to get help. Yeah, **he was really stupid, in my opinion**" (Storm Mienna et al, 2014, p. 247).<br>• **Resistance:** One woman stated that… "**you have to educate yourself about your health** issues and then **demand the right therapy**" (Young & Miller, 2019, p. 7).<br>• **Transformation:** "The women expressed that **realising they were ultimately in charge** was liberating. This is not to say that life had become easier, but that **they no longer put up with treatment that was less than they required and demanded**" (Cox et al., 2003, p. 7). | • Perpetuation: Acting like a "good" patient.<br>• Perpetuation: Changing one's appearance and description of pain to receive care.<br>• Perpetuation: Giving up on seeking treatment.<br>• Perpetuation: Accepting purely psychological explanations for pain.<br>• Critique: Level of knowledge about COPCs.<br>• Critique: Quality of care and medical advice.<br>• Resistance: Counter-emplotment of facts to counter questioning of "realness."<br>• Resistance: Continuing to pursue treatment, diagnosis, and second opinions to counter silencing.<br>• Transformation: Changing conditions which contribute to disenfranchising talk.<br>• Transformation: Shifting communicative context. | Enfranchisement Practices: Perpetuation, Critique, Resistance & Transformation. |

## Dimensions of Disenfranchising Talk: Discrediting, Silencing and Stereotyping

A first key concept emerging from the meta-synthesis refers to the content and functions of *disenfranchising talk (DT)* experienced by patients with COPCs in interactions with others in which their pain or its effects were discussed. The data which contribute to this key concept are: (a) first-order constructs where patients with COPCs describe negative interactions that they have endured and (b) second-order constructs which describe the functions of negative talk. Three sub-concepts of DT were identified: (a) discrediting, (b) silencing, and (c) stereotyping.

**Discrediting: Existence and patients' experiences of pain.** A first sub-concept is the dimension of *discrediting*, comprised of various communicative practices enacted by others in an effort to discredit the experience of living with the COPC (in terms of how serious or severe it is or how it is experienced in comparison to others), and the existence of the COPC. Discrediting talk may first fundamentally question whether the pain or condition exists at all, and second question patients' experiences (i.e., severity and seriousness and how patients experience pain).

Discreditation first occurred when others doubted the existence of the pain or condition itself. For instance, Briones-Vozmediano et al. (2018) noted that many medical providers contest the existence of fibromyalgia, while a patient with fibromyalgia was told by her doctor that "she didn't believe in Fibromyalgia" and that "nobody in New York had Fibromyalgia" (Armentor et al., 2017, p. 467), and a patient with chronic fatigue syndrome reported a rheumatologist telling her that "There is no such thing as CFS/Fibromyalgia" (McManimen et al., 2019, p. 249). Other patients reported being told that there was nothing wrong (Grogan et al., 2018, p. 1370; Holloway et al., 2007, p. 1459) by their doctors, expressing doubt about the existence of pain.

Discreditation second occurred when others questioned patients' experiences of pain, which included both: (a) the seriousness and/or severity of pain and (b) how pain affects patients' lives in comparison to others. Discrediting talk which questioned patients' experiences of pain first questioned the seriousness and/or severity of the pain. This occurred across all COPCs but was particularly prevalent for women with endometriosis. For example, women with endometriosis reported instances of discreditation in interactions with medical providers such as, "The doctor told me that the problem nowadays is that because women take the Pill, they don't know what a real period pain is…" (Ballard et al., 2006, p. 1298), "When I had my period, my mother took me to the family doctor and he said, *this is just what a woman has to put up with* – I can still remember the words…" (Markovic et al., 2008, p. 356, emphasis added), "Menstrual pain is something all girls have…just take some painkillers and it will pass" (Gundström et al., 2017, p. 209), and "I had specifically been told that it was just part of being a woman, it's just one of those things" (Denny, 2004, p. 642, 644, as well as with friends, "They [friends] kind of know it's periods but when I tell them period pain, they think a little bit of pain and she shouldn't be having time off [from work] with that" (Ballard et al., 2006, p. 1300). These quotations demonstrate instances where others downplayed patients' experiences of pain severity.

Discrediting talk also occurred when others contested patients' experiences of pain in terms of whether and to what extent patients' accounts of pain and the effects of pain on their lives were as they claimed (Armentor et al., 2017; Glenton, 2003; Grogan et al., 2018; Hellström et al., 1999; Marriott & Thompson, 2008). For instance, a patient with fibromyalgia reported that ''They (the doctors) *do not think that it hurts as much as one says*" (Hellström et al., 1999, p. 17). Some patients reported that the variability of their symptoms encouraged others to contest their claims of pain, one reporting "Who hasn't heard them say…'Oh yes, she can paint (or mow the lawn, hang up the clothes) so she can't be that ill!" (Glenton, 2003, p. 2248), and another agreeing, "…they believe I'm making more of this than it actually is…when I tell them that this stuff comes on suddenly…that I'm kind of exaggerating the whole thing" (Armentor et al., 2017, p. 467). Here, comparative evidence is also used to question patients' experiences of pain (Cunningham & Jillings, 2006; Dixon-Woods & Critchley, 2000; Young & Miller, 2019).

Women with endometriosis often found that female doctors were less sympathetic to their complaints of menstrual pain (Cox et al., 2003), for example, because female providers also experienced menstrual pain (Denny, 2004; Markovic et al., 2008). As Young and Miller (2019) explained, “One woman in the group shared that *a female doctor* once suggested that her cramps couldn’t be that bad” (p. 129, emphasis added). These examples together illustrate instances of talk which discredit patients’ experiences of COPCs.

**Silencing: Preventing and discouraging talk about COPCs.** A second sub-concept is the dimension of *silencing*, comprised of various communicative practices enacted by others (both explicitly – by *preventing* talk – and in an implied capacity – by *discouraging* talk) in an effort to prevent the patient with COPC from discussing the pain at present and in the future with others (e.g., Durham et al., 2010; Gundström et al., 2017; Young et al., 2019). For instance, in an effort to silence her and discourage her from seeking future care for her pain, a patient with temporomandibular joint disorder reported that her general practitioner *told her “not to bother him anymore”* about her pain (Durham et al., 2010, p. 828). This patient was discouraged from returning to this provider, thus silencing her by preventing her from seeking care. Similarly, another patient with vulvodynia reported being directly silenced by her female gynecologist who “accused me of lying about the condition because she had never heard of it. And every time I tried to say something about it, *she cut me off and wouldn’t let me speak*” (Young et al., 2019, p. 129, emphasis added).

Other patients felt silenced in more covert ways, for example, one patient with endometriosis reported that her provider “sighed, tapped their fingers on the table, avoided eye contact and responded in a monotone voice” and gave her advice like “start exercising or something” which made her “feel like she was being ridiculed” (Gundström et al., 2017, p. 208).

In another example, a woman with chronic fatigue syndrome reported that her doctor "repeatedly *stated that doctors could not help me*, which briefly made me suicidal, since happy thoughts certainly weren't going to cure me…" (McManimen et al., 2019, p. 249, emphasis added). Here, these actions function to silence by discouraging patients from speaking about the pain.

**Stereotyping: Gender and malingering.** A third sub-concept is the dimension of *stereotyping*, comprised of various communicative practices which invoke situationally salient discourses. Although this dimension of DT will be different in each context, two discourses were called upon in disenfranchising talk experienced by women with COPCs, discourses of: (a) *gender* (the histrionic stereotype), and (b) *malingering* (stereotypes about chronic pain patients).

Stereotyping talk first called upon the histrionic discourse, whereby female patients are viewed as melodramatic and theatrical and as feigning illness toward gaining some secondary benefit such as attention or shirking one's ascribed duties (Smith-Rosenberg, 1984). Note that stereotyping talk here is not necessarily always gendered on its face (e.g., calling upon aspects of the patients' gender as a simplistic explanation for pain), rather the histrionic stereotype is characterized by assertions about the experiences of COPCs which tend to be said to female patients more than male patients. For instance, being accused of "being an exaggerator" is not necessarily gendered on its face (i.e., male and nonbinary patients can also be accused of being exaggerators), but women are more likely to be accused of being exaggerators due to gender bias which is called upon in that talk (Schäfer et al., 2016).

Here, covert operations of the histrionic stereotype appeared when female patients were blamed for their pain, or when their pain was attributed to psychological distress (Glenton, 2003), being overweight or not exercising enough (Gundström et al., 2017; Holloway et al., 2007), or being morally corrupt (e.g., women with fibromyalgia being accused of just being “lazy;” Juuso, 2014). Female patients were also suspected to have an ulterior motive such as being attention-seeking (Glenton, 2003), particularly when the variability of symptoms across time roused suspicion about their legitimacy (e.g., Cooper, 2017). Other patients reported more overtly gendered notions regarding their pain. For instance, one patient with chronic fatigue syndrome wrote that their provider asserted “that I was depressed *because my husband worked away from home*” (McManimen et al., 2019, p. 246, emphasis added), while in another example, a patient with vulvodynia reported, “I was told [by physicians] *either that I’m frigid or that I don’t like sex*; just learn to accept it...” (Sadownik et al., 2012, p. 26, emphasis added). These comments harken back to historical notions of female sexuality (i.e., that one is reporting sexual pain in an effort to avoid having sex with one’s partner) and the capacity to handle stress (Smith-Rosenberg, 1984).

These assertions tie directly into the second discourse of biomedicalism, where a lack of objective or externally verifiable evidence fuels assertions that the patient is malingering (e.g., attempting to get disability benefits or pain medications). In the biomedical model, the mind-body dualism is upheld, whereby pain is either explained as being biogenic (biological in origin), through “objectively” visible or detectable symptoms, or if such evidence is lacking, pain is instead explained as being psychogenic (psychological in origin). Thus, it may be possible that these two discourses are conceptually indistinct, as being accused of malingering is both a part of the histrionic stereotype (e.g., trying to receive attention or sympathy) and also separate as a consequence of racism, classism, and the climate regarding the treatment of chronic pain in light of the opioid epidemic. For instance, one patient with chronic low back pain reported that “And he [my doctor] says, ‘*You present like a drug addict.*’” (Buchman et al., 2016, p. 1399, emphasis added).

Patients with COPCs reported that a lack of visible medical evidence (Armentor, 2017; Ashe et al., 2017; Cooper, 2017; Juuso, 2014; Madden & Sim, 2006; Pryma, 2017) or affirmative diagnostic tests were often utilized as "proof" of a patient's feigned illness, malingering, or drug-seeking, and of the presumed psychological origin of pain (Björkman et al., 2014; Brown et al., 2017; Cunningham & Jillings, 2006; Dickson et al., 2007; Glenton, 2003; Håkanson et al., 2010; Juuso et al., 2014; Pryma, 2017). As Winger et al. (2014) put it, "if the illness is not visible to others, does it exist?" (p. 2648). For example, one patient with fibromyalgia recalled that "I was 20, felt like I was 70…*If only the blood test had shown something*, it would have been OK" (Marit Mengshoel & Heggen, 2006, p. 52, emphasis added). Another patient with chronic low back pain reported that "when *it doesn't show up on the pictures*, that's when it becomes difficult because you feel like nobody believes you" (Glenton, 2003, p. 2246, emphasis added). Hence, these findings also indicate that patients' self-knowledge about COPCs is often devalued (Björkman et al., 2016; Chen, 2016; Dixon-Woods & Critchley, 2000; Whelan, 2007) through such claims about their experiences. As one patient with irritable bowel syndrome explained, "[*A*] *doctor's diagnosis has authority,* you know. And self-diagnosing, well it's not, not scientific. *It doesn't have the same authority,* or people don't take it seriously…" (Björkman et al., 2016, p. 2969, emphasis added).

Accusations of malingering are also intertwined to race and class in addition to gender. For example, a Black participant with endometriosis in Pryma's (2017) study who was considering applying for disability benefits noted that, "There's always that feeling from the powers that be that 'Oh *they* are always applying for disability, and they're not really disabled.' So *that whole thing is just going to make it very challenging* for me [to receive benefits]" (p. 71, emphasis added). Another highly educated Black patient with endometriosis receiving disability benefits shared a similar sentiment, noting that “They say that I'm acting … even my sister says that I'm ‘*acting like a crazy so I can get a check*.’ And she spreads this around that I'm a hypochondriac…” (p. 71, emphasis added). These quotations illustrate the inherent raced and classed nature of negotiating for care for COPCs, such that race (i.e., being Black) and class (i.e., stereotypes about welfare, attempting to secure unwarranted disability benefits) become simplistic explanations for patients’ reported symptoms. Here connections to the discourse of biomedicalism are clear. Black women have been historically underrepresented in depictions of endometriosis and are consequently less likely to be viewed as having endometriosis (e.g., Chatman, 1976), and issue which persists to this day (Boujie et al., 2019). Black patients are less likely to have affirmative diagnostic evidence for the existence of endometriosis, and this lack of evidence is drawn upon as a means of stereotyping expressions of pain as malingering.

Yet, even when patients are able to attain a diagnosis or other “proof” of the “realness” of their health complaints, sometimes previous affirmative COPC diagnoses or affirmative medical tests (e.g., results from blood tests) are dismissed as being false or erroneous (Marit Mengsoel & Heggen, 2006; McManimen et a., 2019) toward the aim of contesting the “realness” of a patients’ health complaints. Or a previous affirmative diagnosis may serve as a barrier to receiving future care related to the same issue or another unrelated health issue (Hellström et al., 1999; McManimen et al., 2019). For instance, one patient who had been diagnosed with fibromyalgia reported that “Once you’ve got a diagnosis it’s more difficult to convince doctors that you also might be suffering from another illness” (Helström et al., 1999, p. 13), while another with chronic fatigue syndrome (i.e., ME) reported, “Despite now finally being diagnosed, I now find that I am listened to even less” (McManimen et al., 2019, p. 251) as the very existence of chronic fatigue syndrome (even with a diagnosis) is itself contested.

These sub-concepts of DT confirm that disenfranchising talk is about more than only whether or not a diagnosis is reached, despite largely being characterized this way in the extant literature and other attempts to quantify measures of this talk (e.g., Bontempo, 2019). These findings also indicate that patients with COPCs grapple with a sustained reliance on interactions with others as a means of establishing and defending the "realness" of their pain. For example, Madden and Sim (2006) note that "The need to have pain acknowledged by the medical profession was a dominant feature when informants were trying to understand FMS [fibromyalgia syndrome]" (p. 2970), an assumption which precedes disenfranchising talk that I (building on work by Doka, 1999) am calling *social regulation*. This assumption is further described in the construct explication below as a process which undergirds DT.

### Implications of Disenfranchisement: Proximal Consequences of DT

A second key concept refers to the immediate outcomes or proximal consequences of effects of negative talk experienced by patients with COPCs. Three interrelated proximal consequences function as sub-concepts of this key concept: (a) agency (i.e., negative consequences related to patients' ability or willingness to speak about their pain or its effects on their lives at all or with certain others – to participate in the discourses to which they are subjected), (b) perceived credibility (i.e., negative consequences for patients' ability to be perceived as credible by others) and (c) the ability to exercise rights and privileges (i.e., to attain care, support, and resources).

**Agency.** A first proximal consequence of DT pertains to COPCs patients' inability and/or willingness to talk about their pain or its effects on their lives with others. This occurred in terms of requiring new communicative constraints (Palomares, 2014) regarding: (a) whether to talk, and (b) to whom they are able to talk. These *constraints* represent refinements to the "ongoing concerns, considerations, and…behavioral expectations" such as the "appropriateness" of talk to which patients with COPCs must attend when engaging in talk about their COPCs with others (Palomares, 2014, p. 84). This dimension of PC is distinct from the "silencing" dimension of DT above as silencing is *done to* patients with COPCs whereas this section illustrates how patients make changes in their own communication moving forward given the imposition and awareness of new constraints.

First, when patients experience DT, this holds consequences (i.e., PC) for their ability and/or willingness to engage in talk about COPCs at all or whether to discuss specific salient aspects of their illness experience. For instance, one patient with chronic back pain stated, "I had negative interactions talking about my low back pain with others…*I don't want to talk to anyone*. I don't think anyone would understand" (Glenton, 2003, p. 2247). Second, DT also holds consequences for who patients with COPCs talk to about their illness or its effects on their lives. Disenfranchising talk also results in the avoidance of talk (i.e., PC) about the COPC with specific others (e.g., coworkers, Armentor, 2017; Wuytack & Miller, 2011) for fear of negative attributions (e.g., being labeled a "whiner"; Sallinen, 2011; "hypochondriac"; Dennis, 2013; "attention-seeking", Eaves, 2014; or "neurotic"; Shallcross et al., 2018), or emphasizing or hiding information with certain others (e.g., providers; Ashe et al., 2017).

Disenfranchising talk also results in selectivity by COPCs patients about with whom a topic will be discussed (e.g., only members of the "fibro family"; Ashe et al., 2017), which can bolster COPC patients' feeling isolation and withdrawing from friends (Clarke et al., 2005; Dennis et al., 2013; Holloway et al., 2007; Liedberg et al., 2006; Snellgrove & Liossi, 2009). One patient with fibromyalgia whose friend expressed disbelief about the existence of the pain recalled afterward that "I became very closed off socially…I'm afraid to be judged and I'm afraid of being rejected" (Raymond & Brown, 2000, p. 1102). The inability to achieve an affirmative diagnosis from a medical provider results in a lack of support (PCs) from others, including: (a) *family members and friends* (Briones-Vozmediano et al., 2016; Clarke et al., 2005; Dennis et al., 2013; Durham et al., 2011; Fisher, 2017; Granero-Molina et al., 2018; Juuso et al., 2014; Löfgren et al., 2006; Marit Mengshoel & Heggen, 2006; Pryma, 2017; Sallinen et al., 2011), (b) *a spouse or partner* (Briones-Vozmediano et al., 2016; Brooks, 2014; Granero-Molina et al., 2018), and (c) *an employer or coworkers* (Armentor, 2017; Ballard et al., 2006; Denny, 2004; Gill Taylor et al., 2016; Oldfield et al., 2018; Juuso et al., 2014; Lempp et al., 2009; Pryma, 2017; Sallinen et al., 2011).

**Perceived credibility.** Patients with COPCs also felt that their pain was viewed as a character blemish, or moral or personal failing (Glenton, 2003; Holloway et al., 2007; Snelgrove & Liossi, 2009; Walker et al., 2006) and thus patients lost credibility, as Dima et al. (2013) stated, "Participants were concerned not to be seen as malingerers or hypochondriacs" (p. e494). This resulted in reductions in perceived trustworthiness (Buchman et al., 2016) and credibility as a person (Durham et al., 2011; Eaves, 2014). As one patient noted, "When I was in [hospital]…it was, like—, '*Oh, she's just a junkie looking to get stoned*.' They didn't believe that I was actually suffering and in pain. They thought I was faking it completely..." (Buchman et al., 2016, p. 1398, emphasis added). In another example, upon finally achieving a diagnosis for CFS after many unhelpful encounters with other providers, one female patient wrote, "my husband finally admitted to me the true reason he was divorcing me…*he does not believe me*. He believes that I am depressed and have *deluded myself into thinking that I am ill and convinced doctors, friends and family*…" (CFS, ID#8, emphasis added). Consequences of a loss of perceived credibility stemming from disenfranchising talk include a disruption to intimacy (Briones-Vozmediano et al., 2016; Denny, 2007; LePage & Selk, 2016; Walker, 2006) and romantic relationship (i.e., relational dissolution; Hintz, 2019; LePage & Selk, 2016; Markovic et al., 2008; Wuytack & Miller, 2011), and hesitance to begin new romantic relationships (Marriott & Thompson, 2008). Perceived credibility (as one dimension of PCs) differs from silencing as well as stereotyping (as forms of DT), as a loss of one's perceived credibility is distinct from the talk which catalyzes it. Hence, a loss of one's perceived credibility is argued here to be a consequence of silencing and stereotyping, and as a result implicit or explicit references to credibility appear in these places.

Patients with COPCs also reported a loss of self-esteem, self-worth, and self-confidence and experiencing the introduction of self-doubt and self-blame (Ayling & Ussher, 2008; Björkman et al., 2013; Clarke et al., 2005; Cooper & Gilbert, 2017a; Dixon-Woods & Critchley, 2000; Durham et al., 2010; Håkanson et al., 2010; Hintz, 2019; "Maybe I'm one of those hysterical old cows?", Marit Mengshoel & Heggen, 2006, p. 49; Marriott & Thompson, 2008; Sadowink et al., 2012; Stensland & Sanders, 2018). Not only were patients with COPCs being questioned about the "realness" of their experiences and the existence of the COPC, but this questioning began to extend intrapersonally (i.e., self-talk as a form of PC). As Björkman et al. (2013) explained about female patients with irritable bowel syndrome, "The women reported painful encounters, which led them to *doubt their own experiences* and they began to think that they were imagining their symptoms or that they were going crazy" (p. 1339, emphasis added), while a patient with chronic fatigue syndrome explained, "I think for a while *my self-esteem took a real blow* because of people constantly questioning whether I was sick" (Clarke et al., 2005, p. 1390, emphasis added).

**Ability to exercise rights and privileges.** Disenfranchising talk (Ashe et al., 2017; Dennis et al., 2013; Hallberg & Carlsson, 1998; Hellström et al., 1999; Pryma, 2017; Young et al., 2020) acts as an obstacle to: (a) being afforded support (Armentor, 2017; Glenton, 2003) and being able to exercise illness-related rights and privileges such as (b) accessing resources and future care and/or treatment (Glenton, 2003; Gundström et al., 2017). Aside from losing agency and credibility, losing rights/privileges represents a third form of proximal consequences (PC).

First, DT holds consequences for COPC patients' ability to attain needed support from others. Armentor et al. (2017) aptly summarized how patients with fibromyalgia lost support following negative interactions, "These experiences often left them frustrated and *isolated with…little to no social support* to assist with coping" (p. 468, emphasis added). When this patient finally received a diagnosis, her husband referred to her diagnosing provider as a "quack," affirming his continued perception of her CFS as feigned. This suggests that there are both more immediate (or proximal) outcomes which are specifically tied to the disenfranchising talk (i.e., a patient's loss of credibility and thus support from others), as well as these more distal outcomes which occur later (e.g., the dissolution of a marriage).

Second, DT holds negative consequences for COPC patients' ability to access resources as well as future health care. Examples of these consequences included the denial of disability benefits (Cunningham & Jillings, 2006; Holloway et al., 2007: Pryma, 2017) and workplace accommodations (Juuso, 2014), as well as effects from the codification of disbelief in their medical records which constrained them as they continued to attempt to seek care (Cooper & Gilbert, 2017a; Glenton, 2003). This also occurred through patients' hesitancy to seek future care for the same physical health issue or other mental or physical health issues (Ashe et al., 2017). A patient with fibromyalgia described how "a sense of futility regarding their healthcare" developed following dismissive interactions with their providers, "…if I pulled a muscle *I would probably be unwilling to go to the doctors* because you know they'll just say… 'It's part of your

Fibro …you just have to deal with it'" (Ashe et al., 2017, p. 4, emphasis added). In another example, Pryma (2017) writes that women with fibromyalgia depend on "diagnoses and documentation from medical professionals [which] become the key for the poor to receive disability benefits" (p. 70) although biases against the poor and BIPOC stand as obstacles to this pursuit. Another participant explained, "I certainly *don't dare tell them [doctors] that I'm having a hard time psychologically* now. Then I'll be diagnosed with mental problems instead of back problems" (Glenton, 2003, p. 2247). In another example, a patient with chronic low back pain described their process of seeking care with multiple providers and having their medical records indicating disbelief in their symptoms "follow" them between appointments, "And if you ask to go to some other place and the doctors there (get a copy of the) notes, well, everything becomes a mess then" (p. 2247). In these examples, disenfranchising talk precipitates into consequences in COPC patients' lives.

In sum, proximal consequences of DT include patients with COPCs feeling constrained in their ability to speak and act, losing perceived credibility, and having difficulty exercising rights and privileges such as gaining support and tangible accommodations.

### Negative Goal Inferences: Task, Relational, and Identity Goals

A third key concept refers to how, as a result of experiencing disenfranchising talk in discrete/specific interactions, patients with COPCs sometimes begin to draw more global negative inferences about the conversational goals that others will tend to pursue in <u>future</u> similar interactions with them (Ashe et al., 2017; Buchman et al., 2016; Cunningham & Jillings, 2006; Glenton, 2003; McManimen et al., 2019; Storm Mienna et al., 2014; Wuytack & Miller, 2011; Young et al., 2020). These negative goal inferences (NGIs) can be made about *task goals* (i.e., conversational purposes in the patient-provider interaction related to the evaluation of a patient's symptoms), *relational goals* (i.e., conversational purposes pertaining to the patient-provider relationship) and *identity goals* (i.e., conversational purposes which pertain to patients' own self-concept). Although separate categories here, most of the exemplars below reflect upon how the accomplishment of a communicative task (e.g., seeking care for a COPC) inherently implicates multiple goals (i.e., implications for the patient-provider relationship and patients' identities).

For example, one patient with chronic fatigue syndrome described how she first drew discrete goal inferences after a negative encounter with her provider, "I felt like [my doctor] was making fun of me…It's like she was saying 'Oh, you're just a hypochondriac, you're making all this up, you're not really ill, it's just an excuse for failing in life'" then describing more global goal inferences about future interactions with all doctors, "*Doctors are supposed to be understanding, open-minded, sympathetic and a store of knowledge*….I think that's when I really lost my faith in the medical profession" (Dickson et al., 2007, p. 857). This quotation demonstrates how, when experiencing disenfranchising talk, patients with COPCs may develop negative discrete and global goal inferences (i.e., that *my doctor* and *all doctors* will question my credibility and the legitimacy of my pain). Further, this quotation illustrates the goals the patient had initially expected her provider to attend to (e.g., genuinely trying to understand a patient's pain), what occurred during the interaction, and the implications of that talk in terms of changes in how the patient viewed herself as well as the patient-provider relationship. Similarly, Storm Mienna et al. (2014) reported that women with temporomandibular joint disorder felt as though their "physicians and dentists suspected that their main objective was to be on sick leave or have other secondary gains" (p. 244), representing discrete inferences by patients about pursued goals of their current (and potential future) medical providers. A female patient with endometriosis similarly described her global inferences about doctors' goal tendencies, stating, "They think that you exaggerate, and you need to try hard so that they believe you, because *they don't. You experience that immediately, that they don't believe you*" (Gundström et al., 2018, p. 209, emphasis added).

These exemplars are connected to yet distinct from the concept of DT as described above. Here, based on past experiences in which DT occurred, female patients are making prospective negative inferences about the conversational purposes they anticipate their providers will pursue in future interactions with them. Although there are points of connection between these exemplars and DT dimensions of discrediting and credibility, these exemplars illustrate how having experienced DT changes how female patients expect future interactions to unfold. In sum, these negative goal inferences (NGIs) which pertain to task, relational, and identity goals or conversational purposes represent assumptions made by patients about how they expect future interactions with their provider or a new provider will go (in terms of the goals they anticipate a future provider will pursue in similar interactions with them).

### Enfranchisement Practices: Perpetuation, Critique, Resistance & Transformation

A fourth and final key concept refers to how those subjected to disenfranchising talk respond. In particular, patients with COPCs enact practices which: (a) perpetuate, (b) critique and resist, and (c) transform the status quo as a means of enfranchisement.

**Perpetuation.** First, practices of perpetuation were employed by patients with COPCs to enfranchise themselves again. Practices of perpetuation in a patient-provider context stem from a desire to demonstrate compliance and to enact behaviors consistent with *being a "good patient"* (e.g., being agreeable; Glenton, 2003) as these behaviors are thought to increase the likelihood that health complaints will be taken seriously. For instance, after being dismissed and labeled "neurotic" by medical providers when discussing symptoms of vulvodynia, women described "the need to be obedient ('Whatever anybody tells me to do, I  do it' (Liz)), not challenging incorrect hypotheses of doctors ('But I didn't want to upset him [consultant] by telling him it wasn't my cough cause he was delighted with that' (Bessie)), and continuing to be 'nice' (Liz)" (vulvodynia; Shallcross et al., 2018, p. 970).

However, women who do not look or act "sick enough" may be overlooked for care or be assumed to be managing pain well and thus not in need of care (Armentor, 2017). Conversely, those who look "too sick" or exaggerate symptoms in an effort to procure treatment (Ashe et al., 2017) may be accused of malingering or have pain attributed to a psychological cause (Juuso et al., 2014). Hence, these practices, enacted toward enfranchisement, may actually instead perpetuate the status quo without benefitting those enacting them. Other practices of perpetuation included those such as *giving up on seeking future treatment* or diagnosis (Armentor, 2017; Juuso et al., 2014), which reduces researchers' abilities to accurately estimate the number of patients affected by COPCs (and thus argue for the importance of its study) and *accepting purely psychological explanations* for pain (Cooper & Gilbert, 2017a).

**Critique and Resistance.** Second, practices of critique and resistance were also employed by patients with COPCs toward enfranchisement again. Patients with COPCs *leveled critiques at various aspects of the diagnostic process*, such as medical providers' poor knowledge about COPCs (Whelan, 2007), the poor quality of care they received (Young et al., 2020), unhelpful advice offered (Markovic et al. 2008), the use of psychological explanations for their pain (Björkman et al., 2016), and accusations about ulterior motives for seeking care (Storm Mienna et al., 2014). For instance, one woman with endometriosis who was told by her doctor to "have a baby" to alleviate her endometriosis pain retorted, "Yeah, the first bloke that comes along, I'll take him, no worries" (Markovic et al., 2008, p. 352), while another woman with endometriosis offered this critique, "most doctors are not informed enough [about endometriosis" (Whelan, 2007, p. 964). In another example, a woman with temporomandibular joint disorder was accused by her provider of trying to get out of work and offered this rejoinder, "Yeah, he [doctor] was really stupid, in my opinion" (Storm Mienna et al., 2014, p. 245).

In response to disenfranchising talk, patients with COPCs also enacted practices of resistance as a means of enfranchisement. For instance, as patients with COPCs are subjected to talk which contests whether and to what extent their conditions, symptoms and experiences are "real," patients resisted the status quo by *engaging in the counter-emplotment of facts* through research and self-advocacy (Hintz, 2019; Whelan, 2007; Young  et al., 2020), and tracking health symptoms to gather self-evidence about the validity of symptoms (e.g., tracking the co-occurrence of endometriosis pain and the menstrual cycle; Cox et al., 2003). One patient with vulvodynia noted that her "'own research became her rescue' and that 'you have to educate yourself about your health issues and then demand the right therapy'" (Young & Miller, 2019, p. 7). In another example, two patients with endometriosis noted that "you have to be your own doctor" (Young et al., 2020, p. 26) and that "you...need to be an advocate for yourself" (Young et al., 2020, p. 32). As disenfranchisement operates in part through silencing, *seeking a second opinion* (Cox et al., 2003; Young et al., 2020), continuing to pursue diagnosis (Ashe et al., 2017), and refusing medications such as anti-depressants (Dickson et al., 2007; Granero-Molina et al., 2018) were means of resistance, particularly when such actions could result in being "fired" from a medical clinic for non-compliance (Dickson et al., 2007). These are practices of resistance (Suter, 2016, 2018) because they are efforts to challenge silencing and assertions about the "non-realness" of pain which constitute the status quo.

**Transformation.** Patients with COPCs also enacted practices which sought to transform the status quo toward enfranchisement. A first practice involved *reducing the likelihood of interacting* with those producing disenfranchising talk, which often involved changes to patients' lives. For instance, patients with COPCs described pruning unhelpful connections with friends who did not believe their pain, choosing instead to only speak with those who were supportive (e.g., "I've sorted out everybody in my family that would be helpful or not helpful. The difference with friends—if they're not helpful you don't have to talk to them"; Clarke & Iphofen, 2005, p. 1391), and women with vulvodynia decentered the importance of pursuing romantic and hetero(sexual) partnerships and continuing to have penetrative intercourse (Hintz, 2019).

Some patients also elected to *pursue alternative and non-Western forms of medicine* as a means of removing the possibility that providers would doubt their accounts of pain (Cox et al., 2003). Further, others enacted specific communicative practices which shifted the communicative context in which talk occurred without changing the interactional other. For instance, patients with fibromyalgia stopped acknowledging providers' assertions about whether or not fibromyalgia existed, instead emphasizing the large number of other patients reporting the same symptoms and invoking other forms of evidence external to the conversation as a means of no longer feeding into such debates (Briones-Vozmediano et al., 2018). By changing the conditions which lead to disenfranchising interactions and shifting the communicative context in which such interactions occurred (similar to Goldsmith's (2019) notion of environmental resources), patients with COPCs attempted to transform the status quo. These practices are responses to CD that have implications for the processes that perpetuate and challenge CD. In that sense, these practices may be a part of CD and yet distinct from the conditions which create CD and lead to DT in the first place. Next, a discussion of the findings of study one is offered.

## Study One Discussion

This study one discussion first discusses the line of argument resulting from the meta-synthesis before offering a conceptual model and discussion of the process and constructs of CD.

### Line of Argument

A meta-synthesis ultimately produces a "line of argument" which summarizes the findings of the review (France et al., 2014). To review, such a line of argument can be either a "reciprocal" or "refutational" synthesis, which reflects the extent to which the findings produced by analyzing these articles "agree" or "disagree" with one another (in terms of whether there are similar or competing conceptualizations of key constructs at play) about the selected phenomenon. The line of argument is a sort of "logic" which undergirds *why* various articles agree or disagree (France et al., 2014). A summary of this line of argument is overviewed here and is further developed in the construct explication section which follows.

This analysis demonstrates that study findings for the most part are complementary and do not refute one another. Put differently, most studies contribute to an overarching consensus about what the features of disenfranchising talk experienced by female patients with COPCs are, what happens (both in terms of proximal consequences and negative goal inferences) to those patients subjected to this talk, and what female patients do in response to this talk. One exception is in terms of how participants describe (and study authors interpret) responses to disenfranchising talk. For instance, seeking a second opinion was often described as a means of defiant resistance by patients while at the same time study authors noted that patients perceived to be "doctor shoppers" may have roused the suspicions of their providers. Otherwise, findings from across these 83 studies demonstrate contribute to a coherent narrative about the experience of navigating challenging conversations with important others as a COPC patient.

Hence, following this meta-synthesis, we can more firmly make claims about the negative interactions which patients with COPCs experience. As has been demonstrated above, these findings indicate that discourses about female patients and patients with chronic pain are invoked in talk about COPCs which contest what experiences and responses to those experiences are “real,” and result in a variety of negative consequences. This process unfolds through three dimensions of DT (discrediting, silencing, and stereotyping) and results in negative proximal consequences regarding patients’ agency, perceived credibility, and ability to exercise rights and privileges. When experiencing this disenfranchising talk, patients with COPCs first draw discrete inferences about the task, relational, and identity goal tendencies of specific interactional others which, over time and across subsequent interactions in which pain or its effects are discussed, coalesce into more global inferences about general others’ goal tendencies. In response to disenfranchising talk, patients with COPCs may enact practices in an effort toward enfranchisement which perpetuate, critique, resist, and/or transform the status quo. A discussion of these findings is next offered which moves these findings toward construct explication.

## Discussion: Conceptual Model of TCD: Moving Toward Construct Explication

Building from this line of argument and the third-order constructs which have emerged in the meta-synthesis, a conceptual model of TCD built upon these findings is next proposed in Figure 3. Then, each part of Figure 3 is described and explained in the sections which follow (and this explanation for Figure 3 is summarized in Table 6). This section lays the groundwork for the construct explication and scale development work which follows in chapter four. See Appendix H for a summative glossary of TCD terms. Note that Figure 3 represents the entire theoretical process of TCD (which includes distal outcomes not directly related to CD), while CD is represented by disenfranchising talk itself (DT) and its proximal consequences.

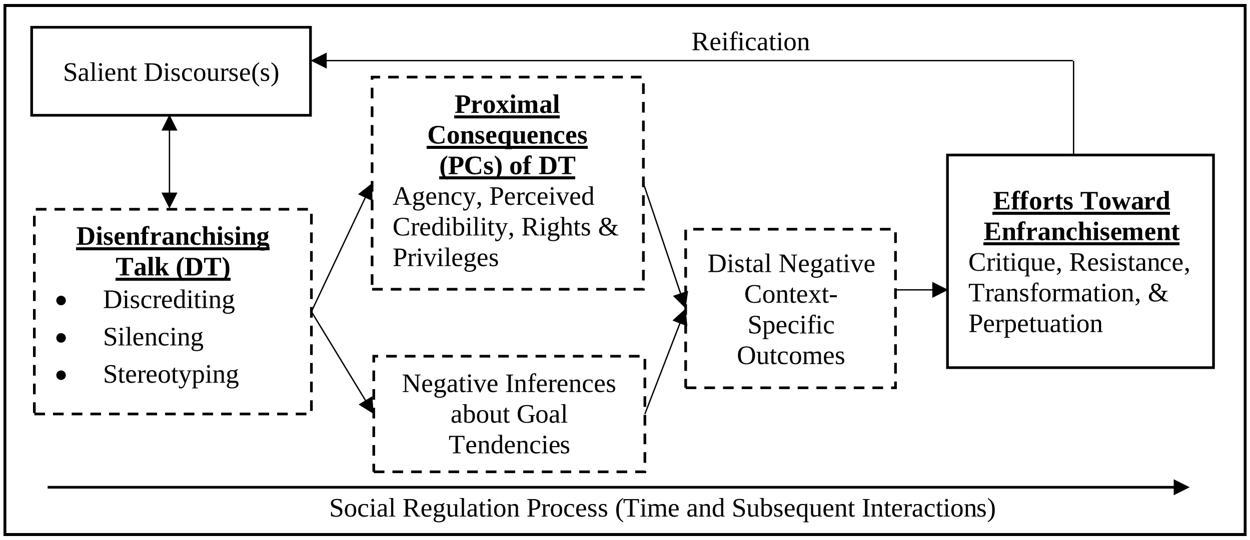

**Figure 3.** Conceptual Process Model of TCD Without Specific Distal Outcomes.

Notice that Figure 3 does not attempt to trace patients' paths through diagnosis from symptom onset. The implied reasoning that diagnosis is a desired end state prevails as dominant in health fields and in the articles included in the meta-synthesis. However, this meta-synthesis confirms that patients' experiences of disenfranchisement do not relate only to the process of seeking diagnosis and do not end when a diagnosis has been reached, a perspective contrary to that proposed by the literature on symptom invalidation (e.g., Bontempo, 2019) which is closest conceptually to CD. Disenfranchising talk is also not only a result of "misdiagnosis" in this context, as the term misdiagnosis implies that there is extant knowledge about COPCs which exists but is not being considered (Mishel, 1990). Hence, efforts toward "improving diagnosis" will not totally resolve the issues faced by female patients with these conditions. In the context of COPCs, a dearth of existing knowledge opens the door to disenfranchisement, and pertinent discourses about gender and chronic pain are called upon to mobilize the disenfranchisement, hence a process model which maps it would not center the diagnostic process. Further, patients' experiences of CD do not end after a diagnosis has been reached (as others may still engage in

DT even when an official “diagnosis” has been made). The implications of this shift in thinking are further clarified in the description of the model which follows.

Also note that Figure 3 does not assume that all phases of the process can be quantified nor can one project encompass all parts of the model. Put differently, not everything that “counts” about TCD can be “counted.” For instance, although participants can be asked to quantitatively reflect on the extent to which stereotypes emerging from discourses about their gender and chronic pain condition have been called upon in past interactions, assessing how those instances of talk *reifiy discourse* is less amenable to quantitative approaches. Hence, a TCD analysis is inherently mixed method, where qualitative data must be included to lend its elucidatory muscle toward addressing other portions of the theory. This also ensures that research about these vulnerable populations continues to be held accountable to their lived experiences. This is of particular importance given that how TCD unfolds will change over time, as disenfranchisement contexts of most interest shift and change (e.g., HIV/AIDS garnered more, and different, attention several decades ago that it does today; Ray, 1996a).

### Social Regulation Process

The first part of Figure 3 which will be discussed is the bottom arrow which represents the assumption that TCD is a social regulation process (see Doka, 1999) which unfolds across time and subsequent interactions. Given the findings of the meta-synthesis, TCD assumes that individuals, relationships, identities, experiences, and our reactions to those experiences (i.e., how a person “copes” with an experience; Doka, 1999) are *socially regulated*, a broader term for Doka’s (1999) concept of “grieving rules” in disenfranchised grief contexts, meaning that these *targets of DT* are subjected to social interactions reinforce rules which dictate what is acceptable or what “should” be. This reliance on social regulation makes disenfranchisement possible.

Otherwise, when experiencing disenfranchising talk, individuals could merely ignore or brush aside its consequences. For instance, a patient's experience of illness as well as how they respond to or manage that illness may become targets of DT. This means that they are first negotiated with others either: (a) *willingly* by the person subjected to disenfranchisement or, (b) *unwillingly* through unwanted interactions with others, such as "bingos" experienced by childfree individuals (Hintz & Brown, 2020). Such interactions may be entered into by those subjected to DT to achieve communicative purposes such as eliciting support or receiving validation or to avoid undesirable implications for our identities and relationships. Such interactions may be entered into by others to achieve communicative purposes such as imposing social sanctions. As findings from the meta-synthesis indicate, social regulation can occur when individuals subjected to DT interface with *specific others* (e.g., a friend, family member, romantic partner, work colleague, or doctor), *institutional others* (e.g., nursing home staff, insurance company representatives) as well as *generalized others* (e.g., the mass media, a social media audience). These specific, institutional, and generalized others may be "producers" of disenfranchising talk.

These findings confirm that disenfranchisement is constituted through talk (i.e., the model explores "the process of CD" rather than "disenfranchised populations"). Hence, talk is both a means for disenfranchisement and enfranchisement again, and individuals *rely upon* social regulation to avoid disenfranchisement (and in the process of doing so may become disenfranchised). For instance, patients with COPCs must engage in potentially disenfranchising interactions in order to procure support from close others as well as diagnosis and treatment, however these interactions also create opportunity for disenfranchisement to occur. In this way, disenfranchisement is a cumulative amalgamation of all interactions in which the target of DT is discussed with others, described in this dissertation as *cumulative illness-course* *disenfranchisement*, or global perceptions of disenfranchisement which arise across interactions with important others (i.e., mostly medical providers) throughout the course of managing pain.

This social regulation process points to myriad possibilities for TCD in communication studies, particularly in health, interpersonal, and family communication contexts, as our interpersonal and familial relationships, forms, and identities, and our health experiences are socially regulated. TCD is also a critical framework, meaning that it aims to facilitate critiques of the status quo, capture inequities, and spur social change. Hence, scholars must utilize findings of a TCD analysis to advocate for both *first-order changes* (changes in the relations which constitute CD but not in the conditions which enable CD to occur) and *second-order changes* (which alter the overarching systems of meaning that create the conditions for CD to occur; see Watzlawick et al., 1974). First-order changes address common-sense problems, such as changing the discursive practices in relations which both constitute and respond to CD. For example, if providers often silence or discredit women who disclose symptoms consistent with CFS, then medical schools can teach residents to listen with empathy as well as acknowledge the limitations of existing medical knowledge about CFS. Pathways to second-order change exist through challenging and reframing the same discursive and material conditions from which CD emerges and to which it contributes, such as systems of funding that lead to less medical research into conditions that affect primarily women.

### Disenfranchising Talk (DT)

We next turn our attention to the “Disenfranchising Talk (DT)” and connected “Salient Discourses” boxes of Figure 3. In DT, individuals call upon salient discourses to make knowledge claims which separate who is and is not “really” in pain. Hence, CD is fundamentally about these systems of meaning, not only individual behavior. TCD assumes that three particular discursive practices (i.e., *disenfranchising talk [DT]*) are employed which facilitate this: (a) discrediting, (b) silencing, and (c) stereotyping. These three discursive practices will serve as dimensions of a measure of DT in the next chapter.

First, these knowledge claims may function to *discredit* a person's relationship, identity, experience, or reaction to an experience by questioning the "realness" of whether: (a) the target of DT is a significant issue/problem (b) the target of DT could be experienced by a person in terms of its effect on their life as they claim, and (c) the target of DT exists at all. These possibilities encompass many of the "primitive terms" used to describe disenfranchising interactions experienced by women with COPCs in the meta-synthesis. For example, in this context, questioning the very existence of pain (e.g., "it's all in your head") or how a person reacts to or manages their pain (e.g., "I see that you are employed. If you were really sick you couldn't work") may constitute "disbelief," while downplaying the severity of pain (e.g., "all women have period cramps") constitutes "normalizing" it and questioning a person's account of their pain (e.g., "if you have vulvodynia, you don't have pain with urination") is "invalidating" it. Hence, through this heuristic framework of discrediting, all possibilities for disenfranchising talk are encompassed and hence a unified framework addresses the conceptual fragmentation which at present prevents meaningful cross-condition and cross-study assessments of findings related to patients' experiences of COPCs.

Second, TCD assumes that those producing disenfranchising talk also promote the present and future *silencing* of talk about the target of DT. For example, a female patient with COPCs who is told by someone that they are "sick of hearing about" or advised that she should not talk about her pain is discouraged from discussing it. Others may also directly obstruct or prevent a person from talking about her pain. For example, a female patient with COPCs may be interrupted, spoken over, ignored, or not given time to speak about her pain in an interaction with others. Silencing sustains discursive operations of power by reducing the possibility that the discourse will be challenged and limiting the means for doing so.

Finally, when discourses are invoked in talk, talk perpetuates the *stereotypes* which are derived from those the system(s) of meaning and in doing so sustains the future possibility of disenfranchisement. For example, calling upon the discourse of hysteria (i.e., stereotypes that women are melodramatic, theatrical, attention-seekers who are feigning illness to shirk ascribed duties) to evaluate women's health complaints as "not real" forwards this stereotype as a plausible explanation for women's accounts of pain. In addition, an invoked discourse about chronic pain patients may result in stereotypes including that women are seeking drugs, are malingering, or are making the pain out to be worse than it really is in an effort to be excused from school or work or receive disability benefits. Multiple discourses may be invoked in talk, as an individual may exist at the intersection of these multiple discourses (e.g., being a woman with chronic pain) and thus may be further disenfranchised (Crenshaw, 1991).

### Dual Mediator #1: Proximal Consequences of DT

The next portion of Figure 3 asserts that there are proximal (more immediate) consequences of DT which mediate the relationship between DT and more distal (context-specific) outcomes (e.g., pain catastrophizing). This portion of Figure 3 encourages us to ask about what happens to people whose relationships, identities, and experiences are subjected to DT? TCD assumes that DT results in three interrelated proximal consequences: (a) agency (constraint in one's ability to speak and with whom they can speak about their pain), (b) perceived credibility (of self), and (c) ability to exercise rights and privileges (i.e., to attain material and immaterial things which are desired – to "receive" –, and to act as one is entitled to or was formerly able to without receiving negative consequences – to "do"). These proximal consequences cross task (i.e., communicative), relational, and identity implications. For example, the proximal consequences of perceived credibility (i.e., that disenfranchising talk results in a reduction in perceived credibility) holds implications for how others view me (i.e., as more or less credible; relational implication), how I view myself (identity implication), and also thus how I am able to (or choose to) talk about the target of DT with others (task implication). Thus, proximal consequences may either be *imposed upon* those subjected to DT (as a direct consequence of disenfranchising votes) or may be *self-imposed* (as a result of global inferences about goal tendencies, see below). For example, task-related implications related to perceived credibility may be imposed by others (e.g., I am *less able* to talk to others about the target of DT because they do not view me as credible), or self-imposed (e.g., I *choose not to* talk to others about the target of DT because they will not view me as credible). These proximal consequences comprise a measure in the next chapter.

### Dual Mediator #2: Negative Goal Inferences About Goal Tendencies

The other mediator of the relationship between DT and distal outcomes in Figure 3 is "Negative Goal Inferences about Goal Tendencies," which assesses how those subjected to DT perceive it and with what outcomes. TCD assumes that those subjected to DT make discrete retrospective inferences about the task, relational, and identity goals that others have tended to pursue in previous interactions in which CD has occurred and will likely pursue in future interactions. For instance, a woman with COPCs who has a negative encounter with a medical provider might make an inference that her provider did not attempt to work together with her to understand her pain (a relational goal) or treat her as though she was a trustworthy person (identity goal). TCD assumes that, as those subjected to DT continue to discuss the target of DT and interface with others across time, negative global inferences about these goal tendencies of others emerge (Caughlin, 2010). Hence, an awareness of one's disenfranchisement emerges from a combination of these experiences and perceptions of the goals that others will tend to pursue in the future. For this reason, task, relational, and identity goals form the basis for the measure of negative goal inferences (NGIs) developed in the next chapter.

### Distal Context-Specific Negative Outcomes

Figure 3 next suggests that DT has both a direct relationship with distal context-specific negative outcomes, and that this relationship is mediated by both negative goal inferences and proximal consequences of DT. The context-specific outcomes of most salience for this study are described in the next chapter, where the process by which they were identified is explained. Examples of these context-specific outcomes include pain catastrophizing, pain disability, and suicidal ideation.

### Efforts Toward Enfranchisement and Reification

Finally, a last part of Figure 3, "Efforts Toward Enfranchisement" suggests that individuals subjected to DT respond to disenfranchisement (and its proximal consequences) may enact discourses and practices which perpetuate the status quo and/or that critique, resist, and transform that status quo. For instance, when women with COPCs doubt their own accounts of the chronic pain they have reported to others, they are perpetuating the status quo and reifying the discourses to which they have been subjected. TCD asserts that individuals who perpetuate the disenfranchisement are complicit in reifying the discourses to which they are subjected in an effort to enfranchise themselves (e.g., trying to act like a "good patient" to have symptoms taken seriously). Conversely, women may reject the notion that they are to blame for their pain, a means of resistance, and continue to speak to others despite social sanctions for doing so.

However, individuals' ability to enact efforts toward enfranchisement are constrained as a result of disenfranchisement. Individuals' efforts toward enfranchisement may be drawn upon by others to reify the discourses to which they are subjected. For example, continued efforts to discuss chronic pain with others may be reinterpreted as further evidence for the delusions to which pain was initially attributed. This assumption most clearly demonstrates the recursive nature of the process of CD, where power operates through discourse as both a means through which disenfranchisement occurs and also a means of sustaining the effects of disenfranchisement. This operates often even despite individuals' efforts toward enfranchising themselves and the target of DT, suggesting the importance of second-order change. See Table 7.

**Table 7.** Summary of Conceptual Model of CD

| **Part of Figure 3** | **Explanation** | **Summary of Key Points** |
|---|---|---|
| Social Regulation Process | Individuals, relationships, familial forms, identities, as well as our experiences and management of those experiences are socially regulated through communication and are thus potential targets of CD. | • A reliance on social regulation creates the conditions for CD to occur.<br>• The social regulation of targets of CD represents a process which is cumulative – unfolding across time and interactions.<br>• All individuals are vulnerable (whether by birth or circumstance) to experiencing CD and are thus only "temporarily enfranchised." |
| Disenfranchising Talk (DT) | Power operates though Discourse – through systems of meaning invoked when making knowledge claims about whose/what types of relationships, families, experiences, etc., are or are not "real." This occurs through three particular discursive practices in disenfranchising talk (DT): (a) discrediting, (b) silencing, and (c) stereotyping. | • Interactants making knowledge claims invoke salient cultural Discourses.<br>• Knowledge claims may contest the "realness" of the significance of the target of DT or the effect of the target on the person's life, whether a person could experience that target as they claim and in comparison to others, or even the very existence of the target itself (discrediting).<br>• Contestations function as social sanctions and promote the present and future silencing of talk about the target of DT.<br>• When Discourses are invoked in talk, stereotypes derived from these systems of meaning sustain the future possibility of disenfranchisement.<br>• CD is about systems of meaning, not individual behavior because Discourses are called upon to make CD possible. |

**Table 7 (Continued)**

| | | |
|---|---|---|
| Proximal Consequences of DT | Disenfranchising talk results in three proximal consequences: (a) agency, (b) perceived credibility (of self), and (c) ability to exercise rights and privileges. | • Individuals are constrained regarding: (a) whether and with whom they are able to talk about the target of DT (agency), (b) whether they can be perceived as credible by others, (c) whether they can exercise rights and privileges (to attain things desired which may be material or immaterial and act as one is entitled without incurring negative consequence).<br>• Proximal consequences of disenfranchisement operate through both: (a) the imposition of constraint as a means of social sanction, and (b) self-constraint as a result of negative global inferences about goal tendencies. |
| Negative Inferences about Goal Tendencies | Individuals draw inferences about others' task, relational, and identity goal tendencies about others' goal tendencies across subsequent interactions in which the target of DT is discussed. | • Individuals subjected to DT draw assessments about the goals pursued by others in interactions in which the target of DT is discussed.<br>• Those subjected to DT begin by making discrete inferences about the goals that others tend to pursue.<br>• Across time and subsequent interactions in which the target of DT is discussed, global inferences about goals that others will tend to pursue emerge. |
| Efforts Toward Enfranchisement and Reification | In response to proximal consequences of disenfranchisement, individuals enact efforts toward enfranchisement, including: (a) perpetuating the status quo and/or (b) critiquing, resisting, and transforming it. | • Individuals are constrained in their ability to enact efforts toward enfranchisement again. |

# CHAPTER FOUR: SCALE DEVELOPMENT METHOD AND RESULTS

This chapter builds upon the conceptual model offered at the end of the previous chapter by discussing the methods and findings of the initial scale development procedures and construct explication upon which the initial scale development procedures are predicated. More specifically, this chapter begins by describing how data from the qualitative meta-synthesis were utilized to identify search terms for scraping Reddit data. Then, the process by which Reddit data were searched, scraped, and screened for inclusion are described at length. Next, the process by which Reddit data were analyzed for the purposes of item generation and identifying salient outcomes is described. Then, tenets of construct explication are overviewed, followed by a section which explains how concepts which emerged from the meta-synthesis (i.e., those in Figure 3) were operationalized to produce draft measures. Specifically, the remainder of the chapter describes the process by which an initial item pool for several constructs in Figure 3 was developed and reduced, and how salient outcomes were identified and selected, as well as offers a measurement and structural models and concordant proposed hypotheses.

## Identifying Search Terms for Reddit Data

The final sample of 82 articles from the meta-analysis was used to initially review articles and identify in vivo codes of qualitative excerpts which could be used as search terms for Reddit using MAXQDA (2020). Reddit was selected because it is a fast, free, and targeted (Shatz, 2017) site where individuals (i.e., “users”) self-select into online communities which are organized around topics (i.e., “subreddits”), including communities of patients with COPCs. To determine a set of search terms, I began by re-reading the second-order constructs (i.e., study authors’ interpretations of participants' data) to again familiarize myself with these data. Within these sections of the sampled studies, I identified verbs (i.e., words used to describe an action) in sampled articles that were used to characterize interactions had by women with COPCs with important others (mostly medical providers, but sometimes romantic partners or family members), as they comprised a common vernacular from which women with COPCs themselves may draw on when discussing potentially disenfranchising interactions with others (see Table 8).

**Table 8.** Search Terms and Subreddits for Qualitative Review.

| **Search Terms for Qualitative Review (*n* = 25)** | | | | **Subreddits for Review (*n* = 12)** | |
|---|---|---|---|---|---|
| Contest* | Dismiss* | Negat* | Pass* off | /r/BackPain | /r/InterstitialCystitis |
| Diminish* | Doubt* | Normaliz* | Psychologiz* | /r/CFS | /r/Migraine |
| Disbelie* | Fobb* off | Not acknowledg* | Reject* | /r/ChronicPain | /r/TMJ |
| Disconfirm* | Gaslight* | Not believ* | Somaticiz* | /r/Endo | /r/Vulvodynia |
| Discredit* | Ignor* | Not listen* | Trivializ* | /r/Endometriosis | |
| Discriminat* | Invalidat* | Not taken seriously | | /r/Fibromyalgia | |
| Discriminat* against | Medically gaslight* | | | /r/Headache | |
| | | | | /r/IBS | |

Selected verbs were included if they described inferences made by publication authors about the *perceived functions or effects of the interaction* for patients with COPCs. For instance, while the verb "disclosing" appeared in the sample, this verb was not included because it refers to a specific communicative act rather than the effect of an important other's response to disclosure. Further, as CD implies the existence of a communicative act made by an important other, verbs describing communicative actions by patients (such as "disclosing") were not included. This criterion is utilized because the process of CD necessarily implies some relationship with the effects or outcomes of potentially disenfranchising interactions (e.g., to "be disenfranchised" typically means being deprived of the right to vote). In the present case, we are interested in the functions of talk (e.g., a patient was "invalidated") as CD is characterized as a communicative process. For this same reason, verbs used to describe the affective states of patients with COPCs (e.g., angry, confused, hostile) were excluded.

For example, an article by Ballard et al. (2006) described the interactions experienced by women with endometriosis as resulting in the “normalization” and “dismissal” of complaints of pain by their medical providers. Hence, the phrases “normaliz*” and “dismiss*” were the coded units and were added to the list in Table 6 (the asterisks indicate tenseless versions of words which are appropriate for database search terms). Words which appeared to be closely related or synonymous (e.g., disbelieve and not believed; ignored and fobbed off; normalized and trivialized) all were retained in order to ensure that all possible synonyms for verbs used to describe patient interactions in which CD occurred were able to be utilized as search terms for Reddit data (described next).

### Reddit Sampling Procedures

Reddit was first searched for all COPC condition names (e.g., “vulvodynia” and “chronic fatigue syndrome”) to identify relevant subreddits. Fourteen relevant subreddits were initially identified. Three subreddits (/r/FibromyalgiaIsReal, /r/ChronicHeadache, and /r/ChronicBackPain) were removed from further analysis because they were inactive, leaving eleven subreddits in the sample (See Table 6). One general chronic pain subreddit, /r/ChronicPain, was included in the sample to capture patients who had not yet achieved a specific diagnosis. Using the list of search terms generated from the review of the qualitative literature described above, a script was written for the free statistical environment R (The R Project, 2020) which uses the RedditExtractoR package (Rivera, 2020) to scrape Reddit data using a variety of search terms and across multiple subreddits in an automated capacity (Hintz & Betts, under review). Each subreddit was searched using each search term listed in Table 9.

**Table 9.** Results of Reddit Scrape for Posts Across All Subreddits and Search Terms.

| **Search Term** | Back Pain | CFS | Chronic Pain | Endo | Endometriosis | Fibromyalgia | Headache | IBS | Interstitial Cystitis | Migraine | TMJ | Vulvodynia | **Total** |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Normalize | 234 | 236 | 247 | 244 | 246 | 243 | 8 | 247 | 245 | 244 | 239 | 141 | 2574 |
| Not Believed | 87 | 236 | 245 | 244 | 185 | 239 | 2 | 231 | 139 | 239 | 108 | 56 | 2011 |
| Negate | 33 | 228 | 241 | 239 | 146 | 239 | 1 | 239 | 237 | 238 | 54 | 91 | 1986 |
| Not Listened | 16 | 150 | 245 | 240 | 117 | 240 | 0 | 181 | 65 | 238 | 31 | 28 | 1551 |
| Ignore | 44 | 139 | 238 | 170 | 65 | 239 | 2 | 173 | 60 | 204 | 45 | 12 | 1391 |
| Doubt | 21 | 126 | 233 | 169 | 64 | 178 | 1 | 157 | 36 | 161 | 28 | 14 | 1188 |
| Dismiss | 14 | 87 | 231 | 210 | 101 | 176 | 0 | 98 | 47 | 96 | 12 | 16 | 1088 |
| Passed off | 16 | 78 | 212 | 163 | 78 | 120 | 1 | 234 | 28 | 195 | 5 | 2 | 1132 |
| Psychologize | 7 | 183 | 231 | 31 | 16 | 102 | 1 | 152 | 24 | 69 | 26 | 14 | 856 |
| N.Taken Ser. | 6 | 47 | 178 | 112 | 41 | 61 | 0 | 70 | 21 | 78 | 6 | 4 | 624 |
| Reject | 2 | 37 | 69 | 30 | 22 | 45 | 0 | 45 | 4 | 36 | 5 | 4 | 299 |
| Not Acknow. | 1 | 29 | 81 | 22 | 10 | 44 | 0 | 23 | 8 | 30 | 6 | 3 | 257 |
| Diminish | 12 | 28 | 49 | 18 | 7 | 22 | 0 | 31 | 6 | 57 | 12 | 2 | 244 |
| Invalidate | 0 | 24 | 79 | 22 | 12 | 31 | 0 | 7 | 3 | 20 | 2 | 1 | 201 |
| Discriminate | 0 | 10 | 54 | 5 | 0 | 17 | 0 | 7 | 3 | 9 | 2 | 0 | 107 |
| Contest | 2 | 15 | 21 | 1 | 2 | 12 | 0 | 9 | 3 | 5 | 0 | 0 | 70 |
| Fobbed off | 2 | 5 | 7 | 19 | 9 | 11 | 0 | 9 | 2 | 2 | 3 | 0 | 69 |
| Trivialize | 0 | 18 | 19 | 4 | 0 | 5 | 0 | 6 | 2 | 10 | 1 | 1 | 66 |
| Gaslight | 0 | 10 | 13 | 20 | 7 | 9 | 0 | 0 | 0 | 1 | 0 | 1 | 61 |
| Discrim. Ag. | 0 | 4 | 22 | 2 | 0 | 7 | 0 | 1 | 1 | 3 | 2 | 0 | 42 |
| Discredit | 0 | 12 | 3 | 2 | 3 | 6 | 0 | 0 | 0 | 1 | 4 | 0 | 31 |
| Disbelieve | 1 | 6 | 7 | 1 | 1 | 3 | 0 | 0 | 1 | 1 | 0 | 0 | 21 |
| Med. Gasl. | 0 | 1 | 4 | 6 | 3 | 2 | 0 | 0 | 0 | 1 | 0 | 1 | 18 |
| Somaticize | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 1 |
| Disconfirm | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Subtotal | 531 | 1937 | 2970 | 2213 | 1281 | 2290 | 17 | 2159 | 1172 | 2177 | 645 | 482 | 17874 |
| Duplicates | 127 | 795 | 935 | 709 | 464 | 689 | 5 | 648 | 560 | 579 | 177 | 212 | 5900 |
| **Total Post-Duplicate Removal** | **404** | **1142** | **2035** | **1504** | **817** | **1601** | **12** | **1511** | **612** | **1598** | **468** | **270** | **11974** |

Note: N. Taken Ser. = Not Taken Seriously. Not Acknow. = Not Acknowledged. Discrim. Ag. = Discriminated Against. Med. Gasl. = Medically Gaslighted.

The R script automatically searches Reddit for each search term and collects both original posts and any comments which contain keywords, such that original posts and comments represent the dataset initially gathered from Reddit. Data gathered from each individual scrape were saved as an individual file for analysis and the number of comments and posts for each scrape was collected. In total, 17,874 posts and 267,342 of their corresponding comments (2.1 GB of data) were initially extracted from Reddit (see Table 9 for a summary of sampled posts). Microsoft Excel was then used to eliminate 5,900 duplicate posts and all 267,342 comments which possessed identical URLs, (such that the final data collection represents the number of posts in each forum that contained *any* of the search terms but not duplicate posts which contain two or more of the search terms) leaving a new sample of 11,974 posts.

Then, random stratified sampling (Krippendorff, 2018) was employed to reduce the total sample size to two percent (1/50th) of its original size (*n* = 239) while retaining proportionate representativeness by subreddit and sampling term. This was calculated by taking the number of posts at each search term and subreddit intersection, dividing that number by 11,974 (the total number of posts), and then multiplying that value by the number of posts at its intersection. If the proportion of the sample by search term and subreddit was less than 0.5, no posts at the intersection of that subreddit and search term were retained. For example, there were initially 87 posts at the intersection of the search term "Not Believed" and the subreddit "Back Pain," where 87 posts comprised .73% of the total sample of 11,974 posts. As the corresponding number of posts which were included to be proportionate to the total sample (.0073 x 87) was .63 posts, 1 post was retained in the final sample. Conversely, there were only 33 posts at the intersection of the search term "Negate" and the subreddit "Back Pain," where those 33 posts comprised only .27% of the total sample of 11,974 posts. Here, the corresponding number of posts which were included proportionately was 0. At this point, 13 search terms (52%) and 1 subreddit (8.3%) were excluded from the sample because those posts comprised less than 1% of the total sample by proportion. The final sample contained 239 Reddit posts from 11 subreddits and 12 of the most prevalent search terms (i.e., normalize, not believe, negate, not listen, ignore, doubt, dismiss, pass off, psychologize, not taken seriously, not acknowledged, and invalidate). See Table 10 for full information about the final sample of Reddit posts.

**Table 10.** Stratified Random Sample of Reddit Posts Across Subreddits and Search Terms.

| **Search Term** | Back Pain | CFS | Chronic Pain | Endo | Endometriosis | Fibromyalgia | Headache | IBS | Interstitial Cystitis | Migraine | TMJ | Vulvodynia | **Total** |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Normalize | 5 | 5 | 5 | 5 | 5 | 5 | 0 | 5 | 5 | 5 | 5 | 2 | 52 |
| Not Believed | 1 | 5 | 5 | 5 | 3 | 5 | 0 | 5 | 2 | 5 | 1 | 0 | 37 |
| Negate | 0 | 4 | 5 | 5 | 2 | 5 | 0 | 5 | 5 | 5 | 0 | 1 | 37 |
| Not Listened | 0 | 2 | 5 | 5 | 1 | 5 | 0 | 3 | 0 | 5 | 0 | 0 | 26 |
| Ignore | 0 | 2 | 5 | 2 | 0 | 5 | 0 | 3 | 0 | 4 | 0 | 0 | 21 |
| Doubt | 0 | 1 | 5 | 2 | 0 | 3 | 0 | 2 | 0 | 2 | 0 | 0 | 15 |
| Dismiss | 0 | 1 | 5 | 4 | 1 | 3 | 0 | 1 | 0 | 1 | 0 | 0 | 16 |
| Passed off | 0 | 1 | 4 | 2 | 1 | 1 | 0 | 5 | 0 | 3 | 0 | 0 | 17 |
| Psychologize | 0 | 3 | 5 | 0 | 0 | 1 | 0 | 2 | 0 | 0 | 0 | 0 | 11 |
| N.Taken Ser. | 0 | 0 | 3 | 1 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 5 |
| Reject | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Not Acknow. | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 |
| Diminish | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Invalidate | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 |
| Discriminate | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Contest | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Fobbed off | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Trivialize | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Gaslight | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Discrim. Ag. | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Discredit | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Disbelieve | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Med. Gasl. | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Somaticize | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Disconfirm | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| **Total Post-Duplicate Removal** | **6** | **24** | **49** | **31** | **13** | **33** | **0** | **31** | **12** | **31** | **5** | **3** | **239** |

Note: N. Taken Ser. = Not Taken Seriously. Not Acknow. = Not Acknowledged. Discrim. Ag. = Discriminated Against. Med. Gasl. = Medically Gaslighted.

**Analysis of Reddit data.** Reddit data were used as pilot data to assist with the development of an initial item pool as well as which outcomes are of most salience for these populations. Hence, an explicit analysis of Reddit data is not reported. To address the remainder of RQ1 (explicating CD), RQ2 (coding for possible outcomes of CD), and assist in the development of an initial pool of scale items (RQ3), all 239 Reddit posts in the final sample were first read in their entirety. Then, after data immersion had occurred, using MAXQDA (2020), I coded each post for: (a) any outcomes mentioned colloquially by users (e.g., “I developed anxiety,” “I didn’t want to go back to the doctor after that”), as well as (b) *in vivo* statements which could contribute to an initial pool of scale items (e.g., “They told me that I was exaggerating”). These possible outcomes of CD and potential scale items were then combined with coding for the potential outcomes which emerged as a result of the meta-synthesis as described above to facilitate construct explication. All Reddit posts were randomly assigned an ID# to which they are referred below.

## Tenets of Construct Explication

*Explication* (Chaffee, 1991), substantively concerned with validity, is the process by which a concept is defined in relation to other concepts and in terms of its own conceptual definition. Explicating the construct of communicative disenfranchisement is useful for “strengthen[ing] the ties among theory, observation, and research” to guide future inquiry into challenging communicative contexts (Chafee, 1991, p. 2). Although Chafee (1991) writes about the role of explication in post-positivist research, the process of concept explication is also relevant to projects with critical aims. Critical scholarship, although broadly conducted to critique unjust operations of power and thus not upholding objectivity as a regulative ideal (Ono, 2009), can benefit from the process of construct explication, and the results of construct explication procedures can in turn be used to critique unjust operations of power.

To engage in concept explication, the researcher begins by viewing messages as “objects” which have “attributes.” For example, messages in patient-provider contexts (i.e., the objects of interest) may be viewed according to the extent to which positive affect is expressed and communication facilitates patient participation (i.e., attributes; e.g., Venetis et al., 2009). From this point, the researcher begins distilling an abstract concept into meaning by reviewing what has been said about it in the extant literature and determining the "essential elements" of the concept (Chaffee, 1991, p. 26). In this dissertation, construct explication was informed by the meta-synthesis of the extant qualitative literature on patient experiences of COPCs and salient theoretical tenets derived from multiple goals theorizing (e.g., multiple meanings of talk, goal inferences) and the CIFC framework (e.g., interpenetration of the public and private spheres). In particular, major findings from the meta-synthesis formed the basis for articulating TCD below.

## Conceptual Definitions for CD Concepts

This section overviews the development of conceptual definitions and likely factors for each concept emerging from the meta-synthesis and serves as the basis for the description of the item generation section which follows. To move toward item development, the process of CD (not including distal outcomes) has been broken up into three measures: (a) a measure of disenfranchising talk (DT) which measures functions of the talk itself, (b) a measure of the proximal consequences (PCs) of the DT, a first mediator from Figure 3; and (c) a measure of negative inferences about goal tendencies (negative goal inferences; NGIs). An extended example of how each concept and dimension applies in the case of a particular condition (i.e., for a patient with fibromyalgia [FM]) is offered below to illustrate its utility. Table 11 reports conceptual definitions and the likely factors for which items are developed in the next section.

**Table 11.** Conceptual Definitions for Concepts Emerging from Meta-Synthesis.

| Concept | Conceptual Definition | Dimensions |
|---|---|---|
| **Measure of Disenfranchising Talk (DT)** | | |
| Discrediting | Things that others say or do which cause *aspects of the target of DT* to seem false or unreliable. Aspects of the target of DT which can be discredited are: (a) its *significance* (its seriousness and severity), (b) the *experience* of it (how much it affects a person and how a person experiences it in comparison to others), and (c) its *existence* (whether it is real, or whether a real problem exists beyond and above what might be considered "normal"). | 1. Significance (One Factor: Seriousness and Severity)<br>2. Experience (Two Factors: Affect and Comparison)<br>3. Existence (Two Factors: Real and Normal) |
| Silencing | Things others say or do which *discourage* (verbally or implied) or *prevent* (directly) the person subjected to DT from speaking. | 1. Discouraging<br>2. Preventing |
| Stereotyping | Things others say or do which call upon widely held and simplistic explanations for the target of DT. The particular stereotypes called upon vary depending upon the context. In the context of COPCs, stereotypes about: (a) *gender*, and (b) *chronic pain patients* are most salient. | 1. Gender<br>2. Chronic Pain |
| **Measure of Proximal Consequences (PCs) of Disenfranchising Talk** | | |
| Agency | A consequence of DT includes individuals' reduced *ability to talk about the target of DT with others in the future*. In particular, individuals may find that they change *whether they talk about the target of DT* and *to whom they can talk about the target of DT*. | 1. Whether to Talk<br>2. To Whom to Talk |
| Credibility | A consequence of DT includes not being viewed by others as a *credible* person (in terms of one's character and competence). | 1. Character<br>2. Competence |
| Ability to Exercise Rights and Privileges | A consequence of DT includes the reduced ability to exercise rights and privileges, more specifically to: (a) *attain something desired* (which may be material or immaterial) or (b) *act as one is entitled (or was formerly able to) without negative consequence* in relation to the target of DT). | 1. Attain Things Desired<br>2. Act |
| **Measure of Negative Goal Inferences (NGIs)** | | |
| Inferences about Goal Tendencies | Individuals subjected to DT draw inferences about the goals they perceive that others will pursue in interactions with them in future interactions. In particular, inferences are drawn about *task goals* (inferences about communicative purposes related to evaluating health complaints), *relational goals* (inferences about communicative purposes related to the interactants' relationship), and *identity goals* (inferences about communicative purposes related to the identity of the individual subjected to DT). | 1. Task Goals<br>2. Relational Goals<br>3. Identity Goals |

## Developing Initial Item Pool

Now that conceptual definitions each concept and dimension have been offered, procedures for the development of an initial item pool and items for each measure are next discussed. As was previewed in the full description of the conceptual model of TCD outlined in Figure 3 and again in the conceptual definitions section above, I have separated CD into three measures to measure three distinct parts of the CD: (a) disenfranchising talk itself (i.e., DT), (b) proximal consequences of DT, (c) negative inferences about goal tendencies (i.e., negative goal inferences; NGIs) resulting from this talk. A discussion of the distal context-specific outcomes of DT will occur after these draft measures and measurement models are proposed, as these distal outcomes are not a part of CD itself.

Selections of text from MAXQDA coded as “potential scale items” were then reviewed. These selections of text were quotations by Reddit users or participants in qualitative studies of the dimensions and effects of negative interactions in which patients discussed pain with important others, a majority of whom were medical providers, but also family members, friends, romantic partners, and colleagues at work. Of the coded selections of text, 170 *in vivo* items covering all parts of the process were initially generated from the Reddit and article data coded in MAXQDA for both CD (i.e., DT, proximal consequences, NGIs) as well as potential distal outcomes to include. These potential scale items were both first and second-order constructs describing what was done and said in various negative interactions had by patients with COPCs with important others (i.e., mostly medical providers). See Appendix F for a complete list of the items in the initial item pool.

The conceptual definitions generated earlier were then reviewed, and items were sorted such that they were grouped tentatively based upon this theorizing. Guided by DeVellis (2017), enough items were included for each concept such that at least 3 or 4 items would remain for each dimension (likely factor) of each concept after the confirmatory factor analysis had been conducted and item loadings had been assessed. Items within factors were written to be unidimensional. Notice that discrediting and silencing can be written generally, while stereotyping items call upon particular salient discourses (e.g., in the context of COPCs, discourses about female patients and discourses about chronic pain) and are thus highly context dependent. Thus, a scholar looking to utilize this measure of DT would write items for the "stereotyping" subdimension which apply specifically to the context of interest.

Several questions immediately arose in the writing of the draft measures, including whether: (a) to write tenseless items or items in the past tense, (b) to have participants reflect about specific experiences of DT or general illness-course disenfranchisement, (c) to write items such that the "object" of disenfranchising talk was "it" (i.e., the experience of illness and pain) or "me" (i.e., the participant), (d) to write items such that only action or also *the absence* of some action could constitute DT, and (e) to write items in the scale that tap retellings of the interaction itself, participants' perceptions of the interaction, and/or how the interaction made participants feel, and which of these should be included in a measure of DT versus its outcomes.

Questions also arose regarding how to write instructions for these three measures. More specifically, I questioned which type of person (e.g., medical providers, family members, romantic partners) participants should be asked to report about? Given the sustained emphasis on patient-provider interactions in the qualitative literature and the capacity of medical providers to make formal assessments regarding whose illnesses are "real," it is important to distinguish these types of interactions from other types of interactions in which DT may occur. Yet, given the constraints of survey time required when completing the same measure multiple times, and the fact that having spoken to a medical provider is an inclusionary criterion for the survey, I elected to ask participants to report about past experiences with only medical providers. Interactions with other important people types (e.g., romantic partners, family members, employers) will be the subject of future investigations.

I elected to write items in the past tense given that participants would be asked to reflect upon instances in which DT had previously occurred. This meant that participants would be asked to reflect about their *cumulative illness-course disenfranchisement*, such that participants who reported more frequent instances of disenfranchising talk were increasingly constituted as disenfranchised across interactions. Hence a measure of DT will assess not only *whether* specific qualities of talk were present, but also the *frequency with which* those qualities have been experienced by an individual over the course of their illness. Given that the effects of DT extend (in part) to perceptions of credibility (related to participants themselves), items were written both to refer to talk about patients as well as their symptoms. Drawing from the findings of the meta-synthesis completed earlier (where dimensions of DT include silencing and discrediting), the absence of an action is considered a feature of DT when the subject of the disenfranchisement makes some effort to be acknowledged by another person. Put differently, there must be something uttered to "silence" and "discredit" – therefore, for example, another person not bringing something up without the subject of disenfranchisement first being mentioning it would not constitute DT because it is only the absence of action. Finally, while most items are intended to be retrospective reports about the content of the potentially disenfranchising talk, there are also items which assess patients' perceptions of talk.

Although the complete theoretical model (Figure 3) includes the efforts of those subjected to DT toward enfranchisement (i.e., perpetuation, critique, resistance, and transformation), the findings from the qualitative meta-synthesis indicate that attempts to measure these efforts in any heuristic way may be challenging. Put differently, what "counts" as a practice of perpetuation or critique or resistance is highly context-dependent, and the same practices could be viewed as serving multiple purposes depending upon whose perspective is considered. In a future study, adapting Orbe and Lapinski's (2007) two co-cultural theory scales, which assess: (a) individuals' *communication approach* when interfacing with members of a majority group (i.e., assertiveness, aggressiveness, and non-assertiveness), and (b) *preferred outcome* for those interactions (i.e., assimilation, accommodation, and separation) may provide one means of assessing how individuals subjected to DT respond. In particular, these measures may be useful as co-cultural theory recognizes that individuals often make choices between various communicative options, none of which are likely to have uniformly desired outcomes, in part because larger discourses can shape perceptions of those choices.

Using the third-order constructs from Figure 3 which have been defined above, the measure of CD taps the three DT dimensions: (a) discrediting, (b) silencing, and (c) stereotyping. See Table 12 for a 58-item draft scale which taps these three dimensions of DT CD, Table 13 for a 34-item draft scale measuring the three proximal consequences of DT: (a) agency, (b) perceived credibility (adapted from McCroskey and Thompson, 1981), and (c) ability to exercise rights and privileges; and Table 14 for a 20-item draft scale which taps discrete and global inferences about goal tendencies. When reviewing Tables 12-14 below, consider how these scales might function to measure a variety of scenarios in addition to the dismissal of COPC patients' accounts of pain and its effects (the topic of this dissertation), such as a university student reporting sexual assault and being disbelieved, and others "bingoing" childfree individuals about their identity.

Measures of DT and PCs are scored on a scale from *never* (1) to *always* (5), while the measure of NGIs is scored on a 7-point Likert scale ranging from *strongly disagree* (1) to *strongly agree* (7). This was done to assess the frequency of experienced disenfranchising talk (rather than only whether talk occurred at all (i.e., yes/no questions) or individuals' perceptions via the degree of agreement that each item had occurred), assessments about the frequencies of these goals in talk with medical providers, and the frequency of experienced outcomes of CD. This presumes that greater scores on measures of CD and goal inferences indicate greater disenfranchisement. As not all participants experience all domains of disenfranchising talk and outcomes equally (e.g., patients with fibromyalgia may be subjected to more disenfranchising talk about whether pain is “real” than a patient with chronic back pain), this measurement scale meets the conceptual need to assess the ways and extent to which disenfranchisement appears in participants’ illness experiences and to assess relationships with relevant outcomes. Items were written to be more parallel within than between factors, to avoid substantial wording overlap between items, and were reviewed to ensure that all items tapped the dimension of the concept for which they were written and only that dimension.

**Table 12.** Measure of Disenfranchising Talk.

<table>
<tr><td colspan="4">Directions: Since the start of your illness, rate each of the following items in terms of how often they have occurred when you have talked with YOUR DOCTOR(S) IN THE PAST about your pain and/or its effects on your life.<br><br>Across all the interactions with doctors you’ve EVER seen about your pain, how often how often has (or have) YOUR DOCTOR(S)…<br><br><i>Scale = Never (1), Sometimes (2), About half the time (3), Most of the time (4), Always (5). Scoring = Higher scores indicate greater cumulative CD.</i></td></tr>
<tr><td>#</td><td>Item (Order Randomized)</td><td>Dimension</td><td>Concept</td></tr>
<tr><td>1</td><td>Doubted whether the pain is as severe as I have explained it to be.</td><td rowspan="6"><i>Significance: Seriousness and Severity</i></td><td rowspan="11">Discrediting</td></tr>
<tr><td>2</td><td>Suggested that the pain is not really as bad as I say it is.</td></tr>
<tr><td>3</td><td>Doubted how significant the pain is.</td></tr>
<tr><td>4</td><td>Expressed skepticism about how bad the pain really is.</td></tr>
<tr><td>5</td><td>Questioned how severe the pain is.</td></tr>
<tr><td>6</td><td>Questioned whether my pain is as serious as I claim it to be.</td></tr>
<tr><td>7</td><td>Suggested that the pain doesn’t affect me as much as I say it does.</td><td rowspan="5"><i>Experience: How Pain Affects Person</i></td></tr>
<tr><td>8</td><td>Suggested that the pain should not matter to me as much as it does.</td></tr>
<tr><td>9</td><td>Suggested that I shouldn’t think about the pain so much.</td></tr>
<tr><td>10</td><td>Suggested that my description of the pain is exaggerated.</td></tr>
<tr><td>11</td><td>Suggested that I shouldn’t let the pain get to me as much as it does.</td></tr>
</table>

**Table 12 (Continued)**

| | | | |
|---|---|---|---|
| 12 | Suggested that I shouldn’t worry so much about the pain. | | |
| 13 | Claimed that I was letting the pain affect my life more than other people do. | *Experience: How Experienced in Comparison to Others* | |
| 14 | Claimed that I act more disabled by my pain than other people like me. | | |
| 15 | Claimed that people like me should be able to do more than I can do. | | |
| 16 | Claimed that I acted like I was in more pain than other people who are “really” sick. | | |
| 17 | Claimed that I was not acting the way someone in pain would act. | | |
| 18 | Claimed that I am limited more by my pain than other people like me. | | |
| 19 | Said or implied that the pain does not really exist. | *Existence: Realness of the Pain* | |
| 20 | Said or implied that the pain was not real. | | |
| 21 | Said or implied that I was imagining the pain. | | |
| 22 | Said or implied that the pain was all in my head. | | |
| 23 | Said or implied that the pain is not really happening to me. | | |
| 24 | Said or implied that I wasn’t actually in pain. | | |
| 25 | Said or implied that the pain was no cause for concern. | *Existence: Problem Beyond What is Normal* | |
| 26 | Said or implied that the pain is normal. | | |
| 27 | Said or implied that everyone experiences pain. | | |
| 28 | Said or implied that the pain is just a part of being human. | | |
| 29 | Said or implied that everyone has to cope with pain. | | |
| 31 | Tried to get me to stop talking about the pain. | *Discouraging* | Silencing |
| 32 | Told me that they were sick of hearing me talk about the pain. | | |
| 33 | Told me that I shouldn’t talk about the pain so much. | | |
| 34 | Changed the subject when I tried to talk about the pain. | | |
| 35 | Told me that I should not have talked about the pain. | | |
| 36 | Acted uninterested in hearing about the pain. | | |
| 37 | Acted preoccupied with their computer or tablet when I tried to talk about the pain. | | |
| 38 | Rolled their eyes when I started to talk about the pain. | | |
| 39 | Criticized me when I mentioned the pain. | | |
| 40 | Interrupted me when I tried to talk about the pain. | *Preventing* | |
| 41 | Ignored me when I brought the pain up. | | |
| 42 | Talked over me when I tried to talk about the pain. | | |
| 43 | Did not give me an opportunity to talk about the pain. | | |
| 44 | Prevented me from talking about the pain. | | |
| 45 | Made it impossible for me to talk about the pain. | | |
| 46 | Suggested that I was being overly emotional. | *Gender* | Stereotyping |
| 47 | Suggested that I was just too sensitive. | | |
| 48 | Suggested that I was being dramatic. | | |
| 49 | Suggested that I was just weak. | | |
| 50 | Suggested that I was just looking for attention. | | |
| 51 | Suggested that I wanted people to feel sorry for me. | | |
| 52 | Assumed that I had an ulterior motive for talking about the pain. | *Chronic Pain (Malingering* | |
| 53 | Assumed that I was just trying to get pain medication. | | |
| 54 | Assumed that I was a drug seeker. | | |
| 55 | Assumed that I was up to no good. | | |
| 56 | Assumed that I was trying to get out of work or school. | | |
| 57 | Assumed that I was trying to get disability benefits. | | |
| 58 | Assumed that I was using the pain to avoid my responsibilities. | | |

**Table 13.** Measure of Proximal Consequences of Disenfranchising Talk.

<table>
<tr><td colspan="4">Directions: Please rate your agreement with each of the following statements. Answer the following questions in terms of whether negative interactions with your doctors changed how you approached conversations with <b><u>both doctors and other people you know</u></b> from then on.<br><br><b>Negative interactions in the past with MY DOCTOR(S) in which we talked about [my pain] have…</b><br><br><i>Scale = Strongly Disagree (1) to Strongly Agree (7)</i></td></tr>
<tr><th>#</th><th>Item</th><th>Dimension</th><th>Concept</th></tr>
<tr><td>1</td><td>Made me hesitant to bring the pain up in future conversations.</td><td rowspan="6"><i>Whether to Talk</i></td><td rowspan="12"><b>Agency</b></td></tr>
<tr><td>2</td><td>Made me talk less about the pain with others moving forward.</td></tr>
<tr><td>3</td><td>Made it harder for me to talk about the pain with others after that.</td></tr>
<tr><td>4</td><td>Made it less likely that I will talk about the pain from now on.</td></tr>
<tr><td>5</td><td>Made me think twice before talking about my pain in the future.</td></tr>
<tr><td>6</td><td>Made me isolate myself from others to avoid talking about my pain.</td></tr>
<tr><td>7</td><td>Made me choose carefully who to talk to about the pain in the future.</td><td rowspan="6"><i>To Whom to Talk</i></td></tr>
<tr><td>8</td><td>Made me distrustful of others who I might talk to about the pain.</td></tr>
<tr><td>9</td><td>Made me more selective about who I talk to about the pain in the future.</td></tr>
<tr><td>10</td><td>Made me change what I said to others about my pain moving forward.</td></tr>
<tr><td>11</td><td>Made me stop talking about the pain with some people I know.</td></tr>
<tr><td>12</td><td>Made me hesitant to talk about the pain with someone new in the future.</td></tr>
<tr><td colspan="4">Directions: Answer the following questions in terms of whether negative interactions with your doctors changed how both doctors and other people viewed you from then on.<br><br><b>Negative interactions in the past with MY DOCTOR(S) in which we talked about [my pain] have…</b></td></tr>
<tr><td>13</td><td>Made me appear to be a dishonest person to others.</td><td rowspan="5"><i>Character</i></td><td rowspan="10"><b>Credibility</b><br><i>(Adapted from McCroskey & Young, 1981)</i></td></tr>
<tr><td>14</td><td>Made me appear to be unworthy of sympathy to others.</td></tr>
<tr><td>15</td><td>Made me seem untrustworthy to others.</td></tr>
<tr><td>16</td><td>Made me appear to be a person of low character to others.</td></tr>
<tr><td>17</td><td>Made me look like a bad person to others.</td></tr>
<tr><td>18</td><td>Made me look unintelligent to others.</td><td rowspan="5"><i>Competence</i></td></tr>
<tr><td>19</td><td>Made me appear to be uninformed to others.</td></tr>
<tr><td>20</td><td>Made me seem incompetent to others.</td></tr>
<tr><td>21</td><td>Made me appear to be stupid to others.</td></tr>
<tr><td>22</td><td>Made me look irrational to others.</td></tr>
<tr><td colspan="4">Directions: Answer the following questions in terms of whether negative interactions with your doctors changed your ability to get what you needed from then on.<br><br><b>Negative interactions in the past with MY DOCTOR(S) in which we talked about [my pain] have…</b></td></tr>
<tr><td>23</td><td>Made me lose out on opportunities in my social life or at work.</td><td rowspan="12"><i>Attain Care, Support, and Resources</i></td><td rowspan="12"><b>Ability to Exercise Rights and Privileges</b></td></tr>
<tr><td>24</td><td>Made it harder for me to receive what I needed to get by.</td></tr>
<tr><td>25</td><td>Made it harder for me to get help when I needed it.</td></tr>
<tr><td>26</td><td>Made it harder for me to find support from others.</td></tr>
<tr><td>27</td><td>Made it harder for me to access disability benefits.</td></tr>
<tr><td>28</td><td>Made it harder for me to receive a diagnosis.</td></tr>
<tr><td>29</td><td>Made it harder for me to be treated for my pain.</td></tr>
<tr><td>30</td><td>Made it harder for me to be excused from work or school.</td></tr>
<tr><td>31</td><td>Made it harder for me to seek future care for my pain.</td></tr>
<tr><td>32</td><td>Made me less likely to seek care for other physical health issues moving forward.</td></tr>
<tr><td>33</td><td>Made me hesitant to seek care for any mental health concerns which may arise in the future.</td></tr>
<tr><td>34</td><td>Made me hesitant to ask for help to cope with my pain.</td></tr>
</table>

**Table 14.** Measure of Discrete and Global Inferences about Goal Tendencies.

Directions: Please fill out the scale below about **your pain and/or its effects on your life.**

**If/When I talk to DOCTORS about my pain IN THE FUTURE, I EXPECT that they will…**

*Scale = Strongly Disagree (1) to Strongly Agree (7). Scoring = LOWER scores indicate greater discrete and global negative inferences about the goal tendencies of specific and nonspecific others.*

| # | Item | Dimensions |
|---|---|---|
| 1 | …Talk to me as though I am really in pain. | **Task Goals** |
| 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 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. | **Relational Goals** |
| 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 | …Commit to helping me even if it is challenging. | |
| 13 | …Treat me the same as they would treat someone WITHOUT chronic pain. | |
| 14 | …Treat me the same as they would treat a man. | |
| 15 | …View me as a competent person when I describe my pain. | **Identity Goals** |
| 16 | …Assume that I am a trustworthy person when I talk about my pain. | |
| 17 | …View me as credible when I discuss my pain. | |
| 18 | …Assume that my motivations for talking about my pain are honest. | |
| 19 | …View me as a person who knows what they are talking about regarding my pain. | |
| 20 | …Assume that I am a good person when I talk about my pain. | |

A measurement models are displayed in Figure 4 and 5 which illustrates DT, whereby disenfranchising talk (i.e., discrediting, silencing, and stereotyping) and proximal consequences (i.e., agency, credibility, and rights and privileges) together comprise CD. This is because, given its name, a measure of *communicative disenfranchisement* should enumerate both what disenfranchising talk "is" and what that talk "does" to those subjected to it.

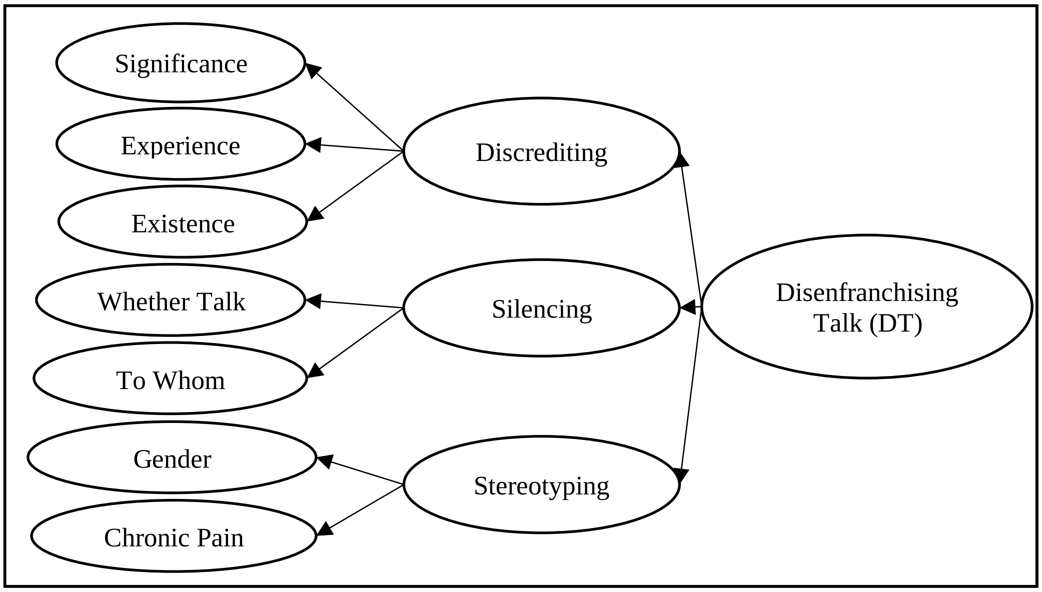

**Figure 4.** Proposed Measurement Model of DT.

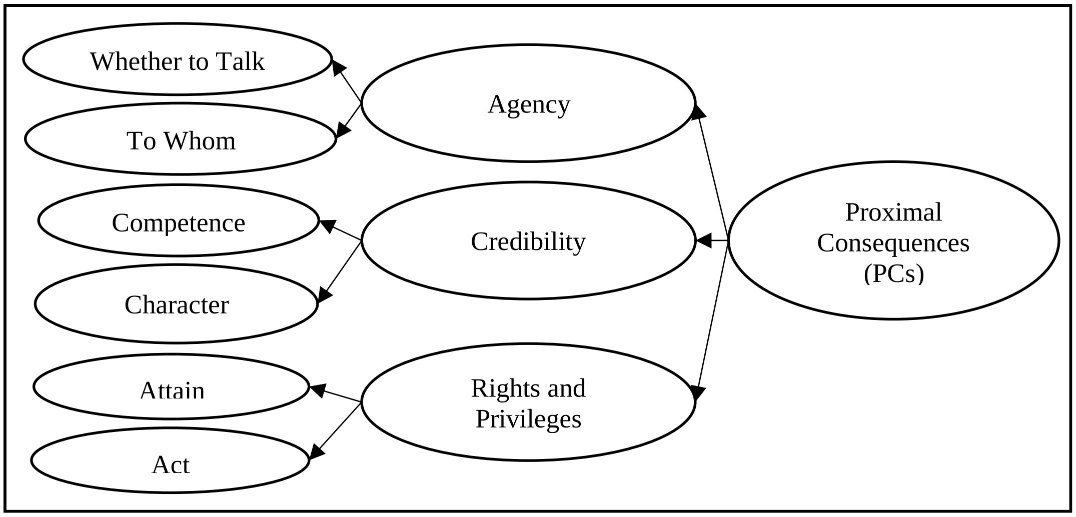

**Figure 5.** Proposed Measurement Model of Proximal Consequences.

Next, Figure 6 offers a second-order measurement model in which three latent factors are embedded within a higher-level NGI latent construct.

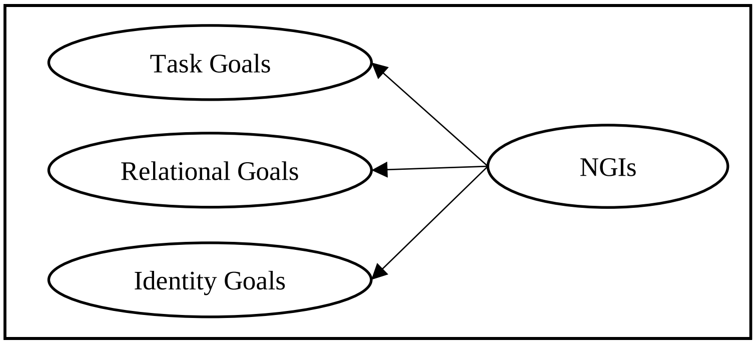

**Figure 6.** Measurement Model for Three-Factor Second-Order Goal Inferences Model.

Next, theoretically salient outcomes and hypotheses for an abbreviated theoretical model of TCD (which does not include participants' efforts toward enfranchisement) will be discussed. A proposed structural model which hypothesizes relationships to these outcomes is also offered.

### Salient Distal Context-Specific Outcomes

Potential distal outcomes which were coded in MAXQDA from sampled qualitative articles and Reddit data were reviewed. A total of 26 outcomes of the talk specifically (rather than only outcomes associated with chronic pain symptoms or life effects) were initially identified via coding with varying degrees of estimated frequency (see Appendix G for a complete list of coded outcomes). Some outcomes without suitable existing measures (e.g., which tap, for example, participants' increased hesitancy to talk with others about their pain or seek future medical care) are represented in the above draft scales.

A variety of published articles and Reddit users specifically or colloquially mentioned *poorer general mental health* as a result of disenfranchising talk, related concepts including hopelessness, loss of self-esteem, and self-doubt (among others). Hence, Snaith's (2003) 14-item Hospital Anxiety and Depression Scale (HADS) was included as a salient outcome, as it offers a brief measure of a person's anxiety and depression status. A single-item measure of *overall health status* (i.e., self-rated health; SRH-5; Eriksson et al., 2001) was also included (i.e., "How would you rate your general health status?”). A *loss of trust in the healthcare system* was the second most common outcome noted in the data. As such, a 12-item adapted form of the Group-Based Medical Mistrust Scale (Thompson et al., 2004), originally created to measure perceived race-based discrimination in health care settings, was included to assess participants’ perceptions of how chronic pain patients in general are treated by medical providers. *Suicidal ideation* was tied for the second most mentioned outcome noted as a result of disenfranchising talk in the data. Thus, the 4-item Suicidal Behaviors Questionnaire (Osman et al., 2001) was included.

Other contextually salient outcomes were also included: (a) *pain catastrophizing* as measured by the 13-item Pain Catastrophizing Scale (PCS; Sullivan et al., 1995) to measure patients’ negative pain-related cognitions across domains of rumination, issue magnification, and helplessness; (b) *pain severity* as measured by the 3-item Pain Severity Subscale of the West Haven-Yale Multidimensional Pain Inventory (Kerns et al., 1985), and (c) *pain disability* as measured by the 7-item Pain Disability Index which assesses the extent of the impact of pain on a variety of life domains (which were mentioned by participants) such as social isolation, intimacy, and one’s ability to work (Tait & Margolis, 1987). These outcomes allow for the assessment of the relationship between CD and patients’ experiences of pain.

To assess convergent validity (i.e., the extent to which theoretically related constructs are associated; Shadish et al., 2001), the 8-item Illness Invalidation Inventory (3*I; Kool et al., 2010) was included. Other measures were considered, such as Bontempo’s (2019) Symptom Invalidation measure. However, as this measure has not yet been published nor factor analysis work completed, the 3*I was instead selected, as it is the most conceptually similar measure currently available. To assess divergent validity (i.e., the extent to which theoretically unrelated constructs are not associated; Shadish et al., 2001), Strahan and Gerbasi’s (1972) 20-item short form of the Marlowe-Crowne social desirability scale was included, as this construct is unrelated to CD. See Table 15 for a summary of included outcome measures.

### Salient Hypotheses

Figure 7 displays a structural model with NGIs as a mediator and hypotheses which assert direct and indirect effects between disenfranchising talk (DT) and the outcomes listed in Table 16. Figure 8 displays a structural model with CD as a moderator and 10 additional hypotheses which assert direct and indirect effects between pain severity (PSS) and outcomes. Two models (Figures 7 and 8) are proposed as TCD first theorizes that greater CD results in greater negative inferences about others' goals. Further, it is expected that CD directly relates to the outcomes included in Table 14, as the meta-synthesis findings suggest these associations. For example, numerous participants described attempting or considering suicide following experiencing disenfranchising talk. Hence, it is hypothesized in Figure 6 below that CD will be positively associated with suicidal ideation (SBQ-R).

Beyond the evidence gathered for the meta-synthesis, a wealth of evidence exists to suggest that negative interactions (e.g., negative responses such as criticism or hostility) result in heightened pain severity, catastrophizing, and disability as well as poorer physical and mental health (e.g., Boothby et al., 2004; Burns et al., 2013; Rosen et al., 2010, 2012). Chronic pain patients are twice as likely to report suicidal behaviors or commit suicide than patients without chronic pain (Racine, 2018). Given that suicidality is more related to psychosocial than physical factors (Racine, 2018; Wilson et al., 2013), and that negative social interactions with various others (e.g., peers; Lebowitz et al. 2019) are associated with suicidal ideation, negative interactions may contribute to the known relationship between chronic pain and suicidal ideation (e.g., Hooley et al., 2014). Further, as CD is conceptually similar to illness invalidation, these two constructs should be related (Molzof et al., 2020). Finally, group-based medical mistrust among chronic pain patients, particularly minority patients, is directly related to biased communicative behaviors (e.g., condescension, more directive communication; Ghoshal et al., 2020). Thus, we should expect that CD and group-based medical mistrust are positively related.

It is also theorized that negative goal inferences (NGIs) will mediate the relationship between CD and these outcomes, as it is not only experiencing disenfranchising talk and its outcome domains, but also the extent to which an individual draws inferences about how and whether the task, relational, and identity goals pursued in disenfranchising talk will be pursued by others in the future. For example, patients who experience DT and its proximal consequences but who do not report high negative goal inferences likely report less suicidal ideation as those similar in CD who do. Hence, the hypotheses below are offered.

**Table 15.** Summary of Included Distal Outcome Measures.

| **Measure [Abbreviation]** | **Citation** | **# of Items** | **Sample Item** |
|---|---|---|---|
| Hospital Anxiety and Depression Scale [HADS] | Snaith (2003) | 14 | I feel tense or wound up. (Anxiety)<br>I feel as if I am slowed down. (Depression) |
| Self-Rated Health [SRH-5] | Eriksson et al. (2001) | 1 | How would you rate your general health status? |
| Suicidal Behaviors Questionnaire – Revised [SBQ-R] | Osman et al. (2001) | 4 | Have you ever thought about or attempted to kill yourself? |
| Group-Based Medical Mistrust [GBMMS] | Thompson et al. (2004) | 12 | People with chronic pain cannot trust doctors and healthcare workers. |
| Pain Severity Subscale, West Haven-Yale Multidimensional Pain Inventory [PSS] | Kerns et al. (1985) | 3 | Rate the level of your pain at the present moment. |
| Pain Catastrophizing Scale [PCS] | Sullivan et al. (1995) | 13 | I keep thinking about how badly I want the pain to stop. |
| Pain Disability Index [PDI] | Tait & Margolis (1987) | 7 | Please indicate the level of disability you typically experience in each domain: Social activity |
| Illness Invalidation Inventory [3*I] | Kool et al. (2010) | 8 | …makes me feel like I am an exaggerator. |
| Marlowe-Crowne Social Desirability Scale – Short Form [MCSDS-S] | Strahan & Gerbasi (1972) | 20 | I'm always willing to admit when I make a mistake. |

Hypotheses for the mediation model are reported here:

- **H1:** Disenfranchising talk (DT) will be positively associated with: (a) proximal consequences (PCs), and (b) negative goal inferences (NGIs).
- **H2:** Proximal consequences (PCs) will be positively associated with distal outcomes, specifically pain disability (PDI; H2a), pain catastrophizing (PCS; H2b), pain severity (PSS; H2c), anxiety and depression (HADS; H2d) and suicidal ideation (SBQR; H2e).
- **H3:** Negative goal inferences (NGIs) would be positively associated with all distal outcomes, specifically pain disability (PDI; H3a), pain catastrophizing (PCS; H3b), pain severity (PSS; H3c), anxiety and depression (HADS; H3d) and suicidal ideation (SBQR; H3e).
- **H4:** Proximal consequences (PCs) will mediate the relationship between disenfranchising talk (DT) and distal outcomes, specifically pain disability (PDI; H4a), pain catastrophizing (PCS; H4b), pain severity (PSS; H4c), anxiety and depression (HADS; H4d) and suicidal ideation (SBQR; H4e).
- **H5:** Negative goal inferences (NGIs) will mediate the relationship between disenfranchising talk (DT) and distal outcomes, specifically pain disability (PDI; H5a), pain catastrophizing (PCS; H5b), pain severity (PSS; H5c), anxiety and depression (HADS; H4d) and suicidal ideation (SBQR; H5e).

Example mediation models are reported in Figures 7-10 below and include pain severity (PSS; Figure 7), and group-based medical mistrust (GBMMS; Figure 8).

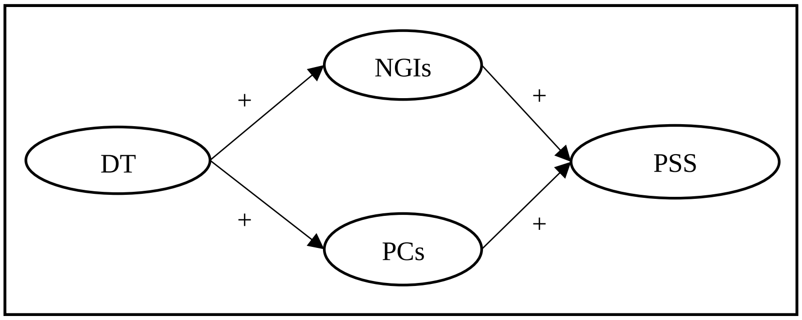

**Figure 7.** Mediation Model for Pain Severity (PSS).

Working through the mediation example in Figure 7, it is hypothesized that DT will be positively associated with NGIs and PCs. It is also hypothesized that NGIs and PCs will mediate the relationship between DT and PSS.

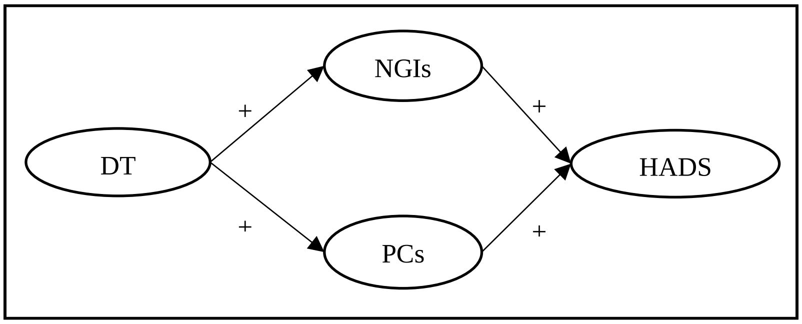

**Figure 8.** Mediation Model for Hospital Anxiety and Depression Scale (HADS).

Working through a second mediation example in Figure 8, it is hypothesized that DT will be positively associated with NGIs and PCs. It is also hypothesized that NGIs and PCs will mediate the relationship between DT and HADS.

In addition to the mediation model proposed above in which the effects of DT on distal outcomes flow through PCs and NGIs, an additional moderation model will also be tested, where associations between pain severity and outcomes are moderated depending on the amount of DT reported by participants. The rationale for this mediation model is driven by the assertion that even when patients are in more severe pain, it is expected that a variety of other outcomes are improved when their pain is taken seriously (i.e., not discredited), when they are able to talk about their pain, and when their reports of pain are not reduced to stereotypes. Hence, having experienced greater illness-course DT can strengthen the association between pain severity and these outcomes (e.g., depression and anxiety), whereas low DT can help to weaken these associations. This model is designed to account for the effects of pain severity and to explore the extent to which the relationship between pain severity and a variety of negative pain-related outcomes is stronger when female patients report greater disenfranchising talk. The previous model displayed in Figure 8 is designed to account for how DT, its proximal consequences, and negative goal inferences which arise predict distal negative outcomes. See Figure 9 below.

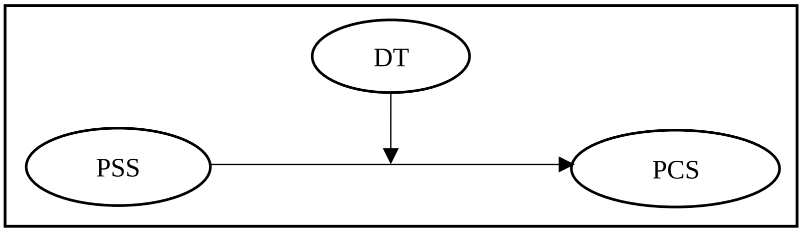

**Figure 9.** Example Moderation Model for Pain Catastrophizing (PCS).

Working through the example moderation model for pain catastrophizing (PCS) in Figure 9, it is expected that pain severity (PSS) will directly predict PCS (Lemeuix et al., 2013; Sullivan et al., 1995), but also that the strength of the association between PSS and PCS will be stronger when participants report having experienced greater DT over the course of their illness. Sullivan et al. (2006) have noted that the degree of pain catastrophizing reported depends (in part) upon others' behaviors toward the person experiencing pain, where positive behaviors such as attention and sympathy increase reports of PCS. Negative responses from others (e.g., criticizing, ignoring, expressing frustration) also increase PCS and pain intensity (e.g., Lemeuix et al., 2013). Hence, having experienced greater DT over the course of one's illness likely moderates the strength of the relationship between PSS and PCS. Given this moderation model, it is expected that:

- **H6:** Disenfranchising talk (DT) will moderate the associations between pain severity (PSS) and: pain disability (PDI; H6a), pain catastrophizing (PCS; H6b), suicidal ideation (SBQ-R; H6c), and anxiety and depression (HADS; H6d), such that PSS will predict these outcomes more strongly as DT increases.

Finally, to assess convergent and divergent validity, the following hypotheses are proposed. Social desirability (MCSDS-S) is included to assess divergent validity, while illness invalidation (3*I) is included to assess convergent validity. As illness invalidation (3*I) is a conceptually similar construct which has been explained above, it is expected that it will be positively associated with the measure of DT. Group-based medical mistrust (GBMMS) will be included as an additional measure of convergent validity for the NGI measure, as making negative inferences about medical providers' future goals is similar conceptually to mistrust. Divergent validity is assessed with a measure of social desirability, as social desirability and DT being related would suggest that, for example, women who report DT may do so because desire to be seen as "good actors" and hence act accordingly. Demonstrating that DT and social desirability are not associated will bolster its validity.

- **H7:** There will be no association between disenfranchising talk (DT) and social desirability (MCSDS-S; to assess divergent validity).
- **H8:** There will be a positive association between disenfranchising talk (DT) and illness invalidation (3*I; to assess convergent validity).
- **H9:** There will be a positive association between negative goal inferences (NGIs) and group-based medical mistrust (G-BMMS; to assess convergent validity).

## Existing Measures of Related Constructs

Before describing procedures, we must review existing measures of related constructs to illustrate the necessity of developing a measure of CD. Specifically, related constructs such as the Illness Invalidation Inventory (Kool et al., 2010), the Illness Cognition Questionnaire (Evers et al., 2001), and Post-Traumatic Embitterment (Linden et al., 2009) are reviewed. See Table 16.

First, the 8-item Illness Invalidation Inventory (3*I; Kool et al., 2010) was developed to assess the negative experiences of patients with fibromyalgia and rheumatoid arthritis in which a variety of important others (i.e., spouses, family members, medical professionals, others in a work environment, and social services) display invalidating behaviors, operationalized as either *discounting* (i.e., denying and patronizing) or *a lack of understanding* (i.e., not supporting and not acknowledging). This measure is the most conceptually similar to CD. Sample items from the III for the "discounting" subdimension include "[person type]…finds it odd that I can do much more on some days than on other days, …thinks I should be tougher, and …makes me feel like I am an exaggerator" while items from the "lack of understanding" subdimension include "[person category]…takes me seriously (R), …understands the consequences of my health problems or illness (R), and …gives me the chance to talk about what is on my mind (R)" (Kool et al., 2010, p. 1992). Findings indicated that patients with fibromyalgia reported significantly higher 3*I scores than individuals with rheumatoid arthritis and experienced greater invalidation from all groups. Findings also revealed that higher scores on the 3*I were inversely associated with mental well-being and social functioning scores and directly correlated with physical disability and pain scores. Although commendable for its multidimensional approach to the study of invalidating responses, its explicit focus on communication, and its consideration of messages received from a variety of relational others, the 3*I is not concerned with the implications of such messages for patients' relationships and identities, and selects two (i.e., discounted, not understood) from among many potential factors which act as responses to illness discussions.

Second, the 15-item Illness Cognition Questionnaire for chronic diseases (ICQ; Evers et al., 2001) was designed to assess the relationship between illness-related cognitions and health outcomes such as stress and illness. Three subscales of the ICQ include *helplessness* (sample items include "My illness frequently makes me feel helpless" and "My illness limits me in everything that is important to me"), *acceptance* (sample items include "I have learned to live with my illness" and "I can accept my illness well"), and *perceived benefits* (sample items include "Dealing with my illness has made me a stronger person" and "I have learned a great deal from my illness"). The ICQ, while useful for understanding a variety of *intra*personal factors which may contribute to a patient's approach to communicating about their symptoms, does not attempt to assess perceptions of others' talk.

Third, the 7-item Institutional Betrayal Questionnaire (IBQ; Smith & Freyd, 2013) assesses feelings of betrayal toward institutions (e.g., the medical system, the Fraternity/Sorority system) stemming from specific events (e.g., sexual assault). The measure asks participants to first think of a specific experience (the parameters for which are study specific, such as a sexual assault on a college campus; Smith & Freyd, 2013; or a lack of support for LGBT employees reporting sexual harassment; Smith & Freyd, 2014) and answer a series of "Yes" or "No" questions which reflect the extent to which participants felt that the *institution* in question played a role in the event. Items include, "Not taking proactive steps to prevent this type of experience?" "Creating an environment in which the experience seemed common or like no big deal?" "Creating an environment in which the experience seemed more likely to occur?" "Making it difficult to report the experience?" "Responding inadequately to the experience, if reported?"

"Covering up the experience?" and "Punishing you in some way for the experience (e.g., loss of privileges or status)?" Responses to these items are then summed to produce a "betrayal" score which can range from 0 to 7. Although commendable for its interest in addressing the conditions which make possible the specific experience, this measure of CD additionally examines talk.

Fourth, the 10-item measure of Symptom Invalidation (SI; Bontempo, 2019) was designed to assess the diagnostic experiences of women with endometriosis, specifically to explore *symptom invalidation,* defined as "difficulty in getting clinicians to acknowledge a physical problem as responsible for their symptoms" (n.p.). Two versions of the scale exist which measure the *invalidation of symptoms* (SI) and the *invalidation of me* (internalized SI). Sample items include, "My doctor did not dismiss my symptoms/me (R)," "My doctor challenged my symptoms/me," and "My doctor believed my symptoms were real/me (R)." Factor analysis has not yet been conducted on data gathered from 1,391 women with endometriosis, although preliminary findings indicate associations with self-esteem and depression. Although useful for exploring diagnostic error, a measure of CD additionally examines the relational implications of talk and explore domains beyond symptom talk.

Fifth, the 39-item Family Member Marginalization Measure (FM$^3$; Dorrance Hall et al., 2020) assesses the process of family distancing and is measured on a scale from 1 = *never* to 7 = *always*). Dimensions of family distancing tapped by the measure include: (a) *difference* (sample items include "My family makes me feel like I am the only one who thinks the way I do" and "My interests conflict with the interests of my family members"), (b) *disapproval* (sample items include "My family looks down on how I live" and "My family wants to fix me") , and (c) *exclusion* (sample items include "My family keeps secrets from me" and "I feel isolated at family events").

**Table 16.** Summary of Existing Measures of Related Constructs.

| Measure Name/Concept Definition | Sample Scale Items | How CD Adds Dimension |
|---|---|---|
| Illness Invalidation Inventory (3*I; Kool et al., 2010). Developed to assess negative experiences of patients in which a variety of important others display invalidating behaviors, operationalized as either *discounting* or *a lack of understanding.* | • …finds it odd that I can do much more on some days than on other days.<br>• …makes me feel like I am an exaggerator.<br>• …understands the consequences of my health problems or illness. (R) | • CD will assess the implications of talk for patients' relationships and identities.<br>• CD will include a wider array of messages (beyond discounting and not understanding). |
| Illness Cognition Questionnaire (ICQ; Evers et al., 2001). Designed to assess the relationship between illness-related cognitions and health outcomes. Three subscales: (a) helplessness, (b) acceptance, (c) perceived benefits. | • My illness frequently makes me feel helpless.<br>• I have learned to live with my illness.<br>• Dealing with my illness has made me a stronger person. | • CD is concerned with the effects of others' talk rather than only one's own cognitions. |
| Institutional Betrayal Questionnaire (IBQ; Smith & Freyd, 2013). Developed to assess feelings of betrayal toward *institutions* stemming from a variety of social harms and injustices. | • Not taking proactive steps to prevent this type of experience?<br>• Creating an environment in which the experience seemed common or like no big deal?<br>• Punishing you in some way for the experience (e.g., loss of privileges or status)? | • CD does not locate power in institutions, rather discourses espoused by individuals. Hence CD will examine talk produced by individuals in addition to the conditions which make CD possible. |
| Symptom Invalidation and Internalized Symptom Invalidation Measure (Bontempo, 2019). Developed to measure *symptom invalidation (SI),* issues experienced by patients in getting medical providers to acknowledge a physical cause for illness symptoms. Two versions of the measure exist: (a) invalidation of symptoms (SI), (b) invalidation of me (internalized SI). | • My doctor did not dismiss my symptoms/me. (R)<br>• My doctor challenged my symptoms/me.<br>• My doctor believed my symptoms were real/me. | • CD will extend beyond only talk about symptoms (and diagnostic error) to assess the implications of talk for patients' relationships. |
| Family Member Marginalization Measure (FM*3; Dorrance Hall et al., 2020). Developed to assess the process of family distancing along dimensions of *difference*, *disapproval*, and *exclusion*. | • My family and I have different values.<br>• My family tells me I am not living my life the way I should be.<br>• At family gatherings I feel intentionally ignored. | • CD extends beyond talk in familial contexts.<br>• CD may encompass marginalization but refers to the process in which dimensions of marginalization become embedded. |
| Post-Traumatic Embitterment Disorder Self-Rating Scale (PTED; Linden et al., 2009). Developed to assesses emotional reactions to a variety of negative life events. Subscales include *psychological status and social functioning* and *emotional response and thoughts of revenge.* | • That lead to a noticeable and persistent negative change in my mental well-being.<br>• That hurt my feelings and caused considerable embitterment.<br>• That I see as very unjust and unfair. | • CD is not concerned only with the outcomes or effects of disenfranchising talk after it has occurred. A measure of CD will also explore the content of disenfranchising talk. |

These dimensions operate at both cognitive and relational levels and capture perceived marginalization and its familial manifestations. While the FM$^3$ is useful for understanding family distancing behaviors across these dimensions, a measure which extends beyond familial contexts and captures aspects of the larger process in which marginalization may be embedded is needed.

Finally, the 17-item Post-Traumatic Embitterment Disorder Self-Rating Scale (PTED; Linden et al., 2009) assesses emotional reactions to a variety of negative life events. Criteria for a qualifying traumatic event include: (a) an event that the person is aware of is seen as the cause of the embitterment reaction, (b) the event is viewed as an injustice, insulting, and humiliating; and (c) the person reacts emotionally and feels bitter, enraged, and helpless when recalling the event (Linden et al., 2009). The scale has two factors: (a) *psychological status and social functioning* (sample items include "That lead to a noticeable and persistent negative change in my mental well-being" and "About which I have to think over and over again"), and (b) *emotional response and thoughts of revenge* (sample items include, "That hurt my feelings and caused considerable embitterment" and "That I see as very unjust and unfair"). Unlike the other two measures described, the PTED specifically examines responses to negative events and changes over time in emotional status. However, the PTED does not specify an event type nor explicitly focus on interactions or talk. Hence, given the limitations of existing measures of related constructs, the need to develop a measure which fills these gaps is apparent.

## Considerations of Validity

*Validity,* a property of inferences (not research design or methodology) refers to "the approximate truth of an inference…the extent to which relevant evidence supports that inference" (Shadish et al., 2001, p. 34). Three philosophical approaches to the understanding of truth are offered: (1) *correspondence theory*, which asserts that a claim is true if it corresponds to what we observe in the world; (2) *coherence theory*, which posits that a claim is true if it coheres to existing knowledge; and (3) *pragmatism*, that claims are believed to be true when they are useful. Shadish et al. (2001) assert that no one theory, in isolation, would be appropriate for justifying scientific claims, instead acknowledging the socially constructed nature of truth and the complementary nature of these seemingly disparate approaches.

Four general types of validity are relevant in quantitative research and should be discussed. First, *statistical conclusion validity* refers to "the validity of inferences about the correlation between treatment and outcome" (Shadish et al., 2001, p. 38). Statistical conclusion validity is primarily concerned with the extent to which cause and effect covary, and the strength and direction of that relationship. For example, it is good practice to report not only significance values, but also values which indicate effect size. Second, *internal validity* refers to whether the observed variation reflects a causal relationship. Internal validity is primarily concerned with whether a causal relationship can be ascertained. Recall that three criteria are necessary for establishing a causal relationship: (a) A must precede B, (b) A covaries with B, and (c) no plausible explanations exist which could alternatively explain the relationship.

*Constructs* are ideas with distinct conceptual features which are not empirically observable (e.g., politeness, resilience). Construct explication and assessment are fundamental tasks for all researchers, as constructs enable us to connect experimental findings to theory and practice. Third, *construct validity*, then, involves "making inferences from sampling particulars to the higher-order constructs they represent" (Shadish et al., 2001, p. 65). For example, we do not use the 21-item Beck Depression Inventory to assess the frequency of 21 behaviors commonly associated with depression, but to make inferences about whether (and the extent to which) an individual is depressed. Such inferences can be made about any of the sampling particulars, from the outcome measures (just discussed), participants (e.g., “disadvantaged” individuals), to the settings (e.g., environments), and treatments (for which manipulation checks are performed). Establishing theoretical parameters pertaining to the construct of CD and using these to guide the development of a measure of CD to avoid tautological associations with outcomes is another example of construct validity. Fourth, *external validity* is the extent to which *causal inferences* are able to “travel,” (i.e., are generalizable) to variations both within and outside of the experimental context. External validity may be threatened if: (a) the causal relationship does not hold for other participant (i.e., unit) populations, (b) variations in treatment, (c) or the observed outcomes, settings, or context interact with the observe causal relationship.

Plausible explanations which could account for the relationship between a manipulation and observed outcomes, and the inferences consequently made, are called *threats to validity*. For each threat to validity, the researcher might ask themselves: (1) How would the threat apply in this case? (2) Is there evidence that the threat is plausible (not only possible)? and (3) Does the threat operate in the same direction as the observed effect? For example, a threat to statistical conclusion validity is low statistical power, where *power* is the ability to detect relationships as they exist within a population. If statistical power is low, the observed relationship may not able to be detected or assessed with precision. A threat to internal validity could be attrition, whereby participants elect to stop participating in the study. If lost participants share similarities (e.g., a majority of lost participants were members of the control group), this becomes a plausible alternative explanation for (threat to) the demonstrated treatment effect.

Three additional types of validity are identified by Shadish et al. (2001) as being paramount in the context of scale development. *Validity* in scale development operations refers to whether item covariation can be attributed to an underlying latent variable. First, *content* *validity* refers to the extent to which a specific set of scale items is reflective of its content domain. Ideally, scale items should reflect a random subset of all possible scale items which could represent a particular construct, and should also reflect the construct explication (i.e., should not extend beyond the conceptual boundaries of the construct). Second, *criterion validity* (i.e., *predictive validity*) refers to whether an item is associated with some other criterion of interest. For example, we would expect that an individual who scores highest on a measure of risky driving would demonstrate a positive association with the number of traffic tickets they receive. Third, *construct validity* refers to the extent to which a scale score upholds a theoretical relationship to another variable. Subtypes of construct validity include: (a) *convergent validity*, referring to whether theoretically related constructs score accordingly (e.g., anxiety and depression scores), and (b) *divergent validity*, referring to whether theoretically dissimilar constructs score accordingly (e.g., anxiety and shoe size; Shadish et al., 2001).

# CHAPTER FIVE: STUDY TWO METHODOLOGY

Study two, following guidance by DeVellis (2017) and foregrounded by the construct explication, specific hypotheses, and outcomes specified in study one, consisted of the initial development and validation of a measure of CD in the context of COPCs.

Although the assumptions of critical perspectives may seem to be at odds with the idea of quantifying perceived CD (Garcia et al., 2018), I approach this effort as one which makes the presently invisible experiences of these women visible through quantification (or as one which may make the communicative issues that count for this population countable). Although typically conceptualized as being disparate, much critical scholarship is grounded in findings from quantitative research (e.g., quantitative research regarding gender disparities in healthcare, racial disparities in pain treatment, maternal mortality, policing, the justice system, the gender wage gap, and the underrepresentation of minorities in media all have spurred or provided additional warrant for the conduct of critical scholarship about these subjects). Further, many scholars have employed quantitative methods and developed scales to measure constructs which advance critical research and theorizing. For example, Chakravarrty et al. (2018) employed quantitative methods to illustrate racial inequities and underrepresentation in scholarly journals, on editorial boards, and in reference lists in communication studies. In another example, Davis (Davis, 2015; Davis & Afifi, 2019) developed SBWCT to better understand how Black women respond to racial microaggressions from White women and to measure the construct of *strength regulation* (observed and self-reported), which refers to “the extent to which Black women reinforce the communication and overall embodiment of the Strong Black Woman in themselves and others" (Davis & Afifi, 2019, p. 3). Thus, it would seem that critical and post-positivist scholarship are united in their pursuit of both construct explication and scale development as a means of advancing theory. They differ most greatly in the extent to which findings are utilized to produce a critique of unjust operations of power (Ono, 2009). Here, measuring CD is a means of understanding the antecedents, mediating role, and outcomes of CD (Chafee, 1991), which can inform critique of discourses as well as policies/practices that otherwise may perpetuate CD.

## Eight Procedural Steps of Scale Development

Scale development proceeded in eight steps in this dissertation, following the eight steps recommended by DeVellis (2017). These eight steps are described below and include conceptualizing the construct and measure(s), compiling an initial item pool, determining a format for measurement, having a team of expert raters assess the draft measures, considering the inclusion of validation items, administering the scales to a development sample, evaluating item performance, and optimizing the length of the measures. Step one is first described below.

In the first step, I determined clearly what I wanted to measure, including identifying conceptual boundaries for the construct (i.e., determining what is and is not CD/TCD). This was accomplished via the meta-synthesis and theoretical explication of CD completed in study one. Specifically, guided by the theoretical explication of CD derived both from tenets of the CIFC and multiple goals frameworks and findings of the meta-synthesis (which are sensitized by these tenets), a clear picture of the final measure developed. The measure has a communicative focus, meaning that items focus on: (a) interactions in which COPCs are discussed with important others (i.e., measures focus on what is (not) said and how it is said; i.e., a measure of DT); (b) the consequences of disenfranchising talk (e.g., losses of perceived agency, credibility and legitimacy, and/or rights and privileges; i.e., a measure of PCs); and (c) the inferences about goals and/or motivations which underlie that talk (i.e., NGIs). Items which do not fit directly into these four categories do not appear in the final CD measure.

Throughout this first step, care was taken to avoid including scale items which were conceptually indistinct from items in existing measures which may be correlated with a measure of CD to assess convergent or divergent validity or to test hypothesized associations among variables. For instance, a measure of CD would not include a scale item which discussed an “outcome” of disenfranchising talk (e.g., psychological distress), if that measure were to be correlated with an existing measure of mental health because any discovered associations would be inherently tautological. As talk necessarily creates and holds implications for our identities and relationships (including power as we locate it in discourse), attending to these material, relational, and identity outcomes rather than affective outcomes tie a measure of CD more closely to communication. Hence, the measure of CD explores the relational and identity implications of disenfranchising talk in addition to the disenfranchising talk itself as a means of distinguishing CD from potential related constructs or outcomes. This distinction also clarifies the relationship between the construct of CD and TCD (the overarching theoretical process in which disenfranchising talk is embedded) such that CD (and any measure developed to assess it) includes talk itself as well as the relational and identity implications of disenfranchising talk, while the construct of CD exists within a larger theoretical process model of disenfranchisement in which connections to antecedents and outcomes are proposed.

Items from similar measures of related constructs are not be taken or adapted for this measure, although other measures can be included in a structural model of TCD which may tap parts of the process of CD. For example, women with COPCs may leap from making goal inferences about their own relationship with their provider (e.g., my provider will question the credibility of my health complaints) to global inferences about all providers (e.g., all providers will question the credibility of my health complaints) and/or others like them (e.g., all women with my symptoms experience the questioning of the credibility of their symptoms by medical providers) which functions to disenfranchise them from further medical care. Other "arms" of the process of CD likely also coalesce to wrap around and support this perception of disenfranchisement. For example, there may be material effects of this process (e.g., a psychological explanation written into a medical record which prevents the future unbiased assessment of symptoms) and also a sense that the reason this happened to them is derived from some larger unchangeable issue within society (e.g., discourses about women in pain). Hence, other measures can also tap aspects of the process of CD (e.g., assessing the extent to which women with COPCs make global attributions about the medical system can be measured by assessing group-based medical mistrust; Thompson et al., 2004).

In the second step, an initial and large pool of scale items (*n* = 170) was developed at the end of Study 1 – i.e., a pool of items which was both *comprehensive* and *exhaustive* (i.e., encompassing the scope of the construct; DeVellis, 2017). Three to four times the number of items were included in the initial pool as ended up being present in the final scales. Characteristics of good items included keeping items short and simple; not using double negatives, double-barreled items, pronouns, or adverbs; including both positively and negatively worded items (i.e., some reverse scored items) and using adjectives over nouns (DeVellis, 2017). Applying these criteria led me to cut 55 items at this step which were either long, included double negatives, were double barreled, or included pronouns or adverbs, leaving 115 items.

Third, a format for measurement (i.e., scaling format, timeframe for questions, and response format) was determined for DT, PCs, and NGIs based upon the conceptual definitions offered previously. For example, participants were asked to rate how often DT had occurred but were asked to rate their amount of agreement regarding PCs and NGIs. To distinguish the measure of DT from the measures of PCs, the measure of DT asked participants to recall interactions which had happened in the past, while the measure of PCs asked participants to reflect on the consequences of that talk which then occurred moving forward (e.g., the way I was spoken to made me look less credible to others from then on). To distinguish PC from the measure of NGIs , the latter asked participants to reflect on how they anticipated future interactions with medical providers would go (in terms of inferences about the goals they anticipate providers will pursue).

In step four, a team of 5 expert raters (i.e., two doctoral students, one Associate Professor, one Professor, and one Emeritus Professor) first reviewed each item (60 items for the DT measure, 34 items for the for the PCs measure, and 21 items for the NGIs measure). For each item, expert raters assessed: (a) relevance to the intended construct, (b) clarity, and (c) conciseness (DeVellis, 2017). Specifically, expert raters were provided with conceptual definitions of DT, PCs, and NGIs as well as draft items intended to tap each construct. Expert raters also offered new suggestions for tapping the construct of CD that may otherwise have been absent. After expert raters reviewed the initial pool and provided feedback, the initial pool was modified according to those recommendations. Specifically, for the measure of DT, two items were cut from the measure and two were rewritten entirely. For example, the DT item "Suggested that I looked more sick or well than other people who are "really" sick" was flagged by expert raters as being unclear and double barreled, and was rewritten as follows to address this feedback: "Claimed that I acted like I was in more pain than other people who are "really" sick." This left a total of 112 items (58 items for DT, 34 for PCs, and 20 for NGIs) at this step.

Fifth, *validation items* which help to determine the validity of the final scale, were considered for inclusion. Two types of validation items are those which help the researcher to assess the validity of the scale (e.g., including a measure of social desirability) and those with help to detect flaws or problems with a measure (e.g., measuring theoretically related constructs to assess whether purported relationships appear in gathered data; DeVellis, 2017).

Sixth, the scale was administered to the participants in Study 2 (details are described below). In a sense, Study 2 participants constitute a “developmental sample” as their responses are being used to select final items for the CD measures as well as to initially validate these scales. The purpose of this sixth step was to assess the factor structure and reliability of the initial scales and their relationships with outcomes of theoretical interest. After the participants in the development sample had completed the survey, seventh, item performance was evaluated (DeVellis, 2017). This involved: (a) examining correlation matrices to determine whether items are highly intercorrelated, (b) examining item-scale correlations, (c) examining item variances and means, (d) assessing dimensionality via factor analysis, and (e) assessing scale reliability (DeVellis, 2017). Finally, using the findings of the analytical procedures specified in step seven, the scale length was optimized. Detail about how each of these steps were accomplished is offered below. In the future, findings will be replicated with a new sample of 300 or more participants to confirm the factor structure (DeVellis, 2017). Research questions and hypotheses which guide this study were proposed above at the end of study one. The remainder of this chapter describes the recruitment and survey administration procedures, participants, and measures included in the scale development study.

### Recruitment and Survey Administration Procedures

Participants for study two were recruited through a variety of methods, including: (a) the author’s own personal social network, which includes participants with COPCs from past studies who indicated a continued interest in participating in research studies, and female friends and colleagues with COPCs; (b) snowball sampling from these participants via email, and (c) online/social media advertisements to platforms including: Facebook, Twitter, Instagram, Reddit, and YouTube. Online/social media advertisements included text, a flyer, and a recruitment video (see Appendix A). Members of this illness population are highly motivated to participate in research studies even without compensation. For example, in this study over 300 responses were collected within the first 38 hours of the study being posted on social media sites. In total, 44 (5.2%) of participants accessed the survey from personal social network recruitment and snowball sampling methods, while the remaining 94.7% ($n$ = 789) participants access the survey through a link posted to a social media site. Total study recruitment lasted exactly one week.

Participants accessed the survey link through the social media posts and emails where study information was posted. Eligible participants completed an initial survey which was preceded by an electronic consent form. Estimated survey completion time for the survey in Qualtrics was 45.6 minutes. Participants consented to participate by indicating this on the first screen of the survey before any survey questions were answered. Participants completing the survey were first exposed to a series of screening questions (i.e., to verify that they were over 18, able to read/write in English, and have spoken to a medical provider at least once about at least one of the 10 COPCs) to determine study eligibility. Participants who passed the screening questions were then asked to describe both positive and negative conversations in which they had discussed their pain with medical providers. Then, participants completed the included outcome measures listed in Table 15 as well as the measures of DT, PCs, and NGIs. Demographic data were collected. See Appendix B for the complete survey. Participant eligibility is next discussed.

## Participant Eligibility

Participants were recruited who were assigned the sex of female at birth (AFAB) or who currently identified as female, were over the age of 18, who could read and write fluently in English, and who had spoken to a medical provider at least once about (regardless of whether they had been affirmatively diagnosed with) one or more of 10 COPCs (i.e., interstitial cystitis (i.e., painful bladder syndrome), irritable bowel syndrome, vulvodynia, endometriosis, temporomandibular disorders, chronic low back pain, headache (two subcategories of chronic tension type headache and chronic migraine), myalgic encephalomyelitis (also called CFS), and fibromyalgia). Participants were eligible if they had been diagnosed with or had ever pursued a diagnosis for any one of these 10 COPCs. Participation was open to participants in any country around the world. Participants were excluded (i.e., not allowed to complete the remainder of the survey) if they: (a) were not assigned the sex of female at birth (AFAB) or did not currently identify as female, (b) were under the age of 18, (c) indicated that they could not fluently read and write in English, or (d) had not ever spoken to a medical provider about one or more COPCs.

The decision to ask only that participants have spoken to a medical provider at least once (as opposed to having been affirmatively diagnosed with at least one COPC) stemmed from a desire to recruit a socioeconomically and racially diverse sample. The treatment of many COPCs remains intertwined to racist ideas about pain which have prevented the equitable diagnosis of pain across racial groups (Goldstein et al., 2009). Further, many COPCs take years and multiple appointments with providers to receive a diagnosis (e.g., 35% of women with vulvodynia spend 3 years and attend 15 appointments to receive a diagnosis; Connor et al., 2013, women with endometriosis wait 10 years on average; Nnoaham et al., 2011), if women even pursue diagnosis to begin with. Hence, the achievement of an affirmative COPC diagnosis is inherently a matter of both race and socioeconomic status and the unintentional exclusion of these participants can be remedied via this inclusionary criterion. Next, data screening procedures are described.

### Data Screening

After data collection was completed, data were first cleaned to improve the quality of the final dataset. Specifically, data were cleaned to remove respondents who: (a) completed the survey in above average speeds by examining the median time required to complete the survey (in seconds) and determining a cutoff point, or (b) provided straight-lined responses to scale items as determined both by simple non-differentiation and by mean root of squares and scale point variation indices (Kim et al., 2019). Providing complete answers to open-ended questions was not included as a requirement during the data screening process because participants were given the option to write “I do not wish to respond” to avoid compelling the recollection of potentially traumatic interactions they had endured. As this survey did not offer compensation, no instances of botting or participants submitting open-ended responses in an effort to receive compensation appeared in the data. Further, participants were required to successfully complete a randomized reCAPTCHA to confirm that they were human before beginning the survey.

The initial dataset contained 833 complete and incomplete responses. Of those, 412 (49.5%) responses were removed because participants had not reached the end of the survey. I then used a combination of time to complete the survey and straight-lining responses to evaluate data quality. For the 421 participants who completed the entire survey, the average time spent taking the survey was 48.93 minutes (*Med* = 29.55, *SD* = 87.63, *IQR* = 23.74–41.76), with 14.13 minutes being the 5th percentile and 18.77 minutes being the 10th percentile. To assess straightlining, I computed the “mean root of pairs” (MRP) index (Kim et al., 2019) for responses to one subscale of DT (discrediting experience of pain), one half of the measure of NGIs (selecting every other item) as well as the HADS (Hospital Anxiety and Depression Scale) where every other item is reverse coded. Based on responses to all pairs of items composing a measure, MRP creates an index ranging from 0-1 where higher scores indicate increasingly similar responses to all items (e.g., non-differentiation of reverse coded items). Based on the distribution of MRP scores, I used .70 or higher as a cutoff. Participants (*n* = 21; 5.0%) who were higher than the cutoff for two or more of the three measures *and* who were faster than the 10th percentile value for survey duration were excluded, resulting in a final sample of *N* = 400. I chose these criteria because the participants I excluded were taking survey measures faster than most other participants and appeared to be achieving that speed by completing measures without differentiating items with distinct content (e.g., reverse coded items for the HADS, types of negative goal inferences tapped by the NGI). Next, participant demographics are offered.

## Participant Demographics

Participants in the final sample (*N* = 400) ranged in age from 18 – 24 to 65 – 74 years (*Mode* = 25-34) and identified predominantly as female (with 8.6% of participants identifying themselves as broadly non-cisgender, such as genderqueer or nonconforming, transgender, or other). Only 53.5% of participants identified as heterosexual or straight, with 46.5% of participants identifying as bisexual, pansexual, lesbian, questioning, asexual, queer, homosexual/gay, or other. Participants were predominantly White (88.0%) (followed by biracial/multiracial, Asian, Hispanic, Middle Eastern, and African). Although a majority of participants reported currently living in the United States (*n* = 268, 67.0%), the sample was an international sample, with 33% (*n* = 132) of participants currently residing in 21 other countries around the world (i.e., most prominently the United Kingdom, Canada, Australia, Germany, Israel, France, the Netherlands, and New Zealand). For participants living in the United States, 40.8% (*n* = 163) reported their current home as being "suburban," while 13.3% (*n* = 53) reported living in an "urban" environment and 12.8% (*n* = 51) reported "rural." U.S. participants represented 47 out of the 50 states (except New Hampshire, South Dakota, and Wyoming).

Twenty-eight percent (*n* =112) of participants identified as legally disabled, and 10.3% of participants currently residing in the United States (*n* = 42) reported that either they themselves or one or both parents were not born in the United States. A majority of participants (*n* = 207; 51.7%) identified as atheist, agnostic, or not religious, while 21.3% (*n* = 85) identified as Christian and 18.5% (*n* = 72) identified as "spiritual but not religious." Only 34% (*n* = 136) of participants were married, while 22.5% (*n* = 90) reported being in a committed relationship and cohabiting, 13.3% (*n* = 53) reported being single and interested in dating, and 12.2% (*n* = 53) reported being single and not interested in dating among other relationship statuses.

Regarding employment status, 50.5% of participants (*n* = 202) reported being employed either full or part-time, while 17.3% reported being students (*n* = 69) and 13.8% (*n* = 55) reported being disabled and unable to work while the remaining 18.5% (*n* = 74) reported either being self-employed, unemployed (looking for work or not looking for work), retired, or elected not to respond. Household income was diverse, with 42.2% (*n* = 168) of participants reporting an annual household income of less than 50,000 and only 19.3% (*n* = 77) reporting an annual household income of 100,000 or more. Most participants described their current financial status as being either "Fair" (*n* = 130; 32.5%) or "Good" (*n* = 140; 35.0%). Educational attainment was also diverse. Although only five participants (1.3%) reported "less than high school," 37.3% (*n* = 153) reported having earned only an Associate's degree or lower. Regarding health insurance status for participants not living in countries with universal coverage, 15 participants (*n* = 3.8%) reported not currently having health insurance, while 14.2% (*n* = 57) reported not having health insurance at some point within the previous 12 months. See Table 17.

**Table 17.** Participant Demographics for Survey (*N* = 400).

| **Characteristic** | **N (%)** |
|---|---|
| Age | |
| 18 – 24 | 81 (20.3%) |
| 25 – 34 | 192 (48.0%) |
| 35 – 44 | 81 (20.3%) |
| 45 – 54 | 31 (7.8%) |
| 55 – 64 | 14 (3.5%) |
| 65 – 74 | 1 (0.3%) |
| Gender | |
| Female | 366 (91.5%) |
| Non-binary | 20 (5.0%) |
| Genderqueer or gender nonconforming | 4 (1.0%) |
| Transgender male/man (AFAB) | 4 (1.0%) |
| Transgender female/woman (AMAB) | 1 (0.3%) |
| Male (as assigned at birth, but then identified as female) | 1 (0.3%) |
| Other | 4 (1.0%) |
| Sexual Orientation | |
| Heterosexual/Straight | 214 (53.5%) |
| Bisexual | 87 (21.8%) |
| Pansexual | 22 (5.5%) |
| Lesbian | 17 (4.3%) |
| Questioning or unsure | 17 (4.3%) |
| Asexual | 15 (3.8%) |
| Queer | 13 (3.3%) |
| Homosexual/Gay | 2 (0.5%) |
| Other | 12 (3.0%) |
| Race/Ethnicity | |
| White or Caucasian | 352 (88.0%) |
| Biracial or Multiracial | 23 (5.8%) |
| Asian American or Asian | 7 (1.8%) |
| Hispanic Latino or Spanish Origin | 5 (1.3%) |
| Middle Eastern or North African | 4 (1.0%) |
| African, African American or Black | 3 (0.8%) |
| Other | 6 (1.5%) |
| Disability Status | |
| Not Legally Disabled | 288 (72.0%) |
| Legally Disabled | 112 (28.0%) |
| Immigration Status (U.S. Only) | |
| Self and Parents Born in U.S. | 262 (65.5%) |
| Self Born U.S., One Parent Not | 15 (3.8%) |
| Self Born U.S., Both Parents Not | 8 (2.0%) |
| Foreign-born Naturalized Citizen | 8 (2.0%) |
| Permanent Legal Resident | 5 (1.5%) |
| Foreign Born on Student Visa | 4 (1.0%) |
| I do not live in the United States | 96 (24.0%) |

**Table 17. (Continued)**

| | |
|---|---|
| Religious Beliefs | |
| Atheism, Agnosticism, or Not Religious | 207 (51.7%) |
| Christianity | 85 (21.3%) |
| Spiritual but not Religious | 74 (18.5%) |
| Judaism | 16 (4.0%) |
| Islam | 3 (0.8%) |
| Relationship Status | |
| Married | 136 (34.0%) |
| Committed Relationship Cohabiting | 90 (22.5%) |
| Single Interested in Dating | 53 (13.3%) |
| Single NOT Interested in Dating | 53 (13.3%) |
| Committed Relationship NOT Cohabiting | 36 (9.0%) |
| Casually Dating NOT Cohabiting | 9 (2.3%) |
| Divorced | 8 (2.0%) |
| Separated | 3 (0.8%) |
| Casually Dating Cohabiting | 2 (0.5%) |
| Widowed | 2 (0.5%) |
| Other | 7 (1.8%) |
| Employment Status | |
| Employed 1-39 Hours per Week | 102 (25.5%) |
| Employed 40 or more Hours per Week | 100 (25.0%) |
| Student | 69 (17.3%) |
| Disabled | 55 (13.8%) |
| Not Employed, NOT Looking for Work | 25 (6.3%) |
| Self-Employed | 25 (6.3%) |
| Not Employed, Looking for Work | 19 (4.8%) |
| Retired | 3 (0.8%) |
| Prefer not to say | 2 (0.5%) |
| Household Income (*n* = 2 missing) | |
| 0 – 9,999 | 37 (9.3%) |
| 10,000 – 19,999 | 23 (5.8%) |
| 20,000 – 29,999 | 38 (9.5%) |
| 30,000 – 39,999 | 39 (9.8%) |
| 40,000 – 49,999 | 31 (7.8%) |
| 50,000 – 59,999 | 25 (6.3%) |
| 60,000 – 69,999 | 32 (8.0%) |
| 70,000 – 79,999 | 22 (5.5%) |
| 80,000 – 89,999 | 12 (3.0%) |
| 90,000 – 99,999 | 19 (4.8%) |
| 100,000 or more | 77 (19.3%) |
| Prefer not to say | 43 (10.8%) |
| Financial Situation (*n* = 1 missing) | |
| Poor | 63 (15.8%) |
| Fair | 130 (32.5%) |
| Good | 140 (35.0%) |
| Excellent | 66 (16.5%) |

**Table 17. (Continued)**

| | |
|---|---|
| Educational Attainment | |
| Less than high school | 5 (1.3%) |
| High school or equivalent | 26 (6.5%) |
| Some college but no degree | 96 (23.0%) |
| Associates degree | 26 (6.5%) |
| Bachelor’s degree | 124 (31.0%) |
| Master’s degree | 94 (23.5%) |
| Professional degree (e.g., JD) | 14 (3.5%) |
| Doctoral degree (e.g., PhD) | 19 (4.8%) |
| Current Health Insurance Status | |
| Has Health Insurance | 288 (72.0%) |
| No Health Insurance | 15 (3.8%) |
| Not Applicable (Universal Coverage) | 97 (24.3%) |
| Without Health Insurance Last 12 Months (*n* = 1 missing) | |
| No | 249 (62.3%) |
| Yes | 57 (14.2%) |
| Not Applicable (Universal Coverage) | 93 (23.3%) |
| Where Born (*n* = 5 missing) | |
| United States | 271 (67.8%) |
| United Kingdom | 41 (10.3%) |
| Canada | 31 (7.8%) |
| Australia | 13 (13.3%) |
| Germany | 8 (2.0%) |
| Netherlands | 3 (0.8%) |
| Norway | 3 (0.8%) |
| Countries with 2 or fewer responses | 25 (6.3%) |
| Current Residence (*n* = 9 missing) | |
| United States | 268 (67.0%) |
| United Kingdom | 41 (10.3%) |
| Canada | 27 (6.8%) |
| Australia | 12 (3.0%) |
| Germany | 10 (2.5%) |
| Israel | 6 (1.5%) |
| France | 4 (1.0%) |
| Netherlands | 3 (0.8%) |
| New Zealand | 3 (0.8%) |
| Countries with 2 or fewer responses | 17 (4.3%) |
| Current Home (U.S. Participants ONLY) | |
| Suburban | 163 (40.8%) |
| Urban | 53 (13.3%) |
| Rural | 51 (12.8%) |

**Table 17. (Continued)**

| | |
|---|---|
| Home State (U.S. Participants ONLY) | |
| Alabama | 3 (0.8%) |
| Alaska | 2 (0.5%) |
| Arizona | 6 (1.5%) |
| Arkansas | 3 (0.8%) |
| California | 34 (8.5%) |
| Colorado | 6 (1.5%) |
| Connecticut | 2 (0.5%) |
| Delaware | 1 (0.3%) |
| Florida | 20 (5.0%) |
| Georgia | 5 (1.3%) |
| Hawaii | 1 (0.3%) |
| Idaho | 2 (0.5%) |
| Illinois | 10 (2.5%) |
| Indiana | 5 (1.3%) |
| Iowa | 1 (0.3%) |
| Kansas | 1 (0.3%) |
| Kentucky | 1 (0.3%) |
| Louisiana | 2 (0.5%) |
| Maine | 2 (0.5%) |
| Maryland | 8 (2.0%) |
| Massachusetts | 9 (2.3%) |
| Michigan | 7 (1.8%) |
| Minnesota | 3 (0.8%) |
| Mississippi | 1 (0.3%) |
| Missouri | 2 (0.5%) |
| Montana | 2 (0.5%) |
| Nebraska | 1 (0.3%) |
| Nevada | 3 (0.8%) |
| New Hampshire | - |
| New Jersey | 3 (0.8%) |
| New Mexico | 3 (0.8%) |
| New York | 6 (1.5%) |
| North Carolina | 8 (2.0%) |
| North Dakota | 1 (0.3%) |
| Ohio | 14 (3.5%) |
| Oklahoma | 2 (0.5%) |
| Oregon | 7 (1.8%) |
| Pennsylvania | 16 (4.0%) |
| Rhode Island | 1 (0.3%) |
| South Carolina | 1 (0.3%) |
| South Dakota | - |
| Tennessee | 3 (0.8%) |
| Texas | 20 (5.0%) |
| Utah | 6 (1.5%) |
| Vermont | 2 (0.5%) |
| Virginia | 4 (1.0%) |
| Washington | 15 (3.8%) |
| West Virginia | 3 (0.8%) |
| Wisconsin | 10 (2.5%) |
| Wyoming | - |

Participants reported having (i.e., having been diagnosed, sought or be currently seeking a diagnosis, or believing they have) the following conditions, IBS (*n* = 212, 53.0%), endometriosis (*n* = 180, 45.0%), chronic low backpain (*n* = 179, 44.8%), chronic migraine (*n* = 158, 39.5%), TMJ (*n* = 150, 37.5%), chronic fatigue syndrome (*n* = 149, 37.3%), fibromyalgia (*n* = 147, 36.8%), chronic tension-type headache (*n* = 102, 25.5%), vulvodynia (*n* = 95, 23.8%), and interstitial cystitis (*n* = 64, 16.0%). Importantly, as these conditions overlap, many participants reported having two or more of these COPCs. See Table 18.

**Table 18.** Conditions Reported by Survey Participants (*N* = 400).

| | Response Options – N (Row %) | | | | | |
|---|---|---|---|---|---|---|
| **Condition** | **Been Diagnosed** | **Seeking Diagnosis** | **Sought Diagnosis in Past** | **Believe I Have** | **Do Not Have** | **Total With (% of 400)** |
| Interstitial Cystitis (IC) | 30 (7.5%) | 17 (4.3%) | 3 (0.8%) | 14 (3.5%) | 336 (84.0%) | 64 (16.0%) |
| Irritable Bowel Syndrome (IBS) | 138 (34.5%) | 26 (6.5%) | 13 (3.3%) | 35 (8.8%) | 188 (47.0%) | 212 (53.0%) |
| Vulvodynia | 62 (15.5%) | 9 (2.3%) | 11 (2.8%) | 13 (3.3%) | 305 (76.3%) | 95 (23.8%) |
| Endometriosis | 93 (23.3%) | 47 (11.8%) | 20 (5.0%) | 20 (5.0%) | 220 (55.0%) | 180 (45.0%) |
| Temporomandibular Joint Disorders (TMJ) | 92 (23.0%) | 14 (3.5%) | 9 (2.3%) | 35 (8.8%) | 250 (62.5%) | 150 (37.5%) |
| Chronic Low Back Pain (CLBP) | 105 (26.3%) | 32 (8.0%) | 13 (3.3%) | 29 (7.2%) | 221 (55.3%) | 179 (44.8%) |
| Chronic Tension-Type Headache (CTTH) | 70 (17.5%) | 14 (3.5%) | 14 (3.5%) | 4 (10.3%) | 261 (65.3%) | 102 (25.5%) |
| Chronic Migraine | 117 (29.3%) | 12 (3.0%) | 10 (2.5%) | 19 (4.8%) | 242 (60.5%) | 158 (39.5%) |
| Chronic Fatigue Syndrome (CFS) | 53 (13.3%) | 36 (9.0%) | 24 (6.0%) | 36 (9.0%) | 251 (62.7%) | 149 (37.3%) |
| Fibromyalgia (FM) | 99 (24.8%) | 16 (4.0%) | 15 (3.8%) | 17 (4.3%) | 253 (63.2%) | 147 (36.8%) |

Participants also reported on a variety of pain-related demographics. Of participants who reported that they had been diagnosed with one or more COPCs, 52.3% (*n* = 209) reported having been diagnosed by a specialist (such as a rheumatologist or gynecologist) while another 23.0% (*n* = 92) reported being diagnosed by a primary care provider or general practitioner.

Time elapsed between a participant's first appointment and an official diagnosis averaged 3.87 years (*SD* = 3.34), while participants reported seeing an average of 4.52 medical providers (SD = 2.76) during this time. Only 13.6% (*n* = 54) participants reported that their pain was "very well managed" or "well managed" by their current treatment regimen. Most participants (*n* = 134, 33.5%) reported seeing a primary care provider or general practitioner for the management of their condition(s), although 21.3% (*n* = 85) reported not regularly seeing any medical provider. Regarding the use of pain medication, 146 participants (36.5%) reported currently taking one or more prescription pain medications. See Table 19.

**Table 19.** Survey Participants' Pain-Related Demographics (*N* = 400).

| **Characteristic** | **N (%)** |
|---|---|
| Type of Provider Diagnosed (Only if Diagnosed Selected) | |
| Specialist | 209 (52.3%) |
| Primary Care Provider (PCP)/General Practitioner (GP) | 92 (23.0%) |
| Pain Management Specialist | 12 (3.0%) |
| Physical Therapist | 5 (1.3%) |
| Physician Assistant (PA) or Nurse Practitioner (NP) | 5 (1.3%) |
| Psychiatrist, Psychologist, Mental Health Provider | 1 (0.3%) |
| Chiropractor | 1 (0.3%) |
| Other | 24 (6.0%) |
| Years Elapsed Between First Appointment and Diagnosis (Only if Diagnosed)<br>*M* = 3.87, *SD* = 3.34 | |
| One Year | 125 (31.3%) |
| Two Years | 46 (11.5%) |
| Three Years | 34 (8.5%) |
| Four Years | 19 (4.8%) |
| Five Years | 17 (4.3%) |
| Six Years | 8 (2.0%) |
| Seven Years | 17 (4.3%) |
| Eight Years | 7 (1.8%) |
| Nine Years | 7 (1.8%) |
| Ten or More Years | 52 (13.0%) |
| Number of Doctors Seen Between First Appointment and Diagnosis (Only if Diagnosed)<br>*M* = 4.52, *SD* = 2.76 | |
| One Doctor | 41 (10.3%) |
| Two Doctors | 51 (12.8%) |
| Three Doctors | 66 (16.5%) |
| Four Doctors | 45 (11.3%) |
| Five Doctors | 39 (9.8%) |
| Six Doctors | 33 (8.3%) |
| Seven Doctors | 14 (3.5%) |
| Eight Doctors | 15 (3.8%) |
| Nine Doctors | 4 (1.0%) |
| Ten or More Doctors | 41 (10.3%) |

**Table 19. (Continued)**

| | |
|---|---|
| How Well Pain is Currently Managed | |
| Very Well Managed | 17 (4.3%) |
| Well Managed | 37 (9.3%) |
| Somewhat Well Managed | 100 (25.0%) |
| Neutral | 40 (10.0%) |
| Somewhat Not Managed | 103 (25.8%) |
| Not Managed | 60 (15.0%) |
| Not Managed At All | 43 (10.8%) |
| Type of Doctor Seen Most Regularly for Pain | |
| Primary Care Provider (PCP)/General Practitioner (GP) | 134 (33.5%) |
| I do not see a healthcare provider for pain. | 85 (21.3%) |
| Other Specialist | 72 (18.0%) |
| Physical Therapist | 39 (9.8%) |
| Other Healthcare Provider | 35 (8.8%) |
| Pain Specialist | 24 (6.0%) |
| Physician Assistant (PA) or Nurse Practitioner (NP) | 8 (2.0%) |
| Physical Medicine | 3 (0.8%) |
| Satisfaction with Most Recent Doctor Visit | |
| Extremely Satisfied | 74 (18.5%) |
| Somewhat Satisfied | 122 (30.5%) |
| Neither Satisfied nor Dissatisfied | 67 (16.8%) |
| Somewhat Dissatisfied | 87 (10.9%) |
| Extremely Dissatisfied | 50 (6.3%) |
| Use of Prescription Pain Medications | |
| Currently Taking | 146 (36.5%) |
| Have Taken in Past | 174 (43.5%) |
| Never Taken | 80 (20.0%) |

### Measures

Descriptive statistics and reliability information for each measure and subscale appear in Table 3. Confirmatory factor analyses (CFAs) with maximum likelihood estimation were conducted using SPSS AMOS 26 for measures of CD (i.e., DT, PCs, NGIs) as well as established measures with four or more items tapping a latent construct (i.e., CFA was not run on the 1-item measure of overall health [SRH-5] or the 3-item measure of pain severity [PSS]) which have continuous response options. CFAs were also not run in cases where a scale does not presume an underlying latent variable. Specifically, CFA was also not run on the four-item measure of suicidal ideation (SBQ-R) as although each behavior signals something of clinical importance (e.g., the frequency of suicidal ideation in the past year and rated likelihood of future suicidal ideation) this measure does not assume that these four items reflect one underlying latent variable. This can be seen, in part, by the use of different measurement scales for each item. Model fit was considered to be adequate when the comparative fix index (CFI) was between .90 and .95 and the root mean square error of approximation (RMSEA) was between .06 and .08, and good when the CFI was .95 or higher and the RMSEA was .06 or lower (Matsunaga, 2010).

### Measures of Communicative Disenfranchisement (CD)

Three measures of CD include the measures of disenfranchising talk (DT), proximal consequences (PCs), and negative goal inferences (NGIs). Variables (i.e., the composite measures) were computed by averaging using the MEAN procedure in SPSS.

**Disenfranchising talk (DT).** Participants rated 58 items (see Table 12) on a 5-point Likert scale (*1 = Never, 5 = Always*) in terms of "how often they have occurred when you have talked with YOUR DOCTOR(S) IN THE PAST about your pain and/or its effects on your life. Across all the doctors you've EVER seen about your pain, how often has (or have) YOUR DOCTOR(S)…" Larger scores indicate greater incidence of disenfranchising talk.

**Proximal consequences (PCs).** Participants rated 34 items (see Table 13) on a 7-point Likert scale (*1 = Strongly Disagree, 7 = Strongly Agree*) in terms of "whether negative interactions with your doctors changed how you approached conversations with both doctors and other people you know from then on. Negative interactions in the past with MY DOCTOR(S) in which we talked about [my pain] have…" Larger scores indicate greater proximal consequences.

**Negative goal inferences (NGIs).** Participants rated 20 items (see Table 14) on a 7-point Likert scale (*1 = Strongly Disagree, 7 = Strongly Agree*) in terms of "pain and/or its effects on your life. If/When I talk to DOCTORS about my pain IN THE FUTURE, I EXPECT that they will…" All items were reversed such that higher scores indicate greater negative goal inferences.

**Marlow-Crowne social desirability scale–short form (MCSDS-S).** Social desirability was measured using Strahan and Gerbasi's (1972) short form of the Marlowe-Crowne social desirability scale. Participants answered "*True*" or "*False*" for each of 20 items. Sample items included, "I always try to practice what I preach" and "I like to gossip at times" (R). Scores were summed after reverse coding; larger scores reflect higher social desirability (*KR*-20 = .759).

**Hospital anxiety and depression scale (HADS).** Anxiety and depression were measured using the 14-item hospital anxiety and depression scale (HADS; Snaith, 2003), where 7 items each represent anxiety (e.g., "I feel tense or 'wound up'") and depression (e.g., "I can laugh and see the funny side of things" (R)). Items each had unique response options which ranged between 0 and 3. Scores were summed such that higher scores indicated higher anxiety and depression (e.g., for the depression item, 0 = As much as I always could, 3 = Not at all). The two-factor structure initially did not fit the data adequately $\chi^2(76) = 315.179$, $\chi^2/df = 4.147$, CFI = .880, RMSEA = .089. After reviewing the modification indices, item 7 ("I can sit at ease and feel relaxed") was cut from the measure, after which the two-factor structure fit the data adequately $\chi^2(64) = 203.189$, $\chi^2/df = 3.175$, CFI = .923, RMSEA = .074. Reliabilities for the anxiety and depression subscales were .790 and .770 respectively.

**Suicidal behaviors questionnaire–revised (SBQ-R).** Suicidal ideation was measured using Osman et al.'s (2001) 4-item suicidal behaviors questionnaire–revised (SBQ-R). Items tap various aspects of suicidal ideation, including lifetime suicide ideation, frequency of suicidal ideation in the past 12 months, the threat of a suicide attempt, and the likelihood of suicidal behavior in the future. Each item has a unique scale (e.g., the item "How likely is it that you will attempt suicide one day?" is scored from 0 (*Never*) to 6 (*Very Likely*)). Scores are summed. Reliability for the measure was .802.

**West Haven-Yale multidimensional pain inventory–pain severity subscale (PSS).** Pain severity was measured using the 3-item pain severity subscale of the West Haven-Yale multidimensional pain inventory (Kerns et al., 1985) which assesses present pain severity and pain over the past month as well as degree of suffering due to pain. Participants answered each semantic differential question which was scored from 0 (e.g., *No Pain*) to 6 (e.g., *Very Intense Pain*) with unique scales for each question. Scores are summed and averaged such that higher average scores indicate greater pain severity. Reliability for the measure was .775.

**Pain catastrophizing scale (PCS).** The 13-item pain catastrophizing scale (PCS; Sullivan et al., 1995) was used to measure negative pain-related cognitions of rumination (e.g., "I worry all the time about whether the pain will end"), magnification (e.g., "It's terrible and I think it's never going to get any better"), and helplessness (e.g., "There's nothing I can do to reduce the intensity of the pain"). Participants rated each item on a Likert scale (*0 = Not At All, 4 = All The Time*). Scores for each subscale are summed such that higher scores indicate greater pain catastrophizing. The three-factor structure fit the data adequately $\chi^2(62) = 226.438$, $\chi^2/df = 3.652$, CFI = .947, RMSEA = .082. Reliabilities for the three subscales ranged from .713 to .887.

**Pain disability index (PDI).** Pain disability was measured using the 7-item pain disability index (PDI; Tait & Margolis, 1987) which asks participants to reflect about the effects of pain in various life domains (e.g., "Social Activity") on a semantic differential scale (from 0 = No Disability to 10 = Total Disability). Scores are summed such that higher scores indicate higher pain-related disability. The seven items loaded inadequately onto one latent factor $\chi^2(14) = 61.314$, $\chi^2/df = 4.380$, CFI = .973, RMSEA = .092. However, after reviewing the modification indices, error terms for items 2 and 6 ("leisure activity" and "self-care activity") were correlated, improving model fit to adequate $\chi^2(13) = 37.400$, $\chi^2/df = 2.877$, CFI = .986, RMSEA = .069.

Correlated error terms suggest that two items share unique content with each other beyond what they both share with the underlying latent construct (i.e., pain disability). The extent to which a person is able to engage in self-care activity (e.g., showering, driving, getting dressed) is likely required for a person to engage in leisure activities (e.g., sports and hobbies). Hence, correlating these error terms is logical for this population of women with COPCs. Scale reliability was .898.

**Self-rated health (SRH-5).** Overall health was assessed using a single-item measure of self-rated health (SRH-5; Eriksson et al., 2001). Participants rated the following item, "How would you rate your general health status" on 5-point Likert scale (0 = Poor, 5 = Very Good). Higher scores indicate greater overall general health.

**Illness invalidation inventory (3*I).** Convergent validity was assessed using the 8-item illness invalidation inventory (3*I; Kool et al., 2010). This scale was administered randomly to roughly half ($n$ = 183) of participants. Measured on a 5-point Likert scale (*1 = Never, 5 = Very Often*), the measure has two factors: (a) discounting (e.g., "…thinks I should be tougher") and (b) lack of understanding (e.g., "…takes me seriously"). All three items comprising the "lack of understanding" factor are reverse scored, such that larger scores indicate greater illness invalidation. The two-factor structure fit the data well $\chi^2(19) = 226.438$, $\chi^2/df = 1.078$, CFI = .997, RMSEA = .021. Reliabilities for subscales were .727 and .848.

**Group-based medical mistrust scale (GBMMS).** Medical mistrust was assessed using an adapted version of Thompson et al.'s (2004) 12-item group-based medical mistrust scale. Originally developed to assess minority patients' mistrust of healthcare professionals, items were rewritten such that the salient in-group became "people with chronic pain" rather than "people of my ethnic group." For example, an original item read "People of my ethic group cannot trust doctors and health care workers" and was rewritten to read "People with chronic pain cannot trust doctors and health care workers." Three factors for the GBMMS are: (a) suspicion (e.g., "People with chronic pain cannot trust doctors and health care workers"), (b) group disparities in health care (e.g., "People with chronic pain receive the same medical care from doctors and health care workers as people with other conditions" (R)) and (c) lack of support (e.g., "Doctors have the best interests of people with chronic pain in mind" (R)). The GBMMS was scored on a 5-point Likert scale (1 = *Strongly Disagree*, 5 = *Strongly Agree*). Three items were reverse scored; larger scores indicate greater group-based medical mistrust. The three-factor structure fit the data well $\chi 2(51) = 107.43$, $\chi 2/df = 2.106$, CFI = .932, RMSEA = .072. Reliabilities for subscales ranged from .639 to .738.

Descriptive statistics for the measures of DT, PCs, and NGIs as well as all outcome measures can be found in Table 20. Normality was assessed for all variables (where skew and kurtosis values ranged between +/-1.0) indicating that they were approximately normally distributed. The stereotyping dimension of DT and rights and privileges dimension of PCs were slightly skewed and the credibility dimension of PCs, NGIs measure, and 3*I were slightly kurtotic. However, these skewness and kurtosis values still fell within +/-2.0 and thus did not indicate significant violations of normality.

**Table 20.** Descriptive Statistics for Study Two.

| **Variable** | ***M*** | ***SD*** | **Possible Range** | ***sk*** | ***ku*** | ***α*** |
|---|---|---|---|---|---|---|
| ***Communicative Disenfranchisement*** | | | | | | |
| Measure of DT | 2.72 | 1.01 | 1-5 | .40 | -.66 | .974 |
| Discrediting Experience | 2.62 | 1.04 | 1-5 | .25 | -.92 | .951 |
| Discrediting Existence | 2.32 | 1.08 | 1-5 | .51 | -.82 | .961 |
| Silencing | 2.18 | .87 | 1-5 | .69 | -.27 | .933 |
| Stereotyping | 1.75 | .90 | 1-5 | 1.27 | .76 | .896 |
| Measure of PCs | 4.65 | 1.36 | 1-7 | -.79 | .14 | .972 |
| Agency | 5.08 | 1.63 | 1-7 | -.93 | .05 | .968 |
| Credibility | 3.56 | 1.61 | 1-7 | -.13 | -1.05 | .964 |
| Rights and Privileges | 5.39 | 1.44 | 1-7 | -1.21 | .959 | .935 |
| Negative Goal Inferences | 3.91 | 1.73 | 1-7 | -.10 | -1.04 | .984 |

**Table 20. (Continued)**

| | | | | | | |
|---|---|---|---|---|---|---|
| ***Distal Outcome Measures*** | | | | | | |
| Social Desirability (MCSDS-S) | 10.73 | 3.63 | 0-20 | .122 | -.450 | .759 |
| Group-Based Medical Mistrust (GBMM) | 40.53 | 7.92 | 12-60 | -.314 | .286 | .849 |
| Suspicion | 17.73 | 4.62 | 6-30 | -.074 | -.183 | .787 |
| Disparities | 12.06 | 2.37 | 3-15 | -.821 | .866 | .738 |
| Lack of Support | 10.07 | 2.55 | 3-15 | -.476 | -.029 | .639 |
| Illness Invalidation Inventory (3*I) | 23.90 | 6.58 | 8-40 | .051 | -1.04 | .855 |
| Discounting | 15.30 | 5.06 | 5-25 | .148 | -.949 | .848 |
| Lack of Understanding | 8.64 | 2.29 | 3-15 | -.053 | -.263 | .727 |
| Anxiety and Depression (HADS) | 17.74 | 6.99 | 0-42 | -.103 | -.604 | .896 |
| Anxiety | 8.79 | 3.96 | 0-21 | -.088 | -.777 | .790 |
| Depression | 8.97 | 4.24 | 0-21 | .085 | -.478 | .770 |
| Suicidal Ideation (SBQ-R) | 7.92 | 3.87 | 3-18 | .492 | -.679 | .802 |
| Pain Severity (WHYMPI-PSS) | 3.09 | 1.27 | 0-6 | -.184 | -.561 | .775 |
| Pain Catastrophizing (PCS) | 27.28 | 11.81 | 0-52 | .122 | -.814 | .932 |
| Rumination | 9.49 | 4.13 | 0-16 | -.159 | -.889 | .877 |
| Magnification | 5.60 | 2.94 | 0-12 | .099 | -.730 | .713 |
| Helplessness | 11.84 | 5.86 | 0-24 | .192 | -.722 | .881 |
| Pain Disability Index (PDI) | 33.11 | 15.29 | 0-70 | -.006 | -.887 | .898 |
| Self-Rated Health (SRH-5) | 2.94 | .978 | 1-5 | -.165 | -.554 | N/A |

Note: GBMMS (*n* = 217) and 3*I (*n* = 183) were each displayed randomly to approximately half of participants.

# CHAPTER SIX: STUDY TWO RESULTS AND DISCUSSION

This chapter reports the results and discussion for study two. First, the exploratory factor analyses for CD measures of DT, PCs, and NGIs are reported as this was the first step toward assessing unidimensionality and predicated the trimming of scale items. Bivariate Pearson correlations are next reported and interpreted among all CD and outcome variables and demographics. Then, findings related to convergent and divergent validity are discussed. Next, the results of multiple regressions conducted to assess the potential influence of demographic variables to be included as control variables are reported, followed by procedures for imputing data. Then, the procedures for conducting confirmatory factor analyses are reported, which include reporting on procedures for the measurement and structural models. Finally, the reporting and interpretation of results for each hypothesis conclude the chapter.

## Exploratory Factor Analyses for CD Measures

Following guidance by DeVellis (2017), data from study two were analyzed via exploratory factor analysis (EFA) to assess the multidimensional nature of the measures of DT, PCs, and NGIs. Exploratory factor analysis with principal axis factoring (and utilizing promax rotation where more than one factor emerged) was run on each measure to assess unidimensionality (Matsunaga, 2010).

Results for the measure of DT initially indicated seven factors with an eigenvalue >1.0 together accounting for 69.3% cumulative variance. I then compared 3, 4, 5, 6, and 7-factor solutions for the measure of DT. The 4-factor solution was selected based upon three criteria: (a) an examination of the eigenvalues (>1.0) as well as the scree plot, (b) whether enough items loaded cleanly (i.e., the item had a loading >0.50 on a primary factor and no loadings >0.30 on any secondary factor; Matsunaga, 2010) onto each factor, and (c) whether factors were interpretable (i.e., whether the items loading onto a factor had a common identifiable theme). In the initial solution, no items loaded cleanly (or >.30) onto the seventh factor. After exploring other possibilities, the four-factor solution was selected as items 1-7 as well as 10, 13, and 15-17, 19-24, 33, 39, and 46-48 loaded cleanly onto a first factor (theorized as “discrediting existence”), items 25-29 loaded onto a second factor (theorized as “discrediting experience”), items 31, 34, 36-38, and 40-45 loaded onto a third factor (theorized as “silencing”), and items 51-58 loaded onto a second factor (theorized as “stereotyping”). These four factors accounted for 62.6% of the cumulative inter-item variance.

Given the length of the original DT scale (i.e., 58 items), several steps were taken to reduce the measure’s length. First, items (*n* = 13; items 5, 8, 11, 12, 14, 15, 18, 25, 35, 38, 46, 47, 49) which did not load cleanly (i.e., >.50) on a primary factor were cut, as were items (*n* = 2; 9, 50) which did load at least .50 on a primary factor but which also cross-loaded above .30 on a secondary factor (Matsunaga, 2010). Second, to further improve the quality of the measure of DT and reduce its length, additional items (*n* = 9; items 3, 13, 16, 17, 33, 37, 39, 48, and 51) that did not have “substantial loadings” (i.e., <0.65; DeVellis, 2017, p. 192) on a primary factor were cut. This second more stringent criterion was only employed for the measure of DT as the other measures were shorter. After cutting these 24 items, another EFA with four factors was conducted with the remaining 32 items. At this point, new items (*n* = 4; items 36, 56, 57, and 58) fell below the substantial loading threshold (>0.65) and were cut from the measure, leaving a total of 28 items in the measure of DT. See Table 21 for factor loadings (second iteration factor loadings in parentheses) and Table 22 for the revised measure of DT.

**Table 21.** Factor Loadings Based on Principal Axis Factoring with Promax Rotation for Measure of Disenfranchising Talk.

| | | **Factor Loadings (Second Iteration EFA)** | | | |
|---|---|---|---|---|---|
| **#** | **Item** | **Discrediting Existence** | **Discrediting Experience** | **Silencing** | **Stereotyping** |
| **1** | **Doubted whether the pain is as severe as I have explained it to be.** | **.673 (.665)** | | | |
| **2** | **Suggested that the pain is not really as bad as I say it is.** | **.780 (.765)** | | | |
| *3* | *Doubted how significant the pain is.* | *.504* | | | |
| **4** | **Expressed skepticism about how bad the pain really is.** | **.703 (.709)** | | | |
| *5* | *Questioned how severe the pain is.* | *.495* | | | |
| **6** | **Questioned whether my pain is as serious as I claim it to be.** | **.688 (.688)** | | | |
| **7** | **Suggested that the pain doesn't affect me as much as I say it does.** | **.714 (.679)** | | | |
| *8* | *Suggested that the pain should not matter to me as much as it does.* | *.459* | *.396* | | |
| *9* | *Suggested that I shouldn't think about the pain so much.* | *.503* | *.430* | | |
| **10** | **Suggested that my description of the pain is exaggerated.** | **.776 (.737)** | | | |
| *11* | *Suggested that I shouldn't let the pain get to me as much as it does.* | *.442* | *.450* | | |
| *12* | *Suggested that I shouldn't worry so much about the pain.* | *.365* | *.559* | | |
| *13* | *Claimed that I was letting the pain affect my life more than other people do.* | *.511* | | | |
| *14* | *Claimed that I act more disabled by my pain than other people like me.* | *.409* | | | *.331* |
| *15* | *Claimed that people like me should be able to do more than I can do.* | *.436* | | | |
| *16* | *Claimed that I acted like I was in more pain than other people who are "really" sick.* | *.527* | | | |
| *17* | *Claimed that I was not acting the way someone in pain would act.* | *.559* | | | |
| *18* | *Claimed that I am limited more by my pain than other people like me.* | *.319* | | | *.361* |
| **19** | **Said or implied that the pain does not really exist.** | **.967 (.940)** | | | |
| **20** | **Said or implied that the pain was not real.** | **.989 (.919)** | | | |
| **21** | **Said or implied that I was imagining the pain.** | **.972 (.911)** | | | |
| **22** | **Said or implied that the pain was all in my head.** | **.872 (.837)** | | | |
| **23** | **Said or implied that the pain is not really happening to me.** | **1.00 (.949)** | | | |
| **24** | **Said or implied that I wasn't actually in pain.** | **.923 (.881)** | | | |
| *25* | *Said or implied that the pain was no cause for concern.* | | *.493* | | |
| **26** | **Said or implied that the pain is normal.** | | **.860 (.808)** | | |
| **27** | **Said or implied that everyone experiences pain.** | | **.857 (.893)** | | |

**Table 21 (Continued)**

| | | | | | |
|---|---|---|---|---|---|
| **28** | **Said or implied that the pain is just a part of being human.** | | **.854 (.848)** | | |
| **29** | **Said or implied that everyone has to cope with pain.** | | **.838 (.838)** | | |
| **31** | **Tried to get me to stop talking about the pain.** | | | **.665 (.718)** | |
| *32* | *Told me that they were sick of hearing me talk about the pain.* | | | | |
| *33* | *Told me that I shouldn't talk about the pain so much.* | *.510* | | | |
| **34** | **Changed the subject when I tried to talk about the pain.** | | | **.748 (.790)** | |
| *35* | *Told me that I should not have talked about the pain.* | | | | *.447* |
| *36* | *Acted uninterested in hearing about the pain.* | | | *.681 (.631)* | |
| *37* | *Acted preoccupied with their computer or tablet when I tried to talk about the pain.* | | | *.626* | |
| *38* | *Rolled their eyes when I started to talk about the pain.* | | | *.345* | |
| *39* | *Criticized me when I mentioned the pain.* | *.502* | | | |
| **40** | **Interrupted me when I tried to talk about the pain.** | | | **.711 (.760)** | |
| **41** | **Ignored me when I brought the pain up.** | | | **.681 (.681)** | |
| **42** | **Talked over me when I tried to talk about the pain.** | | | **.657 (.696)** | |
| **43** | **Did not give me an opportunity to talk about the pain.** | | | **.762 (.777)** | |
| **44** | **Prevented me from talking about the pain.** | | | **.670 (.719)** | |
| **45** | **Made it impossible for me to talk about the pain.** | | | **.709 (.813)** | |
| *46* | *Suggested that I was being overly emotional.* | *.379* | | | |
| *47* | *Suggested that I was just too sensitive.* | *.416* | | | |
| *48* | *Suggested that I was being dramatic.* | *.532* | | | |
| *49* | *Suggested that I was just weak.* | *.304* | | | *.316* |
| *50* | *Suggested that I was just looking for attention.* | *.418* | | | *.573* |
| *51* | *Suggested that I wanted people to feel sorry for me.* | | | | *.639* |
| **52** | **Assumed that I had an ulterior motive for talking about the pain.** | | | | **.910 (.827)** |
| **53** | **Assumed that I was just trying to get pain medication.** | | | | **.760 (.891)** |
| **54** | **Assumed that I was a drug seeker.** | | | | **.791 (.909)** |
| **55** | **Assumed that I was up to no good.** | | | | **.800 (.754)** |
| *56* | *Assumed that I was trying to get out of work or school.* | | | | *.742 (.587)* |
| *57* | *Assumed that I was trying to get disability benefits.* | | | | *.687 (.609)* |
| *58* | *Assumed that I was using the pain to avoid my responsibilities.* | | | | *.761 (.588)* |

Note: Factor loadings <.3 are suppressed. Items in italics were cut from the final scale. Items in bold were retained.

**Table 22.** Revised Disenfranchising Talk (DT) Measure and Factors (28 Items).

| Dimension | Old Item # | New Item # | Item (Items in *Italics* Cut from Final Scale, Bold Items Retained) |
|---|---|---|---|
| Discrediting Existence (12 Items Retained) | **1** | **1** | **Doubted whether the pain is as severe as I have explained it to be.** |
| | **2** | **2** | **Suggested that the pain is not really as bad as I say it is.** |
| | *3* | - | *Doubted how significant the pain is.* |
| | **4** | **3** | **Expressed skepticism about how bad the pain really is.** |
| | *5* | - | *Questioned how severe the pain is.* |
| | **6** | **4** | **Questioned whether my pain is as serious as I claim it to be.** |
| | **7** | **5** | **Suggested that the pain doesn’t affect me as much as I say it does.** |
| | *8* | - | *Suggested that the pain should not matter to me as much as it does.* |
| | *9* | - | *Suggested that I shouldn’t think about the pain so much.* |
| | **10** | **6** | **Suggested that my description of the pain is exaggerated.** |
| | *11* | - | *Suggested that I shouldn’t let the pain get to me as much as it does.* |
| | *12* | - | *Suggested that I shouldn’t worry so much about the pain.* |
| | *13* | - | *Claimed that I was letting the pain affect my life more than other people do.* |
| | *14* | - | *Claimed that I act more disabled by my pain than other people like me.* |
| | *15* | - | *Claimed that people like me should be able to do more than I can do.* |
| | *16* | - | *Claimed that I acted like I was in more pain than other people who are “really” sick.* |
| | *17* | - | *Claimed that I was not acting the way someone in pain would act.* |
| | *18* | - | *Claimed that I am limited more by my pain than other people like me.* |
| | **19** | **7** | **Said or implied that the pain does not really exist.** |
| | **20** | **8** | **Said or implied that the pain was not real.** |
| | **21** | **9** | **Said or implied that I was imagining the pain.** |
| | **22** | **10** | **Said or implied that the pain was all in my head.** |
| | **23** | **11** | **Said or implied that the pain is not really happening to me.** |
| | **24** | **12** | **Said or implied that I wasn’t actually in pain.** |
| Discrediting Experience (4 Items Retained) | *25* | - | *Said or implied that the pain was no cause for concern.* |
| | **26** | **13** | **Said or implied that the pain is normal.** |
| | **27** | **14** | **Said or implied that everyone experiences pain.** |
| | **28** | **15** | **Said or implied that the pain is just a part of being human.** |
| | **29** | **16** | **Said or implied that everyone has to cope with pain.** |
| Silencing (8 Items Retained) | **31** | **17** | **Tried to get me to stop talking about the pain.** |
| | *32* | - | *Told me that they were sick of hearing me talk about the pain.* |
| | *33* | - | *Told me that I shouldn’t talk about the pain so much.* |
| | **34** | **18** | **Changed the subject when I tried to talk about the pain.** |
| | *35* | - | *Told me that I should not have talked about the pain.* |
| | *36* | - | *Acted uninterested in hearing about the pain.* |
| | *37* | - | *Acted preoccupied with their computer or tablet when I tried to talk about the pain.* |
| | *38* | - | *Rolled their eyes when I started to talk about the pain.* |
| | *39* | - | *Criticized me when I mentioned the pain.* |
| | **40** | **19** | **Interrupted me when I tried to talk about the pain.** |
| | **41** | **20** | **Ignored me when I brought the pain up.** |
| | **42** | **21** | **Talked over me when I tried to talk about the pain.** |
| | **43** | **22** | **Did not give me an opportunity to talk about the pain.** |
| | **44** | **23** | **Prevented me from talking about the pain.** |
| | **45** | **24** | **Made it impossible for me to talk about the pain.** |

**Table 22 (Continued)**

| | | | |
|---|---|---|---|
| Stereotyping (4 Items Retained) | *46* | - | *Suggested that I was being overly emotional.* |
| | *47* | - | *Suggested that I was just too sensitive.* |
| | *48* | - | *Suggested that I was being dramatic.* |
| | *49* | - | *Suggested that I was just weak.* |
| | *50* | - | *Suggested that I was just looking for attention.* |
| | *51* | - | *Suggested that I wanted people to feel sorry for me.* |
| | **52** | **25** | **Assumed that I had an ulterior motive for talking about the pain.** |
| | **53** | **26** | **Assumed that I was just trying to get pain medication.** |
| | **54** | **27** | **Assumed that I was a drug seeker.** |
| | **55** | **28** | **Assumed that I was up to no good.** |
| | *56* | | *Assumed that I was trying to get out of work or school.* |
| | *57* | | *Assumed that I was trying to get disability benefits.* |
| | *58* | | *Assumed that I was using the pain to avoid my responsibilities.* |

Separate EFAs also were conducted on the measures of PC as well as NGIs. Results for the PCs measure indicated that three factors emerged with an eigenvalue >1.0 which accounted for 70.5% of the cumulative variance. Items 1-12 loaded cleanly (all loadings >.67) onto one factor (theorized as “agency”) and items 13-22 loaded cleanly (all loadings >.75) onto a second factor (theorized as “credibility”). Items 23-34 loaded onto a third factor (theorized as “ability to exercise rights and privileges”), although item 30 “Made it harder for me to be excused from work or school” was cut because it cross-loaded onto factors two and three, and items 27 and 33 were cut because they had low loadings (<.50). After cutting these three items, the EFA was re-run and all remaining items loaded strongly (>.65) onto their respective factors with the exception of item 23 (“Made me lose out on opportunities in my social life or at work”) which fell below the .50 threshold and was cut. After item 23 was cut, all items loaded strongly (>.65) onto their respective factors and those three factors together accounted for 74.4% of the cumulative inter-item variance. See Table 23 for factor loadings and Table 24 for the revised measure of PCs with updated item numbering.

**Table 23.** Factor Loadings Based on Principal Axis Factoring with Promax Rotation for Measure of Proximal Consequences.

| Item # | Item (Items in *Italics* Cut from Final Scale) | Agency | Credibility | Rights and Privileges |
|---|---|---|---|---|
| **1** | **Made me hesitant to bring the pain up in future conversations.** | **.878** | | |
| **2** | **Made me talk less about the pain moving forward.** | **.927** | | |
| **3** | **Made it harder for me to talk about the pain after that.** | **.888** | | |
| **4** | **Made it less likely that I will talk about the pain with them from now on.** | **.813** | | |
| **5** | **Made me think twice before talking about my pain in the future.** | **.918** | | |
| **6** | **Made me isolate myself from others to avoid talking about my pain.** | **.678** | | |
| **7** | **Made me choose carefully who to talk to about the pain in the future.** | **.862** | | |
| **8** | **Made me distrustful of others who I might talk to about the pain.** | **.650** | | |
| **9** | **Made me more selective about who I talk to about the pain in the future.** | **.853** | | |
| **10** | **Made me change what I said to others about my pain moving forward.** | **.709** | | |
| **11** | **Made me stop talking about the pain with some people I know.** | **.843** | | |
| **12** | **Made me hesitant to talk about the pain with someone new in the future.** | **.916** | | |
| **13** | **Made me appear to be a dishonest person.** | | **.868** | |
| **14** | **Made me appear to be unworthy of sympathy.** | | **.794** | |
| **15** | **Made me seem untrustworthy.** | | **.911** | |
| **16** | **Made me appear to be a person of low character.** | | **.912** | |
| **17** | **Made me look like a bad person.** | | **.879** | |
| **18** | **Made me look unintelligent.** | | **.878** | |
| **19** | **Made me appear to be uninformed.** | | **.756** | |
| **20** | **Made me seem incompetent about.** | | **.823** | |
| **21** | **Made me appear to be stupid.** | | **.889** | |
| **22** | **Made me look irrational.** | | **.778** | |
| *23* | *Made me lose out on opportunities (for example, in my social life or at work).* | | | *.518* |
| **24** | **Made it harder for me to receive what I need to get by.** | | | **.845** |
| **25** | **Made it harder for me to get help when I needed it.** | | | **.889** |
| **26** | **Made it harder for me to find support from others.** | | | **.565** |
| ***27*** | ***Made it harder for me to access disability benefits.*** | | | ***.314*** |
| **28** | **Made it harder for me to receive a diagnosis.** | | | **.737** |
| **29** | **Made it harder for me to be treated for my pain.** | | | **.953** |
| *30* | *Made it harder for me to be excused from work or school.* | | *.342* | *.395* |
| **31** | **Made it harder for me to seek future care for my pain.** | | | **.872** |
| **32** | **Made me less likely to seek care for other physical health issues moving forward.** | | | **.684** |
| *33* | *Made me hesitant to ask for help to cope with my pain.* | | | *.373* |
| **34** | **Made me hesitant to seek care for any mental health concerns which may arise in the future.** | | | **.655** |

Note: Factor loadings <.3 are suppressed. Items in italics indicate items cut from the final scale. Items in bold were retained.

**Table 24.** Revised Proximal Consequences (PCs) Measure and Factors (30 Items).

| Dimension | Old Item # | New Item # | Item |
|---|---|---|---|
| **Agency (12 Items Retained)** | 1 | 1 | Made me hesitant to bring the pain up in future conversations. |
| | 2 | 2 | Made me talk less about the pain moving forward. |
| | 3 | 3 | Made it harder for me to talk about the pain after that. |
| | 4 | 4 | Made it less likely that I will talk about the pain with them from now on. |
| | 5 | 5 | Made me think twice before talking about my pain in the future. |
| | 6 | 6 | Made me isolate myself from others to avoid talking about my pain. |
| | 7 | 7 | Made me choose carefully who to talk to about the pain in the future. |
| | 8 | 8 | Made me distrustful of others who I might talk to about the pain. |
| | 9 | 9 | Made me more selective about who I talk to about the pain in the future. |
| | 10 | 10 | Made me change what I said to others about my pain moving forward. |
| | 11 | 11 | Made me stop talking about the pain with some people I know. |
| | 12 | 12 | Made me hesitant to talk about the pain with someone new in the future. |
| **Credibility (10 Items Retained)** | 13 | 13 | Made me appear to be a dishonest person. |
| | 14 | 14 | Made me appear to be unworthy of sympathy. |
| | 15 | 15 | Made me seem untrustworthy. |
| | 16 | 16 | Made me appear to be a person of low character. |
| | 17 | 17 | Made me look like a bad person. |
| | 18 | 18 | Made me look unintelligent. |
| | 19 | 19 | Made me appear to be uninformed. |
| | 20 | 20 | Made me seem incompetent about. |
| | 21 | 21 | Made me appear to be stupid. |
| | 22 | 22 | Made me look irrational. |
| **Rights and Privileges (8 Items Retained)** | 24 | 23 | Made it harder for me to receive what I need to get by. |
| | 25 | 24 | Made it harder for me to get help when I needed it. |
| | 26 | 25 | Made it harder for me to find support from others. |
| | 28 | 26 | Made it harder for me to receive a diagnosis. |
| | 29 | 27 | Made it harder for me to be treated for my pain. |
| | 31 | 28 | Made it harder for me to seek future care for my pain. |
| | 32 | 29 | Made me less likely to seek care for other physical health issues moving forward. |
| | 34 | 30 | Made me hesitant to seek care for any mental health concerns which may arise in the future. |
| | *23* | - | *Made me lose out on opportunities (for example, in my social life or at work).* |
| | *27* | - | *Made it harder for me to access disability benefits.* |
| | *30* | - | *Made it harder for me to be excused from work or school.* |
| | *33* | - | *Made me hesitant to ask for help to cope with my pain.* |

Results for the NGIs measure indicated unidimensionality – items 1-20 loaded onto a single factor with an eigenvalue >1.0 which accounted for 80.8% of the cumulative inter-item variance. All factor loadings were >0.50. See Table 25 for the revised measure of NGIs.

**Table 25.** Revised Negative Goal Inferences (NGIs) Measure (20 Items).

| # | Item |
|---|---|
| 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 | …Talk to me as if they believe that I experience my pain the way that I say I do. |
| 7 | …Try to help me to get or find what I need to get by. |
| 8 | …Genuinely try to figure out what is going on regarding my pain. |
| 9 | …Work together with me to manage my pain. |
| 10 | …Treat me like an equal partner during our interaction. |
| 11 | …Treat me with respect and fairness. |
| 12 | …Commit to helping me no matter what. |
| 13 | …Treat me the same as they would treat someone WITHOUT chronic pain. |
| 14 | …Treat me the same as they would treat a man. |
| 15 | …Make things better for me by the end of our interaction than before we talked. |
| 16 | …View me as a competent person when I describe my pain. |
| 17 | …Assume that I am a trustworthy person when I talk about my pain. |
| 18 | …View me as credible when I discuss my pain. |
| 19 | …Assume that my motivations for talking about my pain are honest. |
| 20 | …View me as a person who knows what they are talking about regarding my pain. |

Next, I inspected the inter-item correlation means and ranges for the newly modified DT and PC measures and their subscales to assess how closely associations clustered around the mean values (Clark & Watson, 1995). The ranges were determined to be adequate (e.g., 0.275 is the largest subscale inter-item correlation range in Table 26). Hence, no further items were cut from the final measures of DT (28 items), PCs (30 items), and NGIs (20 items) at this stage. See Table 25 for reliabilities and mean, minimum, maximum, and range scores for inter-item correlations for the *final* measures of DT, PCs and NGIs.

Bivariate Pearson correlations among CD measures and subscales are displayed in Table 26, while correlations between CD measures and distal outcome measures are displayed in Tables 27 and 28, and correlations between CD measures and outcomes and study demographics are displayed in Tables 29 and 30. The first correlation matrix revealed significant, positive correlations among all CD measures and dimensions (see Table 26). All CD measures and dimensions (i.e., DT, PCs, NGIs) were significantly negatively associated with overall health and significantly positively associated with pain severity, pain catastrophizing, pain disability, anxiety and depression, suicidal ideation, and illness invalidation (see Tables 28 and 29).

**Table 26.** Inter-Item Correlation Descriptives for DT, PCs, and NGIs Measures.

| | | **Inter-Item Correlation** | | | |
|---|---|---|---|---|---|
| **Scale** | **α** | **Mean** | **Min** | **Max** | **Range** |
| DT: All Subscales | .966 | .504 | .221 | .927 | .705 |
| Discrediting Experience | .967 | .709 | .606 | .823 | .216 |
| Discrediting Existence | .911 | .718 | .686 | .785 | .099 |
| DT: Silencing | .924 | .603 | .512 | .744 | .232 |
| DT: Stereotyping | .910 | .719 | .651 | .927 | .275 |
| PCs: All Subscales | .972 | .536 | .334 | .875 | .541 |
| PCs: Agency | .968 | .722 | .602 | .869 | .267 |
| PCs: Credibility | .964 | .731 | .612 | .875 | .262 |
| PCs: Rights and Privileges | .935 | .648 | .540 | .782 | .241 |
| NGIs | .984 | .800 | .647 | .882 | .236 |

Some demographic variables were dichotomized where relevant (e.g., to distinguish White and broadly non-White, heterosexual and broadly non-heterosexual participants) to add clarity to this phase of the analysis. Although dichotomizing these variables inherently centers Whiteness, heterosexuality, and other non-marginalized identity categories and collapses together the experiences of individuals belonging to various unique cultural groups, there were not enough participants for many groups to maintain more differentiated categories. Regarding race/ethnicity, 88% of participants identified as “White or Caucasian” which meant that all other groups individually constituted less than 6% of participants (see Table 16 in Chapter 5). Regarding sexual orientation, only 54% of participants identified as “Heterosexual/Straight” but the only other category with more than 20% of the sample was “bisexual” with many other categories (e.g., lesbian, questioning, asexual) having a small percentage of participants. Hence, dichotomizing some variables was necessary in order to draw attention to findings unique to broadly non-White, non-heterosexual, etc., populations and groups. As can be seen in Table 30 and 31, demographics with >1 significant correlation to a CD subscale included age, employment status, household income, education, gender identity, sexual orientation, disability status, and current residence (within or outside of the U.S.).

**Table 27.** Correlations Among CD Measures and Subscales.

| **Variable** | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **9** | **10** |
|---|---|---|---|---|---|---|---|---|---|---|
| 1.DT (All) | -- | | | | | | | | | |
| 2.DT: Discrediting Experience | .730 | -- | | | | | | | | |
| 3.DT: Discrediting Existence | .945 | .617 | -- | | | | | | | |
| 4.DT: Silencing | .855 | .523 | .714 | -- | | | | | | |
| 5.DT: Stereotyping | .681 | .374 | .549 | .531 | -- | | | | | |
| 6.PCs (All) | .660 | .467 | .598 | .576 | .530 | -- | | | | |
| 7.PCs: Agency | .525 | .380 | .473 | .457 | .421 | .904 | -- | | | |
| 8.PCs: Credibility | .608 | .392 | .540 | .539 | .551 | .828 | .565 | -- | | |
| 9.PCs: Rights Privileges | .603 | .465 | .566 | .515 | .397 | .858 | .724 | .586 | -- | |
| 10. NGIs | .419 | .287 | .367 | .392 | .342 | .414 | .375 | .287 | .431 | -- |

Note: All correlations in the table are significant at *p* < .01.

### Convergent and Divergent Validity

Convergent and divergent validity were assessed by correlating the measure with variables expected to share positive and negative associations with CD. For instance, social desirability was included as a measure to assess divergent validity, to control for the extent to which reporting disenfranchising talk from important others is influenced by the social desirability of sharing such experiences as a form of solidarity.

To assess convergent validity, scores on the measures of CD (DT, PCs, NGIs) are compared to the 3*I and scores on the NGIs measure are compared to the GBMMS (see Tables 27 and 28). All subscales of the 3*I shared significant (*p* < .001), positive, moderate-to-large sized associations with all CD measures and subscales. The highest associations occurred between the entire measure of DT and the entire measure of 3*I (*r* = .538), as both of these measures assess specific features of talk. The moderate-sized correlations between the 3*I and PCs and NGIs scales ranged from *r* = .214 to *r* = .432, suggesting that the CD measures are both related to but distinct from the measure of 3*I, supporting CD measures' convergent validity. None of the GBMMS subscales shared significant relationships to any CD measure or subscale.

This could be because the modified version of the GBMMS asked participants to reflect about the extent to which *others like them* would experience certain treatment or should hold certain beliefs about doctors and health care workers *generally,* while the measure of NGIs asked participants to reflect on what *their own* future experiences and expectations would be with *their* providers. As items for the GBMMS were written such that the salient "in-group" for a participant was "other people with chronic pain" it is also possible that other salient in-groups take precedent for patients (e.g., other women, other people of my same race/ethnicity) as patients exist at intersections of salient identity categories. These discrepancies could partially account for the lack of association between the GBMMS and measures of CD.

**Table 28.** Correlations Between DT Measure and Distal Outcomes.

| Outcome | DT: All | DT: Experience | DT: Existence | DT: Silencing | DT: Stereotyping |
|---|---|---|---|---|---|
| PSS | .311** | .168** | .259** | .299** | .333** |
| PCS: All | .350** | .248** | .319** | .299* | .285** |
| Rumination | .275** | .192** | .254** | .239** | .211** |
| Magnification | .300** | .223** | .275** | .247** | .242** |
| Helplessness | .360** | .252** | .325** | .309** | .303** |
| PDI | .342** | .256** | .253** | .325** | .397** |
| SRH-5 | -.236** | -.114** | -.204** | -.254** | -.200** |
| MCSDS-S | .055 | .011 | .059 | .052 | .035 |
| HADS: All | .228** | .179** | .156** | .258** | .222** |
| Anxiety | .183** | .167** | .123* | .211** | .149** |
| Depression | .212** | .141** | .147** | .235** | .236** |
| SBQ-R | .263** | .132** | .221** | .246** | .299** |
| GBMMS | .046 | .075 | .053 | .053 | -.070 |
| Suspicion | .079 | .084 | .073 | .100 | -.022 |
| Disparities | .017 | .019 | .024 | .045 | -.073 |
| Lack of Support | -.016 | .062 | .012 | -.059 | -.109 |
| 3*I: All | .519** | .354** | .482** | .451** | .375** |
| Discounting | .510** | .354** | .472** | .429** | .392** |
| Lack of Understanding | .357** | .228** | .328** | .345** | .227** |

Note: PSS = Pain Severity Subscale, PDI = Pain Disability Index, SRH-5 = Self-Rated Health, HADS = Hospital Anxiety and Depression Scale, SBQ-R = Suicidal Behaviors Questionnaire-Revised, GBMM = Group-Based Medical Mistrust, 3*I = Illness Invalidation Inventory. *$p < .05$; **$p < .00$. GBMMS ($n = 217$) and 3*I ($n = 183$) were each displayed randomly to approximately half of participants.

**Table 29.** Correlations Between PCs and NGIs Measures and Distal Outcomes.

| Outcome | PCs: All | PCs: Agency | PCs: Credibility | PCs: Rights & Privileges | NGIs |
|---|---|---|---|---|---|
| PSS | .315** | .278** | .262** | .280** | .198** |
| PCS: All | .279** | .178** | .279** | .297** | .133* |
| Rumination | .169** | .090 | .172** | .206** | .066 |
| Magnification | .295** | .231** | .282** | .264** | .063 |
| Helplessness | .294** | .179** | .300** | .322** | .190** |
| PDI | .416** | .358** | .377* | .342** | .288** |
| SRH-5 | -.270** | -.236** | -.232** | -.234** | -.250** |
| MCSDS-S | .100* | .092 | .069 | .102* | -.065 |
| HADS: All | .244** | .197** | .208** | .242** | .192** |
| Anxiety | .157** | .100* | .146** | .183** | .110* |
| Depression | .258** | .232** | .210** | .229** | .216** |
| SBQ-R | .323** | .264** | .305** | .274** | .276** |
| GBMMS | .068 | .058 | .094 | .012 | -.015 |
| Suspicion | .044 | .018 | .092 | -.004 | -.014 |
| Disparities | .101 | .108 | .105 | .023 | .059 |
| Lack of Support | .039 | .046 | .026 | .025 | -.076 |
| 3*I | .432** | .363** | .399** | .363** | .394** |
| Discounting | .418** | .323** | .424** | .346** | .349** |
| Lack of Understanding | .329** | .341** | .214** | .288** | .361** |

Note: PSS = Pain Severity Subscale, PDI = Pain Disability Index, SRH-5 = Self-Rated Health, HADS = Hospital Anxiety and Depression Scale, SBQ-R = Suicidal Behaviors Questionnaire-Revised, GBMM = Group-Based Medical Mistrust, 3*I = Illness Invalidation Inventory. *$p < .05$; **$p < .00$. GBMMS ($n$ = 217) and 3*I ($n$ = 183) were each displayed randomly to approximately half of participants.

To assess divergent validity, scores across CD measures of DT, PCs, and NGIs are compared to the MCSDS-S measure of social desirability (see Tables 28 and 29). Only the entire PCs measure and the Rights and Privileges subscale of the measure of PCs shared weak ($r = .10$, $r^2 = .01$) but significant ($p < .05$), positive relationships with social desirability. However, given the weakness of these two associations, the lack of other significant associations between social desirability and measures of DT and NGIs, and the relative strength of associations with other outcome measures, these findings support CD measures' divergent validity.

After reviewing Tables 29 and 30, it was determined that age, sexual orientation, and education would be included as covariates in subsequent structural models, as these demographic variables shared the greatest number of significant relationships with CD and outcome measures. To determine whether each of these demographic variables still predicted CD measures when the others were controlled, three separate multiple linear regressions were calculated to predict DT, PCs, or NGIs based on age, sexual orientation, and education. One participant was missing demographic information, and therefore the regression analysis proceeded with $N = 399$.

**Table 30.** Correlations Between CD Measures and Demographics.

| Variable | Age | RS | ES | HI | ED | GI | SO | RE | RB | DS | CR |
|---|---|---|---|---|---|---|---|---|---|---|---|
| DT (All Measure) | -.174** | .018 | .043 | -.071 | -.238** | .058 | .187** | .071 | -.055 | .066 | -.003 |
| DT: Experience | .150** | -.010 | .001 | -.078 | -.131** | .154** | .138** | .077 | -.075 | .031 | .050 |
| DT: Existence | -.189** | .026 | .012 | -.030 | -.207** | .063 | .181** | .092 | -.036 | .027 | .021 |
| DT: Silencing | -.174** | .001 | .071 | -.114* | -.204** | .001 | .155** | .046 | -.067 | .092 | -.002 |
| DT: Stereotyping | .029 | .036 | .093 | -.043 | -.268** | -.031 | .123** | -.034 | -.011 | .118* | -.142** |
| PCs (All Measure) | -.049 | .013 | .093 | -.071 | -.246** | .046 | .208** | .006 | .008 | .110* | -.023 |
| PCs: Agency | -.008 | .029 | .087 | -.055 | -.173** | .015 | .191** | -.043 | -.001 | .119* | -.055 |
| PCs: Credibility | -.023 | .005 | .063 | -.041 | -.269** | .025 | .133** | .015 | .045 | .069 | -.003 |
| PCs: Rights & Privileges | -.127* | -.011 | .094 | -.101* | -.203* | .104* | .228** | .073 | -.034 | .094 | .015 |
| NGIs | -.034 | -.008 | .090 | -.051 | -.105* | .059 | .211** | .049 | -.038 | .121* | -.031 |

Note: RS = Relationship Status, ES = Employment Status, HI = Household Income, ED = Education, GI = Gender Identity, SO = Sexual Orientation, RE = Race/Ethnicity, RB = Religious Beliefs, DS = Disability Status, CR = Current Residence (Within or Outside of the U.S.). Variables for gender identity, sexual orientation, race/ethnicity, current residence, and religious beliefs were artificially dichotomized (e.g., "0" = White, "1" = Non-White). $*p < .05$; $**p < .00$.

For DT, a significant regression equation was found, $F(3, 395) = 12.635$, $p < .001$, with an $R^2$ of .088. Participants' predicted DT score is equal to 2.917 + .122 (Sexual Orientation) - .196 (Education) - .104 (Age), where sexual orientation is coded as 0 = Heterosexual/Straight and 1 = Non-Heterosexual, education is measured such that higher scores equal greater education (e.g., 1 = Less than high school degree, 8 = Doctoral degree (e.g., PhD)), and age is measured in years. Participants' DT score on the 1-5 scale increased .122 points if they identified a sexual orientation other than heterosexual/straight, decreased .196 points for each year of educational attainment, and decreased .104 points for every one-year age increase. Sexual orientation ($p$ = .016), education ($p$ < .001), and age ($p$ = .041) all were significant predictors of DT scores.

For PCs, a significant regression equation was found, $F(3, 395) = 12.965$, $p$ < .000, with an $R^2$ of .090. Participants' predicted PCs score is equal to 5.192 + .179 (Sexual Orientation) - .221 (Education) + .043 (Age). Participants' PCs score on the 1-7 scale increased .179 points if they identified a sexual orientation other than heterosexual/straight, decreased .221 points for each year of educational attainment, and increased .043 points for every one-year age increase. Only two predictors, sexual orientation ($p$ < .001) and education ($p$ < .001) were significant predictors of PCs scores where age was not ($p$ = .399). For NGIs, a significant regression equation was found, $F(3, 395) = 6.825$, $p$ < .000, with an $R^2$ of .049. Participants' predicted NGIs score is equal to 3.714 + .210 (Sexual Orientation) - .067 (Education) + .045 (Age). Participants NGIs score increased .210 points on the 1-7 scale if they identified a sexual orientation other than heterosexual/straight, decreased .067 points for each year of educational attainment, and increased .045 points for every one-year age increase. Only one predictor, sexual orientation ($p$ < .000) was significant, while education ($p$ = .184) and age ($p$ = .389) were not. Given that DT, PCs, and NGIs were included in the same structural models (see below), and that DT and PCs both were associated with multiple demographics, all three demographic variables (age, sexual orientation, education) were included as covariates in subsequent analyses.

**Table 31.** Correlations Between Outcomes and Demographics.

| Variable | Age | RS | ES | HI | ED | GI | SO | RE | RB | DS | CR |
|---|---|---|---|---|---|---|---|---|---|---|---|
| PSS | -.016 | .045 | .197$^{+}$ | -.017 | -.200$^{+}$ | .013 | .108 | .006 | -.012 | .202 | -.067 |
| PCS: All | -.226$^{+}$ | -.019 | .032 | -.077 | -.232$^{+}$ | .052 | .117* | .077 | .010 | .017 | -.095 |
| *Rumination* | -.215$^{+}$ | .018 | -.015 | -.020 | -.178$^{+}$ | .042 | .080 | .069 | .021 | -.022 | -.111* |
| *Magnification* | -.169$^{+}$ | -.010 | -.030 | -.041 | -.163$^{+}$ | -.023 | .084 | .059 | .034 | -.023 | .026 |
| *Helplessness* | -.218 | -.045 | .091 | -.120* | -.259$^{+}$ | .087 | .138$^{+}$ | .077 | -.011 | .062 | -.069 |
| PDI | .109* | .010 | .316$^{+}$ | -.054 | -.199$^{+}$ | .051 | .092 | -.015 | -.017 | .378$^{+}$ | -.085 |
| SRH-5 | .040 | .071 | -.308$^{+}$ | .099* | .168$^{+}$ | -.100* | -.167$^{+}$ | -.075 | .105* | -.354$^{+}$ | -.010 |
| MCSDS-S | .000 | .049 | -.013 | -.017 | -.017 | -.156$^{+}$ | -.110* | -.011 | .000 | .021 | .023 |
| HADS: All | -.121* | -.002 | .069 | -.109* | -.215$^{+}$ | .101* | .203$^{+}$ | .043 | -.086 | .105* | -.008 |
| *Anxiety* | -.228$^{+}$ | -.022 | -.018 | -.096 | -.191$^{+}$ | .123* | .203$^{+}$ | .049 | -.062 | .010 | .049 |
| *Depression* | .012 | .017 | .133$^{+}$ | -.091 | -.173$^{+}$ | .051 | .150$^{+}$ | .025 | -.080 | .171$^{+}$ | -.053 |
| SBQ-R | -.092 | -.148$^{+}$ | .161$^{+}$ | -.086 | -.225$^{+}$ | .166$^{+}$ | .275$^{+}$ | .003 | -.113* | .137$^{+}$ | .046 |
| GBMMS: All | -.063 | -.078 | -.192$^{+}$ | .038 | .032 | .051 | .111 | .035 | .048 | .017 | -.019 |
| *Suspicion* | -.050 | -.027 | -.224$^{+}$ | .036 | .033 | .067 | .113 | .059 | .024 | -.002 | -.030 |
| *Disparities* | -.035 | -.085 | -.042 | .030 | .053 | -.055 | -.005 | -.052 | .013 | .060 | -.031 |
| *Lack of Support* | -.072 | -.113 | -.153* | .024 | -.010 | .088 | .145* | .051 | .095 | .002 | .024 |
| 3*I: All | -.067 | .083 | .031 | -.091 | -.274$^{+}$ | -.033 | .056 | .112 | .045 | .133 | -.026 |
| *Discounting* | -.092 | .053 | .037 | -.081 | -.283$^{+}$ | -.002 | .116 | .113 | .018 | .144 | -.032 |
| *Lack of Understanding* | .007 | .119 | .031 | -.094 | -.161* | -.093 | -.080 | .065 | .02 | .083 | .018 |

Note: RS = Relationship Status, ES = Employment Status, HI = Household Income, ED = Education, GI = Gender Identity, SO = Sexual Orientation, RE = Race/Ethnicity, RB = Religious Beliefs, DS = Disability Status, CR = Current Residence (Within or Outside of the U.S.). PSS = Pain Severity Subscale, PDI = Pain Disability Index, SRH-5 = Self-Rated Health, HADS = Hospital Anxiety and Depression Scale, SBQ-R = Suicidal Behaviors Questionnaire-Revised, GBMM = Group-Based Medical Mistrust, 3*I = Illness Invalidation Inventory. Variables for gender identity, sexual orientation, race/ethnicity, current residence, and religious beliefs were artificially dichotomized (e.g., "0" = White, "1" = Non-White). *$p < .05$; $^{+}p < .00$. GBMMS ($n$ = 217) and 3*I ($n$ = 183) were each displayed randomly to approximately half of participants.

### Multiple Imputation

Prior to beginning confirmatory factor analyses (CFAs) on the measurement models for the measures of CD (i.e., DT, PCs, and NGIs) as well as distal outcomes, multiple imputation was required because AMOS will not produce modification indices for datasets with missing values. The missing value analysis procedure was performed in SPSS using EM (expectation maximization) estimation options. A review of Little's MCAR (Missing Completely at Random) test for all scales and scale items revealed non-significant findings, ($\chi^2$(5499, $N$ =400) = 5557.82, p = .286), meaning that we fail to reject the null hypothesis that the missing data are MCAR and can conclude that no significant patterns exist in the missing data. Missing values were imputed by scale (or subscale, where relevant) using the EM estimation options. Results of Little's MCAR tests are in Table 32 below for the scales/subscales which had missing data.

**Table 32.** Results of Little's MCAR Test for CD and Outcome Measures.

| | Little's MCAR Test | | | |
|---|---|---|---|---|
| Scale or Subscale | *df* | *N* | $\chi^2$ | *p* |
| Disenfranchising Talk (DT) | | | | |
| Discrediting Existence | 14 | 399 | 7.84 | .898 |
| Discrediting Experience | 3 | 399 | 1.88 | .579 |
| Silencing | - | - | - | - |
| Stereotyping | - | - | - | - |
| Proximal Consequences (PCs) | | | | |
| Agency | 86 | 399 | 105.71 | .073 |
| Credibility | 27 | 399 | 29.12 | .355 |
| Rights and Privileges | 19 | 399 | 26.88 | .107 |
| Negative Goal Inferences (NGIs) | 160 | 399 | 95.18 | 1.00 |
| Pain Severity (PSS) | - | - | - | - |
| Pain Catastrophizing (PCS) | 24 | 399 | 25.65 | .371 |
| Pain Disability Index (PDI) | 12 | 399 | 8.52 | .744 |
| Self-Rated Health (SRH-5) | - | - | - | - |
| Social Desirability (MCSDS-S) | 38 | 399 | 28.65 | .864 |
| Anxiety and Depression (HADS) | 12 | 399 | 12.64 | .396 |
| Suicidal Ideation (SBQ-R) | - | - | - | - |
| Group-Based Medical Mistrust (GBMMS) | 30 | 216 | 26.15 | .667 |
| Illness Invalidation (3*I) | 7 | 183 | 7.27 | .401 |

Note: GBMMS (*n* = 217) and 3*I (*n* = 183) were each displayed randomly to approximately half of participants.

## Confirmatory Factor Analysis

Data were then analyzed via confirmatory factor analysis (CFA) using Structural Equation Modeling (SEM) in AMOS 26 to confirm the factor structure for the measures of DT, PCs, and NGIs. Model fit was considered adequate when the comparative fit index (CFI) was between 0.90 and 0.95 and when the root mean square error of approximation was between 0.06 and 0.08, and good when CFI was > .95 and RMSEA was < .06 (see Matsunaga, 2010).

### Disenfranchising Talk (DT) Measure

I first tested a four-factor model of DT consistent with the earlier EFA, where 12 items loaded onto a "discrediting existence" construct, 4 items loaded onto a "discrediting experience" construct, 8 items loaded onto a “silencing” construct, and 4 items loaded onto a “stereotyping” construct. This four-factor model demonstrated adequate fit, $\chi^2(344) = 1210.979$, $\chi^2/df = 3.520$, CFI = .916, RMSEA = .080. The final measure with four factors contained 28 items (reflected in Table 33). The possible range of averaged DT scores ranged from 1 to 5. As an alternative, I also tested a more parsimonious three factor model where the 12 “discrediting existence” and 4 “discrediting experience” items loaded onto a unified “discrediting” construct, 8 items loaded onto a “silencing” construct, and 4 items loaded into a “stereotyping” construct. However, this three-factor model did not demonstrate adequate fit, $\chi^2(347) = 1864.006$, $\chi^2/df = 5.372$, CFI = .853, RMSEA = .105. The four-factor model was retained.

**Table 33.** Final Disenfranchising Talk (DT) Measure and Factors (28 Items).

| **Dimension** | **Old Item #** | **New Item #** | **Item** |
|---|---|---|---|
| Discrediting Existence (12 Items) | 1 | 1 | Doubted whether the pain is as severe as I have explained it to be. |
| | 2 | 2 | Suggested that the pain is not really as bad as I say it is. |
| | 4 | 3 | Expressed skepticism about how bad the pain really is. |
| | 6 | 4 | Questioned whether my pain is as serious as I claim it to be. |
| | 7 | 5 | Suggested that the pain doesn’t affect me as much as I say it does. |
| | 10 | 6 | Suggested that my description of the pain is exaggerated. |
| | 19 | 7 | Said or implied that the pain does not really exist. |
| | 20 | 8 | Said or implied that the pain was not real. |
| | 21 | 9 | Said or implied that I was imagining the pain. |
| | 22 | 10 | Said or implied that the pain was all in my head. |
| | 23 | 11 | Said or implied that the pain is not really happening to me. |
| | 24 | 12 | Said or implied that I wasn’t actually in pain. |
| Discrediting Experience (4 Items) | 26 | 13 | Said or implied that the pain is normal. |
| | 27 | 14 | Said or implied that everyone experiences pain. |
| | 28 | 15 | Said or implied that the pain is just a part of being human. |
| | 29 | 16 | Said or implied that everyone has to cope with pain. |
| Silencing (8 Items) | 31 | 17 | Tried to get me to stop talking about the pain. |
| | 34 | 18 | Changed the subject when I tried to talk about the pain. |
| | 40 | 19 | Interrupted me when I tried to talk about the pain. |
| | 41 | 20 | Ignored me when I brought the pain up. |
| | 42 | 21 | Talked over me when I tried to talk about the pain. |

**Table 33 (Continued)**

| | | | |
|---|---|---|---|
| | 43 | 22 | Did not give me an opportunity to talk about the pain. |
| | 44 | 23 | Prevented me from talking about the pain. |
| | 45 | 24 | Made it impossible for me to talk about the pain. |
| Stereotyping (4 Items) | 52 | 25 | Assumed that I had an ulterior motive for talking about the pain. |
| | 53 | 26 | Assumed that I was just trying to get pain medication. |
| | 54 | 27 | Assumed that I was a drug seeker. |
| | 55 | 28 | Assumed that I was up to no good. |

### Proximal Consequences (PCs) Measure

I tested a 30-item three-factor model of proximal consequences (PCs) as theorized, where 12 items loaded onto an “Agency” construct, 10 items loaded onto a “Credibility” construct, and 8 items loaded onto a “Rights and Privileges” construct. The three-factor model demonstrated marginally adequate fit, $\chi2(402) = 1450.576$, $\chi2/df = 3.608$, CFI = .917, RMSEA = .081. An examination of the modification indices revealed the need to covary error terms for items 18 (“Made me look unintelligent”) and 21 (“Made me appear to be stupid”). With this modification, the model demonstrated adequate fit, $\chi^2(401) = 1315.355$, $\chi2/df = 3.280$, CFI = .928, RMSEA = .076. The final model contained three factors as theorized, 30 items, and one covaried error term. See Table 34. The possible range of PCs scores for the final 30-item measure was 1 to 7.

**Table 34.** Final Proximal Consequences (PCs) Measure and Factors (30 Items).

| **Dimension** | **Old Item #** | **New Item #** | **Item** |
|---|---|---|---|
| Agency (12 Items) | 1 | 1 | Made me hesitant to bring the pain up in future conversations. |
| | 2 | 2 | Made me talk less about the pain moving forward. |
| | 3 | 3 | Made it harder for me to talk about the pain after that. |
| | 4 | 4 | Made it less likely that I will talk about the pain with them from now on. |
| | 5 | 5 | Made me think twice before talking about my pain in the future. |
| | 6 | 6 | Made me isolate myself from others to avoid talking about my pain. |
| | 7 | 7 | Made me choose carefully who to talk to about the pain in the future. |
| | 8 | 8 | Made me distrustful of others who I might talk to about the pain. |
| | 9 | 9 | Made me more selective about who I talk to about the pain in the future. |
| | 10 | 10 | Made me change what I said to others about my pain moving forward. |
| | 11 | 11 | Made me stop talking about the pain with some people I know. |
| | 12 | 12 | Made me hesitant to talk about the pain with someone new in the future. |
| Credibility (10 Items) | 13 | 13 | Made me appear to be a dishonest person. |
| | 14 | 14 | Made me appear to be unworthy of sympathy. |
| | 15 | 15 | Made me seem untrustworthy. |
| | 16 | 16 | Made me appear to be a person of low character. |
| | 17 | 17 | Made me look like a bad person. |
| | 18 | 18 | Made me look unintelligent. |

**Table 34 (Continued)**

| | | | |
|---|---|---|---|
| | 19 | 19 | Made me appear to be uninformed. |
| | 20 | 20 | Made me seem incompetent about. |
| | 21 | 21 | Made me appear to be stupid. |
| | 22 | 22 | Made me look irrational. |
| Rights and Privileges (8 Items) | 24 | 23 | Made it harder for me to receive what I need to get by. |
| | 25 | 24 | Made it harder for me to get help when I needed it. |
| | 26 | 25 | Made it harder for me to find support from others. |
| | 28 | 26 | Made it harder for me to receive a diagnosis. |
| | 29 | 27 | Made it harder for me to be treated for my pain. |
| | 31 | 28 | Made it harder for me to seek future care for my pain. |
| | 32 | 29 | Made me less likely to seek care for other physical health issues moving forward. |
| | 34 | 30 | Made me hesitant to seek care for any mental health concerns which may arise in the future. |

### Negative Goal Inferences (NGIs) Measure

I tested a unidimensional model of negative goal inferences (NGIs), where 20 items loaded onto one latent construct. This model demonstrated inadequate fit, $\chi^2(170) = 768.690$, $\chi^2/df = 4.522$, CFI = .951, RMSEA = .094. An examination of the modification indices revealed the need to cut item 18 ("…View me as credible when I discuss my pain.") after which model fit was only slightly improved, $\chi^2(152) = 646.387$, $\chi^2/df = 4.253$, CFI = .957, RMSEA = .090. At this stage, guided by modification indices, four additional items were cut to improve incremental fit – items 12, 14, 16, and 17 – at which point the model demonstrated adequate fit, $\chi^2(90) = 305.038$, $\chi^2/df = 3.389$, CFI = .975, RMSEA = .077. The final unidimensional model contained 15 items and no covaried error terms. See Table 35. Possible NGIs scores ranged from 1 to 7.

**Table 35.** Final Negative Goal Inferences (NGIs) Measure (15 Items).

| **Old Item #** | **New Item #** | **Item** |
|---|---|---|
| 1 | 1 | …Talk to me as though I am really in pain. |
| 2 | 2 | …Treat me like my pain really exists. |
| 3 | 3 | …Talk to me as if they are really trying to understand my pain. |
| 4 | 4 | …Talk to me as though they believe that I am as limited by my pain as I say that I am. |
| 5 | 5 | …Try to get me to talk about my pain as much as I want or need to. |
| 6 | 6 | …Talk to me as if they believe that I experience my pain the way that I say I do. |
| 7 | 7 | …Try to help me to get or find what I need to get by. |
| 8 | 8 | …Genuinely try to figure out what is going on regarding my pain. |
| 9 | 9 | …Work together with me to manage my pain. |

**Table 35 (Continued)**

| | | |
|---|---|---|
| 10 | 10 | …Treat me like an equal partner during our interaction. |
| 11 | 11 | …Treat me with respect and fairness. |
| 13 | 12 | …Treat me the same as they would treat someone WITHOUT chronic pain. |
| 15 | 13 | …Make things better for me by the end of our interaction than before we talked. |
| 19 | 14 | …Assume that my motivations for talking about my pain are honest. |
| 20 | 15 | …View me as a person who knows what they are talking about regarding my pain. |

### Item Parceling and Structural Models

After measurement models were derived, SEM in AMOS 26 was employed to test the structural model (i.e., proposed hypotheses) and to offer evidence of the CD measures' predictive validity. Following guidance by Matsunaga (2008), items were parceled (following the subset-parcel item approach, where sets of items within a factor are parceled) to reduce the total number of paths in the structural models. Care was taken to assign items within factors randomly to parcels except in cases where there were two or more reverse coded items (in which case those reverse coded items formed a separate parcel) or in which a measure had subdimensions or factors, in which case parcels were created for items within rather than across factors. Further, for cases in which error terms were covaried, these items were assigned to different parcels to avoid negatively impacting model fit. Parcels were computed using the MEAN procedure in SPSS. Parcels were not created for the "discrediting experience" and "stereotyping" factors of DT, as there were only four total items for each of these factors. See Tables 36 and 37 for item parcels for CD and outcome variables and the items assigned to each parcel.

**Table 36.** Item Parcels for CD Variables.

| Variable | Parcel Name | Item Numbers (Old Item Numbers for CD Measures) |
|---|---|---|
| Disenfranchising Talk (DT) | DT28ExistP1 | 1, 6, 19, 22 |
| | DT28ExistP2 | 2, 7, 20, 23 |
| | DT28ExistP3 | 4, 10, 21, 24 |
| | DT28SilP1 | 31, 41, 44 |
| | DT28SilP2 | 34, 42, 45 |
| | DT28SilP3 | 40, 43 |

**Table 36 (Continued)**

| | | |
|---|---|---|
| Proximal Consequences (PCs) | PCsAg1 | 1, 2, 5, 10 |
| | PCsAg2 | 3, 6, 7, 11 |
| | PCsAg3 | 4, 8, 9, 12 |
| | PCsCr1 | 13, 14, 19 |
| | PCsCr2 | 15, 17, 20, 21 |
| | PCsCr3 | 16, 18, 22 |
| | PCsRP1 | 24, 25 |
| | PCsRP2 | 26, 29, 34 |
| | PCsRP3 | 28, 31, 32 |
| Negative Goal Inferences (NGIs) | NGIs1 | 1, 2, 8 |
| | NGIs2 | 4, 10, 15 |
| | NGIs3 | 5, 6, 19 |
| | NGIs4 | 7, 11, 20 |
| | NGIs5 | 3, 9, 13 |

**Table 37.** Item Parcels for Outcome Variables.

| Variable | Parcel Name | Item Numbers (Old Item Numbers for CD Measures) |
|---|---|---|
| Anxiety/Depression | HADSA1 | 1, 9, 11 |
| | HADSA2 | 3, 5, 13 |
| | HADSD1 | 2, 4, 8, 14 |
| | HADSD2 | 6, 10, 12 |
| Pain Severity | PSS_Parcel | 1, 2, 3 |
| Group-Based Medical Mistrust | GBMMS1 | 1, 3, 4, 6 |
| | GBMMS2 | 5, 7, 9, 12 |
| | GBMMSR3 | 2, 8, 10, 11 |
| Illness Invalidation | 3I1 | 3, 5, 8 |
| | 3I2 | 1, 2, 4, 6, 7 |
| Social Desirability | SDS1 | 1, 2, 3, 4, 5 |
| | SDS2 | 6, 7, 8, 9, 10 |
| | SDS3 | 11, 12, 13, 14, 15 |
| | SDS4 | 16, 17, 18, 19, 20 |
| Pain Disability | PDI1 | 1, 2, 3, 4 |
| | PDI2 | 5, 6, 7 |
| Suicidal Ideation | SBQR_P1 | 1, 4 |
| | SBQR_P2 | 2, 3 |
| Pain Catastrophizing | PCSRum1 | 8, 9, 10, 11 |
| | PCSMag2 | 6, 7, 13 |
| | PCSHelp3 | 1, 2, 3, 4, 5, 12 |

### Model Testing

Using these initial item parcels, two structural models were run, one for pain-related outcomes of pain disability, severity, and catastrophizing and one for well-being outcomes of anxiety and depression and suicidal ideation. Both the pain ($\chi^2(576) = 1228.659$, $\chi^2/df = 2.133$, CFI = .960, RMSEA = .053) and well-being ($\chi^2(450) = 899.758$, $\chi^2/df = 1.999$, CFI = .970, RMSEA = .050) models fit well. Then, three control variables were added to both models for participants' age, sexual orientation, and education. Further, although not theorized, direct effects between DT and outcome variables were added into the model to partial them out. New model fit was as follows for the pain model (outcomes included pain disability, catastrophizing, and severity; $\chi^2(663) = 1331.914$, $\chi^2/df = 2.009$, CFI = .959, RMSEA = .050) and the well-being model (outcomes include anxiety and depression and suicidal ideation; $\chi^2(531) = 1047.199$, $\chi^2/df = 1.980$, CFI = .966, RMSEA = .050). See Figures 10 and Figure 11 for structural models.

Given that the covariance path between pain disability (PDI) and pain severity (PSS) was greater than 1.0 (a likely indication of multicollinearity), separate individual models for PDI, PCS and PSS were run to ensure that the results were largely the same as in Figure 10. Given that findings in the individual models for PDI, PSS, and PCS were the same as the pain model with all three pain-related DVs, these three DVs were kept in the same model for parsimony's sake despite the covariance path being greater than 1.0.

All hypotheses were tested by using structural equation modeling (SEM) in AMOS 26 and using maximum likelihood estimation options. Age, education, and sexual orientation were included as control variables in both the pain and well-being models. Hypotheses 7, 8, and 9 which ask about convergent and divergent validity (specifically the associations between DT and social desirability and illness invalidation, and between NGIs and group-based medical mistrust) were addressed above where correlations were described.

H1 predicted that disenfranchising talk (DT) would be positively associated with both the proximal consequences of that talk (PCs) and the negative goal inferences (NGIs) made about how anticipated future interactions would go. In both pain and well-being models, DT was significantly positively associated with both PCs and NGIs ($p < .001$). Figures 10 and 11 report all standardized path coefficients. Therefore, H1 was supported. The model (including covariates) explained 60% of the variance in PCs and 25% of the variance in NGIs.

H2 predicted that PCs would be positively associated with distal outcomes: pain disability (PDI; H2a), pain catastrophizing (PCS; H2b), pain severity (PSS; H2c), anxiety and depression (HADS; H2d) and suicidal ideation (SBQR; H2e). In the pain model (H2a-c), PCs were significantly associated with pain disability (*p* = .002) but not with pain severity (*p* = .102) or pain catastrophizing (*p* = .426). Therefore, H2b and H2c are not supported, although H2a is supported. In the well-being model (H2d-e), PCs were significantly positively associated with suicidal ideation (*p* = .033) but not anxiety and depression (*p* = .125). H2d is not supported, although H2e is supported.

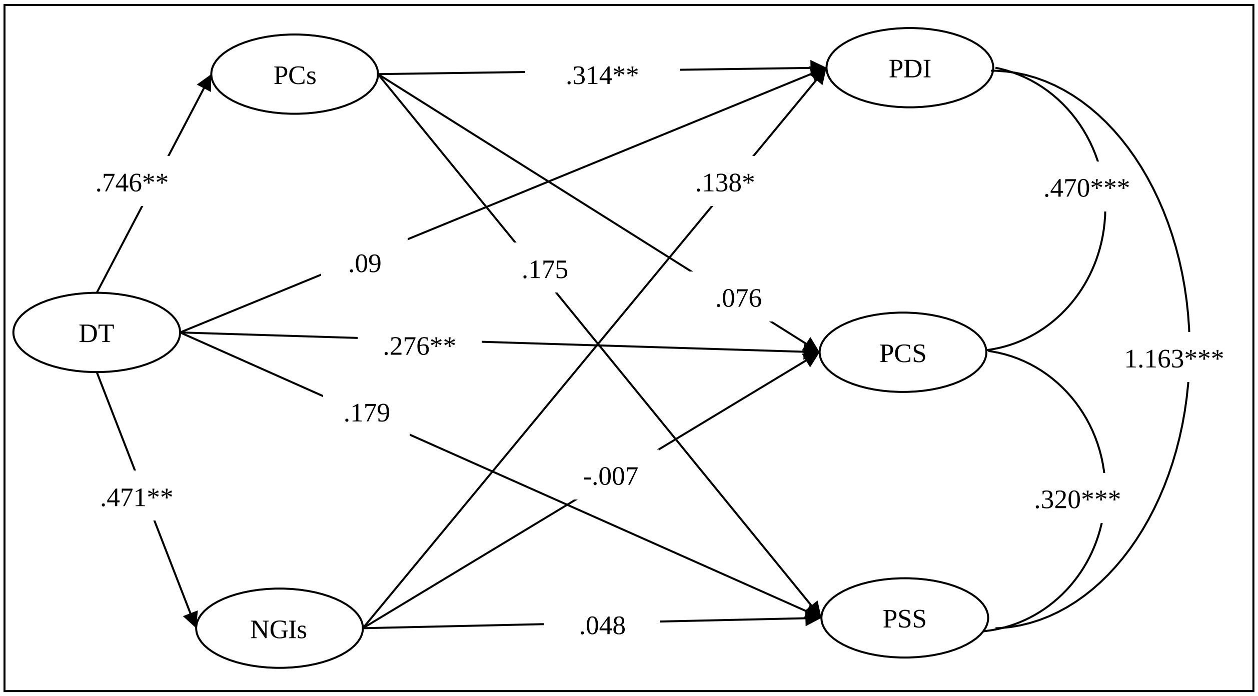

**Figure 10.** Structural Model for Pain-Related Outcomes.

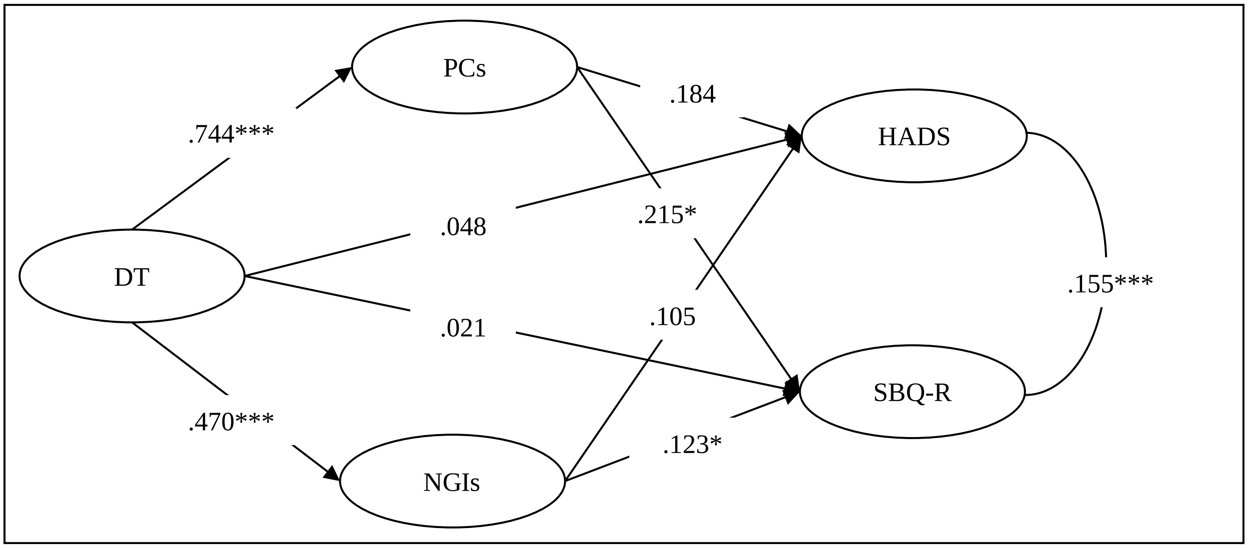

**Figure 11.** Structural Model for Well-Being Outcomes.

Note: Age, sexual orientation, and education were controlled as covariates in both models. * = *p* < .05, ** = *p* < .01, *** *p* < 001.

H3 predicted that NGIs would be positively associated with all distal outcomes, specifically pain disability (PDI; H3a), pain catastrophizing (PCS; H3b), pain severity (PSS; H3c), anxiety and depression (HADS; H3d) and suicidal ideation (SBQR; H3e). In the pain model (H3a-c), NGIs were significantly positively associated with pain disability (*p* = .016) but not with pain catastrophizing (*p* = .435) or pain severity (*p* = .435). Therefore, H3a is supported, but H3b and H3c are not supported. The model explained 20% of the variance in pain catastrophizing, 28% of the variance in pain disability, and 17% of the variance in pain severity. In the well-being model (H3d-e), NGIs were significantly positively associated with suicidal ideation (*p* = .037) but not with anxiety and depression (*p* = .134). Therefore, H3e is supported whereas H3d is not supported. The model explained 21% of the variance in suicidal ideation and 17% of the variance in anxiety and depression. In general, PCs and NGIs were both consistent predictors of about half of the distal outcomes when both were included in the model.

## Mediation Analyses

H4 predicted that PCs would mediate the relationship between disenfranchising talk (DT) and distal outcomes, specifically pain disability (PDI; H4a), pain catastrophizing (PCS; H4b), pain severity (PSS; H4c), anxiety and depression (HADS; H4d) and suicidal ideation (SBQR; H4e). To request specific indirect, direct, and total effects, user-defined estimands were requested using the general approach (AMOS, 2021). Unstandardized regression coefficients (which are the product of user-defined estimands) for these effects are reported below. Bootstrapping was employed in tandem with estimands to produce confidence intervals (CIs) for estimated effects. In the pain model (H4a-c), results indicated that PCs significantly mediated DT's effect on pain disability (H4a; *b* = .543, $CI_{95}$ = .205, .931, *p* = .003). However, the mediated effect of PCs was not significant for pain catastrophizing (H4b; *b* = .053, $CI_{95}$ = -.092, .178, *p* = .454) or for pain severity (H4c; b = .163, $CI_{95}$ = -.034, .394, *p* = .092). Therefore, H4a is supported, whereas H4b and H4c are not supported. In the well-being model (H4d-e), results indicated that PCs significantly mediated DT's effect on anxiety and depression (H4d; b = .200, $CI_{95}$ = .011, 420, *p* = .037) but not on suicidal ideation (H4e; b = .058, $CI_{95}$ = -.017, .148, *p* = .092). Therefore, H4d is supported but H4e is not supported.

H5 predicted that NGIs would mediate the relationship between disenfranchising talk (DT) and distal outcomes, specifically pain disability (PDI; H5a), pain catastrophizing (PCS; H5b), pain severity (PSS; H5c), anxiety and depression (HADS; H4d) and suicidal ideation (SBQR; H5e). In the pain model (H5a-c), results indicated that NGIs significantly mediated DT's effect on pain disability (H5a; *b* = .150, $CI_{95}$ = .027, .293, *p* = .021) but not on pain catastrophizing (H5b; *b* = -.003, $CI_{95}$ = -.061, .057, *p* = .921) or pain severity (H5c; *b* = .028, $CI_{95}$ = -.046, .113, *p* = .386). Therefore, H4a is supported but H4b and H4c are not supported. In the well-being model (H5d-e), results indicated that NGIs significantly mediated DT's effect on anxiety and depression (H5d; *b* = .072, $CI_{95}$ = .006, .160, *p* = .033) but not on suicidal ideation (H5e; *b* = .021, $CI_{95}$ = -.005, .055, *p* = .108). H5d is supported but H5e is not supported. Once again, PCs and NGIs both mediated the impact of DT on about half of included distal outcomes.

In terms of direct effects, in the pain model, the direct effect of DT on pain disability (b = .229, $CI_{95}$ = -.234, .716, *p* = .331) and pain severity (b = .222, $CI_{95}$ = -.072, .487, *p* = .135) were not significant, although the direct effect of DT on pain catastrophizing (b = .256, $CI_{95}$ = .083, .461, *p* = .004) was significant. In the well-being model, the direct effect of DT on anxiety and depression (b = .027, $CI_{95}$ = -.247, .295, *p* = .804) and suicidal ideation (b = .020, $CI_{95}$ = -.080, .155, *p* = .671) were both not significant. These findings regarding direct effects support the current model and use of mediators to explain the relationship between DT and distal outcomes, as only the direct effect of DT on pain catastrophizing was significant. In other words, connections between DT and most outcomes appear to be better explained than through PCs and NGIs than via the direct effects of DT.

In terms of the combined indirect effects of PCs and NGIs, in the pain model, the total summed indirect effect of both PCs and NGIs was significant for pain disability (*b* = .693, $CI_{95}$ = .339, 1.095, *p* = .001) but not for pain catastrophizing (*b* = .050, $CI_{95}$ = -.096, .186, *p* = .467) or pain severity (*b* = .191, $CI_{95}$ = -.005, .424, *p* = .056). In the well-being model, the total summed indirect effect of both PCs and NGIs was significant for anxiety and depression (*b* = .273, $CI_{95}$ = .074, .508, *p* = .008) and for suicidal ideation (*b* = .079, $CI_{95}$ = .002, .173, *p* = .047).

In terms of total effects (i.e., direct + indirect effects), in the pain model, the total effect of DT, PCs, and NGIs on outcomes (the sum of both direct and indirect effects) was significant for pain disability (*b* = .922, $CI_{95}$ = .654, 1.213, *p* = .001), pain catastrophizing (*b* = .306, $CI_{95}$ =

.204, .414, *p* = .001), as well as pain severity (*b* = .413, $CI_{95}$ = .253, .574, *p* = .001). In the well-being model, the total effect of DT, PCs, and NGIs on outcomes was significant for both anxiety and depression (*b* = .299, $CI_{95}$ = .151, .457, *p* = .001) and suicidal ideation (*b* = .100, $CI_{95}$ = .035, .179, *p* = .003). These findings offer empirical support for the utility of CD measures as predictors of these more distal pain-related and well-being outcomes.

**Moderation Analyses**

To test H6, which asked about whether DT would moderate the associations between pain severity (PSS) and: pain disability (PDI; H6a), pain catastrophizing (PCS; H6b), suicidal ideation (SBQ-R; H6c), and anxiety and depression (HADS; H6d), separate moderation models were created for each distal outcome. Variables of PSS and DT were standardized prior to the computing of the interaction variable (the product of DT and PSS) to test whether DT moderated the effect of PSS on each outcome. Age, sexual orientation, and education were included as controls for all models.

First, a model was created to assess the moderating effect of DT on the relationship between PSS and PDI (H6a). Results indicated that the independent variable (PSS) had a significant main effect on the dependent variable (PDI; *b* = .542, *p* < .001). The main effect for DT also was significant (*b* = ,238, *p* < .001). However, the interaction variable (PSS*DT) was not significant (*b* = -.041, *p* = .352), suggesting the absence of a moderating effect of DT on the relationship between PSS and PDI. H6a is not supported.

Second, a model was created to assess the moderating effect of DT on the relationship between PSS and PCS (H6b). Results indicated that the independent variable (PSS) had a significant main effect on the dependent variable (PCS; *b* = .348, *p* < .001), as did the proposed moderation variable (DT; *b* = .237, *p* < .001). However, the interaction variable (PSS*DT) again was not significant (*b* = 038, *p* = .404), suggesting the absence of a moderating effect of DT on the relationship between PSS and PCS. H6b is not supported.

Third, a model assessing the moderating effect of DT on the relationship between PSS and SBQR (H6c) was created. Results indicated that the independent variable (PSS) did not have a significant main effect on the dependent variable (SBQR; *b* = .132, *p* = .019), although DT did (*b* = .191, *p* < .001). The interaction effect also was not significant (PSS*DT; *b* = .068, *p* = .175). H6c is not supported.

Finally, a model was created to assess the moderating effect of DT on the relationship between PSS and HADS (H6c). Results indicated that the independent variable (PSS) did have a significant main effect on the dependent variable (HADS; b = .408, *p* < .001). However, both the DT main effect (*b* = .104, *p* = .111) and interaction variable (PSS*DT; *b* = .058, *p* = .313) were not significant, suggesting the absence of a moderation effect of DT on the relationship between PSS and HADS. H6d is not supported. See Figure 12 for an example model. A summary of all findings for each hypothesis are displayed in Table 38 below.

**Table 38.** Summary of Study Two Findings by Hypothesis.

| **Model Testing** | | | | |
|---|---|---|---|---|
| **H#** | **Description** | **b** | ***p*** | **Result** |
| H1 | DT positively associated with PCs and NGIs. | .746/.471 | <.001 | S |
| H2a | PCs positively associated with PDI. | .314 | .002 | S |
| H2b | PCs positively associated with PCS. | .076 | .201 | NS |
| H2c | PCs positively associated with PSS. | .175 | .102 | NS |
| H2d | PCs positively associated with HADS. | .184 | .125 | NS |
| H2e | PCs positively associated with SBQR. | .215 | .033 | S |
| H3a | NGIs positively associated with PDI. | .138 | .016 | S |
| H3b | NGIs positively associated with PCS. | -.007 | .426 | NS |
| H3c | NGIs positively associated with PSS. | .048 | .435 | NS |
| H3d | NGIs positively associated with HADS. | .105 | .134 | NS |
| H3e | NGIs positively associated with SBQR. | .123 | .037 | S |

**Table 38 (Continued)**

**Mediation Analyses**

| H# | Description | b (CI$_{95}$) | *p* | Result |
|---|---|---|---|---|
| H4a | PCs mediate relationship between DT and PDI. | .543 (.205, .931) | .003 | S |
| H4b | PCs mediate relationship between DT and PCS. | .053 (-.092, .178) | .454 | NS |
| H4c | PCs mediate relationship between DT and PSS. | .163 (-.034, .394) | .092 | NS |
| H4d | PCs mediate relationship between DT and HADS. | .200 (.011, .420) | .037 | S |
| H4e | PCs mediate relationship between DT and SBQR. | .058 (-.017, .148) | .092 | NS |
| H5a | NGIs mediate relationship between DT and PDI. | .150 (.027, .293) | .021 | S |
| H5b | NGIs mediate relationship between DT and PCS. | -.003 (-.061, .057) | .921 | NS |
| H5c | NGIs mediate relationship between DT and PSS. | .028 (-.046, .113) | .386 | NS |
| H5d | NGIs mediate relationship between DT and HADS. | .072 (.006, .160) | .033 | S |
| H5e | NGIs mediate relationship between DT and SBQR. | .021 (-.005, .055) | .108 | NS |

**Moderation Analyses**

| H# | Description | b | *p* | Result |
|---|---|---|---|---|
| H6a | DT moderate relationship between PSS and PDI. | .542 (PSS) | <.001 | NS |
| | | .238 (DT) | <.001 | |
| | | -.041 (PSS*DT) | .352 | |
| H6b | DT moderate relationship between PSS and PCS. | .348 (PSS) | <.001 | NS |
| | | .237 (DT) | <.001 | |
| | | .038 (PSS*DT) | .404 | |
| H6c | DT moderate relationship between PSS and SBQR. | .132 (PSS) | .019 | NS |
| | | .191 (DT) | <.001 | |
| | | .068 (PSS*DT) | .175 | |
| H6d | DT moderate relationship between PSS and HADS. | .408 (PSS) | <.001 | NS |
| | | .104 (DT) | .111 | |
| | | .058 (PSS*DT) | .313 | |

**Convergent and Divergent Validity**

| H# | Description | Pearson's *r* (range) | *p* | Result |
|---|---|---|---|---|
| H7 | No association between CD scales and MCSDS-S. | -.065 – .102 | <.05 | PS |
| H8 | Positive association between CD scales and 3*I. | .228 – .519 | <.00 | S |
| H9 | Positive association between NGIs and GBMMS. | -.076 – .108 | - | NS |

Note: Standardized regression coefficients are reported. S = Supported, PS = Partially Supported, NS = Not Supported.

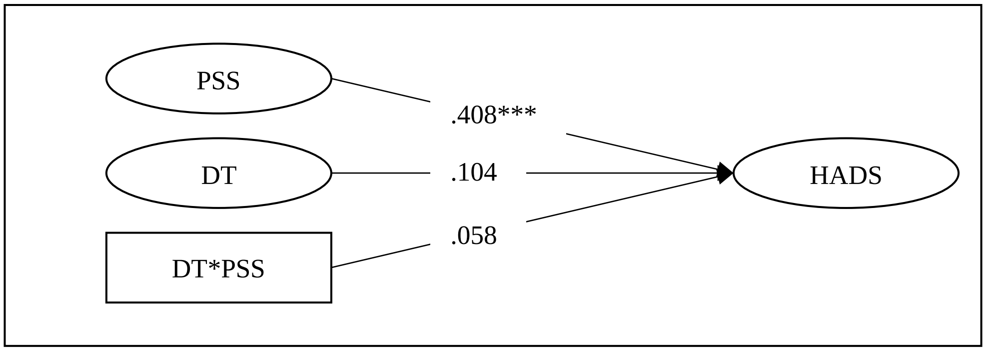

**Figure 12.** Example Moderation Model for Anxiety and Depression (HADS).

Note: Age, sexual orientation, and education were controlled as covariates in both models. *** *p* < 001.

### Study Two Discussion

Although the findings of study two have been interpreted above, some additional discussion of the general pattern of findings and implications of study two is warranted. Study two developed and evaluated measures of the various constructs of the process of communicative disenfranchisement (CD), which included measures of disenfranchising talk (DT), the proximal consequences (PCs) of that talk, and the negative inferences about others' goals (NGIs) that those subjected to disenfranchising talk make about anticipated future interactions. These measures were completed by female patients with chronic overlapping pain conditions (COPCs) who were reflecting about past interactions with medical providers. Unlike existing measures which assess only some aspects of this talk (thus neglecting to examine the numerous dimensions of this talk and its outcomes), these CD measures offer an expansive yet concise means of assessing the prevalence of DT and the extent to which individuals have experienced PCs and make NGIs.

These data suggest that, for instance, patients who have experienced more DT (i.e., more discrediting, silencing, and stereotyping as a proportion of the total number of interactions they have had with medical providers) are more likely to report greater PCs of that talk (i.e., negative effects on their agency, perceived credibility, and ability to exercise rights and privileges), and make greater NGIs about their medical providers in terms of the goals they anticipate those medical providers will tend to pursue with them in future interactions. Having experienced greater PCs and making greater NGIs is linked to more distal outcomes such as heightened pain disability and greater suicidal ideation. This process occurs even after controlling demographic variables including a person's age, level of education, and sexual orientation, though it merits note that patients who were younger, less educated, and reported a sexual orientation other than heterosexual or straight were more likely to report DT, PCs and NGIs as well as these outcomes.

Analyses also confirmed the importance of PCs and NGIs as mediators, as all but one direct effect of DT (for pain catastrophizing) on these outcomes were not significant. This suggests that the DT is associated with distal outcomes such as pain catastrophizing scores primarily through the mediators of PCs and NGIs. Hence, the operation of CD as theorized at the end of study one finds empirical support in these data and further bolsters the importance and utility of examining TCD as it is theorized to unfold across time. The measure of DT asked participants to reflect on all past encounters with medical providers about their COPC(s), while the measure of PCs asked about the extent to which that talk had resulted in a series of more immediate consequences. Next, participants were asked to reflect about if and how these experiences had changed how they anticipated future similar interactions would unfold. This tripartite model of CD which asks about the past, present, and future in terms of disenfranchisement begins the work of empirically theorizing TCD as a process (Poole, 2013).

Further, the psychometric properties of these measures are promising. The measures of DT, PCs, and NGIs were all highly reliable (ranging from .966 to .984). Further, these measures were only weakly related to social desirability (divergent validity) and were moderately and positively associated with their most conceptually similar measure (the 3*I; convergent validity) although no associations between CD measures and the GBMMS were noted. Significant associations between CD measures and outcomes such as pain disability, anxiety and depression, and suicidal ideation were also noted, offering empirical evidence for the findings from the qualitative meta-synthesis and linkages between CD constructs and distal outcomes.

Exploratory and confirmatory factor analyses (EFA and CFA) were conducted to elucidate the underlying factor structure of each measure and assess the extent to which the provided data match the implied covariance matrix as specified. Although the measure of DT initially had 7 factors with an eigenvalue greater than 1.0, constraining the model to four factors created the greatest parsimony for the purposes of interpretation. The measure of PCs loaded cleanly onto three factors as theorized, while the measure of NGIs was unidimensional. The unidimensionality of the measure of NGIs is theoretically cogent, as although goal "types" are often separated for the purpose of analysis, multiple goals theorizing suggests that any message almost always is motivated by multiple goals, which may be contradictory or complimentary in nature. Hence, any number of goals may become salient during a particular interaction, and the unidimensionality of a measure for which items were written to reflect task, relational, and identity goals suggests that inferences about these types of goals are strongly related. For example, when a patient infers that a provider genuinely is trying to understand what is going on regarding the patient's pain, they are also more likely to infer that the provider views them as credible and is working with them as a partner. Findings lead to the reduction of the measure of DT from 58 items down to 28 items, the measure of PCs from 34 items down to 30 items, and the measure of NGIs from 20 items down to 15 items (which comprised the final scale for each). Items were parceled to improve the parsimony of the model.

During the CFA phase of the analysis, model fit was adequate (Matsunaga, 2010) for all models after items were parceled. Further, when covariates were added, model fit approached (but did not reach) "good" fit for both CFI (>0.95) and RMSEA (<0.06; Hu & Bentler, 1999). Outcomes tested within these models were separated into two groups, one with pain-related outcomes of pain disability, catastrophizing, and severity (the "pain model") and one with well-being related outcomes of anxiety and depression and suicidal ideation (the “well-being model”). Although overall health was also measured with a single item (as rated by the SRH-5), this outcome was not tested as imputations for missing data cannot be performed on single items. Further, to reduce the overall length of the survey, the GBMMS and 3*I were only shown randomly to approximately half of all participants, hence these outcomes were not tested beyond their utility for assessing convergent and divergent validity for CD measures.

### Discussion of Findings by Hypothesis

Some of the hypotheses in study two were supported, including that: DT and PCs and NGIs would be positively associated (H1), PCs would predict pain disability and suicidal ideation (H2), NGIs would predict pain disability and suicidal ideation (H3), PCs would mediate the relationship between DT and pain disability and anxiety and depression (H4), and NGIs would mediate the relationship between DT and pain disability and anxiety and depression (H5).

However, some hypotheses were not supported, and these unexpected findings warrant discussion. First, PCs and NGIs did not predict pain catastrophizing as hypothesized (H2b, H3b). There are several possible explanations for this, the most likely being that DT directly predicted pain catastrophizing, and thus having experienced DT is a better predictor of PCS than these dual mediators. Another possible explanation is that patients are aware of (and dislike) this measure and its use and intentionally provided different ratings than they otherwise may have in an effort to resist the notion that their pain is psychological in origin. Patient-led efforts have resulted in significant recent calls for changing this measure and its use in studies about chronic pain, including one recently lead by Stanford Medicine (2021).

Second, PCs and NGIs also did not predict pain severity or anxiety and depression (H2c-d, H3c-d). While the same issue regarding pain catastrophizing may have affected that measure here as well, this same issue likely did not affect the measure of anxiety and depression, as the HADS performed as expected for other analyses. Given that NGIs ask about future anticipated interactions rather than how one feels at present or has felt within the past week or month, this may help to explain why PCs and NGIs and pain catastrophizing, anxiety and depression, and pain severity are unrelated as theorized in these data.

Third, there were unexpected findings related to the mediation analyses. First, PCs and NGIs both did not mediate the relationship between DT and pain catastrophizing (H4b, H5b). This finding is explained by the significant direct effect of DT on pain catastrophizing, suggesting that it is having experienced DT itself rather than mediating outcomes of DT which most directly affect participants' reports of the severity of their pain. Additional unexpected findings included that PCs and NGIs did not mediate the relationship between DT and pain severity (H4c, H5c) or suicidal ideation (H4e, H5e). Participants reported pain severity at the present moment and in the previous week, which could explain why potentially distant past interactions in which DT occurred and the PCs of that talk and NGIs made after experiencing that talk did not act as mediating variables between DT and pain severity. It is also worth discussing that these nonsignificant results are very close to being significant (i.e., the lower bounds of the CIs are just below zero). Further, upon examining the distribution of the suicidal ideation (SBQR) variable, although not skewed or kurtotic, the modal value was the lowest possible scale score of three (indicating no suicidal ideation). In the future, potential transformations of this variable will be explored to better approximate normality.

An additional potential explanation for these findings comes from the wording of the instructions for the NGI measure. Several participants emailed me to report that the instructions for the measure of NGIs had confused them, because the instructions asked them to report about what they “expected” future interactions with their medical providers to look like. Although the intention was for participants to report about what they realistically anticipate they will encounter in future interactions, this ambiguous wording may have led some participants to report about what they ideally would expect from a medical provider. These two disparate meanings and the often diametrically opposed scale responses they each inhere may explain many of the nonsignificant and surprising findings related to NGIs in study two. These directions will be modified in future versions of the survey to avoid this double meaning.

A fourth surprising finding was that DT did not moderate the relationship between pain severity and any outcomes, which included pain disability (H6a), pain catastrophizing (H6b), suicidal ideation (H6c), and anxiety and depression (H6d). Put differently, participants with greater pain severity did not report greater pain disability, pain catastrophizing, suicidal ideation, or anxiety and depression when they had experienced more DT. It is worth noting that there were significant main effects for pain severity on pain disability, pain catastrophizing, and anxiety and depression such that those with more severe pain reported greater disability, catastrophizing, and anxiety and depression. There were also significant main effects for DT on pain disability, pain catastrophizing, and suicidal ideation, such that those who reported having experienced greater DT reported greater pain disability, catastrophizing, and suicidal ideation. Importantly, these DT main effects were obtained even with PS in the model, which means that DT independently predicts these negative health outcomes even after controlling for the severity of participants’ pain. Given that the interaction term was not significant for any outcome, findings indicate although pain severity and DT both affect several outcomes, they do not interact such that one amplifies the negative effects of the other with regard to these outcomes.

These findings, although nonsignificant, are important because they begin the work of separating the consequences of living with chronic pain (e.g., the severity of a person's pain) from the consequences of having experienced DT. Despite these nonsignificant findings for the moderation analyses, PCs and NGIs are significantly positively associated with pain disability and suicidal ideation, and PCs and NGIs also mediate the relationship between DT and pain disability and anxiety and depression. These findings suggest that this talk and its consequences (e.g., being viewed as less credible, feeling unable to talk about the pain or seek future care, forming negative inferences about the goals you anticipate your provider will pursue) is associated with how disabled you are by pain as well as how anxious and depressed you are.

In sum, although only some of the hypotheses were supported, the findings which were not supported add important information which will inform the development of subsequent studies using these measures and examining the process of CD and TCD. A general discussion of the findings of this dissertation is next offered, including a discussion of the theoretical and practical implications of these findings.

# CHAPTER SEVEN: GENERAL DISCUSSION

This dissertation integrated concepts and findings of qualitative scholarship from the fields of medicine, public health, psychology, and sociology (among others) to theoretically explicate and measure the process of communicative disenfranchisement. Serving to partially remedy the conceptual fragmentation and disciplinary siloing characterizing the extant scholarship about female patients' experiences of negative interactions with others (particularly medical providers), this dissertation generates heuristic value from these findings across fields and offers a unifying vocabulary for characterizing this talk in a variety of contexts. Put succinctly, communicative disenfranchisement is a process which inheres multiple constructs and has demonstrated empirical linkages to a variety of pain and well-being related outcomes.

The two studies which comprise this dissertation together facilitated these aims, where: (a) study one facilitated the explication of CD, generation of an initial item pool, and potential outcomes, and (b) study two empirically tested this explication by crafting and validating measures and examining associations between CD constructs and various outcomes. Together, the two studies contribute to a body of scholarship concerning the experiences of female patients with poorly understood chronic pain syndromes and offer measures which make these experiences and their effects visible through quantification.

As the findings from study one and two are discussed at length at the end of their respective chapters, here only three important findings are highlighted. A first important finding from study one pertains to the confluence of two decades of qualitative scholarship from around the world regarding female patients' experiences of living with COPCs. Despite cultural differences among studies and changes across time, the findings of the 82 studies capturing over 2,500 patients' experiences since 1998 mostly agree about what comprises the experiences of women seeking care from medical providers. The findings from study one, which served as the basis for the conceptual model of CD, suggest that disenfranchising talk is similar across international contexts (at least those which publish in English) and is relatively stable (having not changed greatly across time), pointing to the necessity of examining the salient discourses which motivate such talk and the operations of power which have sustained those discourses and made them a continually viable explanation for female patients' pain across time (Suter, 2016).

A second important finding pertains to the tripartite model of CD (i.e., DT, PCs, and NGIs) which was explicated in study one and empirically tested in study two. It is proposed that the dimensions of the talk itself, the consequences of that talk, and the negative inferences made by participants as a result of having experienced this talk are distinct. This tripartite model, which was supported by the findings from study two (i.e., that DT was distinct from but would predict PCs and NGIs) begins the work of capturing this as a process which unfolds across time (Poole, 2013). Further, this tripartite model captures more parts of the process and talk than the existing measure of illness invalidation (Kool et al., 2010), which assesses only limited aspects of the talk itself. Patients with COPCs are faced with communication issues beyond only the matter of diagnosis, as this talk affects the way others view them and erodes their own view of how future conversations in which pain is discussed will unfold.

A third important finding pertains to empirical linkages between CD constructs and outcomes (i.e., study two) that were described by patients quoted in the qualitative sample (study one). Such outcomes with significant associations included suicidal ideation, pain disability, and anxiety and depression. Suicidal ideation, the most commonly referenced outcome in the qualitative scholarship, was predicted by both PCs and NGIs in the well-being structural model. DT itself also directly and strongly predicted pain catastrophizing. These findings begin the work of separating the consequences of living with pain from the consequences of the *social experience* of being a person in pain. Although pain severity did predict pain catastrophizing in this study, DT also predicted pain catastrophizing, confirming that it is not only *intra*personal factors but also *inter*personal factors which contribute to COPC patients' experiences of pain. Complementing existing research that emphasizes intrapersonal factors (e.g., Schütze et al., 2020), this dissertation highlights interpersonal factors by showing that how patients are spoken to about their pain holds consequences for how they experience that pain. In this study, this is accomplished by illustrating how the consequences of talk in a particular setting (e.g., the patient-provider interaction) can extend beyond the end of that interaction to affect more distal outcomes for patients. This dissertation also illustrates the utility of drawing upon the extant qualitative scholarship as the basis for testing empirical associations among constructs.

In addition to offering further discussion regarding the findings of studies one and two, this general discussion chapter also serves to: (a) highlight theoretical and practice implications of this dissertation, as well as (b) outline limitations and future directions and (c) conclude.

## Theoretical Implications

In addition to the development of a theory of communicative disenfranchisement (TCD) and earlier discussion of how TCD extends numerous lines of more traditional interpersonal, family, and health communication research (including marginalization, estrangement, hurtful communication, (dis)confirmation, attribution, uncertainty perspectives, stigma perspectives, and disenfranchised grief), this dissertation also offers theoretical implications for both the critical interpersonal and family communication heuristic (Suter, 2016, 2018) as well as multiple goals theorizing (cf. Caughlin, 2010; Goldsmith, 2019).

### Implications for the CIFC Heuristic

This dissertation first offers several theoretical implications for the CIFC heuristic. These findings suggest the utility of critical perspectives in examining interpersonal health contexts and in employing a mixed method research design. As Suter (2016) intended, TCD builds on but also moves beyond the CIFC heuristic (Suter, 2016, 2018) to produce a novel theoretical framework useful for critical examinations of IFC contexts. Most centrally, then, TCD works to partially rectify the dearth of critical interpersonal theorizing which has hampered the proliferation of critical research in these subfields (Suter, 2018) and is among the first “home grown” communication frameworks beyond RDT 2.0 to do so (for other examples, see strong Black woman collective theory; Davis & Afifi, 2019; and performative face theory; Moore, 2017b).

In doing so, this dissertation also contributes to the CIFC heuristic first by tracing the process by which power operates through disenfranchising talk (which invokes salient and culturally available discourses to stereotype others’ experiences) and its proximal and more distal consequences. These findings illustrate the ways in which patients and providers contend with and call upon pertinent discourses and highlight the factors beyond only the immediate interaction which make this possible (e.g., a female patient’s medically unexplained symptoms renders a discursively available psychological explanation viable). This process also likely involves larger structural issues. The lack of a biomedical explanation (e.g., affirmative test results) for pain is called upon as a reason for the pain not being “real,” yet providers often do not have efficacious means by which to meaningfully assess many COPCs because there is often little funding to develop diagnostic tools. This argument shows the importance of examining how public sphere factors affect private sphere interactions (Suter, 2016).

This dissertation also contributes to the CIFC heuristic by underscoring the utility of quantitative methods to advance critical aims toward social justice ends (Davis & Afifi, 2019; Dutta et al., 2017, 2019; Scharrer & Ramasubmaranian, 2021; Suter, 2018). Although critical theorizing and quantitative methods are seemingly disparate, there has been an increasing discussion of how such aims and methods could be fruitfully combined to ask and answer novel questions of practical and social significance. For instance, Garcia et al. (2018) questioned how and whether critical race theory could be fruitfully explored via quantitative approaches (and what such a project would entail in terms of modifying ontological assumptions), while Lowe et al. (2020) proposed a quantitative means of assessing thematic saturation in qualitative research, in part, to increase the appeal of qualitative research for new audiences who might not otherwise engage with such work. As communication scholars grapple with wicked social problems, crossing methodological and paradigmatic boundaries may catalyze innovative research well suited for these aims.

### Implications for Multiple Goals Theorizing

Second, this dissertation also offers four theoretical implications for multiple goals theorizing. First, findings from this dissertation reinforce the assumption from multiple goal theories that patient-provider interactions are particularly consequential for patients because of their relational and identity implications. Second, these findings suggest that talk can change the way that individuals ascribe anticipated goals to others (and thus viewing interactions as historical is important). A third implication for multiple goals theorizing is that interpretive lenses may be negatively valenced and applied in the encoding as well as decoding of talk (e.g., Pillai, 1992). Finally, these findings highlight the importance of considering interactants' own personal histories as well as the role of discourses which create the conditions for stereotyping to occur as important aspects of the sociocultural context in which talk occurs. Each of these four points is elaborated in greater detail below.

First, findings offer support for the multiple goals tenet (Goldsmith, 2019) that patient-provider interactions are about more than just the pursuit of a particular task (such as seeking diagnosis and/or treatment for a COPC). In this context, there are multiple salient conversational purposes to which providers and patients must attend. This notion that multiple salient goals are omnipresent and interconnected was evidenced by the unidimensionality of the measure of NGIs even though items were initially written to assess task, relational, and identity goals separately. Hence, multiple goals must be considered in patient-provider interactions in which COPCs are discussed with female patients. This conceptualization of the patient-provider interaction exists at odds with the way negative patient-provider interactions are characterized in the extant literature (i.e., as an issue of diagnostic inexactitude; e.g., Bontempo, 2019). Talk may be disenfranchising in patient-provider interactions because such otherwise seemingly banal talk holds implications for patients' identities and relationships with others. Therefore, as this dissertation demonstrates, the negative effects of disenfranchising talk also extend beyond only the patient's pursuit of diagnosis and treatment. By affecting the way that they are viewed by others (identity implications) and able to talk about the pain with others, as well as how they anticipate others will interact with them in the future (relational implications), female patients with COPCs become disenfranchised and those consequences are sustained.

Second, these findings illustrate that the way that a person is spoken to changes the way that they ascribe anticipated goals to others in the future (Caughlin, 2010). Here, a point of connection between otherwise differing conceptualizations of multiple goals theorizing (Caughlin, 2010; Goldsmith, 2019) is noted. In normative rhetorical theory, Goldsmith defines interpretive lenses as “choices relational partners make about how to view a situation that then shape how the understand their talk” (p. 221). For example, a patient managing a cardiac event might reinterpreting their partner’s nagging reminders about lifestyle changes as caring (Goldsmith et al., 2012). According to Goldsmith, participants may apply interpretive lenses proactively as a means of managing dilemmas. Interpretive lenses thus are employed to understand how participants *decode* and understand others’ talk (e.g., making charitable attributions about a partner’s behavior; Goldsmith et al., 2012). The current study’s conceptualization of negative goal inferences also suggests that individuals may also make proactive inferences about how they expect conversations to go (what might be called *anticipated decoding*), which shape and constrain the way they prepare and plan for talk and *encode* their own talk (e.g., similar to some aspects of the concept of communication work; Donovan, 2019). Hence, NGIs enables the consideration not only of how talk is evaluated or understood, but also how previous interactions (Caughlin, 2010) shape the way that communicators come to view a particular situation and consequently choose to talk and attend to particular communicative purposes.

As the goal inferences studied in this dissertation are negatively valenced, this shows another point of comparison with interpretive lenses being employed to offer a more charitable interpretation of another’s communication. Questions can be raised about whether interpretive lenses necessarily are positively valenced. For example, Hintz (in press) noted that childfree patients seeking voluntary sterilization from medical providers proactively adopted an interpretive lens of *presumed negative intent* which sensitized them to the obstacles they anticipated encountering (e.g., request denial on the basis of various aspects of one's identity) and shaped the way they approached patient-provider interactions in an effort to circumvent them. In this dissertation, female patients with COPCs subjected to disenfranchising talk make negative inferences about the goals to which they anticipate medical providers will attend in future interactions with them. Drawing on this notion of goal inferences in which interactants assign meaning to their own and others' actions elucidates why female patients with COPCs may develop more negative interpretive lenses that *lead them to manage dilemmas by responding in ways which are suboptimal* (as noted in the next paragraph). The existence of limited options for responding to dilemmas signals operations of power and clarifies how the management of multiple goals may lead to reduced perceptions of agency.

Fourth and finally, this conceptualization of interpretive lenses highlights the importance of considering historical factors (e.g., a person's history of interactions with providers) as one aspect of the sociocultural context which may shape and constrain how interactants attend to and respond to specific goals. As Goldsmith (2019) notes, "context is multifaceted" (p. 218) and includes both the history of a given relationship as well as the larger cultural context in which such talk becomes embedded. For instance, patients with chronic pain are often stereotyped as being "difficult" or aggressive and hostile (Wasan et al., 2005), and most of the research which explores this subject inquires as to whether hostility/aggressiveness (conceptualized as a stable aspect of one's personality) predisposes individuals to develop chronic pain or experience heightened pain. These findings, however, beg the question as to what role patients' own past interactions and negative goal inferences play in contributing to this observed behavior. Perhaps this perceived "difficult" demeanor is a communication approach undertaken intentionally by a patient in response to previous dissatisfying or negative interactions with their provider who believes that this choice will contribute to their preferred outcome for the interaction (Orbe & Lapinski, 2007). Here, past interactions are salient aspects of the sociocultural context which shapes and constrains how talk unfolds and potentially how interactants respond to dilemmas.

Aside from personal history, findings from this dissertation also underscore the importance of viewing discourses as a salient aspect of the broader sociocultural context in which talk occurs and which shapes meaning, often seen in the form of stereotyping. For instance, stereotypes pertaining to military culture and the stigma regarding military mental health shaped how family members attempted to encourage their service member to seek behavioral health care (Wilson et al., 2015). Stereotypes in the context of this dissertation are simplistic explanations of a female patient with COPCs' symptoms and are lenses through which providers may interpret female patients' account of pain. In both examples, stereotypes arise as a result of culturally available systems of meaning existing beyond the particular interaction which influence talk (Goldsmith, 2019). An increased research focus on discourses would further augment a critical take on normative rhetorical theorizing.

This fourth point is particularly salient as Goldsmith (2019) calls for moving normative rhetorical theorizing in a more critical direction which acknowledges that interactions are political and power-laden. For instance, Goldsmith (2019) describes her recent research about blogs curated by mothers with autistic children. She describes her struggles to grapple with "culturally fraught" notions about what it means to be a "good mother" when identifying as a mother who allies with the autism acceptance movement. She also notes that talking about autism online often requires taking sides regarding contentious issues with political overtones (e.g., the debate regarding the supposed link between vaccines and autism) which holds implications for one's own identity (e.g., being marked as a "liberal" or "conservative") and may catalyze advocacy efforts by those implicated. Although Goldsmith (2019) does not explicitly use the word “discourse” here, she describes a discourse and its operations of power in the Foucauldian sense. A culturally available system of meaning about what it means to be a “good mother” is discussed and contested online and sometimes reified and continued through the blogging community. Further, more recent multiple goals theorizing (e.g., Gettings, 2019) has drawn connections between Goldsmith’s (2004) framework and discourse perspectives pertaining to meanings of retirement, underscoring the importance and utility of this extension.

A critical take on multiple goals theorizing which builds upon the findings of this dissertation leads to several questions for future research: To whose goals must women with COPCs and their providers orient, attend, or acquiesce, and on what basis (e.g., authority, gender, perceived credibility) do interactants come to know this? Under what conditions and for what purpose are the relational and identity implications of talk considered, drawn upon, or acknowledged in talk? How do patients who anticipate orienting to providers’ goals enact communicative practices (e.g., becoming increasingly assertive or compliant), interpretive lenses (which may be positively or negatively valenced and may be utilized both in the encoding of their own talk and decoding of others’ talk) and environmental resources (salient discourses as well as routines and interactions, online communities which counter-emplot knowledge as a means of resistance; Whelan, 2007)? Through these practices, how are women able to change or acknowledge these goals and manage their implications? When framing Goldsmith’s (2019) assumptions in a more explicitly critical light, connections to the concepts of perpetuation, resistance, and transformation can be seen (Suter, 2016) and the utility of further analytically integrating the notion of discourses is underscored.

### Practical Implications

There are also clear practical implications of this work, which include: (a) offering empirical support for over two decades' worth of qualitative research about female patients' experiences of seeking care for COPCs, (b) illustrating the impetus for change by elucidating how disenfranchising talk contributes to and sustains negative pain-related and well-being outcomes for female patients with COPCs, and (c) beginning the work of rectifying the disciplinary siloing which has hindered the meaningful transdisciplinary research about patients' experiences negotiating for care for COPCs.

First, this dissertation offers empirical evidence to support the relationships between disenfranchising talk and a variety of negative outcomes as reported by patients in qualitative studies over the last two decades. This dissertation created working measures of DT, PCs, and NGIs based upon qualitative findings which elucidated the dimensions and functions of negative talk experienced by women with COPCs, making countable the issues that count for this marginalized population of female patients and creating the means for meaningfully assessing the effects of negative patient-provider interactions on these salient outcomes. For example, this study illustrated that patients who experience greater disenfranchising talk report greater pain catastrophizing (rumination, magnification, and helplessness) and that patients who report greater negative proximal consequences of that talk and make greater negative inferences about their anticipated future interactions with providers report greater pain disability and suicidal ideation. These negative proximal consequences of disenfranchising talk (e.g., reduced agency, perceived credibility, and ability to access care, support, and resources) and negative goal inferences also mediate the relationship between disenfranchising talk and anxiety and depression, suggesting the possibility that it is through these negative consequences and inferences that mental health symptoms may precipitate after experiencing disenfranchising talk. Utilizing these measures to assess patient-provider interactions, following the collection of longitudinal data, would potentially elucidate both patients' perceptions of disenfranchising talk as well as how this talk changes patients' perceptions of the patient-provider interaction.

Hence, second, this study also suggests the impetus for changing this talk by illustrating how disenfranchising talk and its consequences contribute to and sustain negative mental and psychological health outcomes. These findings affirm that talk in patient-provider interactions holds implications beyond only the primary communicative purpose or immediate interaction. Reviews of the interrelationship between chronic pain and suicidality continue to affirm the surprising lack of association between pain characteristics (e.g., severity, type, intensity, duration) and suicidal ideation, instead suggesting the importance of examining psychosocial factors (e.g., pain catastrophizing; Racine, 2018). Put differently, the social and psychological experience of managing the pain, rather than the pain itself, most predicts suicide risk. This dissertation suggests the patient-provider interaction (and disenfranchising talk, more specifically) as an additional site of targeted intervention for reducing suicidal ideation in chronic pain patients and affirms the existence of empirical linkages between disenfranchising talk and anxiety and depression and pain catastrophizing (factors which contribute to suicide risk) as well as suicidal ideation itself.

Further, the outcomes demonstrated in this dissertation to be associated with this talk and its consequences (e.g., anxiety and depression) are then often in turn drawn upon by medical providers to question the existence, cause, or nature of the pain. These findings suggest that patient-provider interactions in which disenfranchising talk occurs and the consequences of those interactions for patients (beyond only the experience of living with the pain itself) may be (often unintentionally) contributing to greater pain disability, suicidal ideation, and mental health symptoms (anxiety and depression) in female patients. Here, medical providers may be unintentionally inflicting harm by contributing to the same consequences upon which the existence and/or severity of pain is then blamed. Additionally, patients who develop mental health symptoms or suicidal ideation as a comorbidity of patient-provider interactions may then be reluctant or unable to seek mental health care (Bao et al., 2003), as seeking care for mental health symptoms would further bolster this simplistic explanation for the pain and potentially preclude the future untainted assessment of their symptoms. Feeling unable to seek future care is a proximal consequence of this talk. In short, disenfranchising talk and its consequences both contribute to serious negative outcomes such as suicidal ideation, but also prevent patients from seeking mental health care, a dualistic illustration of how this talk acts to disenfranchise patients and sustain that disenfranchisement.

Closing the gap between communication theory and *praxis*, the "putting of theory into action for social change" (Soritin & Ellingson, 2018, p. 113) is essential for communication researchers aiming to address social issues (Dutta, 2021) like those highlighted by these findings. Praxis is a central aim of the overarching program of research to which this dissertation belongs and also an aim of the research to be conducted using this theoretical framework and these measures. To accomplish this, I consider implications for intervention in terms of medical education as well as for advocacy organizations supporting women with COPCs. These implications should be viewed as preliminary due to the lack of longitudinal and multiperspectival data which would elucidate the causal interrelationships of CD (see below).

Possibilities for intervention design for medical education include addressing the root motivations for DT as well as teaching providers to manage uncertainty and ambiguity in ways which do not resort to the use of gender or condition-based stereotypes. Although characterized as an issue of misdiagnosis or diagnostic error at present, these interactions matter because what providers say and do when they do not know what to do hold implications for patients which long outlast the interaction (e.g., PCs, NGIs, suicidal ideation, anxiety and depression). The knowledge that women with COPCs are more likely to experience DT and that DT is directly associated with pain catastrophizing and through mediators with suicidal ideation and anxiety and depression points to the need for additional support and resources for these patients. The implications of such efforts would also extend far beyond COPCs, as such an intervention would be particularly salient for cases in which symptoms go unexplained. Consultations in general practice for "medically unexplained symptoms" comprise an estimated 45% of all visits, and 50% of these patients are still not diagnosed after three months (Chew-Graham et al., 2017). What can providers do and say when faced with uncertainty and the demanding of an explanation by patients? This is, at present, a stumbling block which may inadvertently contribute to greater patient disability. However, given this it is also an opportunity for reducing adverse physical and psychological outcomes by reducing and/or foregoing talk which discredits, silences, and stereotypes patients and their experiences of health and illness. The particular interventions pursued and explored will depend upon the resources and collaborative opportunities available at my next institution.

Advocacy organizations which address specific COPCs may develop resources to assist patients with preparing and planning for appointments with medical providers and managing their negative effects. Further, community organizations (particularly online communities) could continue to develop resources to direct patients to providers who may be less likely to produce DT. Such lists could be updated and providers added and removed in response to patient feedback regarding their experiences. For instance, members of the /r/childfree community on Reddit maintain an international “Childfree Friendly Doctors List” where users can find doctors who are accepting of the childfree choice and supportive of childfree patients’ reproductive choices. The popular Facebook group “Nancy’s Nook” similarly curates a list of “Nook Approved” providers for women with endometriosis to locate surgeons to excise and ablate endometrial lesions. Similar resources could be developed for patients with COPCs to assist them with avoiding these interactions with providers likely to produce DT. Future research will be conducted in an engaged capacity (see Dempsey & Barge, 2014), and research interests will be allied with the needs of community organizations such as the U.S. Pain Foundation.

Third and finally, this dissertation begins the work of rectifying disciplinary siloing which has hindered the meaningful assessment of patients’ experiences across fields. This was the aim of study one, which included the synthesis of over 80 published qualitative studies reporting about over 2,500 patients’ experiences. Working to counter disciplinary siloing is also accomplished in this dissertation by offering a unifying theoretical vocabulary which abstracts from more primitive terms (e.g., dismissed, disbelieved) derived terms (i.e., CD concepts) which capture the functions and dimensions of this talk across conditions and contexts (Chafee, 1991). The findings of this dissertation will be returned to participants (Hintz & Dean, 2020), disseminated broadly, and published in journals both within and outside of the field of communication studies to further this aim.

## Limitations and Future Directions

This dissertation has many strengths, including its rigorous mixed method research design, conceptual explication grounded in a substantive corpus of qualitative data, and sufficient survey sample size. The dissertation crosses method (i.e., qualitative synthesis and scale development procedures) and meta-theory (i.e., critical perspectives) to elucidate the process of CD and thus draws upon the benefits of employing multiple methods and paradigms (Fay & Moon, 1994). However, some limitations also should be acknowledged and discussed.

The meta-synthesis completed in study one, although systematic in sampling procedures and analysis, does not (and could not) encompass every study ever published about female patients' experiences of talking with others about COPCs. It is possible that SCOPUS constrained or omitted articles which may have changed how CD and its constructs were conceptualized. Meta-syntheses are also customarily (although not always) completed by multiple authors who together participate in the synthesizing of a sample of qualitative scholarship. Although another coder was involved throughout the sampling procedures, another coder may be involved prior to the publication in a re-analysis of the meta-synthesis data to further bolster the rigor of the analysis.

Further, although this dissertation began the process of theorizing communicative disenfranchisement as a process, measures assessing how individuals subjected to disenfranchising talk respond were not developed in this dissertation. An important related future direction will include considering how patients who have experienced disenfranchising talk and its negative consequences and who have made negative inferences about the goals they anticipate their provider will pursue in future interactions change how they communicate moving forward. Adapting Orbe and Lapinski's (2007) co-cultural theory scales to measure patients' chosen communication approaches and preferred outcomes could be fruitful toward this end. Doing so could potentially elucidate why patients with chronic pain have a reputation for being "difficult," meaning (in part) that they are often hostile, aggressive, and argumentative in their demeanor (Wasan et al., 2005). This would enable the assessment of the extent to which a patient's communication approach and preferred outcome for the interaction change following disenfranchising talk, as well as how a patient's communication approach and preferred outcome for the interaction are related to salient outcomes.

For instance, we might expect that patients with COPCs who experience more DT report greater assertiveness and aggressiveness in their interactions with others in which their pain is discussed. Further, patients in the meta-synthesis reported desiring both assimilation with and accommodation to others (i.e., trying to appear "normal" or trying to be a "good patient" in an effort to elicit understanding), as well as separation (i.e., drawing attention to differences between themselves and others with chronic pain). This may stem from an eroded trust in oneself as a result of experiencing disenfranchising talk, which represents another potential future direction for this work. Understanding not only what disenfranchising talk *does* to patients in terms of outcomes, but also how patients respond to the disenfranchisement would further bolster this impetus for changing disenfranchising talk. If evidence is found that this talk not only contributes negatively to serious pain-related and well-being outcomes but may also be unintentionally fueling the hostility and aggressiveness which stereotypically characterize "difficult" chronic pain patients, soliciting provider buy-in for changing talk in these interactions would be less challenging. Future studies will also consist of qualitative analyses of the scraped Reddit data which was only superficially utilized in this dissertation and which are not represented in the meta-synthesis (which synthesizes the findings of published studies).

Four limitations and future directions related to study two should also be discussed. First, study two was cross-sectional in nature. Although measures asked participants to reflect both on past events, the consequences of those past events, as well as how past events have changed the way participants anticipate future interactions will unfold, participants did so at one point in time. The well-known principle of “correlation does not prove causation” is relevant in interpreting some Study 2 findings. For instance, although study two tests associations between CD constructs and outcomes (e.g., PCs and NGIs mediate the relationship between DT and anxiety and depression (HADS)), the directionality of these relationships is at present unknown. It is known that individuals with depression (and young women in particular) tend to attribute negative events to stable, global causes (Hu et al., 2015). Without longitudinal data, the observed relationships between CD constructs and HADS could indicate two scenarios. First, this finding could indicate that female patients who have experienced greater DT also experience more PCs and make greater NGIs about future patient-provider interactions, and that these mediators result in heightened anxiety and depression. Second, this finding could suggest that female patients are already depressed (which may related or unrelated to the COPCs) and that depressed female patients with COPCs expect that their interactions with providers will go more poorly and behave in ways which are more likely to elicit DT. Collecting longitudinal data would clarify whether DT leads to anxiety and depression rather than the inverse scenario. TCD theorizes that disenfranchisement emerges across time and interactions, therefore longitudinal research is needed to assess how the process of CD unfolds across time as well as how CD constructs are related to salient outcomes.

Second, caution should be taken when generalizing the findings of study two due to limitations related to the participants. Although this international sample of participants is diverse (approximately representative or better) in terms of some demographic characteristics such as sexual orientation and gender identity as well as household income, participants are still predominantly White, Western and educated. The online nature of the survey and recruitment efforts likely limited the extent to which non-English speakers, participants without access to the

Internet, and those without basic computer skills could participate. Future studies should work actively to include the experiences of Black, Latinx, and Asian participants as well as participants without a college education and without access to the Internet. It warrants attention that nearly half of the participants in study two identified a sexual orientation other than heterosexual or straight, begging the question as to why so many broadly non-heterosexual women participated in this survey as well as how these experiences may be unique in ways a survey may not entirely capture (e.g., lesbian and bisexual women experience less negative effects of vulvodynia pain on their romantic relationships than heterosexual women; Blair et al., 2015). It is possible that the survey posting was shared by other participants to LGBT+ groups to which they belong. Further qualitative explorations of this participant population may further elucidate the role of sexual orientation in patient-provider interactions in which DT occurred.

The findings of study two are reported after controlling for the impact of factors which were correlated with study constructs including participants' age, sexual orientation, and level of educational attainment. However, this does not consider individuals who exist at these intersections nor the importance of future research considering the roles of other intersections. Given the importance of intersectionality (Crenshaw, 1991) and its purported utility for advancing CIFC aims (Hintz, 2019; Suter, 2018), examining individuals who exist at additional/other intersections (e.g., Black women with COPCs) would further elucidate the role of discourses and stereotyping in the experience of CD, as other discourses become salient and may be called upon in talk (e.g., about Black patients' pain; Hoffman et al., 2016). Further, taking this particular intersection as a guiding example, these patients may be subjected to greater DT (e.g., as they have been historically excluded from depictions of illnesses such as endometriosis and are thus perceived as being less likely to have it; Chatman, 1976), and have more and differing pre-existing expectations for how they expect interactions with medical providers to unfold which may affect the extent to which they report greater NGIs following DT.

Third, given that this study utilized a convenience sample, it is unknown about the extent to which study two data are representative of the broader experience of negotiating for care for COPCs. For instance, it is possible given the focus of the study that those participants who had experienced negative interactions were more likely to take part. Future studies should solicit the experiences of patients with COPCs or other conditions without disclosing this point of interest.

Fourth, data were collected only from the perspective of the patient, neglecting to include the experiences and perspectives of medical providers. Multiperspectival, dyadic, and/or observational data should be collected to further elucidate discrepancies between perceptions of the extent to which DT did or did not occur in a particular interaction and what constitutes it. These discrepancies between patients and other interactants are important and are demonstrated across an array of scholarship. As one example, patients may paradoxically report being more satisfied with patient-centered interactions than non-patient-centered interactions but still present with worse health outcomes (Epstein & Street, 2011). In another example, women with vulvodynia both report preferring responses from their sexual partners which demonstrate attention and sympathy yet are ultimately more disabled by the maladaptive coping behaviors reinforced by such responses (Rosen et al., 2012). These examples suggest the utility and necessity of collecting data which offers multiple viewpoints in an effort to determine what specifically motivates both the production and evaluation of DT. Without such knowledge, the ability to curate interventions which target specific behaviors and features of talk, as well as addressing the rationale behind such talk, is hindered. The collection of data of this type is essential for offering practical recommendations for improving patient-provider interactions.

Finally, both studies in this dissertation explored CD in one specific context (i.e., women living with COPCs), and caution is warranted in generalizing the findings to other contexts where features of DT may differ. Having said this, the current framework holds promise for being adapted to more generally suit a wide variety of contexts in which those who have been disenfranchised interface with others who seek to discredit and silence them and make it more difficult for them to access care, support, and resources related to their experiences. To list a few examples, future research which utilizes TCD could examine how power operates in terms of what unfolds communicatively when whistleblowers or victims of hate crimes, workplace sexual harassment, or college campus sexual assault report their experiences; or when members of the LGBT+ community or other minoritized identities, relationship types, and familial forms discuss or defend these identities, relationships, and families to others. Scholars should ask what is reinscribed as being true and good in these interactions and whose interests are served when disenfranchising talk occurs.

## Conclusion

This dissertation aimed to make visible and measurable a formerly silent epidemic affecting women living with poorly understood chronic pain conditions. In doing so, this dissertation partially rectifies the dearth of critical theory in interpersonal and family communication studies as well as the conceptual fragmentation and disciplinary siloing preventing the meaningful synthesis of the extant findings, concepts, and frameworks addressing this important social issue. Findings illustrate empirical linkages between CD constructs and outcomes such as suicidal ideation, further underscoring the importance and practical utility of examining this talk and its consequences. These findings also offer meaningful contributions to critical interpersonal and family communication theorizing as well as multiple goals perspectives. Despite the limitations of this study, there are strengths and opportunities for future research which will further advance research about negative interactions in women's health contexts, further validate measures of DT, PCs, and NGIs, and further test and extend TCD.

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# APPENDIX A: RECRUITMENT MATERIALS

## Recruitment Email A – New Interested Participants

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Dear [Participant],

Thank you for expressing your interest in participating in this research study about communication and chronic pain. My name is Elizabeth Hintz and I am a Doctoral Candidate in the Department of Communication at the University of South Florida. This study is a part of my dissertation project. The purpose of the study is to understand how patients with one or more chronic overlapping pain conditions (COPCs) such as vulvodynia experience negative talk from others and with what outcomes in an effort to affect positive social change.

You are being asked to take part because you are an adult patient over the age of 18 who was assigned the sex of female at birth (or you identify as female) who has seen a medical provider at least once (you do not necessarily have to have been diagnosed) for one or more of the conditions on the following list: interstitial cystitis (painful bladder syndrome), irritable bowel syndrome (IBS), vulvodynia, endometriosis, temporomandibular disorders (TMJ), chronic low back pain, chronic tension type headache, chronic migraine, myalgic encephalomyelitis (CFS), and fibromyalgia. You are also able to read and write in English fluently and have had at least one conversation about your COPC(s) with another person such as a spouse/romantic partner, medical professional, or family member.

If you are interested in participating, you may complete the survey at this link: **[LINK HERE]**

The survey will take no longer than 60 minutes to complete. You will not be compensated for completing the survey.

Thank you for your interest in this study and I look forward to your participation. Please let me know if you have any questions, comments, or concerns.

Thank you for your time,

Elizabeth Hintz
Doctoral Candidate
Department of Communication
University of South Florida

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**Recruitment Email B – Snowball Sampling**

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Dear [Participant],

Thank you for participating in my study and wanting to share my study with others you know. Below is a sample email you can send them to explain the study.

Thanks again,

Elizabeth Hintz
Doctoral Student
Department of Communication
University of South Florida

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Sample Email:

I recently participated in a research study with a woman from the University of South Florida about chronic pain and wanted to share some information with you. She wants to understand how patients with one or more chronic overlapping pain conditions (COPCs) experience negative talk from others and with what outcomes in an effort to affect positive social change.

To do this, she wants to talk to adult patients (over the age of 18) who were assigned the sex of female at birth (or you identify as female) who has seen a medical provider at least once (you do not necessarily have to have been diagnosed) for one or more of the conditions on the following list: interstitial cystitis (painful bladder syndrome), irritable bowel syndrome (IBS), vulvodynia, endometriosis, temporomandibular disorders (TMJ), chronic low back pain, chronic tension type headache, chronic migraine, myalgic encephalomyelitis (CFS), and fibromyalgia. You must also be able to read and write in English fluently.

If you decide to participate, here's what you can expect. If you are interested, you'll first email Elizabeth at ehintz@usf.edu. She will send you a link to a survey which will take no longer than one hour to complete. After a series of screening questions to determine your eligibility, you will then be asked to recall a time where you spoke to another person about your condition(s), describe the conversation, indicate to whom you spoke, and then complete a variety of scale which ask questions about what happened in that interaction, how you felt, and what the effects were.

Feel free to ask me or email her if you have questions or are interested in participating (her email is ehintz@usf.edu).

## Recruitment Email C – Past Interested Participants

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Dear [Participant],

Several years ago, you participated in a research study in which you were interviewed about your experiences living with and communicating about vulvodynia. At the end of our interview, you agreed that I could retain your contact information for future research studies. My name is Elizabeth Hintz and I am now a Doctoral Candidate in the Department of Communication at the University of South Florida. I am emailing you with a new research opportunity for which you would be eligible (if you are interested). This study (#1185) is a part of my dissertation project. The purpose of the study is to understand how patients with one or more chronic overlapping pain conditions (COPCs) such as vulvodynia experience negative talk from others and with what outcomes in an effort to affect positive social change.

You are being asked to take part because you are an adult patient over the age of 18 who was assigned the sex of female at birth (or you identify as female) who either has been diagnosed with or has seen a medical provider at least once for one or more of the conditions on the following list: interstitial cystitis (painful bladder syndrome), irritable bowel syndrome (IBS), vulvodynia, endometriosis, temporomandibular disorders (TMJ), chronic low back pain, chronic tension type headache, chronic migraine, myalgic encephalomyelitis (CFS), and fibromyalgia. You are also able to read and write in English fluently.

If you are interested in participating, you may complete the survey at this link: **[LINK HERE]**

The survey will take no longer than 60 minutes to complete. You will not be compensated for completing this survey.

Thank you for your interest in this study and I look forward to your participation. Please let me know if you have any questions, comments, or concerns.

Thank you for your time,

Elizabeth Hintz
Doctoral Candidate
Department of Communication
University of South Florida

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## Social Network Recruitment A: *Text-Only* Post

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Title: “It’s all in your head”: A study on negative interactions experienced by women with chronic pain

**Overview:** You are being asked to take part in a research study at the University of South Florida (IRB Study #001185). The information in this document should help you to decide if you would like to participate. The sections in this Overview provide the basic information about the study. More detailed information is provided in the remainder of the document.

Study Staff: This study is being led by Elizabeth A. Hintz who is a Doctoral Candidate at University of South Florida. This person is called the Principal Investigator. She is being guided in this research by Dr. Steven R Wilson. Other approved research staff may act on behalf of the Principal Investigator.

Study Details: This study is being conducted at University of South Florida. The purpose of the study is to understand how patients with one or more chronic overlapping pain conditions (COPCs) experience negative talk from others and with what outcomes. Your participation in this study will involve completing an online survey which will take no longer than one-hour to complete in which you will be asked to recall interactions you have had in which you have discussed your COPC(s) with others.

Eligibility: You are being asked to take part because you:

(a) are over the age of 18,
(b) were assigned the sex of female at birth (or you identify as female),
(c) have either: (a) been diagnosed with one of the conditions on the list below, (b) sought a diagnosis for one of the conditions on the list below, or (c) be currently seeking a diagnosis for one of the conditions on the list below. In other words, you must have visited a medical provider AT LEAST ONCE for at least one of these conditions: interstitial cystitis, irritable bowel syndrome (IBS), vulvodynia, endometriosis, temporomandibular disorders (TMJ), chronic low back pain, chronic tension type headache, chronic migraine, myalgic encephalomyelitis (CFS), or fibromyalgia; and,
(d) are able to read and write in English fluently.

Voluntary Participation: Your participation is voluntary. You do not have to participate and may stop your participation at any time. There will be no penalties or loss of benefits or opportunities if you do not participate or decide to stop once you start.

Benefits, Compensation, and Risk: We do not know if you will receive any benefit from your participation. There is no cost to participate. You will not be compensated for taking this survey. This research is considered minimal risk. Minimal risk means that study risks are the same as the risks you face in daily life.

Confidentiality: Even if we publish the findings from this study, we will keep your study information private and confidential. Anyone with the authority to look at your records must keep them confidential.

*If you are interested in participating, please take the survey here: [SURVEY LINK]

**If you have any questions, please email Elizabeth Hintz in the Department of Communication at University of South Florida at ehintz@usf.edu.

## Social Network Recruitment B: Video Transcript

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Video Title: “It’s all in your head”: A research study about the negative experiences of women with chronic pain conditions

Transcript Begins:

Hello, thank you for clicking on this video and for your interest in learning more about this research study (USF IRB **Study #** **001185)**.

My name is Elizabeth Hintz, and I am a Doctoral Candidate in the Department of Communication at the University of South Florida. I am a social scientist who studies interpersonal health communication, meaning that I study how people communicate about health issues in an effort to improve that talk.

In order to graduate with my PhD, I am conducting a research study for my dissertation about the negative experiences that women with chronic pain sometimes experience when discussing chronic pain with their doctors or other medical professionals, such as being told that pain is “all in your head.” The specific chronic pain conditions that I am interested in are those poorly understood conditions which are called chronic overlapping pain conditions (COPCs), including interstitial cystitis (painful bladder syndrome), irritable bowel syndrome (IBS), vulvodynia, endometriosis, temporomandibular disorders (TMJ), chronic low back pain, chronic tension type headache, chronic migraine, myalgic encephalomyelitis (CFS), and fibromyalgia.

To be eligible to participate in this study, you must have been assigned the sex of female at birth (or currently identify as female) and have been diagnosed with or spoken to a doctor or other medical professional about one or more of the conditions I just listed. You must have either: (a) been diagnosed with one of the conditions on the list below, (b) sought a diagnosis for one of the conditions on the list below, or (c) be currently seeking a diagnosis for one of the conditions on the list below currently. In other words, you have to have visited a medical provider AT LEAST ONCE.

The only other eligibility criteria are that you must be able to read and write in English fluently. You may live in any country or region.

If you take part in this study, you will be asked to complete an online survey through Qualtrics lasting no longer than one hour (probably closer to 45 minutes) which is preceded by on online consent form. Other than your GeoIP information which Qualtrics collects, this survey will not require you to divulge any personally identifiable information which can connect you specifically to the responses you provide.

I am interested in this topic because when I was a teenager I was diagnosed with vulvodynia and irritable bowel syndrome, two of the ten conditions on this list. I also believe that I have endometriosis but have not been diagnosed. While attempting to seek help for the pain I was experiencing, I had a number of negative interactions with others, such as my pain being attributed to being "a nervous girl." These interactions had lasting effects on how I viewed myself and on my ability to talk with others about my pain in the future.

When I began graduate school in 2016, I wanted to make a difference by studying this sort of talk. Findings from my master's thesis which started to do this have been published in top academic journals in my field and have received national research awards. I also returned these findings to interested participants as well as disseminated them to the broader public through media interviews, blog posts, and being a patient representative.

However, much work remains to be done. In 2019, the *Journal of the American Medical Association* called these sorts of negative interactions experienced by female patients "medicine's silent epidemic." My ultimate goal with this project is to develop a way of measuring this sort of talk and its effects so that this is no longer a silent epidemic. If we can create the means for measuring this experience shared by so many of us, we can make claims about its effects in ways that matter to people who can affect change.

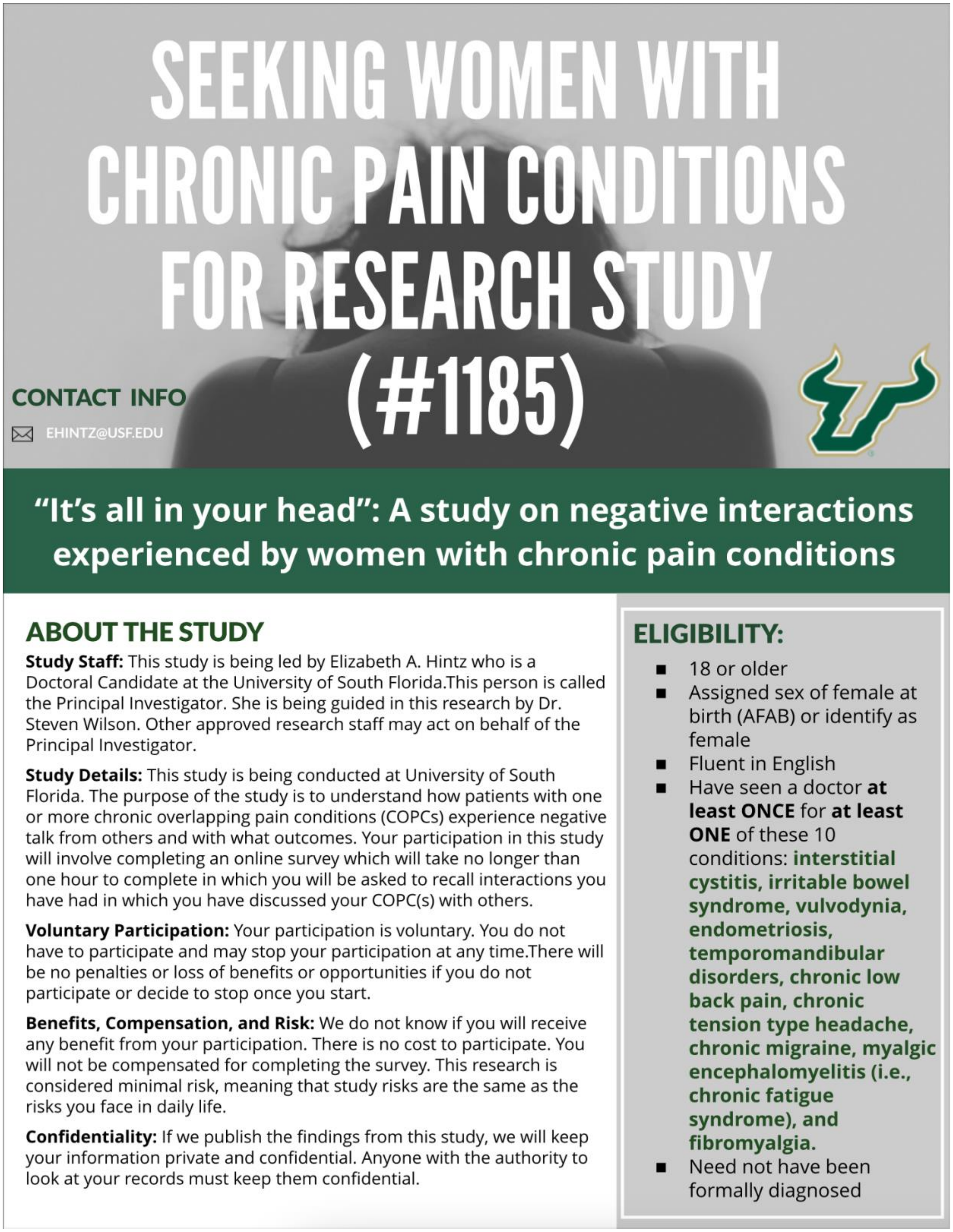
Of course, your participation in this study is voluntary. You do not have to participate and may stop your participation at any time. There will be no penalties or loss of benefits or opportunities if you do not participate or decide to stop once you start.

I cannot say for certain whether you will receive any benefit from your participation. There is no cost to participate. You will be not be compensated for completing the survey. This research is considered minimal risk, which means that study risks are the same as the risks you face when you talk about your experiences in daily life.

When I publish the findings from this study, I will keep your study information private and confidential. Anyone with the authority to look at your records must keep them confidential.

If you are interested in participating, please click the survey link included in the post or thread where you found this video. Feel free to email me at ehintz@usf.edu with any questions or concerns that you may have.

## Social Network Recruitment C: Flyer



# SEEKING WOMEN WITH CHRONIC PAIN CONDITIONS FOR RESEARCH STUDY (#1185)

**CONTACT INFO**

✉ EHINTZ@USF.EDU

## “It’s all in your head”: A study on negative interactions experienced by women with chronic pain conditions

## ABOUT THE STUDY

**Study Staff:** This study is being led by Elizabeth A. Hintz who is a Doctoral Candidate at the University of South Florida.This person is called the Principal Investigator. She is being guided in this research by Dr. Steven Wilson. Other approved research staff may act on behalf of the Principal Investigator.

**Study Details:** This study is being conducted at University of South Florida. The purpose of the study is to understand how patients with one or more chronic overlapping pain conditions (COPCs) experience negative talk from others and with what outcomes. Your participation in this study will involve completing an online survey which will take no longer than one hour to complete in which you will be asked to recall interactions you have had in which you have discussed your COPC(s) with others.

**Voluntary Participation:** Your participation is voluntary. You do not have to participate and may stop your participation at any time.There will be no penalties or loss of benefits or opportunities if you do not participate or decide to stop once you start.

**Benefits, Compensation, and Risk:** We do not know if you will receive any benefit from your participation. There is no cost to participate. You will not be compensated for completing the survey. This research is considered minimal risk, meaning that study risks are the same as the risks you face in daily life.

**Confidentiality:** If we publish the findings from this study, we will keep your information private and confidential. Anyone with the authority to look at your records must keep them confidential.

## ELIGIBILITY:

- 18 or older
- Assigned sex of female at birth (AFAB) or identify as female
- Fluent in English
- Have seen a doctor **at least ONCE** for **at least ONE** of these 10 conditions: **interstitial cystitis, irritable bowel syndrome, vulvodynia, endometriosis, temporomandibular disorders, chronic low back pain, chronic tension type headache, chronic migraine, myalgic encephalomyelitis (i.e., chronic fatigue syndrome), and fibromyalgia.**
- Need not have been formally diagnosed

## APPENDIX B: SURVEY

### SECTION A: Consent Form (1 Item)

| Q# | |
|---|---|
| | **Informed Consent to Participate in Research**<br>Information to Consider Before Taking Part in this Research Study<br>**Title:** *Explicating the Process of Communicative Disenfranchisement for Women with Chronic Overlapping Pain Conditions (COPCs)*<br>**Study # 001185**<br><br>**Overview:** You are being asked to take part in a research study. The information in this document should help you to decide if you would like to participate. The sections in this Overview provide the basic information about the study. More detailed information is provided in the remainder of the document.<br>Study Staff: This study is being led by Elizabeth A. Hintz who is a Doctoral Candidate at University of South Florida. This person is called the Principal Investigator. She is being guided in this research by Dr. Steven R Wilson. Other approved research staff may act on behalf of the Principal Investigator.<br>Study Details: This study is being conducted at University of South Florida. The purpose of the study is to understand how patients with one or more chronic overlapping pain conditions (COPCs) experience negative talk from others and with what outcomes. Your participation in this study will involve completing an online survey which will take no longer than one-hour to complete in which you will be asked to recall interactions you have had in which you have discussed your COPC(s) with others.<br>Participants: You are being asked to take part because you are an adult patient over the age of 18 who was assigned the sex of female at birth (or you identify as female) who either has been diagnosed with or believe you have one or more of the conditions on the following list: interstitial cystitis (painful bladder syndrome), irritable bowel syndrome (IBS), vulvodynia, endometriosis, temporomandibular disorders (TMJ), chronic low back pain, chronic tension type headache, chronic migraine, myalgic encephalomyelitis (CFS), and fibromyalgia. You are also able to read and write in English fluently and have had at least one conversation about your COPC(s) with a doctor or other medical professional.<br>Voluntary Participation: Your participation is voluntary. You do not have to participate and may stop your participation at any time. There will be no penalties or loss of benefits or opportunities if you do not participate or decide to stop once you start.<br>Benefits, Compensation, and Risk: We do not know if you will receive any benefit from your participation. There is no cost to participate. There is no compensation for completing this survey. This research is considered minimal risk. Minimal risk means that study risks are the same as the risks you face in daily life. |

Confidentiality: Even if we publish the findings from this study, we will keep your study information private and confidential. Anyone with the authority to look at your records must keep them confidential.

**Why are you being asked to take part?**

You are being asked to take part in this study because you: (a) have been assigned the sex of female at birth (or identify as female), (b) are 18 years or older, (c) are fluently able to read and write in English, (d) have either been diagnosed with or believe that you have **at least one** (or more) of 10 chronic overlapping pain conditions (which are interstitial cystitis (also called painful bladder syndrome), irritable bowel syndrome, vulvodynia, endometriosis, temporomandibular disorders, chronic low back pain, headache (with two subcategories of chronic tension type headache and chronic migraine), myalgic encephalomyelitis (also called CFS), and fibromyalgia), and (e) you have had at least one conversation with a doctor or other medical provider about your chronic pain condition(s). You may have any one of these 10 chronic pain conditions and can currently reside in any country around the world.

**Study Procedures**

If you take part in this study, you will be asked to complete an online survey through Qualtrics lasting no longer than one hour which is preceded by this online consent form. We will not collect any identifiable information which can be linked to your survey response or identity.

**Alternatives / Voluntary Participation / Withdrawal**

You do not have to participate in this research study. You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study.

**Benefits and Risks**

We are unsure if you will receive any benefits by taking part in this research study. This research is considered to be minimal risk.

**Compensation**

You will not be compensated for completing this survey.

**Privacy and Confidentiality**

We will do our best to keep your records private and confidential. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Certain people may need to see your study records. The only people who will be allowed to see these records are: the Principal Investigator, the advising professor, and the University of South Florida Institutional Review Board (IRB).

| | |
|---|---|
| | It is possible, although unlikely, that unauthorized individuals could gain access to your responses because you are responding online. Confidentiality will be maintained to the degree permitted by the technology used. No guarantees can be made regarding the interception of data sent via the Internet. However, your participation in this online survey involves risks similar to a person's everyday use of the Internet. If you complete and submit an anonymous survey and later request your data be withdrawn, this may or may not be possible as the researcher may be unable to extract anonymous data from the database.<br>**Contact Information**<br>If you have any questions, concerns or complaints about this study, email Elizabeth A. Hintz at ehintz@usf.edu. If you have questions about your rights, complaints, or issues as a person taking part in this study, call the USF IRB at (813) 974-5638 or contact the IRB by email at RSCH-IRB@usf.edu.<br>We may publish what we learn from this study. If we do, we will not let anyone know your name. We will not publish anything else that would let people know who you are. You can print a copy of this consent form for your records.<br>I freely give my consent to take part in this study. I understand that by proceeding with this survey, I am agreeing to take part in research and I am 18 years of age or older. |
| 1 | I have reviewed the consent form and consent to participate in this study.<br>I do not consent to participate in this study. > END OF STUDY |

**SECTION B: Screening Questions (20 items)**

| Q# | |
|---|---|
| 2 | Were you assigned the sex of female at birth?<br>Yes<br>No |
| 3 | IF NO<br>Do you currently identify as female?<br>Yes<br>No > END OF STUDY |
| 4 | What is your age as of today? [DROP DOWN MENU]<br>IF UNDER 18 > END OF STUDY |
| 5 | Are you able to fluently read and write in English?<br>Yes<br>No > END OF STUDY |
| 6 | Below this question are a list of conditions called Chronic Overlapping Pain Conditions (COPCs). Please indicate which (if any) of these conditions you have been FORMALLY diagnosed with by a medical provider, as well as which of these conditions (if any) you BELIEVE THAT YOU HAVE although you have not been diagnosed.<br>You must have either: (a) been diagnosed with one of the conditions on the list below, (b) sought a diagnosis for one of the conditions on the list below, or (c) be currently seeking a diagnosis for one of the conditions on the list below currently. In other words, you have |

| | |
|---|---|
| | to have visited a medical provider AT LEAST ONCE for AT LEAST ONE of these conditions to be eligible to complete the rest of this survey.<br><br>Options for each condition:<br>I have been diagnosed with this condition.<br>I have sought a diagnosis for this condition in the past.<br>I am seeking a diagnosis for this condition currently.<br>I believe I have this condition but have not seen a medical provider.<br>None of the above.<br><br>Conditions:<br>Interstitial cystitis (also called painful bladder syndrome)<br>Irritable bowel syndrome<br>Vulvodynia (also called/has subtypes of vulvar vestibulitis, vestibulodynia, provoked vulvodynia, unprovoked vulvodynia, primary vulvodynia, secondary vulvodynia, etc.)<br>Endometriosis<br>Temporomandibular joint disorders (also called TMJ, TMJ syndrome)<br>Chronic low back pain<br>Chronic tension type headache (also called chronic stress headache)<br>Chronic migraine (also called chronic migraine headache)<br>Chronic fatigue syndrome (also called myalgic encephalomyelitis)<br>Fibromyalgia (also called fibrositis)<br><br>IF "NONE OF THE ABOVE" OR "HAVE NOT SEEN A MEDICAL PROVIDER" SELECTED FOR ALL CONDITIONS > END OF STUDY |
| 8 | In what year (approximately) did you first notice symptoms of your condition(s)? [LIST] |
| 9 | In what year (approximately) did you first SEEK diagnosis or treatment for your symptoms? [LIST] |
| 10 | **IF "I HAVE BEEN DIAGNOSED" SELECTED FOR ANY**<br>You selected "I have been diagnosed" for one or more of these conditions.<br><br>What type of provider diagnosed you?<br>**Primary care provider (PCP)/ General practitioner/family practitioner (GP)**<br>**Other Specialist (e.g., Rheumatologist, Gynecologist, etc.)**<br>**Pain specialist/pain management doctor**<br>**Psychiatrist, psychologist, or other mental health professional**<br>**Naturopath**<br>**Acupuncturist**<br>**Massage therapist**<br>**Spiritual healer**<br>**Physical therapist**<br>**Occupational therapist**<br>**Chiropractor**<br>**Other healthcare provider: [SPECIFY]**<br>**Can't remember/I don't know** |

|  |  |
|---|---|
| 11 | IF SELECTED DIAGNOSED FOR ANY: In what year did you receive a diagnosis?<br>[LIST] |
| **12** | **How many doctors did you see between your first appointment and the appointment at which you were diagnosed? If you don't remember exactly, give us your best estimate. (Example: Maria has seen her primary care provider, an urgent care doctor, a urologist, a gynecologist, a pelvic floor physical therapist, and a urogynecologist who diagnosed her. She reports 6 providers).**<br>**[DROP DOWN LIST OF NUMBERS]** |
| 13 | To whom have you spoken about your pain condition(s)? (Select ALL that apply)<br>Spouse or romantic partner<br>Family member(s)<br>Friend(s)<br>People at work (such as a coworker, employer/boss, or human resources representative)<br>Medical professional(s) (such as a nurse, doctor, or therapist)<br>Social service worker(s) (such as a social worker or insurance representative)<br>Other patient(s)<br>Other (please list): [TEXT BOX]<br>IF NONE SELECTED > END OF STUDY |

## SECTION C: Open-Ended Questions About Living with Chronic Pain (3 Items)

| Q# |  |
|---|---|
| 14-16 | *Adapted from the McGill Illness Narrative Interview Protocol (Groleau et al., 2006)*<br>We'd like to learn little bit more about your chronic pain story. Please tell us your story by responding to each of the prompts below.<br>You can write as much or as little as you would like to, but you must write something in response to each question.<br>There will be other questions later in the survey which touch on topics not covered here.<br>• When did the chronic pain begin? When/how did you realize that something was wrong?<br>[OPEN ENDED RESPONSE]<br>• Why do you believe your pain started when it did? According to you, what caused your pain? Are there other causes that you think played a role?<br>[OPEN ENDED RESPONSE]<br>• How do you explain what your pain condition(s) are and how they affect you to others?<br>[OPEN ENDED RESPONSE] |

## SECTION D: General Questions About Pain Experiences (5 Items)

| Q# | |
|---|---|
| **17** | **How well is your pain managed with your current treatment plan? This includes both prescriptions, over the counter, and alternative/complementary therapies. (1 = Not at All Managed to 7 = Very Well Managed).** |
| 18 | Who do you see most regularly for managing your pain?<br>**Primary care provider (PCP)/ General practitioner/family practitioner (GP)**<br>Pain specialist/pain management doctor<br>Other specialist<br>Physical medicine and rehabilitation doctor<br>Physical therapist<br>Other healthcare provider<br>I currently do not see a healthcare provider for my pain. |
| **19** | **What types of doctors or healthcare providers have you EVER SEEN specifically for your chronic pain conditions? (Select all that apply)**<br>**Primary care provider (PCP)/ General practitioner/family practitioner (GP)**<br>**Pain specialist/pain management doctor**<br>**Other Specialist (e.g., Rheumatologist, Gynecologist, etc.)**<br>**Psychiatrist, psychologist, or other mental health professional**<br>**Naturopath**<br>**Acupuncturist**<br>**Massage therapist**<br>**Spiritual healer**<br>**Physical therapist**<br>**Occupational therapist**<br>**Chiropractor**<br>**Other healthcare provider: [SPECIFY]**<br>**I have never seen a specialist or spoken to any healthcare provider about my pain.** |
| **20** | **Do you now or have you ever taken prescription pain medications?**<br>**Yes, I am currently taking them.**<br>**No, I do not take them now, but I have taken them before.**<br>**No, I do not take them now, nor have I ever taken them.** |

## SECTION E: Scale Block A – Distal Outcome Measures (44 items)

| *Q#* | *# of Items* | *Randomized Scale Order and Items within Scales* |
|---|---|---|
| 21 | ***3*** | ***Pain Severity Subscale, West Haven-Yale Multidimensional Pain Inventory (Kerns et al., 1985)***<br>• Rate the level of your pain at the present moment (0 = No pain, 6 = Very intense pain)<br>• On the average, how severe has your pain been during the last week? (0 = Not at all severe, 6 = Extremely severe)<br>• How much suffering do you experience because of your pain? (0 = No suffering, 6 = Extreme suffering) |

|  |  |  |
|---|---|---|
| 22 | ***13*** | ***Pain Catastrophizing Scale (Sullivan et al., 1995)***<br>*0 = not at all, 1 = to a slight degree, 2 = to a moderate degree, 3 = to a great degree, 4 = all the time. When I'm in pain…*<br>I worry all the time about whether the pain will end.<br>I feel I can't go on.<br>It's terrible and I think it's never going to get any better.<br>It's awful and I feel that it overwhelms me.<br>I feel I can't stand it anymore.<br>I become afraid that the pain will get worse.<br>I keep thinking of other painful events.<br>I anxiously want the pain to go away.<br>I can't seem to keep it out of my mind.<br>I keep thinking about how much it hurts.<br>I keep thinking about how badly I want the pain to stop.<br>There's nothing I can do to reduce the intensity of the pain.<br>I wonder whether something serious may happen. |
| 23 | ***7*** | ***Pain Disability Index (Tait & Margolis, 1987)***<br>*Scale = 0=No Disability, 10=Total Disability*<br>Family/home responsibilities<br>Recreation<br>Social activity<br>Occupation<br>Sexual behavior<br>Self-care<br>Life support activity |
| 24 | ***1*** | ***Self-Rated Health (SRH-5) (Eriksson et al., 2001)***<br>*Response options: Very good, quite good, neither good nor poor, quite poor, poor.*<br>"How would you rate your general health status?" |
| 25 | ***20*** | ***Marlowe-Crowne Social Desirability Scale – Short Form [MCSDS-S]***<br>*Response Options: True/False*<br>I'm always willing to admit it when I make a mistake.<br>I always try to practice what I preach.<br>I never resent being asked to return a favor.<br>I have never been irked when people expressed ideas very different from my own. I have never deliberately said something that hurt someone's feelings.<br>I like to gossip at times.<br>There have been occasions when I took advantage of someone. I sometimes try to get even rather than forgive and forget.<br>At times I have really insisted on having things my own way. There have been occasions when I felt like smashing things.<br>I never hesitate to go out of my way to help someone in trouble. I have never intensely disliked anyone.<br>When I don't know something I don't at all mind admitting it.<br>I am always courteous, even to people who are disagreeable.<br>I would never think of letting someone else be punished for my wrong doings. |

| | | |
|---|---|---|
| | | I sometimes feel resentful when I don't get my way.<br>There have been times when I felt like rebelling against people in authority even though I knew they were right.<br>I can remember "playing sick" to get out of something.<br>There have been times when I was quite jealous of the good fortune of others.<br>I am sometimes irritated by people who ask favors of me. |

## SECTION G: CD Measures (116 Items)

### MEASURE #1: DT

Directions: **Since the start of your illness**, rate each of the following items in terms of how often they have occurred **when you have talked with YOUR DOCTOR(S) IN THE PAST about your pain and/or its effects on your life.** How often has (or have) YOUR DOCTOR(S)…

*Scale = Never (1), Sometimes (2), About half the time (3), Most of the time (4), Always (5)).*
*Scoring = Higher scores indicate greater cumulative CD.*

| # | **Item (Order Randomized)** | **Dimension** | **Concept** |
|---|---|---|---|
| 1 | Doubted whether the pain is as severe as I have explained. | *Significance: Seriousness and Severity* | **Discrediting** |
| 2 | Suggested that the pain is not really as bad as I say it is. | | |
| 3 | Doubted how significant the pain is. | | |
| 4 | Expressed skepticism about how bad the pain really is. | | |
| 5 | Questioned how serious the pain is. | | |
| 6 | Questioned whether my pain is as serious as I claim. | | |
| 7 | Suggested that it doesn’t affect me as much as I say it does. | *Experience: How Pain Affects Person* | |
| 8 | Suggested that the pain should not matter to me as much as it does. | | |
| 9 | Suggested that I shouldn’t think about the pain so much. | | |
| 10 | Suggested that I shouldn’t let the pain get to me as much as it does. | | |
| 11 | Suggested that I shouldn’t worry so much about the pain. | | |
| 12 | Suggested that the pain affects my life more than other people like me. | *Experience: How Experienced in Comparison to Others* | |
| 13 | Suggested that my pain prevents me from doing things more than other people like me. | | |
| 14 | Suggested that I seem to be doing worse than other people like me. | | |
| 15 | Suggested that people like me should be able to do more than I can do. | | |
| 16 | Suggested that I looked more sick or well than other people who are “really” sick. | | |
| 17 | Suggested that I was not acting the way someone in pain would. | | |
| 18 | Suggested that I was responding to my pain differently than other people like me. | | |

|  |  |  |  |
|---|---|---|---|
| 19 | Said or implied that the pain does not really exist. | *Existence: Realness of the Pain* |  |
| 20 | Said or implied that the pain was not real. |  |  |
| 21 | Said or implied that I was imagining the pain. |  |  |
| 22 | Said or implied that the pain was all in my head. |  |  |
| 23 | Said or implied that the pain is not really happening to me. |  |  |
| 24 | Said or implied that I wasn't really in pain. |  |  |
| 25 | Said or implied that the pain was no cause for concern. | *Existence: Problem Beyond What is Normal* |  |
| 26 | Said or implied that the pain is normal. |  |  |
| 27 | Said or implied that everyone experiences the pain. |  |  |
| 28 | Said or implied that the pain is just a part of being human. |  |  |
| 29 | Said or implied that everyone has to cope with pain. |  |  |
| 30 | Said or implied that I was overreacting to something everyone goes through. |  |  |
| 31 | Tried to get me to stop talking about the pain. | *Discouraging* | **Silencing** |
| 32 | Told me that they were sick of hearing me talk about the pain. |  |  |
| 33 | Told me that I shouldn't talk about the pain so much. |  |  |
| 34 | Told me that I was wrong for having talked about the pain. |  |  |
| 35 | Changed the subject when I tried to talk about the pain. |  |  |
| 36 | Told me that I should not have talked about the pain. |  |  |
| 37 | Acted like they did not have time to talk with me about the pain. |  |  |
| 38 | Ridiculed or criticized me when I mentioned the pain. |  |  |
| 39 | Interrupted me when I tried to talk about the pain. | *Preventing* |  |
| 40 | Ignored me when I brought the pain up. |  |  |
| 41 | Talked over me when I tried to talk about the pain. |  |  |
| 42 | Did not give me an opportunity to talk about the pain. |  |  |
| 43 | Prevented me from talking about the pain. |  |  |
| 44 | Made it impossible for me to talk about the pain. |  |  |
| 45 | Suggested that I was being overly emotional. | *Gender* | **Stereotyping** |
| 46 | Suggested that I was just too sensitive. |  |  |
| 47 | Suggested that I was being dramatic. |  |  |
| 48 | Suggested that I was just weak. |  |  |
| 49 | Suggested that I was just looking for attention. |  |  |
| 50 | Suggested that I wanted people to feel sorry for me. |  |  |
| 51 | Said or implied that I was just anxious or depressed. |  |  |
| 52 | Said or implied the pain had a psychological origin. |  |  |
| 53 | Said or implied that I should see a therapist for my pain. |  |  |
| 54 | Assumed that I had an ulterior motive for talking about the pain. | *Chronic Pain* |  |
| 55 | Assumed that I was making it seem worse than it actually is. |  |  |
| 56 | Assumed that I was just trying to get pain medication. |  |  |
| 57 | Assumed that I was a drug seeker. |  |  |
| 58 | Assumed that I was up to no good. |  |  |

|  |  |  |  |
|---|---|---|---|
| 59 | Assumed that I was trying to get out of work or school. |  |  |
| 60 | Assumed that I was trying to get disability benefits. |  |  |
| 61 | Assumed that I was using the pain to avoid my responsibilities. |  |  |

**Measure #2: PCs**

Directions: Please rate your agreement with each of the following statements. **Negative interactions in the past with MY DOCTOR(S) in which we talked about [my pain] have…**

*Scale = Never (1), Sometimes (2), About half the time (3), Most of the time (4), Always (5)).*
*Scoring = Higher scores indicate greater proximal consequences.*

| **#** | **Item** | **Dimension** | **Concept** |
|---|---|---|---|
| 1 | Made me hesitant to bring the pain up in future conversations. | *Whether to Talk* | **Agency** |
| 2 | Made me talk less about the pain moving forward. |  |  |
| 3 | Made it harder for me to talk about the pain after that. |  |  |
| 4 | Made it less likely that I will talk about the pain with them 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. | *To Whom to Talk* |  |
| 8 | Made me distrustful of others who I might talk to about the pain. |  |  |
| 9 | Made me more 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. | Character | **Credibility** *(Adapted from McCroskey & Young, 1981)* |
| 14 | Made me appear to be unworthy of sympathy. |  |  |
| 15 | Made me seem untrustworthy. |  |  |
| 16 | Made me appear to be a person of low character. |  |  |
| 17 | Made me look like a bad person. |  |  |
| 18 | Made me look unintelligent. | Competence |  |
| 19 | Made me appear to be uninformed. |  |  |
| 20 | Made me seem incompetent about. |  |  |
| 21 | Made me appear to be stupid. |  |  |
| 22 | Made me look irrational. |  |  |

|  |  |  |  |
|---|---|---|---|
| 23 | Made me lose out on opportunities (for example, in my social life or at work). | *Attain Things Desired* | **Ability to Exercise Rights and Privileges** |
| 24 | Made it harder for me to receive what I need to get by. |  |  |
| 25 | Made it harder for me to get help when I needed it. |  |  |
| 26 | Made it harder for me to find support from others. |  |  |
| 27 | Made it harder for me to access disability benefits. |  |  |
| 28 | Made it harder for me to receive a diagnosis. |  |  |
| 29 | Made it harder for me to be treated for my pain. |  |  |
| 30 | Made it harder for me to be excused from work or school. |  |  |
| 31 | Made it harder for me to seek future care for my pain. | *Act as Entitled* |  |
| 32 | Made me less likely to seek care for other physical health issues moving forward. |  |  |
| 33 | Made me hesitant to seek care for any mental health concerns which may arise in the future. |  |  |
| 34 | Made me hesitant to ask for help to cope with my pain. |  |  |

**Measure #3: NGIs**

Directions: Please fill out the scale below about **<u>your pain and/or its effects on your life.</u>**

**<u>If/When I talk to DOCTORS about my pain IN THE FUTURE, I ANTICIPATE that they will…</u>**

*Scale = Strongly Disagree (0) to Strongly Agree (7). Scoring = LOWER scores indicate greater discrete and global negative inferences about the goal tendencies of specific and nonspecific others.*

| # | **Item** | **Dimensions** |
|---|---|---|
| 1 | …Talk to me as though I am really in pain. | **Task Goals** |
| 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 | …Talk to me as if they believe that I experience my pain the way that I say I do. |  |
| 7 | …Try to help me to get or find what I need to get by. |  |
| 8 | …Genuinely try to figure out what is going on regarding my pain. | **Relational Goals** |
| 9 | …Work together with me to manage my pain. |  |
| 10 | …Treat me like an equal partner during our interaction. |  |
| 11 | …Treat me with respect and fairness. |  |
| 12 | …Commit to helping me no matter what. |  |
| 13 | …Treat me the same as they would treat someone WITHOUT chronic pain. |  |
| 14 | …Treat me the same as they would treat a man. |  |

| | | |
|---|---|---|
| 15 | …Make things better for me by the end of our interaction than before we talked. | |
| 16 | …View me as a competent person when I describe my pain. | **Identity Goals** |
| 17 | …Assume that I am a trustworthy person when I talk about my pain. | |
| 18 | …View me as credible when I discuss my pain. | |
| 19 | …Assume that my motivations for talking about my pain are honest. | |
| 20 | …View me as a person who knows what they are talking about regarding my pain. | |
| 21 | …Assume that I am a good person when I talk about my pain. | |

### SECTION H: Scale Block B – Distal Outcome Measures (38 items)

| Q# | *# of Items* | *Randomized Scale Order and Items within Scales* |
|---|---|---|
| 29 | ***8*** | ***Illness Invalidation Inventory (Kool et al., 2010)***<br>*Scale = 1=never, 2=seldom, 3=sometimes, 4=often, 5=very often*<br>Discounting Items (1,2,4,6,7)<br>…finds it odd that I can do much more on some days than on other days<br>…things I should be tougher<br>…gives me unhelpful advice<br>…makes me feel like I am an exaggerator<br>…things I can work more than I do<br>Lack of Understanding Items (3,5,8)<br>…takes me seriously (R)<br>…understands the consequences of my health problems or illness (R)<br>…gives me the chance to talk about what is on my mind (R) |
| 30 | ***12*** | ***Adapted Form of the Group-Based Medical Mistrust Scale (Thompson et al., 2004)***<br>*12 items, Scale = 1 SD to 5 SA*<br>People with chronic pain cannot trust doctors and healthcare workers.<br>People with chronic pain should be suspicious of information from doctors and healthcare workers.<br>People with chronic pain should not confide in doctors and health care workers because it will be used against them.<br>People with chronic pain should be suspicious of modern medicine.<br>Doctors and healthcare workers treat people with chronic pain like "guinea pigs."<br>Doctors and healthcare workers do not take the medical complaints of people with chronic pain seriously.<br>People with chronic pain are treated the same as people of other groups by doctors and healthcare workers.<br>People with chronic pain receive the same medical care from doctors and healthcare workers as people from other groups.<br>In most hospitals, people with different illnesses receive the same kind of care.<br>Doctors have the best interests of people with chronic pain in mind.<br>Doctors and healthcare workers sometimes hide information from patients with chronic pain. |

| | | |
|---|---|---|
| | | I have personally been treated poorly or unfairly by doctors or healthcare workers because I have chronic pain. |
| 31 | ***14*** | ***Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983)***<br>*Select the reply that is closest to how you have been feeling in the past week.*<br><br>I feel tense or “wound up” (A)<br>Most of the time (3)<br>A lot of the time (2)<br>From time to time, occasionally (1)<br>Not at all (0)<br><br>I still enjoy the things I used to enjoy (D)<br>Definitely as much (0)<br>Not quite so much (1)<br>Only a little (2)<br>Hardly at all (3)<br><br>I get a sort of frightened feeling as though something awful is about to happen (A)<br>Very definitely and quite badly (3)<br>Yes, but not too badly (2)<br>A little, but doesn’t worry me (1)<br>Not at all (0)<br><br>I can laugh and see the funny side of things (D)<br>As much as I always could (0)<br>Not quite so much now (1)<br>Definitely not so much now (2)<br>Not at all (3)<br><br>Worrying thoughts go through my mind (A)<br>A great deal of the time (3)<br>A lot of the time (2)<br>From time to time, but not too often (1)<br>Only occasionally (0)<br><br>I feel cheerful (D)<br>Not at all (3)<br>Not often (2)<br>Sometimes (1)<br>Most of the time (0)<br><br>I can sit at ease and feel relaxed (A)<br>Definitely (0)<br>Usually (1)<br>Not Often (2) |

| | | |
|---|---|---|
| | | Not at all (3)<br><br>I feel as if I am slowed down (D)<br>Nearly all the time (3)<br>Very often (2)<br>Sometimes (1)<br>Not at all (0)<br><br>I get sort of a frightened feeling like butterflies in the stomach (A)<br>Not at all (0)<br>Occasionally (1)<br>Quite often (2)<br>Very often (3)<br><br>I have lost interest in my appearance (D)<br>Definitely (3)<br>I don’t take as much care as I should (2)<br>I may not take quite as much care (1)<br>I take just as much care as ever (0)<br><br>I feel restless as I have to be on the move (A)<br>Very much indeed (3)<br>Quite a lot (2)<br>Not very much (1)<br>Not at all (0)<br><br>I look forward with enjoyment to things (D)<br>As much as I ever did (0)<br>Rather less than I used to (1)<br>Definitely less than I used to (2)<br>Hardly at all (3)<br><br>I get sudden feelings of panic (A)<br>Very often indeed (3)<br>Quite often (2)<br>Not very often (1)<br>Not at all (0)<br><br>I can enjoy a good book or radio or TV program (D)<br>Often (0)<br>Sometimes (1)<br>Not often (2)<br>Very often (3) |
| 32 | **4** | **[TO BE DISPLAYED IMMEDIATELY BEFORE]**<br>Answering the questions on this page may expose you to experiencing unwanted feelings, such as sadness, discomfort, or anxiety. If you are |

|  |  |  |
|---|---|---|
|  |  | experiencing any of these feelings and would like someone to speak to, the following toll-free mental health resources are available to you:<br>• The National Alliance on Mental Illness: 1-800-950-NAMI (6264)<br>• The Crisis Call Center: 1-800-273-8255<br>*Suicidal Behaviors Questionnaire – Revised (Osman et al., 2001)*<br>Have you ever thought about or attempted to kill yourself? (Select one)<br>1=Never<br>2=It was just a brief passing thought<br>3a=I have had a plan at least once to kill myself but did not try to do it.<br>3b = I have had a plan at least once to kill myself and really hoped to die.<br>How often have you thought about killing yourself in the past year?<br>1=Never, 2=Rarely (1time), 3=Sometimes(2times), 4=Often (3-4 times), 5=Very Often (5 or more times)<br>Have you ever told someone that you were going to commit suicide or that you might do it?<br>1=No<br>2a=Yes, at one time, but did not really want to die<br>2b=Yes, at one time, and really wanted to do it<br>3a=Yes, more than once, but did not want to do it<br>3b=Yes, more than once, and really wanted to do it<br>How likely is it that you will attempt suicide someday?<br>0=Never, 1=No chance at all, 2=Rather unlikely, 3=Unlikely, 4=Likely, 5=Rather likely, 6=Very likely |

**SECTION I: Demographic Questions (16 Items)**

| Q# |  |
|---|---|
| 33 | My gender is:<br>Female<br>Male<br>Non-binary<br>Genderqueer or gender nonconforming<br>Male-to-female transgender<br>Female-to-male transgender<br>Other: [ENTER] |
| 34 | My sexual orientation is:<br>Asexual<br>Bisexual<br>Gay<br>Heterosexual/Straight<br>Lesbian |

| | |
|---|---|
| | Pansexual<br>Queer<br>Questioning or unsure<br>Other (self-identify): [ENTER] |
| 35 | My racial and ethnic identity(ies) is/are: (Select all that apply):<br>African American or Black<br>American Indian or Alaska Native<br>Asian American or Asian<br>Hispanic, Latino, or Spanish Origin<br>Middle Eastern or North African<br>Native Hawaiian or Other Pacific Islander<br>White or Caucasian<br>Another race or ethnicity not listed here (specify): [ENTER] |
| 36 | Do you legally identify as someone with a disability or impairment?<br>Yes<br>No |
| 37 | Which of the following most accurately describes your background?<br>My parents/legal guardians and I were born in the U.S.<br>I was born in the U.S.; one parent/guardian was not<br>I was born in the U.S.; both of my parents/guardians were not<br>Foreign-born naturalized citizen<br>Permanent legal resident<br>Foreign born on student visa<br>Deferred Action for Childhood Arrivals (DACA) recipient<br>Refugee status<br>Prefer not to answer |
| 38 | My religious beliefs are:<br>Atheism, Agnosticism, or Not Religious<br>Christianity<br>Islam<br>Hinduism<br>Buddhism<br>Judaism<br>Spiritual but not religious<br>An belief not listed, please specify: [TEXT BOX]_______________ |
| 39 | My relationship status is:<br>Single AND interested in dating<br>Single and NOT interested in dating<br>Casually dating AND living together<br>Casually dating and NOT living together<br>In a committed relationship AND living together<br>In a committed relationship and NOT living together<br>Married<br>Separated<br>Divorced<br>Widowed |

| | |
|---|---|
| | Other [specify]: |
| **40** | **My employment status is:**<br>Employed, working 1-39 hours per week<br>Employed, working 40 or more hours per week<br>Not employed, looking for work<br>Not employed, NOT looking for work<br>Student<br>Self-employed<br>Retired<br>Disabled, not able to work<br>Prefer not to say |
| **41** | **My combined household income (including income earned by all people that live in my household) last year was:**<br>0 – 9,999<br>10,000 – 19,999<br>20,000 – 29,999<br>30,000 – 39,999<br>40,000 – 49,999<br>50,000 – 59,999<br>60,000 – 69,999<br>70,000 – 79,999<br>80,000 – 89,999<br>90,000 – 99,999<br>100,000 or more<br>Prefer not to say |
| **42** | **How would you rate your household's financial situation today?**<br>**Excellent**<br>**Good**<br>**Fair**<br>**Poor** |
| **43** | **My highest completed level of education is:**<br>Less than high school degree<br>High school degree or equivalent (e.g., GED)<br>Some college but no degree<br>Associates degree<br>Bachelor's degree<br>Master's degree<br>Professional degree (e.g., JD)<br>Doctoral degree (e.g., PhD) |
| **44** | **Do you currently have health insurance?**<br>**Yes**<br>**No**<br>**N/A – I live in a country with universal coverage.** |
| **45** | **Were you without health insurance at any point over the last 12 months?**<br>**Yes**<br>**No** |

| | |
|---|---|
| | **N/A – I live in a country with universal coverage.** |
| **46** | **In what country were you born? [DROP DOWN LIST]** |
| **47** | **In what country do you currently reside? [DROP DOWN LIST]** |
| **48** | **IF UNITED STATES**<br>**Within what region of the United States do you reside? [DROP DOWN LIST]** |
| **49** | **Which of the following best describes the location of your current home?**<br>**Urban**<br>**Suburban**<br>**Rural** |

**SECTION J: Follow-Up Logistics Questions (2 Items)**

| **Q#** | |
|---|---|
| 50 | Answering these questions may have exposed you to experiencing feelings associated with the experience(s) you described, such as sadness, discomfort, or anxiety. If you are experiencing any of these feelings and would like someone to speak to, the following toll-free mental health resources are available to you:<br>• The National Alliance on Mental Illness: 1-800-950-NAMI (6264)<br>• The Crisis Call Center: 1-800-273-8255<br>***PLEASE CLICK THE NEXT BUTTON, THERE ARE JUST A FEW MORE SHORT QUESTIONS*** |
| 51 | Are you interested in receiving the published results of these study findings via email? These may include peer-reviewed journal articles and summary reports of the dissertation.<br>Yes<br>No<br>Are you interested in participating in future study opportunities? If you select “YES” below, we will retain the contact information you provide in order to contact you with future research opportunities.<br>Yes<br>No<br>**IF YES TO EITHER [ON A SEPARATE SURVEY],** please enter the email address to which you would like published study findings to be sent and/or contacted about future research opportunities. |

# APPENDIX C: DISSERTATION STUDY ONE ARTICLE SAMPLING CODEBOOK

## 1. REL = RELEVANCE

*Read the title and abstract of the study. Is the study:*

- <u>qualitative (does the study primarily employ qualitative methods such as interviews, focus groups, etc.)?</u>
    - Example: A study assessing the efficacy of various chronic pain treatment methods would be EXCLUDED.
    - Example: Studies which are reporting survey data, and which describe data from one open-ended question would be EXCLUDED.
    - Example: Highly structured interviews conducted for the purpose of conducting statistical analyses would be EXCLUDED.
- <u>about patients' experiences of living with chronic pain or seeking diagnosis or treatment for chronic pain?</u>
    - Example: Studies seeking to explain why more patients with COPCs don't participate in clinical trials would be EXCLUDED.
    - Example: Studies evaluating the effectiveness of interventions or programs for chronic pain patients would be EXCLUDED.
- <u>about the specific chronic pain condition identified in the search term?</u>
    - IF an article includes ONE COPC but another condition which is NOT a COPC is also included, EXCLUDE that article.
        - Example: A study about patients' experiences with IBS and IBD would be EXCLUDED because IBD is not a COPC.
    - IF an article includes MORE THAN ONE COPC, INCLUDE that article.
        - Example: A study about patients' experiences with fibromyalgia AND chronic low back pain would be INCLUDED because fibromyalgia and chronic low back pain are BOTH COPCs.
    - List of COPCs:
        - interstitial cystitis (also called painful bladder syndrome),
        - irritable bowel syndrome,
        - vulvodynia,
        - endometriosis,
        - temporomandibular disorders,
        - chronic low back pain, headache (with two subcategories of chronic tension type headache and chronic migraine),
        - myalgic encephalomyelitis (also called CFS), and
        - fibromyalgia.

0 = NO
1 = YES

IF 1 = YES, REVIEW THE FULL ARTICLE AND SKIP TO 5 BELOW.

IF 0 = NO, CODE 2–4 BELOW for the specific reason of the three criteria listed here **WHY** the article is NOT relevant.

**2. NOTQUAL = NOT A QUALITATIVE STUDY**
0 = NO
1 = YES

**3. NABTPATIENT = NOT ABOUT PATIENT EXPERIENCES**
0 = NO
1 = YES

**4. NABTCONDITION = NOT ABOUT THE CONDITION IN THE SEARCH TERM**
0 = NO
1 = YES

After reviewing the FULL TEXT of the article, assess whether the FINDINGS or RESULTS of the article, code YES (1) below IF:

- The article discusses INTERACTIONS that patients OR patients AND their medical providers (not ONLY providers) engaged in,
- OR – the article discusses the PERCEPTIONS OF INTERACTIONS as reported by patients AND/OR their providers,
- AND the article discusses ASPECTS OF, OR THE IMPLICATIONS OR EFFECTS of INTERACTIONS (rather than ONLY of LIVING WITH a particular condition).
- Example: An article which discusses the effects of living with vulvodynia and how living with vulvodynia affects individuals' identities and relationships, but which does NOT discuss INTERACTIONS had by those patients would be EXCLUDED.

**5. FULLTEXTREL = RELEVANCE AFTER FULL TEXT REVIEW**
0 = NO
1 = YES

# APPENDIX D: LIST OF INCLUDED STUDIES BY CONDITION

| **COPC** | **First Author Last Name** | **Year** | **Title** | **Journal** | **Discipline** |
|---|---|---|---|---|---|
| CFS | Gray | 2003 | Illness experience and occupations of people with chronic fatigue syndrome | Australian Occupational Therapy | Physical Therapy |
| CFS | Clarke | 2005 | The radicalized self: the impact on the self of the contested nature of the diagnosis of chronic fatigue syndrome | Social Science & Medicine | Sociology |
| CFS | Dickson | 2007 | Stigma and the delegitimation experience: An interpretative phenomenological analysis of people living with chronic fatigue syndrome | Psychology and Health | Psychology |
| CFS | Winger | 2014 | 'Sometimes it feels as if the world goes on without me': adolescents' experiences of living with chronic fatigue syndrome | Journal of Clinical Nursing | Nursing |
| CFS | Brooks | 2014 | Couples' experiences of interacting with outside others in chronic fatigue syndrome: A qualitative study | Chronic Illness | Psychology |
| CFS | Fisher | 2017 | Why do young people with CFS/ME feel anxious? A qualitative study | Clinical Child Psychology and Psychiatry | Medicine |
| CFS | Brown | 2017 | 'Betwixt and between'; liminality in recovery stories from people with myalgic encephalomyelitis (ME) or chronic fatigue syndrome (CFS) | Sociology of Health & Illness | Applied Social Sciences |
| CFS | Broughton | 2017 | Adult patients' experiences of NHS specialist services for chronic fatigue syndrome (CFS/ME): A qualitative study in England | BMC Health Services Research | Medicine |
| CFS | McManimen | 2019 | Dismissing chronic illness: A qualitative analysis of negative health care experiences | Health Care for Women International | Community Research |
| CLBP | Glenton | 2003 | Chronic back pain sufferers—striving for the sick role (Chronic back pain sufferers - Striving for the sick role | Social Science & Medicine | Health Services |
| CLBP | Walker | 2006 | The experience of chronic back pain: Accounts of loss in those seeking help from pain clinics (The experience of chronic back pain- Accounts of loss in those | European Journal of Pain | Health Sciences |
| CLBP | Holloway | 2007 | The stigmatisation of people with chronic back pain (The stigmatisation of people with chronic back pain | Disability and Rehabilitation | Health Studies |

| | | | | | |
|---|---|---|---|---|---|
| CLBP | Snelgrove | 2009 | An interpretative phenomenological analysis of living with chronic low back pain: An interpretative phenomenological analysis of living with chronic back pain | British Journal of Health Psychology | Health Sciences |
| CLBP | Crowe | 2010 | Listening to the body and talking to myself – the impact of chronic lower back pain: A qualitative study (Listening to the body and talking to myself - the impact of chronic lower back pain | International Journal of Nursing Studies | Nursing |
| CLBP | Allgretti | 2010 | Paired interviews of shared experiences around chronic low back pain: classic mismatch between patients and their doctors (Paired interviews of shared experiences around chronic low back pain | Family Practice | Medicine |
| CLBP | Cedraschi | 2012 | Representations of Symptom History in Women with Fibromyalgia vs Chronic Low Back Pain:<br>A Qualitative Study (Representations of Symptom History in Women with Fibromyalgia | Pain Medicine | Medicine |
| CLBP | Lin | 2012 | ‘I am absolutely shattered’: The impact of chronic low back pain on Australian Aboriginal people ('I am absolutely shattered'- The impact of chronic low back pain | European Journal of Pain | Health Studies |
| CLBP | Dima | 2013 | Identifying patients’ beliefs about treatments for<br>chronic low back pain in primary care: (Identifying patients' beliefs about treatments for chronic low back pain: A focus group study | British Journal of General Practice | Medicine |
| CLBP | Snelgrove | 2013 | Living with chronic low back pain: a metasynthesis of qualitative research | Chronic Illness | Health Sciences |
| CLBP | Buchman | 2016 | You Present like a Drug Addict: Patient and Clinician Perspectives on Trust and Trustworthiness in Chronic Pain Management | Pain Medicine | Medicine |
| CLBP | Singh | 2018 | Exploring the lived experience and chronic low back pain beliefs of English-speaking Punjabi and white British people: a qualitative study within the NHS | BMJ Open | Physical Therapy |
| CLBP | Stensland | 2018 | “It has changed my whole life”: The systemic implications of chronic low back pain among older adults | Journal of Gerontoogical Social Work | Social Work |
| CLBP | Lampard | 2019 | ‘Falling through the cracks’: recognising sitting disabilities | Disability & Society | Sociology |
| CLBP | Allvin | 2019 | Struggling to be seen and understood as a person – Chronic back pain patients’ experiences of encounters in health care: An interview study | Nursing Open | Medicine |
| CM | Palacios-Ceña | 2017 | Living with chronic migraine: A qualitative study on female patients' perspectives from a specialised headache clinic in Spain | BMJ Open | Physical Therapy |

|  |  |  |  |  |  |
|---|---|---|---|---|---|
| CTTH | Lonardi | 2007 | The passing dilemma in socially invisible diseases: Narratives on chronic headache | Social Science & Medicine | Education |
| CTTH | Skogvold | 2018 | Chronic tension-type headache and coping strategies in adolescents: A qualitative interview study | Physiotherapy Research International | Health Sciences |
| ENDO | Cox | 2003 | Focus group study of endometriosis: Struggle, loss and the medical merry-go-round | International Journal of Nursing Practice | Nursing |
| ENDO | Denny | 2004 | Women's experience of endometriosis | Journal of Advanced Nursing | Health Studies |
| ENDO | Ballard | 2006 | What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis | Fertility and Sterility | Medicine |
| ENDO | Denny | 2007 | Endometriosis and the primary care consultation | European Journal of Obstetrics & Gynecology | Medicine |
| ENDO | Whelan | 2007 | 'No one agrees except for those of us who have it': Endometriosis patients as an epistemological community | Sociology of Health & Illness | Sociology |
| ENDO | Markovic | 2008 | Endurance and contest: Women's narratives of endometriosis | Health | Psychology |
| ENDO | Hudson | 2016 | 'We needed to change the mission statement of the marriage': biographical disruptions, appraisals and revisions among couples living with endometriosis | Sociology of Health & Illness | Health Sciences |
| ENDO | Gundström | 2017 | The double-edged experience of healthcare encounters among women with endometriosis: A qualitative study | Journal of Clinical Nursing | Medicine |
| ENDO | Pryma | 2017 | "Even my sister says I'm acting like a crazy to get a check": Race, gender, and moral boundary-work in women's claims of disabling chronic pain | Social Science & Medicine | Sociology |
| ENDO | Grogan | 2018 | 'So many women suffer in silence': a thematic analysis of women's written accounts of coping with endometriosis | Psychology and Health | Psychology |
| ENDO | Young | 2020 | Partners instead of patients: Women negotiating power and knowledge within medical encounters for endometriosis | Feminism & Psychology | Public Health |
| FM | Hallberg | 1998 | Psychosocial Vulnerability and Maintaining Forces Related to Fibromyalgia | Scandinavian Journal of Caring Sciences | Psychology |
| FM | Hallberg | 2000 | Coping with Fibromyalgia: A Qualitative Study | Scandinavian Journal of Caring Sciences | Psychology |
| FM | Hellström | 1999 | A phenomenological study of fibromyalgia. Patient perspectives | Scandinavian Journal of Primary Health Care | Medicine |
| FM | Raymond | 2000 | Experience of fibromyalgia | Canadian Family Physician | Medicine |

| | | | | | |
|---|---|---|---|---|---|
| FM | Marit Mengshoel | 2004 | Recovery from fibromyalgia – previous patients' own experiences | Disability and Rehabilitation | Health Sciences |
| FM | Löfgren | 2006 | ‘A constant struggle’: Successful strategies of women in work despite fibromyalgia | Disability and Rehabilitation | Public Health |
| FM | Liedberg | 2006 | Young women with fibromyalgia in the United States and Sweden: Perceived difficulties during the first year after diagnosis | Disability and Rehabilitation | Medicine |
| FM | Cunningham | 2006 | Individuals’ Descriptions of Living With Fibromyalgia | Clinical Nursing Research | Nursing |
| FM | Madden | 2006 | Creating meaning in fibromyalgia syndrome | Social Science & Medicine | Medicine |
| FM | Lempp | 2009 | Patients' experiences of living with and receiving treatment for fibromyalgia syndrome: A qualitative study | BMC Musculoskeletal Disorders | Medicine |
| FM | Wuytack | 2011 | The lived experience of fibromyalgia in female patients, a phenomenological study | Chiropractic & Manual Therapies | Physical Therapy |
| FM | Sallinen | 2011 | Finally heard, believed and accepted – Peer support in the narratives of women with fibromyalgia | Patient Education and Counseling | Applied Sciences |
| FM | Juuso | 2013 | Meanings of Feeling Well for Women with Fibromyalgia | Health Care for Women International | Nursing |
| FM | Dennis | 2013 | ‘A giant mess’ – making sense of complexity in the accounts of people with fibromyalgia | British Journal of Health Psychology | Psychology |
| FM | Juuso | 2014 | Meanings of Being Received and Met by Others as Experienced by Women with Fibromyalgia | Qualitative Health Research | Nursing |
| FM | Gill Taylor | 2016 | Perspectives on Living with Fibromyalgia | Global Qualitative Nursing Research | Nursing |
| FM | Briones-Vozmediano | 2016 | “I'm not the woman I was”: Women's perceptions of the effects of fibromyalgia on private life | Health Care for Women International | Nursing |
| FM | Chen | 2016 | The Relationship Between Health Management and Information Behavior Over Time: A Study of the Illness Journeys of People Living with Fibromyalgia | Journal of Medical Internet Research | Medicine |
| FM | Armentor | 2017 | Living with a Contested, Stigmatized Illness: Experiences of Managing Relationships Among Women With Fibromyalgia | Qualitative Health Research | Sociology |
| FM | Cooper | 2017 | An exploratory study of the experience of fibromyalgia diagnosis in South Africa | Health | Sociology |
| FM | Cooper | 2017 | The role of ‘social support’ in the experience of fibromyalgia – narratives from South Africa | Health and Social Care in the Community | Sociology |

| | | | | | |
|---|---|---|---|---|---|
| FM | Ashe | 2017 | A qualitative exploration of the experiences of living with and being treated for fibromyalgia | Health Psychology Open | Psychology |
| FM | Granero-Molina | 2018 | Social Support for Female Sexual Dysfunction in Fibromyalgia | Clinical Nursing Research | Nursing |
| FM | Oldfield | 2018 | 'You want to show you're a valuable employee': A critical discourse analysis of multi-perspective portrayals of employed women with fibromyalgia | Chronic Illness | Physical Therapy |
| FM | Briones-Vozmediano | 2018 | "The complaining women": health professionals' perceptions on patients with fibromyalgia in Spain | Disability and Rehabilitation | Nursing |
| IBS | Dixon-Woods | 2000 | Medical and lay views of irritable bowel syndrome | Family Practice | Public Health |
| IBS | Håkanson | 2010 | Being in the Patient Position: Experiences of Health Care Among People with Irritable Bowel Syndrome | Qualitative Health Research | Medicine |
| IBS | Björkman | 2013 | The gendered impact of Irritable Bowel Syndrome: A qualitative study of patients' experiences | Journal of Advanced Nursing | Medicine |
| IBS | Björkman | 2016 | Patients' experiences of healthcare encounters in severe irritable bowel syndrome: An analysis based on narrative and feminist theory | Journal of Clinical Nursing | Medicine |
| TMJ | Durham | 2010 | Living with Uncertainty: Temporomandibular Disorders | Journal of Dental Research | Dental Sciences |
| TMJ | Vuckovic | 2010 | Journey into healing: The transformative experience of shamanic healing on women with temporomandibular joint disorders | Explore | Health Sciences |
| TMJ | Durham | 2011 | Temporomandibular disorder patients' journey through care | Community Dentistry and Oral Epidemiology | Dental Sciences |
| TMJ | Storm Mienna | 2014 | "Grin(d) and Bear it": Narratives from Sami Women with and Without Temporomandibular Disorders. A Qualitative Study | Journal of Oral & Facial Pain and Headache | Dental Sciences |
| TMJ | Eaves | 2014 | Works of Illness and the Challenges of Social Risk and the Specter of Pain in the Lived Experience of TMD | Medical Anthropology Quarterly | Anthropology |
| VV | Denny | 2007 | Endometriosis-associated dyspareunia: the impact on women's lives | Journal of Family and Reproductive Health Care | Medicine |
| VV | Marriott | 2008 | Managing threats to femininity: Personal and interpersonal experience of living with vulval pain | Psychology and Health | Psychology |
| VV | Ayling | 2008 | "If Sex Hurts, Am I Still a Woman?" The Subjective Experience of Vulvodynia in Hetero-Sexual Women | Archives of Sexual Behavior | Psychology |

| | | | | | |
|---|---|---|---|---|---|
| VV | Sadowink | 2012 | Provoked vestibulodynia: A qualitative exploration of women's experiences | British Columbia Medical Journal | Medicine |
| VV | LePage | 2016 | What Do Patients Want? A Needs Assessment of Vulvodynia Patients Attending a Vulvar Diseases Clinic | Sexual Medicine | Medicine |
| VV | Shallcross | 2018 | Women's Experiences of Vulvodynia: An Interpretative Phenomenological Analysis of the Journey Toward Diagnosis | Archives of Sexual Behavior | Psychology |
| VV | Hintz | 2019 | Disrupting Sexual Norms: An Application of the Critical Interpersonal and Family Communication<br>(CIFC) Framework in the Context of Vulvodynia | Journal of Family Communication | Communication |
| VV | Hintz | 2019 | The Vulvar Vernacular: Dilemmas Experienced and Strategies Recommended by Women with Chronic Genital Pain | Health Communication | Communication |
| VV | Leusink | 2019 | Women's appraisal of the management of vulvodynia by their general practitioner: A qualitative study | Family Practice | Medicine |
| VV | Young | 2019 | "This Girl is on Fire" Sensemaking in an Online Health Community for Vulvodynia | CHI 2019 | Computer Science |

Note: CFS = chronic fatigue syndrome, CLBP = chronic low back pain, CM = chronic migraine, CTTH = chronic tension type headache, ENDO = endometriosis, FM = fibromyalgia, IBS = irritable bowel syndrome, TMJ = temporomandibular joint disorders, VV = vulvodynia.

## APPENDIX E: MATRIX TABLE OF KEY CONCEPTS

| | Critical Interpersonal and Family Communication Framework | | | Multiple Goals Theoretical Perspectives | | | |
|---|---|---|---|---|---|---|---|
| **Study** | **Knowledge Claims** | **Interpenetration of the Public Sphere** | **Practices of Perpetuation, Critique, Resistance, & Transformation** | **Task Implications** | **Relational Implications** | **Identity Implications** | **Movement from Discrete to Global Goal Inferences** |
| Gray (2003) [CFS] | Medical diagnosis and access to health care as "proof" of illness, lack of visible or medical evidence as "proof" of feigned illness, need for psychiatric care to address hypochondriasis, malingering, seeking or drug-seeking. | - | - | - | - | - | - |
| Clarke (2005) [CFS] | Desire for legitimized illnesses like cancer which begets symptom recognition. | - | Transformation: Pruning unhelpful connections with friends to speak only to those who are supportive. | Comparison to other well-known and understood illnesses. | Isolation and withdrawal from friends.<br>Medical providers unwilling to provide diagnosis, friends doubted severity of illness. | Loss of self-confidence and self-esteem. | - |
| Dickson (2007) [CFS] | Insinuation that pain is psychological in origin.<br>If my husband doesn't believe | - | Perpetuation: Accepting that some people will never understand CFS. | - | Pruning unhelpful friends from network. | - | My doctor evaluated me as a hypochondriac, doctors are |

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| | me, who else will? | | Resistance: Refusing to take anti-depressants after being threatened with “firing” from the clinic. | | Interaction in which provider called her a “hypochondriac” who was “making it up” caused loss of faith in the medical system. | | supposed to be open-minded and knowledgeable, I lost my faith in the medical system. |
| Winger (2014) [CFS] | - | - | - | - | ‘if the illness is not visible to others, does it exist?’<br>Family members had difficulty believing symptoms. | - | - |
| Brooks (2014) [CFS] | - | - | - | - | Lack of understanding from others.<br>Spouse had not believed symptoms, ignored symptoms, etc. | - | - |
| Fisher (2017) [CFS] | - | - | - | - | Family and friends express disbelief and distrust in symptoms as being fabricated. | - | - |
| Brown (2017) [CFS] | Insinuation that pain is psychological in origin. | - | - | - | Provider offered antidepressants as only treatment option. | - | - |
| Broughton (2017) [CFS] | Diagnostic tests as “proof” of illness. | - | - | - | - | - | - |

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| McManimen (2019) [CFS] | Insinuation that pain is psychological in origin and thus beyond medical help.<br>Dismissal of a previous diagnosis.<br>Previous diagnosis as a barrier to future care.<br>Dismissal of affirmative blood test results as error. | Medical record with CFS/ME listed causes biased assessments of future health issues. | - | - | Provider expressed disbelief about existence of pain by attributing illness to past (non-existent) trauma, stress, and mental illness. | - | My doctor told me that doctors couldn't help me, so I believed that no doctors would be able to help me. Doctors will be biased in their evaluation of me because I have been diagnosed with CFS. |
| Glenton (2003) [CLBP] | Insinuation that pain is feigned for secondary benefits (e.g., release from work) of some sort or as a moral failing, weakness, or character flaw. | Lack of "proof" of illness (diagnosis, treatment, visible disabilities) leads to denial of medication and sick leave because of regulations which require this "proof."<br>Medical records follow patients between appointments. | Perpetuation: Desire to be seen as a "good" patient. | - | - | Back pain as a character blemish. Being treated like a "drug addict" or "hypochondriac" or "social security sneaker." | I had negative interactions talking about my low back pain with others…I don't think that anyone will understand me. I don't want to talk to anyone. |
| Walker (2006) [CLBP] | - | - | - | - | Disbelief by romantic partner causes conflict and disruption | Loss of identity-afraid of being branded a "fake." | Others will try to evaluate the credibility of low back pain |

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| | | | | | to intimacy. | | complaints. |
| Holloway (2007) [CLBP] | There’s nothing wrong with you. Blame for symptoms on patient’s physical fitness. | Denial of benefits and compensation due to objective tests. | - | - | Disbelief by romantic partner causes conflict and relational dissolution.<br>Fear of disbelief causes withdrawal and social isolation. | “Moral stigma” – disempowerment and shame due to fear of being labeled a hypochondriac. | - |
| Snelgrove (2009) [CLBP] | Patients’ insistence about physical origin for symptoms. | Lack of public awareness about chronic pain conditions. | - | Talking about pain as a consequence of a physical issue rather than my own fault. | Disconnection from unsympathetic friends. | Patients positioned themselves as moral, physically ill people. | - |
| Crowe (2010) [CLBP] | - | - | - | - | - | Articulate the body as external to one’s sense of self. | - |
| Allgretti (2010) [CLBP] | Disconnect between patient and provider explanatory models of illness. | - | - | - | - | - | - |
| Cedraschi (2012) [CLBP] | - | - | - | Communicating pain pessimistically – as permanent and incurable. | - | - | - |
| Lin (2012) [CLBP] | - | - | - | - | - | Anger at self for inability to participate in social and cultural rituals. | - |

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| Dima (2013) [CLBP] | - | - | - | - | - | Fear of being seen as a malingerer or hypochondriac. | - |
| Snelgrove (2013) [CLBP] | - | - | - | - | Pain as burdensome to family members. | - | - |
| Buchman (2016) [CLBP] | - | Patients’ histories of drug/alcohol addiction decreased perceived credibility. | - | - | Patients distrust their providers and report being “fired” by their clinicians – accused of being drug seekers or addicts and those labels changing how other providers view them in the future. | Reductions in patients’ perceived trustworthiness.<br>Fear of being branded an “addict” or “alcoholic” due to requesting pain treatment. | Providers will try to evaluate my treatment-seeking motivations.<br>Negative interactions with providers in which my authority was questioned eroded my trust in the medical profession.<br>Providers will use my race and medical history against me. |
| Singh (2018) [CLBP] | - | - | - | - | Adjustments to management of household chores as a result of pain cause conflict and rouse suspicions about | - | - |

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|  |  |  |  |  | credibility of pain complaints.<br>Fatigue of family and friends hearing about pain causes doubt about symptoms. |  |  |
| Stensland (2018) [CLBP] | - | - | - | - | - | Feeling like a “non-person” due to pain. | - |
| Lampard (2019) [CLBP] | - | Disconnect between expectations for my body and what my body is able to do. | - | - | - | - | - |
| Allvin (2019) [CLBP] | - | - | - | - | - | - | My doctor was trying to follow guidelines instead of listening to my wishes.<br>Negative interactions with providers caused a lack of trust. |
| Palacios-Ceña (2017) [CM] | - | - | - | - | Family members express disbelief about the existence or severity of pain. | Stereotypes about pain (e.g., “nervous and stressed”) used to explain symptoms. | - |
| Lonardi (2007) [CTTH] | - | - | - | - | Lack of support from | - | - |

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| | | | | | colleagues at work. | | |
| Skogvold (2018) [CTTH] | - | - | - | - | - | - | No one has been able to help me, therefore I have lost hope. |
| Cox (2003) [ENDO] | Patients feel that “real” pain has an organic biomedical origin. | - | Resistance: Tracking symptoms to gather own evidence of endometriosis.<br>Resistance: Getting a second opinion.<br>Transformation: De-emphasizing the role of traditional medicine. | - | Providers disbelieve and trivialize accounts of pain, suggest that women are “too young” to have endo. | - | - |
| Denny (2004) [ENDO] | Menstrual pain normalized. | - | - | - | Employer disbelieves that patient is truly in pain. | - | - |
| Ballard (2006) [ENDO] | - | - | - | - | Provider normalized period pain and minimized its seriousness.<br>Employers and friends express skepticism about the seriousness of menstrual pain. | - | - |
| Denny (2007) [ENDO] | - | - | - | - | Providers do not view symptoms as serious, normalize | - | - |

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| | | | | | menstrual pain. | | |
| Whelan (2007) [ENDO] | Patients and providers each possess knowledge about FM which must be considered. | - | Critique: Criticize lack of knowledge among providers about endometriosis.<br>Resistance: Self-advocacy and research. | - | - | - | - |
| Markovic (2008) [ENDO] | Menstrual pain normalized. | - | Critique: Criticize advice to “have a baby” to mitigate endometriosis symptoms. | - | Relational dissolution following diagnosis of endometriosis. | - | - |
| Hudson (2016) [ENDO] | - | - | - | - | Couples adapted to new demands of endometriosis and accepted its seriousness. | - | - |
| Gundström (2017) [ENDO] | Need to convince others that pain is “real.”<br>Blame women for their pain (lack of exercise).<br>Menstrual pain normalized. | - | - | - | Providers perceived to be ridiculing patients and impatient with them. | - | After experiencing disbelief immediately, I realized that they all think that you exaggerate. |
| Pryma (2017) [ENDO] | Medical diagnosis as a primary means of making suffering visible and legitimate. | Lack of “proof” of illness (diagnosis, treatment, visible disabilities) leads to denial of | - | - | Family disbelieve that FM is truly disabling.<br>Workplaces and employers | - | - |

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|  |  | medication and sick leave because of regulations which require this "proof."<br>Perceptions of race and welfare – using pain as an excuse to apply for welfare. |  |  | unable to accommodate needs.<br>Provider disbelieves accounts of pain. |  |  |
| Grogan (2018) [ENDO] | Nothing wrong with you.<br>Menstrual pain normalized. | - | - | - | Provider did not believe that there was anything wrong.<br>Pruning unsupportive friendships. | - | - |
| Young (2020) [ENDO] | Doctor has the power to legitimate pain or label women.<br>Patients and providers each possess knowledge about FM which must be considered. | - | Critique: Criticize poor quality of healthcare received.<br>Resistance: Continuing to ask questions, push for care, report issues when they arise.<br>Resistance: Getting a second opinion. | - | Providers question the existence and severity of pain. | - | Doctors will try to label you as a "mad woman" or "hypochondriac." Be careful. |
| Hallberg (1998) [FM] | Doctor has the power to legitimate pain. | - | - | - | - | - | - |
| Hallberg (2000) [FM] | Patients feel that "real" pain has an organic biomedical origin whereas "imagined" | - | - | - | - | - | - |

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| | pain has a psychological origin. | | | | | | |
| Hellström (1999) [FM] | Diagnosis as a means of confirming reality of illness AND as a barrier to future medical care. | - | - | - | Others express doubt about whether a person is “really” ill. | - | - |
| Raymond (2000) [FM] | - | - | - | Avoid discussing pain for fear of dismissal. | Socially isolate oneself to avoid judgement and rejection. | - | - |
| Marit Mengshoel (2006) [FM] | Patient’s symptoms dismissed when blood test results come back normal. | - | - | - | Others accuse patients of being “work shy” and feigning illness to shirk responsibilities in the workplace. | Self-doubt after illness is questioned, am I a “hysterical old cow?” | - |
| Löfgren (2006) [FM] | - | - | - | - | Colleagues express a lack of support for the patient. | - | - |
| Liedberg (2006) [FM] | - | - | - | - | Patients withdraw and isolate themselves. | - | - |
| Cunningham (2006) [FM] | Dismissal of others’ health complaints until developing fibromyalgia oneself.<br>Pain dismissed as psychological in origin. | Refusal to sign disability paperwork. | - | - | - | - | My doctor told me that I need to go to a psychologist…the whole medical profession does not take FM seriously. |
| Madden (2006) [FM] | Pain dismissed as normal. | Lack of public awareness about chronic | - | - | - | - | - |

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| | Lack of visible physical disability. | pain conditions. | | | | | |
| Lempp (2009) [FM] | - | - | - | - | Colleagues express a lack of support for the patient. | - | - |
| Wuytack (2011) [FM] | - | - | - | Avoid discussing pain with others. | Disbelief by romantic partner causes conflict and relational dissolution.<br>Disbelief, denial, and a lack of interest and commitment from providers. | Continued stigmatization after diagnosis with FM. | I can’t be bothered to talk about FM with anyone. No one wants to try to understand. |
| Sallinen (2011) [FM] | - | - | - | Avoid discussing pain with others for fear of being a “whiner.” | Family and colleagues are unsupportive about pain and other symptoms. | - | - |
| Juuso (2013) [FM] | - | - | - | - | Being acknowledged by friends and family promote well-being. | - | - |
| Dennis (2013) [FM] | Doctor can offer or withhold diagnosis, treatment, recognition. | - | - | Avoid discussing with others for fear of being labeled “hypochondriac.” | Unfulfilling patient-provider relationship.<br>Reluctance to discuss pain with friends who do not understand and express lack of approval. | - | Dissatisfying interactions with medical providers coalesce into dissatisfaction with doctors and a loss of faith in their capacity to help. |

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| | | | | | Family members accuse of being “hypochondriac.” | | |
| Juuso (2014) [FM] | Patients not viewed as credible because they lacked “proof” of FM in the form of physical signs of illness.<br>Moral failures of women as lazy. | Not receiving accommodations at work.<br>After diagnosis, unable to secure prompt appointments with medical providers. | Perpetuation: Giving up on seeking treatment.<br>Perpetuation: Applying makeup to be viewed as “doing well” in an effort to procure treatment and avoid psychological explanation for pain. | - | Repeatedly forced to discuss pain with others who did not take them seriously.<br>Pruning friendships with those who are unsupportive.<br>Not listened to or taken seriously by medical providers.<br>Family members criticize patients as “not having it together” for being unable to participate in activities.<br>Supported by colleagues once pain was made visible via accommodations. | - | - |
| Gill Taylor (2016) [FM] | - | - | - | Required to repeatedly justify symptoms to those | Employers and providers insensitive to symptoms and pain. | - | - |

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|  |  |  |  | around them. |  |  |  |
| Briones-Vozmediano (2016) [FM] | - | - | - | - | Spouses and family members accuse patients of fabricating symptoms.<br>Spouses who disbelieve pain become frustrated by lack of sexual activity. | - | - |
| Chen (2016) [FM] | Patients and providers each possess knowledge about FM which must be considered. | - | - | - | - | - | - |
| Armentor (2017) [FM] | Women who do not “look sick” do not receive adequate care.<br>Social support withheld until a diagnosis was received.<br>Lack of objective evidence for symptoms. | Reliance on gendered ideologies about female pain and hysteria to evaluate women’s health complaints across time. | Perpetuation: Giving up on seeking treatment after being told that FM does not exist. | Being direct and upfront about FM.<br>Communicating FM as comparable to other more well-known illnesses.<br>Making “invisible” pain and fatigue visible to family and friends through cues related to behavior, appearance, and talk. | Medical providers express skepticism about illness/symptoms of FM.<br>Periods of talk in which patients are questioned indicate a lack of trust and social acceptance of FM. | - | - |

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| | | | | Being selective about who to communicate to (e.g., not disclosing pain to co-workers for fear of being viewed as lazy). | | | |
| Cooper (2017) [FM] | Lack of objective evidence for symptoms.<br>Variability of symptoms across time rouses suspicion about the credibility of health complaints. | Medical records follow patients between appointments. | Perpetuation: Accepting a purely psychological explanation for pain. | - | - | Self-doubt about "realness" of pain. | I finally got in to see a specialist and he told me to take antidepressants…the medical profession is unhelpful. |
| Cooper (2017) [FM] | - | - | - | - | Symptom inconsistencies (e.g., "episodes" of FM) create impatience and reluctance to make accommodations. | - | - |
| Ashe (2017) [FM] | Lack of a diagnosis, and clear cause causes FM to be contested. | - | Perpetuation: Exaggerating symptoms in an effort to procure treatment.<br>Resistance: Continuing to seek a diagnosis despite negative interactions with providers. | Pursue conversations about pain despite discouragement from doing so.<br>Hesitancy to seek future care for other health issues. | Finding a "fibro-family" who will validate experiences of illness. | - | A lack of acknowledgement from others over time lead to frustration with everyone.<br>Dismissive attitudes by individual providers over time |

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| | | | | De-emphasizing or hiding symptoms due to a perceived lack of genuine interest. | | | coalesce into a hesitance to seek care for future health concerns. |
| Granero-Molina (2018) [FM] | - | - | Resistance: Refusal to take unwanted medications with severe side effects. | Obscure information about FM from providers who do not believe in FM. | Skepticism about pain and severity of effects causes distancing and a lack of support from family and romantic partners. | - | - |
| Oldfield (2018) [FM] | - | - | - | - | Employer expresses disbelief and fights against medical leave for FM. | - | - |
| Briones-Vozmediano (2018) [FM] | Providers don't "believe in" FM. | FM is poorly understood, but our understanding of FM will evolve over time. | Transformation: Changing the context of the argument to de-emphasize debates about the validity of the condition. | - | Female FM patients viewed as demanding depressed complainer, suspicion of secondary benefits afforded by a diagnosis. | - | - |
| Dixon-Woods (2000) [IBS] | Doctors have two definitions of IBS: what is in a textbook and what they glean from interacting with patients.<br>Mind-body dualism and issue of timing | Conditions like IBS are considered to be psychological in origin until we become able to ascertain a | - | - | Providers dismiss symptoms as psychological. | Questioning the relationship between pain and their "neurotic" personalities. | All doctors put us into one bag, we're "neurotic" |

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| | (does IBS cause mental illness or does mental illness cause IBS)? | biological cause. | | | | | |
| Håkanson (2010) [IBS] | Insinuation that pain is psychological in origin. | - | - | - | - | Questioning oneself and one’s sanity. | There wasn’t anyone who took me seriously. |
| Björkman (2013) [IBS] | Insinuation that pain is psychological in origin. | - | - | - | Providers tell patient to “pull herself together.” | Doubt own experiences, wondering if they are imagining symptoms or going crazy.<br>Self-blame. | - |
| Björkman (2016) [IBS] | Patients and providers each possess knowledge about FM which must be considered. | - | Critique: Criticize psychological explanation for pain. | - | - | - | - |
| Durham (2010) [TMJ] | - | - | - | - | Providers typecast women with TMJ as “troublesome” or “difficult.” | Self-doubt about whether pain is “psychosomatic.” | - |
| Vuckovic (2010) [TMJ] | - | - | - | - | - | - | - |
| Durham (2011) [TMJ] | - | - | - | - | Family members who do not understand grow frustrated.<br>Providers view patients as fabricating symptoms. | Loss of personal legitimacy. Viewed as a “malingerer.” | - |

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| Storm Mienna (2014) [TMJ] | - | - | Critique: Push back against notion that patient sought medical help to procure sick leave. | - | - | - | My provider thought that I was trying to get work release or receive some other secondary gain. |
| Eaves (2014) [TMJ] | - | - | - | Avoid discussing pain with others for fear of being perceived as attention-seeking. | - | Patients worked to differentiate themselves from other patients. "I'm not the kind of person who…" | - |
| Denny (2007) [VV] | - | - | - | - | Lack of understanding by romantic partners causes frustration when sexual activity is halted. | - | - |
| Marriott (2008) [VV] | - | - | - | - | Hesitance to begin new romantic/sexual relationship.<br>Providers know little about VV and express disbelief. | Women considered whether they had an "aversion to sex" when their accounts of pain were questioned. | Being repeatedly questioned about whether VV was psychological or physical in origin coalesces into perception that everyone believes that I am making it up. |

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| Ayling (2008) [VV] | - | - | - | - | - | Patients feel like “not real women” or “inadequate women” due to VV. | |
| Sadowink (2012) [VV] | - | - | - | - | - | Negative impact on self-esteem/confidence.<br>Feeling “not normal.”<br>Told that they are “frigid and don’t like sex.” | - |
| LePage (2016) [VV] | - | - | - | - | Relational conflict caused by pain and halting of sexual activity and intimacy. | - | - |
| Shallcross (2018) [VV] | - | Reliance on gendered ideologies about female pain and hysteria to evaluate women’s health complaints across time. | | Avoidance - women fear the consequences of being labeled “neurotic” by important others. | Patient-provider relationship become tense and strained – patients fearful of consequences of negative interactions. | Acknowledging the psychological consequences of dealing with the medical system. | One doctor gave me a pelvic exam without warning and lacked compassion…I hate doctors.<br>Iatrogenesis…unintended consequences of healthcare interactions. |

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| | | | | | | | Negative interactions caused patients to stop seeking health care. |
| Hintz (2019) [VV] | - | Media representations of sex and intimacy. | Perpetuation: Stereotyping all men and offering to open the relationship.<br>Resistance: Demanding increased partner engagement and developing a self-advocating orientation.<br>Transformation: Adopting a conditional view of romantic relationships, negotiating a new sexual normal. | - | Relational dissolution as a result of disbelief about VV. | Failing to have sex means failing as a woman. | - |
| Hintz (2019) [VV] | - | - | - | - | The uncertain nature of pain jeopardizes romantic relationship and makes new relationship difficult to begin. | - | - |
| Leusink (2019) [VV] | - | - | - | - | Patients perceived that providers did not listen or take | - | - |

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| | | | | | complaints of pain seriously, causing frustration and anger. | | |
| Young (2019) [VV] | Female providers draw upon own experiences to normalize VV pain. | - | Resistance: Seeking a second opinion after being told that pain with intercourse was normal.<br>Resistance: Self-advocacy and research. Counter-emplotment of facts. | - | - | - | - |

Note: CFS = chronic fatigue syndrome, CLBP = chronic low back pain, CM = chronic migraine, CTTH = chronic tension type headache, ENDO = endometriosis, FM = fibromyalgia, IBS = irritable bowel syndrome, TMJ = temporomandibular joint disorders, VV = vulvodynia.

# APPENDIX F: INITIAL LIST OF SCALE ITEMS

| Item # | Draft Scale Item |
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| 1 | Did not believe me. |
| 2 | Doubted me. |
| 3 | Gaslighted me. |
| 4 | Did not take me seriously. |
| 5 | Doesn’t understand it. |
| 6 | Dismissed me. |
| 7 | Ignored me. |
| 8 | Judged me. |
| 9 | Joked about it. |
| 10 | Mocked me |
| 11 | Ridiculed me. |
| 12 | Humiliated me. |
| 13 | Made me feel stupid. |
| 14 | Gave up on me. |
| 15 | Mocked me for being upset. |
| 16 | Became frustrated with me. |
| 17 | Didn’t try to help me. |
| 18 | Discriminated against me because I am in pain. |
| 19 | Discriminated against me because I am a woman. |
| 20 | Discriminated against me because I am diagnosed with a chronic pain condition. |
| 21 | Discriminated against me because I am diagnosed with a mental health condition. |
| 22 | Discriminated against me because I have a history of mental illness. |
| 23 | Discriminated against me because I have a history of addiction. |
| 24 | Discriminated against me because of my past traumatic experiences. |
| 25 | Did not care about me. |
| 26 | Doesn’t understand me. |
| 27 | Was unempathetic toward me. |
| 28 | Acted like they did not have time to hear me. |
| 29 | Acted like I was wasting their time. |
| 30 | Acted annoyed by me. |
| 31 | Ridiculed me for talking about it. |
| 32 | Ridiculed me when I talked about it. |
| 33 | Told me to pull myself up by the bootstraps. |
| 34 | Told me to pull myself together. |
| 35 | Told me to get it together. |
| 36 | Tried to get me to stop talking about it. |
| 37 | Gave me unwanted advice. |
| 38 | Gave me unhelpful advice. |

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| 39 | Ignored things about it that I brought up. |
| 40 | Suspected that I had an ulterior motive for talking about it. |
| 41 | Was skeptical about why I was talking about it. |
| 42 | Suspected that I wanted pain medication. |
| 43 | Suspected that I was a malingerer. |
| 44 | Suspected that I was a drug seeker. |
| 45 | Suspected that I was up to no good. |
| 46 | Suspected that I wasn’t really in pain (or wasn’t really dealing with it). |
| 47 | Suspected that I was looking for attention. |
| 48 | Suspected that I was trying to get out of work. |
| 49 | Suspected that I was trying to get disability benefits. |
| 50 | Suspected that I was mentally ill. |
| 51 | Assumed that I was not telling the truth. |
| 52 | Questioned my character. |
| 53 | Told me that there was nothing wrong. |
| 54 | Told me that I was just anxious. |
| 55 | Told me that I was just stressed. |
| 56 | Told me that I needed to relax. |
| 57 | Told me that I was just depressed. |
| 58 | Told me that it was not real. |
| 59 | Told me that I did not need help. |
| 60 | Implied that it was not real. |
| 61 | Told me that it does not exist. |
| 62 | Told me that it is not happening to me. |
| 63 | Compared their experiences to mine. |
| 64 | Told me to go see a therapist/counselor/psychologist/psychiatrist. |
| 65 | Told me that I caused it. |
| 66 | Told me that I chose it. |
| 67 | Told me that it was my fault. |
| 68 | Told me that I wanted to be sick. |
| 69 | Told me that it could get better if I wanted it to. |
| 70 | Told me that I did not want to get better. |
| 71 | Told me that I was choosing to be sick. |
| 72 | Told me that I was using it as an excuse. |
| 73 | Told me that I was lazy. |
| 74 | Told me that I was faking it. |
| 75 | Told me that I am complicit in it. |
| 76 | Does not recognize how hard I am trying. |
| 77 | Downplayed how severe it is. |
| 78 | Told me that it wasn’t as severe as it is. |
| 79 | Downplayed how serious it is. |
| 80 | Underestimated its effect on me/my life. |
| 81 | Downplayed its effect on my life. |
| 82 | Blamed me for it. |
| 83 | Blamed it on mental illness. |

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| 84 | Told me that I was not trying to deal with it. |
| 85 | Told me that I was making it up. |
| 86 | Told me that it was imaginary. |
| 87 | Told me that I was imagining it. |
| 88 | Told me that I was lying. |
| 89 | Told me that I was making it worse. |
| 90 | Told others that I was imagining it. |
| 91 | Made it harder for me to talk to others about it. |
| 92 | Made it harder for others to listen to me without bias. |
| 93 | Made it harder for others to take me seriously in the future. |
| 94 | Made it harder for me to seek care for it in the future. |
| 95 | Made me feel small. |
| 96 | Made me feel worthless. |
| 97 | Made me feel like less of a person. |
| 98 | Made me feel like a bad person. |
| 99 | Made me feel like an immoral person. |
| 100 | Told me that I did not deserve sympathy. |
| 101 | Told me that it did not warrant sympathy. |
| 102 | Told me that I was noncompliant. |
| 103 | Told me that it was all in my head. |
| 104 | Told me that they were fed up when I talked about it. |
| 105 | Told me that it was normal. |
| 106 | Told me that it wasn’t so bad. |
| 107 | Told me it wasn’t a big deal. |
| 108 | Told me that I did not look sick enough. |
| 109 | Told me that I looked too well to have it. |
| 110 | Told me that I was not acting the way I should. |
| 111 | Told me that I had not acted the way I should. |
| 112 | Told me that I was not responding to it the way I should. |
| 113 | Told me that I had not responded to it the way I should. |
| 114 | Did not try to understand it. |
| 115 | Did not try to understand me. |
| 116 | Demanded/Wanted “proof” for it. |
| 117 | Wouldn’t believe me without “proof.” |
| 118 | Don’t believe it because they can’t see it. |
| 119 | Made me wish that I had a visible marker for it. |
| 120 | Made me feel that it was not valid. |
| 121 | Said that they could not help me. |
| 122 | Said that no one could help me. |
| 123 | Made me feel like I was overreacting. |
| 124 | Made me feel like an exaggerator. |
| 125 | Made me feel like a hypochondriac. |
| 126 | Made me feel like I should not have talked about it. |
| 127 | Made me feel wrong for talking about it. |
| 128 | Made me feel like I want attention. |

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| 129 | Told me that I was dramatic. |
| 130 | Told me that I was making excuses to not get better. |
| 131 | Told me that something else (other than what I think) caused it. |
| 132 | Said that it was normal for a woman. |
| 133 | Did not take me seriously because I was a woman. |
| 134 | Did not take me seriously because I was a pain patient. |
| 135 | Did not take me seriously because I had a diagnosis for mental illness/addiction. |
| 136 | Dismissed it as anxiety. |
| 137 | Did not take me seriously because I had a prescription for opioids. |
| 138 | Treated me worse than other people with it. |
| 139 | Caused me to question its severity. |
| 140 | Caused me to question whether I was making it worse. |
| 141 | I wondered whether it was my fault. |
| 142 | I doubted whether it was real. |
| 143 | I wondered whether I had caused it. |
| 144 | I wondered whether it was all in my head. |
| 145 | I questioned whether I had a mental illness. |
| 146 | I felt like giving up (overlap with suicidal ideation) |
| 147 | I wondered whether I was making it up. |
| 148 | I felt I had to get angry to be taken seriously. |
| 149 | I lost trust in [them]. |
| 150 | I lost trust in the [medical system]. |
| 151 | I stopped talking to others about it. |
| 152 | I became more selective about who I tell about it. |
| 153 | I became more selective about who I was around. |
| 154 | I stopped spending time with some people. |
| 155 | I withdrew from others. |
| 156 | I isolated myself from others. |
| 157 | I hesitate to talk to others about it. |
| 158 | I became more hesitant to talk to others about it. |
| 159 | I became less tolerant of others’ complaints. |
| 160 | I had less patience for others’ complaints. |
| 161 | I feared that others would not believe me. |
| 162 | I hesitated to see other [doctors] about it. |
| 163 | I hesitated to tell other [doctors] about it. |
| 164 | I had to be more assertive when talking about it. (overlap with patient advocacy measure) |
| 165 | I had to be more aggressive when talking about it. |
| 166 | Wrote their view of me into my medical record. |
| 167 | Refused to take pain medication (because it would make me look like a drug seeker). |
| 168 | Avoided seeking health care for it. |
| 169 | Avoided seeking health care for another medical issue. |
| 170 | Avoided seeking mental health care (because it would fuel the myth of my mental illness as the cause for my pain). |

# APPENDIX G: POTENTIAL CONTEXTUAL OUTCOMES OF CD

| **Outcome Mentioned** | **Approximate Frequency** |
|---|---|
| Social withdrawal/isolation | 22 |
| Loss of trust in system | 18 |
| Suicidal ideation | 18 |
| Reluctance to talk to others | 17 |
| Loss of perceived social support | 15 |
| Self-doubt | 15 |
| Biased assessments of future health symptoms | 15 |
| Hopelessness | 12 |
| Loss of credibility | 12 |
| Mental health | 12 |
| Diagnostic delay | 10 |
| Actual or perceived threat of relational dissolution | 9 |
| Denial of disability benefits/handicap parking/accommodations | 8 |
| Loss of job | 7 |
| Loss of intimacy | 6 |
| Reduced quality of life | 5 |
| Loss of self-esteem | 4 |
| Loss of trust in provider | 4 |
| Perceived burdensomeness | 4 |
| Denial of disability benefits | 4 |
| Medical records indicate psychological explanation for diagnosis | 4 |
| Won’t provide excuse for work or school | 4 |
| Resentment/Embitterment | 3 |
| Reluctance to disclose mental health symptoms | 2 |
| Won’t release medical records | 2 |
| Screening/blocking patients’ calls and messages | 2 |

# APPENDIX H: GLOSSARY OF TCD TERMS

| TCD Term | Definition |
|---|---|
| Communicative disenfranchisement (CD) | CD occurs in instances of talk which share a locus of disempowerment and which result in an individual or group's diminished capacity to participate meaningfully in society through effects on agency, perceived credibility, and/or rights and privileges. CD occurs through three particular discursive practices: "silencing them, discrediting their claims…or perpetuating the structure that enables disenfranchisement in the first place" (Ray, 1996a, p. xv). |
| Constitutive view of communication | Communication as the means through which our experience of reality is formed, contested, and altered rather than only a means of exchanging information and creating knowledge. |
| Constraint (imposed and self-imposed) | Disenfranchisement operates through the imposition of interference across domains of disenfranchisement which are always some combination of self-imposed (resulting from global goal inferences) and externally imposed (resulting directly from CD). |
| Cumulative illness-course disenfranchisement | Instances of disenfranchising talk over the course of one's illness coalesce into a cumulative awareness of disenfranchisement and the prospective future possibility of experiencing disenfranchising talk. In this context, cumulative disenfranchisement more specifically references cumulative illness-course disenfranchisement, or global perceptions of disenfranchisement which arise across subsequent interactions with important others throughout the course of managing chronic pain. |
| D/discourse | TCD conceptualizes discourses in two senses – as big "D" discourse and little "d" discourse (Alvesson & Karreman, 2000), where the former serves the purposes of the "social construction, maintenance, and validation of reality" and the latter of "local communicative acts" (Allen, 2019, p. 109). Big "D" Discourse is utilized when Discourses are described as systems of meaning which circulate within the public sphere, and little "d" discourse is utilized to discuss how discourses and practices are employed in interaction. |
| Dimension of CD: Discrediting | Others contest the "realness" of: (a) the significance of the target of DT, or (b) the effect of the target on the person's life, (c) whether a person could experience that target as they claim, or even (d) the very existence of the target itself. |
| Dimension of CD: Stereotyping | By calling upon salient discourses in disenfranchising talk (e.g., discourses about female patients), that system of meaning is continued. |
| Dimension of CD: Silencing | Communicative acts employed to discourage the person subjected to disenfranchisement from discussing the target of DT both at present and in the future. |
| Discrete → global inferences about goal tendencies | Individuals experiencing disenfranchising talk make assessments about the purposes that specific others were attempting to pursue in specific interactions with them. Over time and across subsequent interactions, individuals make assessments about the task, relational, and identity purposes that others will tend to pursue in future interactions with them. |
| Disenfranchisement | "The state of being deprived of a right or privilege, especially the right to vote" (Oxford Dictionary, 2020) |
| Disenfranchisement domain: Ability to exercise rights and privileges | Individuals subjected to DT experience a reduced capacity to act on otherwise afforded entitlements. |
| Disenfranchisement domain: Agency | Individuals experience constraint in their ability to speak and act or self-constrain because of assessments that speaking or acting would be disadvantageous. |

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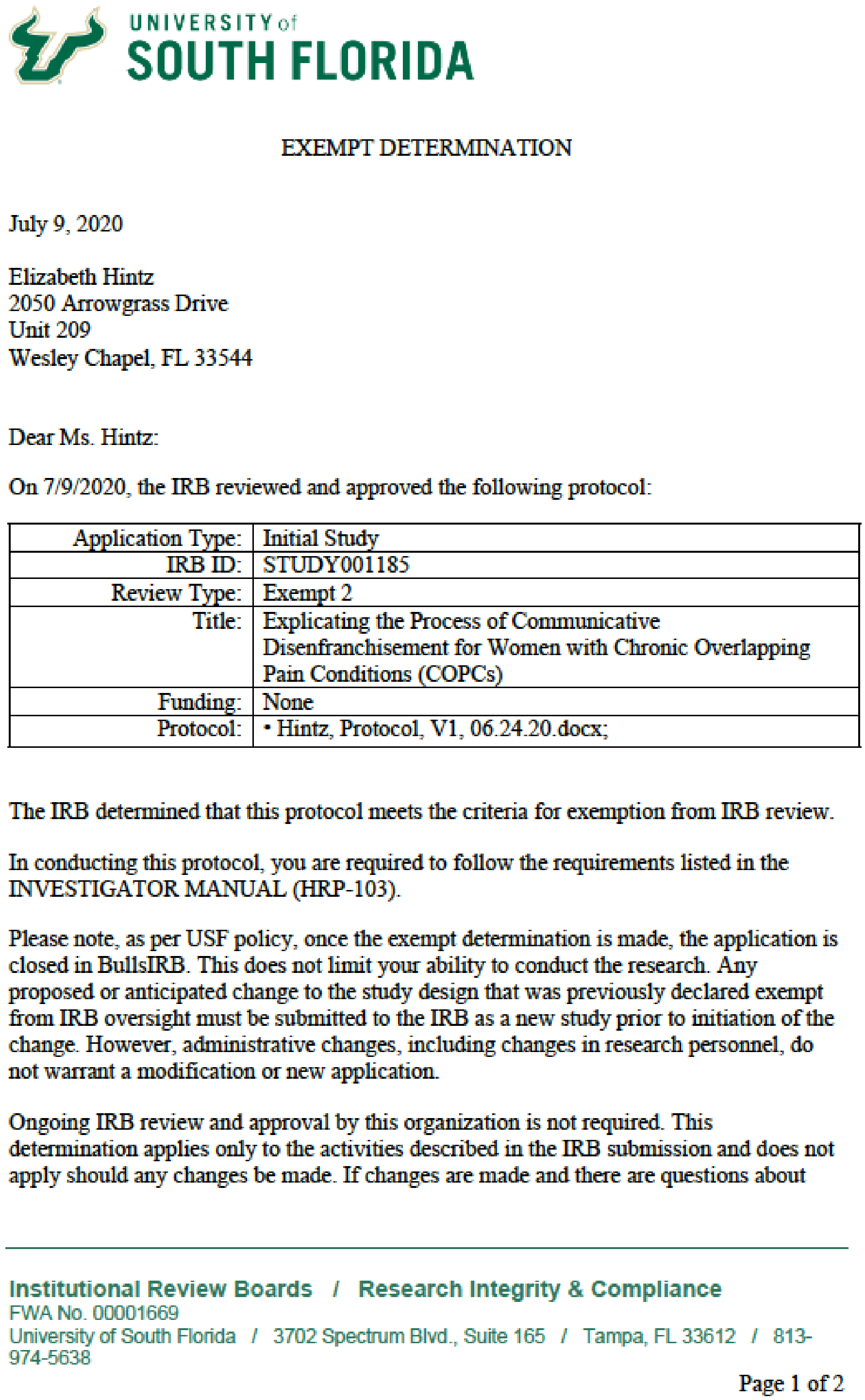
| Disenfranchisement domain: Perceived credibility. | Individuals subjected to DT experience interference in their ability to be perceived as credible by others. |
| Efforts toward enfranchisement: Critique, resistance, and transformation. | When individuals enact discourses and practices which critique, resist, and transform the status quo. Transformation can occur in both first order (in the relations which constitute CD but not in the conditions which enable CD to occur), and second-order capacities (which alter the systems of meaning that create the conditions for CD to occur). |
| Efforts toward reification: Perpetuation | Individuals may be complicit in reifying discourses which have been called upon in interactions with them and thus in contributing to those same discourses which comprise the status quo. |
| Knowledge claims | Power is sustained by making knowledge claims (i.e., calling upon discourses) about what is true while silencing other claims. Foucault (1980) calls this idea "*power/knowledge*," again reiterating the idea that knowledge cannot exist without power. |
| Material consequences | Those conditions (related to one's body and the physical environment) which lay beyond the rational control of the subject. |
| Power | Power is seen as occurring through the struggle of human interaction. Power is a productive (not repressive) process (not an object). We legitimize and constitute power relations through discourse, and discourse is also the means through which power is maintained and disrupted. |
| Process view of communication | Theorizing process elucidates how a series of cases (i.e., discrete interactions) are united by a common process (i.e., CD). This process must be *versatile* enough to encompass the complexities and differing timeframes which constitute the process as well as distinguish the "noise" which is unrelated to the process. Although a process may take different timeframes, have different typologies of sequences, and be enacted by a diverse group of people under different circumstances, it should recognizable across disparate contexts (Poole, 2007). |
| Precipitation | Through disenfranchising talk which invokes discourse, discourses precipitate into material consequences for targets of CD. |
| Reification (by others) | Efforts toward critique, resistance, and transformation can be used by others as further "evidence" for the subject of CD. The material consequences of disenfranchisement can also be used in this way. |
| Social regulation | Because of the discourses upon which individuals, relationships, familial forms, identities, as well as our experiences and management of those experiences depend, the reality and nature of those experiences are necessarily managed through interactions with others. For example, because being taken seriously by others regarding a health issue often depends upon one's ability to procure a diagnosis, medical providers become social regulators for the illness experience. |
| Targets of communicative disenfranchisement | Individuals, relationships, familial forms, identities, as well as our experiences and management of those experiences can be the "targets" toward which disenfranchising talk is directed. |
| Task, relational, and identity purposes | Purposes that individuals pursue in interactions related to pursuing particular communicative tasks (e.g., pursuing diagnosis, seeking support), relating to others, and how individuals are viewed by others. |

# APPENDIX I: IRB APPROVAL LETTER



UNIVERSITY of
SOUTH FLORIDA

EXEMPT DETERMINATION

July 9, 2020

Elizabeth Hintz
2050 Arrowgrass Drive
Unit 209
Wesley Chapel, FL 33544

Dear Ms. Hintz:

On 7/9/2020, the IRB reviewed and approved the following protocol:

| | |
|---|---|
| Application Type: | Initial Study |
| IRB ID: | STUDY001185 |
| Review Type: | Exempt 2 |
| Title: | Explicating the Process of Communicative Disenfranchisement for Women with Chronic Overlapping Pain Conditions (COPCs) |
| Funding: | None |
| Protocol: | • Hintz, Protocol, V1, 06.24.20.docx; |

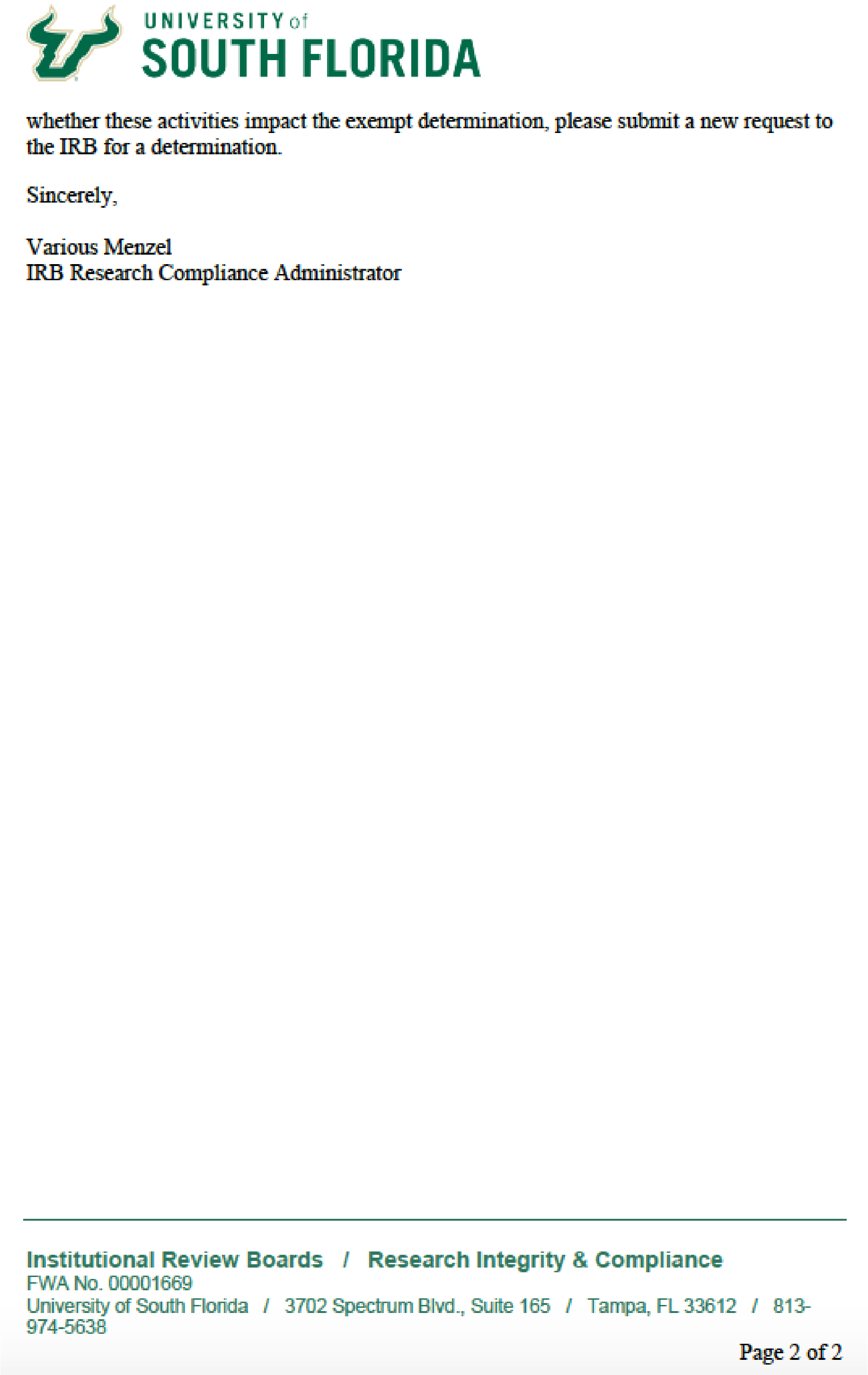
The IRB determined that this protocol meets the criteria for exemption from IRB review.

In conducting this protocol, you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Please note, as per USF policy, once the exempt determination is made, the application is closed in BullsIRB. This does not limit your ability to conduct the research. Any proposed or anticipated change to the study design that was previously declared exempt from IRB oversight must be submitted to the IRB as a new study prior to initiation of the change. However, administrative changes, including changes in research personnel, do not warrant a modification or new application.

Ongoing IRB review and approval by this organization is not required. This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about

**Institutional Review Boards / Research Integrity & Compliance**
FWA No. 00001669
University of South Florida / 3702 Spectrum Blvd., Suite 165 / Tampa, FL 33612 / 813-974-5638



whether these activities impact the exempt determination, please submit a new request to the IRB for a determination.

Sincerely,

Various Menzel
IRB Research Compliance Administrator