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Don't Put Me in "Quotes": Examining Communication Episodes of Health-Related Stigma

Ashley Archiopoli

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Ashley Marie Archiopoli

Candidate

Communication & Journalism

Department

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Julie Delaney Shields , Chairperson

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John G. Oetzel

Tamar Ginossar

Magdalena Avila

DON'T PUT ME IN "QUOTES":
EXAMINING COMMUNICATION EPISODES OF
HEALTH-RELATED STIGMA

by

ASHLEY MARIE ARCHIOPOLI

Master of Arts in Communication
Wichita State University, May 2010
Bachelor of Arts in Communication
Wichita State University, December 2007

DISSERTATION

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Albuquerque, New Mexico

DEDICATION

I want to dedicate my dissertation to my family, thank you for always loving and supporting me. I love you more than you will ever know. You have all inspired me in your own ways. To my parents: Laura and Paul. To my Mom, Laura Archiopoli, you are the kindest and most caring mother I could have. Thank you for loving me unconditionally, and helping me whenever I need it, day or night. To my Dad, Paul Archiopoli, you may know me better than I know myself, because, apparently, I am you. Thank you for helping me think through all of my major life decisions. And to my siblings: Chris, Mike, and Aileen. To Chris Archiopoli, though you deny it so vehemently—you are a wonderful person, I treasure you, and I am so glad that you are my big brother. To Mike, thank you for the instrumental support you have continuously provided me, I know that you are always there when I need you. You are my brother bear. To Aileen, thank you for acting as my voice of reason and partner in crime at the same time. You are my best friend.

DON'T PUT ME IN "QUOTES": EXAMINING COMMUNICATION EPISODES OF HEALTH-RELATED STIGMA

by

Ashley Marie Archiopoli

B.A., Communication, Wichita State University, 2007
M.A., Communication, Wichita State University, 2010
Ph.D., Communication, The University of New Mexico, 2014

ABSTRACT

This study examined communication episodes of health-related stigma, which includes instances where individuals were made to feel bullied, excluded, rejected, blamed, or embarrassed due to a health condition they or someone they know possesses. This study used the coordinated management of meaning (CMM) to approach this study; in particular the DICA model advanced by Pearce (2007), which moves through a process of description, interpretation, critique, and action was used in study design. Six research questions were developed that roughly correspond to the DICA model. This study used a grounded approach to data collection and analysis: data were collected in two stages that built upon each other. The first stage was a recruitment stage; used to inform individuals about the study and invite them to participate in the second stage: in-depth interviews. Two hundred thirty individuals took part in the recruitment phase of research, 24 individuals took part in in-depth interviews. Methods of grounded theory were used to analyze interview data, this included a circular three-step process of analysis: open coding, integration, and dimensionalization. Twenty-one themes and 25 related subthemes emerged to reveal the patterned nature of health-related stigma. Findings are presented in five context areas—description, meaning, interpretation, action, and stigma.

These context areas correspond to the DICA model and the six research questions. The major findings of this study were the patterned nature of health-related stigma, and further that these patterns can be interrupted and reconstructed in a way that reframes negative experiences and promotes a more positive perspective for approaching issues of health-related stigma.

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CHAPTER ONE: INTRODUCTION

"A stigma is defined as a socialized, simplified, standardized image of the disgrace of a particular social group" (Smith, 2012, p. 258). According to Goffman (1963), a stigmatized person is to be avoided, particularly in public places. He continued that stigmas result in a person feeling discriminated or dehumanized. Weiss and Ramakrishna (2004) aptly described health-related stigmas as an addition to the "burden of illness" (p. 3), meaning that living with a stigmatized condition may produce additional stressors of social pressure that can make caring for oneself more difficult.

The construct of stigma can be attached to a number of health issues such as cancer, obesity, sexually transmitted disease, or various mental illnesses (Lupton, 2000; Smith, 2011; Weiss & Ramakrisha, 2004; 2006). For example, if one has cancer they may be stigmatized as an individual who did it to her or himself because of overexposure or overindulgence to or in food, sun, or cigarette smoking (Lupton, 2000). Similarly, someone who is obese may be stigmatized as an individual who cannot control their eating. HIV is often linked to traditionally "immoral" behaviors such as men who have sex with men or intravenous drug users (Lupton, 2000). While, seeking mental health treatment or counseling can be linked to having a mental deficiency and an inability to contribute to society, or that the individual is somehow responsible for their mental condition (Romer & Bock, 2008).

The World Health Organization (WHO) identified health-related stigmas as one of the leading individual barriers to accessing health care worldwide (Smith, 2011). Evidently, stigma is related to physical and mental health outcomes. Often the mental stress of stigma can compound the effects of living with a stigmatized condition. It is

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strongly correlated with self-esteem, depression, and stress (Link & Phelan, 2006; Link, Stuening, Neese-Todd, Asmussen, & Phelan, 2002; Romer & Bock, 2008). In addition to limiting an individual's agency to seek care, stigma can limit other aspects of life quality such as employment, housing, social capital, and the like (Link & Phelan, 2006).

Defining the Problem

Stigma is something that I believe that many of us struggle with, in particular health-related stigma. The conversation about stigma is primarily related to issues of wellness and quality of life. It is a part of a greater narrative of stigma that I have seen my friends and family negotiate instances of as the stigmatizer and the stigmatized, sometimes successfully and other times unsuccessfully. I am particularly interested in exploring instances of health-related stigma as this aligns with my personal and research experiences. This includes personal instances such as friends and family living with diabetes or seeking mental health care in addition to working with HIV communities. These experiences have influenced me to pursue research that aims at improving quality of life through communication. Further, I agree with the WHO (1954) definition of health that defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." (n.p.). In turn, I believe this is a topic of great importance to the betterment of society as a whole and what is being made through our everyday interactions. This being said, the communication problem is to examine how health-related social stigmas are constructed in society in order to (re)construct them in a more positive and productive manner.

The study of health-related stigmas and the conversations it initiates can have a tremendous impact on our physical and mental health, and one's sense of self and

identity. Also, I believe that deconstructing and further challenging stigma can create

openings for communicating about stigmatized conditions to combat taboo topics and

create an atmosphere of support where individuals feel free to discuss topics that are

traditionally stigmatized.

Similarly, challenging stigma and discussing stigmatized conditions would foster

social worlds where individuals might feel more comfortable seeking health care, such as

routine check-ups, follow-ups, and in particular, recommended health screenings. For

example, many people do not get tested for sexually transmitted infections, cancer, or

other treatable illnesses because they fear the outcome, are afraid of being seen at the

testing center or lab, and/or fear the stigma that is attached to the action of seeking health

care (Lupton, 2000; Smith, 2011; Weiss & Ramakrishna, 2004; 2006). An integral part of

this conversation is the discourses that (re)produce health-related stigma in society (Link

et al., 2002), such as unfavorable jokes, uninformed comments, and media portrayals of

mental illness (Wahl, 1999). Productive interpersonal conversations about health-related

stigma and how to manage those stigmas could lead to better mental and physical health

outcomes.

Thus, the purpose of this study is to examine what occurs in negative and positive

instances of health-related stigma in an effort to understand the processes of health-

related stigma to learn how negative instances can be improved. These instances are

defined as communication episodes, which is a concept from the theoretical framework

of the coordinated management of meaning (CMM) (Pearce & Cronen, 1980) that guides

this study. An episode of communication is a series of communicative acts that send a

message, defined as speech acts, within a period of time that is marked with a beginning

and an end. Episodes of communication are linked together in a way that creates a narrative for the social actors involved (Pearce, 2007).

An example of an episode within the context of health is an appointment with a medical provider—for example, an individual who receives massage therapy regularly may become acquainted with the process and the narrative that develops out of those interactions. The episode begins as the patient enters the massage therapists' office. Initially, the patient and provider may discuss the reason the individual is seeking massage therapy, and if there are particular areas that need to be addressed, then the massage therapist leaves and allows the patient to prepare for their massage. This is followed by a predetermined amount of massage; after the massage is completed there may be discussion about the effect of the massage and when to schedule the next appointment, which marks the end of the episode. As the patient continues to see the massage therapist a narrative about their relationship develops and both become familiar with the sequence of speech acts within their episodes. The massage therapist may become familiar with the patients' areas of tension, while the patient becomes familiar with the massage therapists' massage style and strengths. As members of society we learn to manage episodes of communication by learning the appropriate speech acts within different kinds of episodes (Pearce, 2007), we learn this system of behavior through the socialization process. Now that the definition of communication episodes has been established, the next section provides the thesis of this study.

This study examines communication episodes of health-related stigma in a way that considers the various facets that contribute to health stigma experiences. This approach to the study of health-related stigmas developed a fuller deconstruct those

stigma experiences. The research questions and methods for this project are guided by the four-phase sequence advanced by Pearce (2007) for using the coordinated management of meaning. The four phases are: description, interpretation, critical questions, and action. These four-phases move through a progression that moves from broad to specific. The theoretical framework of the coordinated management of meaning, and further the four-stage process, were used in every aspect of this study from design to analysis. Research questions for this study, as detailed in Chapter 2, were designed with this four-phase process in mind. Similarly these four-phases were used in the data analysis process detailed in Chapter 3 and as the structure for presenting findings in Chapter 4. The following section outlines assumptions theory and research used in the creation of this project.

Assumptions

These assumptions inform the background literature that is presented in this study as well as the direction of the research. The first philosophical assumption that must be addressed is epistemology, or how knowledge is produced. I believe that knowledge is socially constructed. That is that knowledge is produced through interaction with artifacts and interpersonal relationships, which are set within context. Thus, knowledge is produced through social experiences and interactions with the others. It makes sense that both the ontological and epistemological assumptions take the social constructionist perspective since the two depend on each other as outlined by Anderson and Baym (2004). The dependent relationship of ontology and epistemology means that knowledge cannot be produced without first understanding the nature of its existence.

As knowledge is socially constructed so are our social worlds. There are multiple social worlds that exist and these can be uncovered through multiple forms of inquiry. Further the theoretical framework of the coordinated management of meaning, which is essential to this study, promotes the ideal that there are an unlimited number of social worlds that exist and they are continually being constructed and re-constructed through interaction (Pearce, 2007). Similarly, the concept of stigma is constructed through social interaction. Stigma is often seen in conjunction with the word social, which emphasizes that stigma is a product of social interaction. As it is a product of social interaction, this means that negative stigma can be improved through interaction and engagement that aims at improving social worlds. This study is the first step in that direction.

The following set of assumptions deal with human nature and experience. Essential to this project is the assumption that health and communication are both vital aspects of the human experience (Wright, Sparks, & O'Hair, 2008; 2013). Our health is important because it is so tied to our experience of life and death, and it affects the way individuals move through the world and essential human experiences. While, communication is present within every aspect of life as the processing of information, utterance, text, the understanding and misunderstanding that derives from any communicative activity.

Finally, this study advances three assumptions about health-related stigma: (a) the concept of stigma and experiences within are complex and cannot be explained simply, which is why it is one of the leading barriers to care as identified by the World Health Organization; (b) stigma is constructed differently for the individual or community based on their values, beliefs, customs, and norms; (c) while stigma is prevalent in other

disciplines it is primarily a communicative concept because it is dependent on interpersonal interaction and is in turn created through communication (Smith, 2007; 2009; 2011). That is, stigma is directly related to symbol using, meaning making, and the primary defining characteristics of communication. These assumptions are important for understanding how this study was conceived, and how each step of the dissertation process will be approached. The next chapter provides a review of literature and theories that are relevant to this study.

Finally, an assumption about research, I believe that research is a tool that can help us as researchers, to better understand our social worlds. Although, I believe that sometimes it would be somewhat easier to approach each research problem in the simplest way possible, I think that it would be an injustice as researchers to both society and ourselves. Instead, I agree with Feilzer (2010) when she discussed the complexity and messiness of research as a way to understand our social worlds. Research and research methods are complex and sometimes messy, but I believe that this is the only way that research should be approached; it is a combination of trial and error, quantitative, qualitative, and an engagement of the senses. The following section provides a brief overview of the rest of the study.

Preview of the Study

This study develops in five chapters. The first chapter, this chapter, introduced the research problem and the purpose for this study. The second chapter reviews the theoretical grounding and relevant background literature that guide this study. From there, the third chapter details the research methods used for co-producing and analyzing data. The fourth chapter presents findings of the present study. And the fifth, and final,

chapter provides a discussion of the findings their implications, future research,

limitations and concludes the study.

CHAPTER TWO: LITERATURE REVIEW

This literature review outlines the most important elements that provide the context for this dissertation. The study aims to explore communication episodes of health-related stigma in an effort to better understand what occurs in these complex interactions. This inquiry into health-related stigmas is guided by the theoretical framework of the coordinated management of meaning (CMM). CMM provides a rich framework for engaging with health-related stigma that examines what is being created through communication. This chapter develops the argument for the study of health-related stigma using the lens of CMM in two major sections: the first provides the theories that guide this work, including communication and health, social approaches, the framework that guides this study, CMM, and cultural context. The second section reviews extant literature that establishes the need to study health-related stigma. This includes dimensions of stigma and its implications. These two sections then lead into the rationale and research questions for this study. Literature begins with the grounding of this study within communication and more specifically, health communication.

Theoretical Grounding

This section includes four parts that build upon each other to provide theoretical context for this study. The social approaches used in this study provide a unique perspective to unpack experiences of health-related stigma in a way that honors the complex communicative system in which these experiences occur.

Communication and Health

Because this is a communication study, it is important first to situate this study within the discipline of communication. The discipline of human communication is

widely understood as the act of symbol using and meaning making within the world. However, several definitions of communication may be used from the simple transmission model to the communication complex (Parrish-Sprowl, 2013). As knowledge and nuanced understanding of communication grows, so does the field. Craig (1999) organized communication theory into seven traditions. These traditions exemplify the set of dynamic approaches and concepts that contribute to the study of human communication. Of those seven traditions, this study aligns most closely with the cybernetic tradition of communication, which is the study of complex systems that examines the flow and feedback of communication (Craig, 1999; Littlejohn, 2009). Accordingly, this study uses the following definition of communication: "a symbolic process whereby reality is produced, maintained, repaired, and transformed" (Carey, 1975). This definition of communication recognizes the complex processes that contribute to communication.

Craig's framework helped to unify the field of communication; further, the distinction of the seven traditions helped to establish the contexts that can communication be studied in, such as media, interpersonal, health, intercultural, etc. This study is situated primarily within the subdiscipline of health communication. Health is just one of many contexts in which communication can be studied. This subdiscipline provides several avenues of inquiry for communication scholars that draw from the seven traditions of communication theory as well as from a variety of health communication problems. Study examples include examining patient-provider communication, illness identity construction and narrative, and health organization assessments.

Health communication, the study of communication within the context of health, features characteristics that set it apart from other subdisciplines of communication. First, health communication is pragmatic (Kreps, 2011); it works toward practical goals aimed at improving health outcomes of individuals and communities. Because the subdiscipline of health communication is pragmatic, it is inherently applied and engaged (Kreps, 2011). Scholars in health communication often are engaged in empirical research that connects them with individuals and communities. These engagements are integral to learning about health experiences and in turn to producing research that can improve health outcomes.

Further, health communication promotes advocacy on behalf of marginalized populations that traditionally have poorer health outcomes. Advocacy for these populations promotes change in those communities and in turn tries to promote a sense of agency. Finally, health communication can be interdisciplinary (Parrott & Kreuter, 2011); health communication scholars have the opportunity to work with others outside of their field, such as health education, public health, or a variety of professions within the medical field among others, to examine problems of health communication that need to be addressed in a given context. Interdisciplinary engagement teaches us to appreciate perspectives different from our own, and it can teach us novel ways of approaching a research problem. Communication scholars provide a special perspective that emphasizes the importance of what is being made through communication.

While communication scholars can take many approaches when examining problems of health communication, this study employs social approaches to inquiry. The term social approaches is used to encompass a variety of approaches to the study of our social worlds that incorporates the greater system of social and cultural influences that

contribute to what is constructed in social worlds (Craig, 1995; Leeds-Hurwitz, 1995). The next section provides an outline of the social approaches used in the conceptualization of this study, including social construction, language choices, and the communication perspective and its importance.

Social Approaches

Social approaches provide a framework for interpretivist study. These approaches to research are under a plural label, as all social approaches to research are not the same, and each provides a varied stance to this type of study (Leeds-Hurwitz, 1995). For example, while two theorists may both use a social approach to research their approaches may have areas of disagreement. This section grounds the present study in social approaches to research; these approaches provide the structure for the inquiry into health-related stigmas in this study. This section develops with an explication of social constructionist theory, then language and language choices, and finally the communication perspective, which leads into the next section of CMM.

The theory of social construction provides a framework for understanding and assigning meaning to communication and the nature of knowledge. Within this theory, knowledge develops through communal interchange; thus, inquiry within social construction investigates the social processes that individuals use to arrive at their knowledge of their social world (Gergen, 1982; Gergen & Gergen, 2003). This includes an examination of significant social artifacts, relationships, and the meaning that is made within. The knowledge that one has of their social world creates negotiated interaction that shifts as individuals interact and engage with the other.

All constructions are relational or social in nature (Berger & Luckmann, 1967; Gergen, 1982; Gergen & Gergen, 2003); our realities are constructed through a combination of social artifacts and interaction with the other (Berger & Luckmann, 1967). Traditionally, interactions with the other are understood as interpersonal interactions with others that one might engage with such as family, friends, providers, or even someone in line at the grocery. Contemporary definitions of the other have been expanded to include nonhuman others such as nature (Walker, 2007) or illness (Charon, 2009). Both interpersonal interaction and interaction with mental and/or physical health conditions are of particular importance to this study.

Important to social construction is the notion that concepts can evolve, develop, and be discarded. The degree to which a concept is sustained over time is dependent on the social processes that negotiate and constitute it (Gergen, 1982; Gergen & Gergen, 2003). That is, socially constructed concepts are constructed to be useful for explaining social and cultural experiences. For example, the concept of a *teenager* is a relatively new concept that developed out of a need to define the burgeoning period between childhood and adulthood that began in the 20th century.

Similarly, stigma is seen as a socially constructed concept that is continually evolving. Smith (2007) discussed the etymology of the word stigma; it was first a term used by Ancient Greeks to describe the process of tattooing. Ancient Greeks used marks on the skin to identify a person as deviant. For example, slaves, criminals and prisoners were physically marked so they could be identified if they tried to escape. Today stigmas are perceived as assigned marks of devaluation that are seen and unseen (Smith, 2007).

Close to social construction is the construction of language and language choices. Using a constitutive view of language, language and language choices are understood as the way that reality is constructed. This means that individual social actors cannot live outside of their knowledge of language, and their experiences and choices influence their later experiences and perceptions. For example, some people may refer to diabetes as "sugars" because they understand diabetes as a problem with their sugar as opposed to the clinical definition. Language is highly meaningful: The phrases and words one chooses can hold both connotation and denotation that directly relate to the overall meaning of language (Littlejohn, 2009). The denotation refers to the dictionary, or precise, definition of a word. The connotation refers to the thoughts, feelings, or emotions that can be attached to a word. It is important as a researcher to understand these critical differences and to delve into language choices (Littlejohn, 2009). The word retarded is a good example of this. The denotation of retarded is something or someone slow making progress, while the connotation most often refers to a person who is acting what is deemed as "stupid" or "dumb." Denotations and connotations can be impactful—some words are more loaded than others—a command of language can create better social worlds. In particular, language and language choices can construct what is being communicated through one's resources or vernacular. These can either be negative or positive depending on the word choices. But, communication is not limited to symbols such as words. Theoretical grounding now moves into a richer understanding of the field of communication and the communication perspective.

Watzlawick, Beavin, and Jackson (1967) advanced five tentative axioms of communication for social approaches to communication. These axioms discuss inherent

properties of communication. These axioms are the impossibility of not communicating, the content and relationship levels of communication, the punctuation of the sequence of events, digital and analogic communication, and symmetrical and complementary interaction. The axioms emphasize pragmatic approaches to communication, the individual does not solely communicate; rather the individual is a part of a greater system of communication that is co-constructed through action and interaction (Watzlawick, Beavin, & Jackson, 1967). The communication axiom that discusses the impossibility of not communicating exemplifies this concept. That is that one cannot, not communicate. Simply, despite efforts on behalf of the individual social actor, messages are still communicated from one individual to the other. For example, if an individual chose to not speak to another person in the same room, this might communicate messages of dislike or shyness on behalf of that person. Every action and interaction, whether a direct message is transmitted, has communicative value.

This axiom furthers the point that communication is one of the most vital of human experiences (as pointed out by Wright, O'Hair, & Sparks, 2008; 2013). Communication is in everything we do as humans and cannot be avoided. It is important to understand the gravity of communication and the study of it. The communication perspective promotes communication as the focal point of activity—that is, that meaning assigned to acts is constructed through communication (Pearce, 2007). Other disciplines may view communication as a mediator to another activity. Taking the communication perspective is a reflexive practice—that considers contributions of the self—that moves through a process constructing and (re)constructing social worlds through communicative acts. Just as one can take a political or religious perspective on an issue, communicative

acts are the focal point within the communication perspective (Pearce, 2007). In their

work, Communication, Action, and Meaning, Pearce and Cronen (1980) stated:

> Whatever the other ambiguities of the new key, communication has become a
>
> focal point rather than an ancillary concern. All forms of communication,
>
> particularly those that appear the most quotidian and mundane are now seen as the
>
> focus of powerful forces that affect development of the self, of social institutions,
>
> of knowledge of external reality, of other mind, and of human philosophy itself.
>
> Consistent with this new perspective, persons are seen as living within a world of
>
> symbolic meanings . . . These symbolic meanings are negotiated and exchanged
>
> by persons through communication. The study of communication thus becomes
>
> an inquiry into the nature and origin of the world in which persons live (p. 14).

In this perspective, communication is seen as both object and theory, and therefore there

is a recursive relationship between communication, social realities, and the meaning that

is made within (Pearce & Cronen, 1980). Social worlds in which these meanings are

exchanged construct the narrative in which lives are lived. In the process of construction

and (re)construction, all communication acts are contextualized and are a part of a greater

narrative; every act is set within context and in turn provides context for later acts

(Pearce, 1989). The individual is part of a larger body—our social worlds are narratives

that contribute to the context of the entire story (Pearce, 1989). For example, the

classroom is a social world in which the teacher and students contribute their narratives to

constructing the social world of the classroom. The communication perspective promotes

dynamism and the evolution of social worlds (Pearce & Cronen, 1980).

Understanding the communication perspective provides context for the theoretical framework of coordinated management of meaning (CMM) developed by Pearce and Cronen (Littlejohn & Foss, 2005), which provides the structure for the study of health-related stigmas in this study. The following section provides an overview of CMM and its use in previous studies.

Coordinated Management of Meaning

CMM is a practical theory that developed as a way to approach the study of phenomena through the communication perspective, specifically examining what is *made* through communication. Examining what is made through communication—for example, communication choices of action and interaction—in turn provides direction for how communication can be improved to in turn improve social worlds (Pearce, 1989; 2005; 2007). Pearce (2007) advanced that CMM is "naming and participating in the process of communication" (p. 79). What is important to note about CMM is that it is concerned primarily with making our social worlds better (Pearce, 1989; 2005; 2007) through practical engagement with people and ideas. This is consistent with the subdiscipline of health communication because both health communication and CMM promote pragmatism.

CMM is built on three core concepts: coordination, coherence, and mystery, which work interactively with one another in the communication process (Pearce, 2007). Coordination is the practice of interaction. This is the process of communicative acts between two parties that may occur in interactions, in particular how the two parties work together in a process of two-way communication (Pearce, 1989). Coherence then is the meaning made within the coordinated acts or how they are interpreted and influence

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action and later communication episodes. Coordination and coherence reflect upon one another so that changes in one can create changes in the other, the relationship between them is an important part of the theory (Pearce, 1989). The reflexive relationship between the two is also called a feedback loop (Pearce, 1989). Through engagement with social worlds where one learns the set of coordinated practices appropriate to the context by learning how acts work together and what responses certain coordinated acts will evoke. The third concept—mystery—emphasizes the inherent fallibility and incompleteness of an individual's social world, that factors contribute to every interaction that are not readily apparent, such as an individual's field of experience, which may include their past, culture, and/or personality (Pearce, 2007). The three aspects of CMM— coordination, coherence, and mystery— are what construct social worlds, and these social worlds   continually evolve as coordination, coherence, and mystery shift. Then, it is through the communicative acts that meaning is made and social worlds are constructed.

The theoretical framework of CMM advances several characteristics of communication that contribute to the construction of social worlds. These include speech acts, episodes, the self, and relationships (Pearce, 2007). Speech acts, as defined previously, are verbal or nonverbal acts of communication that convey a message such as agreement, dislike, insult, or compliment. They are the essential elements to constructing our social worlds (Pearce, 2007). Further, there are an unlimited number of speech acts that an individual can use in interaction (Pearce, 2007). One's ability to use and understand speech acts influences how one moves through the world and comprehends their interactions with others.

The next concept of CMM, of particular importance to this study, is the communication episode. These are sequences of interaction or speech acts that are punctuated with a beginning and an end. An example of an episode is an interaction between a patient and provider in a routine physical check-up. Individuals learn which speech acts are acceptable in communication episodes through a learning process that includes coordination, coherence, and mystery. Communication episodes linked together over time create larger narratives of experience (Pearce, 2007); thus, episodes provide context for one another. The meaning of a particular episode is understood within the context of a larger story evolving over time; earlier episodes provide context for later speech. As an individual engages in similar episodes of communication, one learns the best practices for engaging in that type of interaction.

In episodes of communication, an individual also constitutes a sense of self. Pearce (2007) outlined three epistemologies of self: the socialized self, self-authoring self, and self-transforming self. The socialized self internalizes and enacts values learned from their surroundings; this is the process of becoming "a member of the tribe" (p. 183). An example is learning which speech acts are culturally acceptable. The self-authoring self is an individual's interpretation of values, choosing which values are important and at the same time choosing which ones to ignore. And the self-transforming self is the self that evolves through a variety of forms of consciousness.

The last concept of CMM that is essential to this study is the relational aspect. Social worlds are constructed through relationships, one's interaction with the other. The relational process constructs are social worlds and the way that social worlds are understood. This is tangential to the epistemology of social construction.

CMM provides a framework for understanding interactional sequences and their meaning. Studies that use the CMM framework vary based on the needs of their individual study. For example, Montgomery (2010), Orbe and Camara (2010), and Bruss et al. (2006) use the CMM framework in their studies. However, each applied different aspects of it in their analyses. Montgomery (2010) used CMM to examine the differences between stories told and stories lived within middle-eastern refugee families where the father had been tortured. The authors used CMM to consider the multiple meanings made among the family members and the hierarchies of meaning that influence the family's recollection of the time.

Orbe and Camara (2010) conducted a study using the CMM framework to analyze episodes of discrimination in a variety of contexts. The analysis was part of a larger study that collected narratives from college students about instances of discrimination. Their 2010 study examined 957 participant narratives about discrimination. The authors used a hierarchy model of CMM that has six components: the content or language used, speech acts, contracts known as the rules (formal and informal) that individuals follow in interaction, episodes, life scripts or one's sense of identity, and the overall meaning derived from the interaction. Narratives about instances of discrimination were deconstructed into the components of the hierarchy of meaning and were used to understand and assign meaning to these interactions.

CMM provides several frameworks for the study of social interaction; this study employs the DICA model, which moves through a process of general description to specific action steps in a four-stage process that includes: description, interpretation, critique, and action (Pearce, 2007). In the description phase, the research intends to

provide an explanation of the problem. The purpose of this phase is to describe how the phenomenon currently exists in the world. As with everything, phenomena change and then must be described or re-described (Pearce, 2007). Therefore, the first step in this process is to provide a description of the present state of health-related stigma. The second phase is interpretation. This phase emphasizes the human characteristic of storytelling (Pearce, 2007); this phase allows for the entire story to be told and specifically what meaning is made in these interactions. In this study, the interpretation stage examines how individuals interpreted their experiences of health-related stigma, essentially the meaning made. The third phase is the critique stage. In this stage, the critical questions of "what are we making," "how are we making it," and "how can we make better social worlds" serve as guides to examine outcomes. The purpose of this phase is to develop connections between action and meaning, examining the ways individuals adjusted their behavior due to past experiences. The final stage is the stage of action or practice, in which actors apply what is learned in earlier stages to begin the process of change to improve social worlds.

This study is unique in the sense that it uses CMM as a tool to examine and unpack the complex processes of health-related stigma. This model provides a structure for examining health-related stigma that recognizes the inherent facets of health-related stigma. First, it provides a broad description of the state of health-related stigma, specifically to describe which mental and physical health conditions stigma is attached to, and further it identifies in what contexts are these interactions occurring. The next steps of interpretation and critique take a deeper look at those interactions and in the ways that those interactions have influenced the individual and the individual's behavior. Finally,

this study examines ways in which these instances of health-related stigma can be improved through action. The theoretical framework of CMM allows for health-related stigma to be examined in a way that deconstructs the experience of an individual living with a stigmatized health condition. CMM also considers cultural implications as people act in communication patterns based on their culture (Pearce, 2007). The next section provides a broad definition of culture.

Cultural Context

Several scholars have advanced definitions of culture. These definitions cover a spectrum of perspectives. This study will use the following definition of culture: "a learned system of meaning that fosters a particular sense of shared identity-hood and community-hood among its group members. It is a complex frame of reference that consists of a pattern of traditions, beliefs, values, norms, symbols, and meanings that are shared to varying degrees by interacting members of an identity group" (Ting-Toomey & Takai, 2006, p. 691). Culture provides the reference through which individuals understand and experience their social worlds (Oetzel, 2009). Further, culture is co-constructed through social interaction.

One theory predominant in health communication is the culture-centered approach (Dutta, 2008). This approach to health communication research emphasizes culture as the frame through which individuals understand health and illness. In this theory, culture is understood as the local interpretation of health based on the values, beliefs, and practices held by the local social actors. It is influenced by tradition and by current trends or structures. Local health culture is produced by individuals' day-to-day health and illness interactions. The culture-centered approach examines the interaction of

culture, structures, and agency and how these key constructs gain meaning from each other and influence individual and community health experiences. For example, Archiopoli (2010) examined older adults perceptions of falls to consider how the culture created in their community influenced their interactions with structures such as senior centers and health centers as well as the agency enacted within those structures.

Understanding the cultural frames through which individuals assign stigma and act upon stigma will lend to the ability to further understand which variables influence stigma and how these may vary culturally. Specifically, this calls attention to the fact that some health conditions may be considered more stigmatizing than others in different cultural groups.

The second part of this chapter provides relevant background literature that was essential to the development of this study, the literature presented here outlines stigma, its implications, and related concepts.

Understanding Health-Related Stigma

The previous section outlined the theoretical underpinnings of social approaches and social construction; this section develops in three major parts: stigma, social construction, and communication; dimensions of stigma; and implications of stigma. The first section examines stigma as a social construction and how stigma is constituted through communication. The second section outlines the dimensions of stigma, including characteristics of stigma, the individual's relationship with stigma, and the types of stigma that one can experience. The third section explores implications of stigma, including othering, identity and stigma, and health outcomes, respectively. The review begins with the relatedness of stigma, social construction, and communication.

Stigma, Social Construction, and Communication

At the outset of this paper, it was advanced that stigma is primarily a communicative concept. This section furthers that assumption by providing support for the argument. Stigma and communication are intrinsically linked. Stigmas are a social construction, and every way stigma is created, maintained, and communicated is done so socially (Smith, 2007; 2009; 2011). The following definition of stigma, advanced by Weiss and Ramakrishna (2004), is used as the conceptual definition of stigma within this study:

> Stigma is typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group. This judgment is based on an enduring feature of identity conferred by a health problem or health-related condition, and the judgment is in some essential way medically unwarranted. In addition to its application to persons or a group, the discriminatory social judgment may also be applied to disease or designated health problem itself with repercussions in social and health policy. Other forms of stigma, which result from adverse social judgments about enduring features of identity apart from health-related conditions (e.g., race, ethnicity, sexual preferences), may also affect health; these are also matters of interest that concern questions of health-related stigma. (p. 13)

Stigma is socially constructed through interaction with "the other" when discrediting characteristics are communicated from one person to the other where a person is made to feel rejected or categorized as less than. As Falk (2001) stated, then stigma is constructed

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within "the eye of the beholder" (p. 24) and is not necessarily linked to quality of the individual. He also said that stigma is constructed by the persons making internal or external judgments on the stigmatized condition. Thus, problems with stigmas are found primarily within social interactions (Weiss & Ramakrishna, 2004). That is, one encounters a communication episode of stigma within interpersonal interaction, such as with one's family, friends, co-workers, or health care provider.

Adding to the socially constructed nature of stigma, it can be considered a temporal quality. That is, a condition that once was stigmatized can lose the stigma attached to it. To exemplify this, Falk (2001) described the processes of stigmatizing unmarried mothers, which is a quality that previously had been stigmatized that is no longer considered a point of devaluation. Similarly, in her (2012) study, Smith found that some stigmas may be shifting, for example she found that the stigma attached to homosexuality may be dissipating.

Additionally, stigma might change based on the social or cultural context that interpersonal interactions are set within; this also may affect the way that stigma is performed (Weiss & Ramakrishna, 2004). For example, seeking mental health services may be more stigmatized in some cultural groups than in others. Depending on one's social or cultural context, stigmatizing might be direct, such as teasing the person, or indirect, such as isolating or ignoring the person.

The possession of a stigmatized condition can be communicated through visual cues; that is, an individual can be visually identified or through disclosure of information about the individual if the individual is a member of a stigmatized group. This can be disclosed either by the individual or others who have knowledge of the person. "Stigma

communication, then is the messages spread through communities to teach their members to recognize the disgraced (i.e., recognizing stigmata) and to react accordingly" (Smith, 2007, p. 464).

This section explained the interrelatedness of social construction, communication, and stigma, that is, stigma is socially constructed through communication. The following section outlines dimensions of stigma and moves the evolution of stigma theory to provide background for the conceptual definition and how stigma is understood within this study.

Dimensions of Stigma

Stigma is wrought with complexity, meaning, and interpretation. Current literature advances several models of stigma. Phelan and Link (2006) provided a five-component approach to understanding stigma. First, they assumed that human experiences are varied and can dramatically affect one's stigma experience. Second, they found that stigmatized individuals are stereotyped to hold certain characteristics. Third, they found that distinctions are made between the in-group and the out-group, those who are inside or outside of the stigmatized group. Fourth, they found that victims of stigmatization are likely to experience a loss of status or be on the fringes of society. Finally, they determined that stigmatization cannot take place without the presence of power dynamics. This model provides a picture of stigma, however, this section serves to explore provide a fuller description of stigma describing additional literature that contributes to a fuller understanding of stigma and situates it at as a communicative concept. This includes three aspects of stigma: dimensions of stigma, varying relationships with stigma, and types of stigma.

Characteristics of stigma. The first characteristic of stigma is the content cues that are used as points of reference to perpetuate stigma. Smith (2007; 2009; 2011) outlined four types of content cues of stigma communication that are used to quickly identify a stigmatized group and further engage in stigmatizing practices that are somehow justified by stigmatization. The first content cue is the "mark." This is the most overt way an individual may be identified as having a stigmatized condition. This is a visual representation that allows others outside of the stigmatized group to see and reject persons from that group based on visual cues. An example of this may be an individual who is visually recognized as obese; their condition is marked on their body. The next content cue is a label or name given to a stigmatized group. This may include a name that is ascribed based on the clinical definition of their disease, such as "those epileptics." The next content cue of stigma is the responsibility. Those outside of the stigmatized group may believe that an individual within the stigmatized group is responsible for their diagnosis and that they somehow failed in a way that brought their diagnosis upon herself or himself; an example of this is someone with diabetes. Smith's content cue of stigma communication is peril, or the peril that an individual brings to the community based on their diagnosis; for example, many people fear people with tuberculosis for this reason. Smith calls for action that purges these cues, uses social support and mobilization cues, and is mindful of unintentional consequences of stigma (Smith, 2011).

An additional dimension of stigma is that it often is confounded with related concepts. For example, health-related stigma is coupled with other factors of marginalization, such as socioeconomic factors, ethnicity, sexual orientation, and other characteristics that can contribute to the disadvantage of an individual (Weiss &

Ramakrishma, 2004). This also might indicate why stigma so often is confounded with other concepts, such as prejudice, discrimination, or stereotyping. Phelan, Link, and Dovidio (2008) provided a distinction between stigma and prejudice. They found that prejudice is related to the human characteristic of race, while stigma develops as a result of what can be considered deviant behavior or identities and diseases or disabilities an individual may possess. Crandall and Cohen (1994) believed that stereotyping, prejudice, and discrimination may confound stigma experiences. The definition they used to define stigma more generally categorized the individual as "different" and less desirable than others, and the individual is a part of the outgroup. The next section outlines the varying relationships that one can have with stigma.

Relationships with stigma. The second dimension of stigma is the type of relationship or orientation that one can have with stigma. This can be a direct or a periphery relationship. Goffman (1963) provided a classification scheme of stigma, which includes the own, the wise, and the normals. This scheme provides a framework for understanding one's relationship with stigma. Members of the own group are individuals who are a part of a stigmatized group. The normals are individuals who see their own population as "others" and engage in stigmatizing communicative acts that create social distance between them and the perceived devalued group. Phelan and Link use the terms in-group and out-group to describe the same concept. The third classification is the wise, who are individuals who are not members of the stigmatized group but are wise enough to understand the experiences of the individuals in the stigmatized group and thus are sympathetic and supportive. Classifications are a social process; belonging to a certain classification varies with an individuals' field of

experience, which includes their interpersonal interactions and similarities they may have with the stigmatized group.

Smith (2012) conducted a study to extend Goffman's classes of stigmatization. She used an empirical test that examined the classifications of own, wise, and normals. Through her analysis, she found four classes of stigmatization: own, normals, wise-active, and wise-passive. In particular, she expanded upon the category of the wise to include two types: active and passive. The wise-active are individuals who support stigmatized groups by advocating education and challenging perceptions about the illness, while the wise-passive sympathize with the own group but do not actively support the group through direct action. The wise-active supporters play a key role in the mitigation of stigma through their social support for members of the own group as well as play a key role in providing education to members of the normal group that may convert them to be a member of the wise group (either passive or active). Finding the two levels of supporters lends itself to the complexity of the situation and of the gradient within stigmatization.

Individuals of the wise group also may be co-owners of a stigmatized condition. When a stigmatized individual shares information about their condition with another individual, the two become co-owners of the information, and thus the unlabeled person might encourage the labeled person to act in a way that is closer to their own values because then they mutually own the information (Smith & Hipper, 2010). Smith and Hipper (2010) conducted a study to understand the coping strategies that unlabeled individuals use to encourage their labeled loved ones to adopt. In particular, personal relevance—the relation to one's self—was found to have a positive correlation with the

communication coping strategy of withdrawal. The authors believe this can be explained either by the unlabeled persons awareness of the social devaluation that may occur with the co-ownership of their confidant's condition, or it can be related to the unlabeled person's concern for managing the information and avoiding public shaming.

Smith and Hipper (2010) also found that weaker relationships—such as classmates—might open the labeled individual to greater levels of stigmatization while disclosure in more well-developed relationships may create a greater sense of co-ownership, which then is related to a greater role that the unlabeled co-owner might want to play in the disclosure/coping strategy decision-making process. Finally, the authors found that unlabeled individuals with previous experience with the labeled condition have a different perspective to co-ownership of the condition. Smith and Hipper (2010) also pointed out that emotions are left out of current models of how individuals react to labeled conditions. Emotions can take the dimensions of shame, guilt, or pride. The form they take is dependent on the condition and how that reflects on the labeled. Link et al. (2002) identified that feelings of being misunderstood or being different or ashamed are related to stigma. Now that the dimensions of characteristics of stigma and relationship with stigma have been established, the following section outlines the types of stigma that one might experience.

Types of stigma. The third dimension of stigma is the type of stigma that may be produced, Falk (2001) distinguished between two types of stigma, defined as existential stigma and achieved stigma. Existential stigma is defined as one that the individual being stigmatized has little control over, such as, homosexuality, the mentally handicapped, and older adults. These conditions are inherent to one's being. Achieved stigma has been

"earned" by some action; examples include the homeless, drug and alcohol addicts, and criminals. Another type of stigma that one might experience is stigma by association. Stigma may attach to individuals who do not possess the stigmatizing condition but have a connection. For example, Rintimaki and Weaver (2008) found that homosexuals and drug users carry the stigma of HIV even if they do not carry the disease. Similarly, Smith and Hipper (2010) stated that individuals who educate others about stigmatized conditions risk experiencing the same stigma even though they may not carry the condition.

Stigma also can be internal or external. External stigma is stigma that an individual feels when interacting with others, such as family, friends, peers, instructors, or providers. For example, an individual might feel bullied in the classroom for their learning disability or one might feel blamed by their provider for seeking STD testing. To be considered external stigma, one must have had an interaction with another person who produced the feeling of stigma. Internal stigma is defined as the distress produced from the anticipation or possibility of external stigma. Internal stigma often is not experienced; it lies in the potential of what may happen (Quinn & Chaundoir, 2009) Living with a concealable stigmatized identity such as mental illness, HIV, or alcohol addiction are examples of health conditions that may produce internalized sigma (Quinn & Chaundoir, 2009). The stigma one feels from anticipated interactions can have the same effect as an actual interaction on the individual (Goffman, 1963; Weiss & Ramakrishna, 2004). Additionally, Quinn and Chaundoir (2009) examined personal stigma and associative stigma; they found that both have the same effect on an individual.

Implications of Stigma

The previous section examined dimensions of stigma that were used to examine the current understanding of stigma through its dimensions, the relationship one can have with stigma and the type of stigma experienced. This section explores the negative impact one may experience living with a stigmatized condition in society. This includes othering, stigma and identity, and stigma and health outcomes. The concept is one of othering.

Othering. Within human communication, the concept of othering was born out of feminist research. This is the act of making others feel less than and (re)produces dominant and subordinate relationships (Johnson et al., 2004). Laws also may (re)produce this dominant discourse of stigmatizing (Burris, 2006). Othering objectifies individuals at the same time it dehumanizes them and does not recognize their complex set of human emotions. This process creates distance between the stigmatized group and the stigmatizers (Johnson et al., 2004). Shapiro (2008) determined that othering is used as a coping mechanism for dealing with the vulnerability of the human condition. She also found that recognizing the subjectivity within the social interaction can help the interpersonal interaction.

Van Breda (2012) developed a model of othering through research about othering of people living with HIV in southern Africa. The author developed a model of other where othering is the center point; emotions, theology, and lack of knowledge contribute to othering; and disengagement and prejudice are products of othering. Distancing, disconnection, and lack of empathic contact were identified as dimensions of othering.

Othering is an especially important concept related to instances of health. For example, Archiopoli (2010), when discussing falls prevention with older adults, found

that in general they believed falls happen to "other" people and that they are not at risk of falling. This is an instance of blame-shifting; that is, taking the blame off of oneself and applying it to an abstract other. Individuals who are aware of the negative attitude reflected on them from the generalized other then can then internalize that negative attitude, and it may become a part of their self-concept (Crocker & Major, 1989). With stigma and othering, cultural aspects may influence interactions. Studies have identified the relationship between stigma and othering (Van Breda, 2012). Considering the complex set of concepts that contributes to stigma, it can have a great effect on an individual's sense of identity. The next section explores how identity can be constructed through stigma.

Identity and stigma. Another construct that is central to this project is identity. It is the reflection of values from our family, gender, culture, ethnic, and individual socialization process that formulate the self (Ting-Toomey, 2005). Social identities are the characteristics of the individual, such as cultural/ethnic/racial group membership, gender, sexual orientation, social class, age, disability, and profession. Personal identities are the characteristics that are specific to the self that others within social identity groups often do not share. Identity, like stigma, is developed through interaction with others (Ting-Toomey, 2005).

Interpersonal interaction has a great influence on the way individuals construct their identities. Cline (2011) emphasized the importance of interpersonal communication and how everyday interactions contribute to the overall health experience and the individual sense of self. She advanced several tenets of communication that should be considered when examining the health experience. First, she believes that social reality

and social norms, which are socially constructed, are the basis for interaction. The behaviors are then intersubjective and contribute to a construction and (re)construction of our social worlds. Second, she believes in the centrality of language, or that language that surrounds a particular disease can help to frame the illness and assign meaning. Finally, the meanings assigned to words and illness guide human action. Research indicates that the traditional age of college students, late teens to early 20s, is the most critical time for identity negotiation (Nurmi, 2004). It is during this life stage, known as emerging adulthood (Arnett, 2000), that individuals begin to negotiate processes such as engaging in diversity, developing and refining critical thinking, and decision-making skills (Arnett, 2000).

One identity that individuals may need to incorporate into their self is the stigmatized identity. Charon (2009) asserted that an individual's experience with illness helps to construct a sense of identity and self. That is, identity and self are constructed through the process of learning about illness. Both internal and external stigma can affect the identity of an individual (Goffman, 1963). For example, even if an individual chooses not to share a stigmatized condition with others, the anticipated stigma that is internalized by that person can be damaging to their identity (Goffman, 1963). Additionally, the effect that illness has on an individual is influenced by the centrality and salience of the stigmatized condition on an individual (Quinn & Chaundoir, 2009).

Daftary (2012) found that individuals living with both HIV and tuberculosis needed to manage the double diagnosis by creating a dual identity. Emphasis on the stigmatized condition can have negative effects on the stigmatized individual (Pinel, 1999). Individuals need to move beyond their stigmatized condition. One area of research

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that makes strides in this area is HIV research; in particular; it focuses on identity

negotiation with a stigmatized condition. Baumgartner and David (2009) conducted a

follow-up study of a previous study conducted by Baumgartner (2007). Both studies

examined the process of identity negotiation given an HIV positive status. The first study

was conducted with individuals diagnosed with HIV, before life extending medications

such as highly active retroviral (HAART), and the second study was conducted with

individuals after the life extending medications were introduced to examine the

differences in the post-diagnosis identity negotiation. The major difference they found is

that fewer steps were necessary to the process identity negotiation in the later study. In

the first study there were five steps in the identity negotiation process while there were

three found in the second study. The three steps of identity negotiation of the "poz"

identity—shorthand for being HIV positive adopted by some individuals—were:

diagnosis, post-diagnosis turning point, and integration.

The first step of identity integration was the initial diagnosis. For many, the

diagnosis period brought feelings of fear or denial. These reactions are typical. But at

some point, sooner for some than for others, there was the second stage of a post-

diagnosis turning point. This turning point could be due to several factors, such as

education, which helped to alleviate the fear; disclosure to others; and for some, the need

for medical intervention. After the turning point, the individuals' ability to get managed

care is the final step of identity integration. In this step, the individual was able to

integrate their positive status with the rest of their identity.

One important finding of this article is that the HIV identity is no longer the

dominant one. Instead, individuals living with HIV tend to identify with other identities

as well and do not let their HIV status dominate their life. This article is especially

important because it first shows the changing nature of HIV—that it no longer has to

dominate the individual like it did when individuals first were diagnosed. Additionally, in

the diagnosis stage, several aspects of stigma were identified as being relevant; of

importance to this study is that the post-diagnosis turning point can be encouraged

through education about HIV. The following section examines health-related stigma and

its impact on health outcomes.

Stigma and health outcomes. A relationship between stigma and health

outcomes has been well established in the literature. As noted in several studies, the

hidden burden of health-related stigma can be more impactful than the disease itself

(Rintimaki & Weaver, 2008; Weiss & Ramakrishna, 2004). The impact of health-related

stigma is an emotional one that is influenced by social and cultural meanings (Weiss &

Ramakrishna, 2004). It also has been found that the stigma one feels can be related to

their illness and/or to the treatment they must endure   to treat their illness (Holland,

Kelly, & Weinberger, 2010). For example, cancer patients might feel stigmatized with

their cancer diagnosis, and at the same time they also might need to manage the stigma

they endure by seeking mental health services to manage the complex set of emotions

they're experiencing alongside their cancer.

Stigma can affect both the psychological and physical health of an individual

(Holland et al., 2010; Quinn & Chaundoir, 2009). It previously was established that

stigma is one of the leading barriers to seeking health care. For example, Weiss and

Ramakrishna (2004) identified several diseases that are highly treatable if screened for

and treated early; they provide examples such as leprosy, tuberculosis, or mental health

disorders. If not treated early, each of those health conditions can deteriorate into worse conditions and symptoms. However, the stigma that is attached to those illnesses can prevent individuals from seeking the health care they need.

The literature on mental health stigma is voluminous. In particular, mental health stigma is strongly related to lower self-esteem and depression (Link et al., 2002). Wahl (1999) studied the stigma that actual consumers of mental health services experience. The study had two parts: a survey and that was followed by in-depth interviews. The survey asked about common experiences that consumers of mental health might encounter, such as interpersonal stigma, devaluation by others or the media, and societal discrimination they might encounter when seeking employment or a place to live. In total, 1,301 individuals took part in the survey, and 100 of those participants were randomly selected for an in-depth interview. The most common diagnoses in both samples were bipolar disorder, schizophrenia, and major depression.

The survey produced findings on stigma and discrimination experiences. The most-reported stigma experiences were related to witnessing stigmatizing comments about individuals with mental illness (78%) and negative depictions of mental illness in the media (77%). More than half of the participants (55%) indicated that they worry that their status as a consumer of mental health will be disclosed often or very often. Important findings about stigma discrimination: 8% of consumers indicated they had lied or concealed their mental illness in some of the instances the survey asked about; 32% of respondents reported being denied a job because they are a mental health consumer; and 32% had been denied health benefits because their mental health status was considered a pre-existing condition.

The interviews examined issues of the source of stigma, consequences of stigma, and strategies for managing stigma. First, it was found that stigma can come from a variety of sources, family, friends, caregivers, and the media, but the general community was the most predominant, with 46 of the 100 interviewees reporting this as the source of their stigma experiences. Some 95 of the 100 interviewee indicated their stigma experiences resulted in long-term consequences, which included limited disclosure to others, avoidance of social contact, and aversion to applying for jobs. The interviews also discovered the ways that individuals manage their stigma. The leading management strategy was advocacy and promoting understanding of mental illness.

This study was a start to fill gaps in the literature about the experiences of consumers of mental health services. Previously, studies about mental health stigma had been conducted only with a general population. This study developed the importance of talking directly to stigmatized individuals about their experiences surrounding stigma; these ideas are applied in the current study.

Quinn and Chaudoir (2009) conducted a study to understand the relationship between distress and the health of individuals with a concealable, stigmatized identity. Distress was measured by anxiety and depression, while health was measured by illness symptoms. The authors of this study emphasized the importance of examining all of the variables that can have either a direct and indirect effect on an individual's mental or physical health outcomes. This study included two studies that were designed to build upon each other. The first study tested a mediated model to predict distress using of intra-individual (intrapersonal) stigma: anticipated stigma, centrality, and salience; and external stigma. The second study tested a mediated model to predict both the

psychological distress and health. Concealable stigmatized identities are defined as an identity that must be disclosed to the other; this may include mental illness, history of being raped, epilepsy, HIV, or substance abuse, to name a few.

For both studies, participants were recruited from the population of students enrolled in introductory psychology classes at the university. For both studies, students were screened to determine if they have stigmatized identity that they conceal from others. For study one, 2,057 students were screened, 36% of those individuals qualified for the study, 377 took part in the study, and 300 of those met the standards to be included in the study. Similar procedures were used in Study 2; in this study, students were screened to determine if they fit within one of 13 concealed stigmatized identities as found in Study 1. In total, 3,956 students were screened, 1,063 admitted to concealing a stigmatized identity, 272 qualified for the study, and 235 provided data that met the standards. All participants remained anonymous. Both studies used self-report measures that examined the variables of anticipated stigma, centrality, salience, cultural stigma, distress, and health.

Data were analyzed using SPSS Amos to build structural equation models that examined the direct and indirect effect of the variables on psychological distress and health. Study 1 found that both the intrapersonal and external variables predict stigma related to distress. Further analysis indicated that both anticipated stigma and cultural stigma had direct effects on distress. As well, anticipated stigma had an indirect effect that was mediated through centrality and salience to the individual's identity, meaning that individuals who anticipated stigma had higher levels of centrality and salience to their identity. Study 1 also examined associative versus personal distress. It found that

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personal distress was higher than associative distress. Study 2 built upon findings in Study 1 with the addition of the health variable as measured by illness symptoms. Cultural stigma did not directly predict distress in this model, but it did directly affect health. Anticipated stigma directly predicted both distress and health, while centrality and salience had an indirect effect on health by causing further psychological distress. The authors concluded that stigma is not contained within the individual; instead, it is influenced by societal devaluation of their stigmatized identity.

This study did an excellent job of identifying and examining variables that may have a direct and indirect effect on stigma. Three important findings can be applied to the current study. First, the study found that internal and external stigma can affect both distress and health outcomes; this emphasizes the importance of studying stigma and ways to manage it. Second, this study highlights the variables of centrality and salience and how these can mediate the effects of stigma on distress and health. Finally, findings indicate the same model can predict both associative and personal stigma. This means that this current study can examine communication episodes of health-related stigma both from the personal perspective and associative perspective.

Stigma may also influence an individual's agency or access to health care. Sayles, Wong, Kinsler, Martins, and Cunningham (2009) conducted a study that examined internalized HIV stigma and how it is associated with access to care and medication adherence. The study used a self-report of stigma, source of care, medication adherence, mental health, and demographics. Data were collected using a convenience sample of 202 people living in the Los Angeles area. The researchers were interested in the relationship between stigma and access to care and if mental health status mediated the relationship.

They found that individuals who experienced higher levels of stigma had lower access to care. This was indicated by a strong relationship between the two variables. Similarly, the research found that individuals with higher levels of stigma reported lower medication adherence; further analysis revealed that the relationship between stigma and medication adherence was mediated by lower mental health status. Interestingly, the research also found that individuals who had been diagnosed less than five years ago reported higher levels of stigma, while those who had been diagnosed more than five years ago had lower levels. This indicates that the longer an individual has been living with a stigmatized condition, the less stigma they might feel through time. Thus, time living with a certain health condition may also be a factor in this study. The following section provides the rationale for the present study using relevant background literature.

Summary of Background Literature

This literature review established the need for the present study and provides guidelines for the conduct of research within this study based on lessons learned from previous studies on stigma. It is well established that health-related stigma is socially constructed and that social constructions can change and evolve based on society (Berger & Luckman, 1967; Falk, 2001; Gergen, 1982; Gergen & Gergen, 2004). This includes usage and meaning of language (Cline, 2011; Littlejohn, 2009). Stigma is complex and ever evolving (Smith 2011; 2009) and can affect people in different ways (Falk, 2001; Goffman, 1963; Quinn & Chaundoir, 2009; Smith, 2012). It also is related to adverse health outcomes. However, it is understood that felt stigma can lessen over time (Baumgartner & David, 2009; Sayles et al., 2009).

Wahl (1999) established that it is important to understand the actual lived experience of the stigmatized population as opposed to attitudes of the general population because lived experiences of stigma are what make social worlds. Then, this study aims to understand the complex processes of stigma through communication episodes of health related-stigma. Quinn and Chaundoir (2009) highlighted the importance of considering both internal and external stigma, examining ways that stigma can be managed and that associated and personal stigma should be treated the same. This will be particularly important when examining communication episodes of health-related stigma in the present study because we can gather a greater depth of these kinds of communication episodes and look for varied interpretations. The literature also provides guidelines for this study to begin the process of improving these types of communication episodes.

As outlined earlier, social constructions can change and develop over time. Thus, this project seeks to examine stigma using a grounded approach, with no assumptions about what current social actors do and do not stigmatize. The grounded approach will be used as a first step to understand from the perspective of social actors what are the emergent stigmatized health conditions or choices. Further, this study examines the language and experiences that surround these stigmatized health conditions or choices so that a dialogue on these issues can begin. The four-phase DICA model provided by Pearce (2007) was used in the conception of this study. The following research questions roughly follow the model presented by Pearce and build upon each other to develop an understanding of health-related stigma, and further how it can be improved through action steps. Findings from this study will be useful for improving these types of negative

interactions in the future. The next section outlines the six research questions this study posits.

Research Questions

The first two research questions were designed to describe the current state of stigma. The first research question examines with what kinds of health conditions have individuals had experiences of stigma. The second research question asks what kinds of communication episodes most commonly produce health-related stigma. The third research question examines the meaning made out of specific constructions of stigma. This question examines how individuals interpret communication episodes of health-related stigma, including interactions, identity, response, and health outcomes. The fourth research question delves deeper into health-related stigma communication episodes and looks at the critical question of managing of health-related stigma: what are the outcomes? The fifth research question is aimed at action and asks what can be done to construct better social and health outcomes within health-related communication episodes. The sixth research question asks how the participants perceive the label of stigma. The research questions for the present study are:

RQ1: What kinds of health conditions are attached to stigma?

RQ2: What kinds of communication episodes most commonly create conditions of health-related stigma?

RQ3: How do participants interpret various interactions within particular cases of health-related stigma-producing communication episodes?

RQ4: What outcomes are created by participants' communication choices, in particular, cases of health-related stigma-producing episodes?

RQ5: How can participants in health-related stigma episodes create positive social and health outcomes?

RQ6: How do participants perceive the concept of stigma?

These research questions will be answered through a combination of recruitment questionnaires and in-depth interviews. The dissertation methods are detailed in the third chapter.

CHAPTER THREE: METHODS

This chapter reviews the methods used in this study: data collection and analysis. The social constructionist perspective established in the previous chapters guide the research design choices found in this chapter. Data for this study were collected in two phases that built upon each other. The first phase was a recruitment phase where students were introduced to the study and were recruited from classes to take part in the study. The second phase was a series of in-depth interviews with individuals who self-selected into the process to share more of their experiences with health-related stigma. This chapter develops in four major sections. It begins by outlining the grounded approach used in this study. This is followed by a detailed description of the recruitment phase and then by a detailed description of the in-depth interview phase. The final section outlines the methods used for analysis. The University of New Mexico's Institutional Review Board (IRB) approved the methods used in this study. Aspects of the grounded theory approach were used in the design of this research study. The next section details grounded theory and how it was applied in the present study.

Grounded Approach

This study was designed using a grounded approach that allowed for explanatory themes to emerge from the social actors. This approach to research was considered in all decisions of research design. This design type helped examine what is being made through communication. Approaches in this study are derivative of the grounded theory, which is an approach to qualitative discovery developed by Glaser and Strauss (1967) as a response to positivist methods. This is a process of qualitative research that uses a series of procedures to arrive at a substantive theory (Charmaz, 2006; Lindlof & Taylor, 2011). Precise method choices for grounded theory are often a point of contention among

grounded theory scholars (Lindlof & Taylor, 2011). This study recognizes the debate and uses a modified process of grounded theory that utilizes the theoretical underpinnings of grounded theory, but is not pure grounded theory, in research design. Lindlof and Taylor (2011) highlighted the three features of grounded theory that distinguish it from other approaches. First, grounded theory develops an emergent theory that is "grounded in" the data, the themes, and the relationships among themes therein. Second, grounded theory uses a process of comparing data as it is collected to develop categories; this process also is known as constant comparative method. Third, grounded theory is a dynamic process that evolves as the researcher engages with the data as it is being produced. This process allows for flexibility in data collection and analysis. The next section discusses how the grounded theory approach is consistent with the framework of the coordinated management of meaning (CMM).

Consistency with CMM

Methods of grounded theory are consistent with CMM because both the theory and the method aim to discover how our social worlds work. CMM provides a framework for understanding our worlds, while grounded theory provides systematic methods for approaching data analysis. Throughout data collect and analysis, the framework of CMM provided a clear guide to examine what is made through communicative action and interaction. Further, the description, interpretation, critique, and action model created a rich progression in the analysis process that guided the emergent themes as well as made them more manageable. Data collection methods and analysis for the recruitment and in-depth interview phases are described in detail in the following sections.

Recruitment Phase

Participants of this study were recruited during the first 10 minutes of their class, which was taught by instructors in the Department of Communication & Journalism at the University of New Mexico. This type of sampling is considered a convenience sample. A convenience sample is comprised of individuals to whom the researcher has access to and are willing to take part in the study (Lindlof & Taylor, 2011). This sampling method is consistent with the needs of this study because this study was interested in health-related stigma during emerging adulthood, which is the life stage at which many individuals attending universities (Arnett, 2000). Classroom visits were arranged via email correspondence with the instructors; the initial email was sent to the department listserv that reaches faculty, adjuncts, part-time instructors, and graduate teaching assistants. The email introduced my study and the need to recruit participants as well as to schedule a time to visit their class. It detailed the research question of health-related stigma and the process of data collection in the classroom. Further, I attached the script for the class visit and the questionnaire that students would be asked to fill out. Finally, I offered additional information if anyone had questions about my research process. The full email is available in Appendix A.

In total, I visited 11 classrooms taught by instructors in the Department of Communication & Journalism. Time of day and subject varied, ranging from a general education course such as public speaking to major courses such as communication research methods. Visiting students in a variety of courses

expanded the sample beyond students majoring only in communication. During

the classroom visits, I introduced the study in this fashion:

> I am currently working on my dissertation research, and I am seeking out
> individuals who have had experiences with my research topic. Specifically, I am
> interested in talking to individuals who may have experienced an instance of
> bullying, exclusion, rejection, blame, or embarrassment that they believe is due to
> a physical or mental health condition they possess. For example, an individual
> might feel bullied or devalued because of a learning disability or another might
> feel blamed for being diagnosed with cancer. These are just two examples; there
> are many reasons that one might feel bullied, excluded, rejected, blamed, or
> embarrassed due to a health-related condition, and that is what I want to learn
> from you. The goal of my research is to learn about these types of negative
> communication interactions in order to find ways to better them in the future.

> The entire script used in the classroom visits is available in Appendix B.

The purpose of the classroom visit was to introduce the students to the study and

its purpose as well as to ask for their participation in the recruitment stage and the

in-depth interview stage. I went into the classrooms to act as the face of the study

to connect the research with a person and in turn to make connections with the

students. During the in-depth interview phase, I found this was vital to the

recruitment process. Many of the individuals who met for interviews felt

somehow connected to me, the project, or both, and that connection encouraged

their participation. For example, when asked about what prompted them to meet

for an interview, one individual replied:

Well, you seemed really nice, so I wasn't scared. I've had my own

personal mental health issues since probably before I was 15; mental

health issues have been in my family forever. Suicide has been in my

family, so it's kind . . . I feel like can't even think anymore after that

whole fiasco [she had an issue with a presentation earlier in the day].

Stigma along with mental health is something that I've dealt with pretty

much my whole life—whether it is firsthand because of me or because of

my mom or my schizophrenic uncle. It's always been a part of me or

around. And I find that researching should be important, especially when

it comes to relations with people.

Similarly, another participant said, "You seemed like you needed help . . . Also, I

talk about TBI and PTSD; it doesn't really offend me for people to know I have

PTSD or TBI."

During the classroom visits, the students were given specific instruction

on the ways they could or could not participate in the study, and they were

informed that their participation in the study was voluntary. Participation in the

recruitment stage included filling out the recruitment questionnaire and returning

it to me. The recruitment questionnaire is available in Appendix C. It asked

students about experiences that they or someone they know might have had that

led to bullying, exclusion, rejection, blame, or embarrassment that they believed

was due to a physical or mental health condition they possess. The first question

asked them to indicate if this was an experience that they or anyone they know

has had. The second question asked them to describe the situation, if possible.

Further, students were asked to indicate if they would like to participate in a one-on-one interview to discuss their experiences. If they were interested in participating in the interview process they were asked to provide their name and email address so they could be contacted. Finally, the questionnaire asked basic demographic questions such as age, year in school, major, sex, sexual identity, and ethnicity.

To create privacy and promote the fact that participation in the study was voluntary, the questionnaires were distributed in two-pocket folders. Students were instructed to stand up the folders on their desk to create a physical boundary for themselves. Distributing the questionnaires in folders was a requirement so that this study would be approved by the IRB. After the folders were passed out, the students stood the folders on their desk and were able to take the questionnaire out of the pocket of the folder and fill it out to the degree they were comfortable with without nearby classmates seeing. The recruitment questionnaire was approved using an assent process, meaning that if the student returned a completed questionnaire, it was their assent to be a part of this part of the study. The students' replies ranged from declining to take part to answering only the demographic questions to providing full narratives.

Record of recruitment data

In total, 230 students took part in the recruitment phase. Demographic information from the sample of 230 participants was analyzed using quantitative analysis software SPSS to get a sense of who took part in the study. Data collected from the recruitment stage was recorded in a three-step process. First,

the completed questionnaires were given an identifying number, which was used to keep track of the questionnaires; from there, all data were entered into an SPSS file. The SPSS file was used to organize responses and to analyze demographics. SPSS package 21.0 was used to examine descriptive statistics of the data as they were collected; these were run after every major data collection in order to get a sense of who was responding to the questionnaire. After all 230 questionnaires were collected, the descriptive statistics were run a final time to get a complete view of who participated in the recruitment stage.

Individuals who participated in this phase of research ranged in age from 18 to 57, for a mean age of 23. Participants ranged in sex at birth, sexual identity, year in school, major, and ethnicity. A majority of the sample identified themselves as female at birth (64%), while 29% identified themselves as male at birth; 7% did not indicate. Eighty-four percent of the sample identified as heterosexual, 4% bisexual, 2% lesbian, 1% gay, 1% as other and this data was not provided by 8% of the sample. All years in school were represented in this sample, but some years were more prevalent than others. The sample included 11% freshmen, 12% sophomore, 29% junior, 39% senior, and 0.4% graduate student; with 8% of the students, this data was not provided. The students' majors included a range of disciplines; the largest percentage of majors was communication or journalism at 45%, followed by 20% majoring in liberal arts and social sciences, with the smallest percentage of students majoring in fine arts. The students' major was not collected as a mutually exclusive variable to account for students who had a double major. The final demographic characteristic that

was collected was ethnicity. This also was not collected as a mutually exclusive variable, which allowed for individuals to identify themselves as accurately as possible. Some 47% of the sample identified as Hispanic; 43% as White, non-Hispanic; 5% as American Indian; 4% African American; 3% Asian/Pacific Islander; and 3% selected: other. Full demographics are presented in Table 1 below.

Table 1	
Demographic characteristics of recruitment phase sample	
<u>Characteristic</u>	<u>Percentage (*n*)</u>
Sex	
Female	64 (148)
Male	29 (66)
Did not indicate	7 (16)
Sexual identity	
Heterosexual	84 (192)
Bisexual	4 (10)
Lesbian	2 (4)
Gay	1 (2)
Other	1 (3)
Missing	8 (19)
Year in school	
Freshmen	11 (26)
Sophomore	12 (27)
Junior	29 (67)
Senior	39 (90)
Grad Student	.4 (1)
Missing	8 (19)
Major*	
Communication	45 (104)
Liberal arts and social sciences	20 (45)
Education	11 (26)
Hard sciences	10 (20)
Health professions	7 (16)
Business	4 (10)
Undecided/missing	7 (16)
Engineering	2 (5)
Fine arts	1 (2)
Ethnicity*	
Hispanic	47 (109)
White, non-Hispanic	43 (98)
American Indian	5 (12)
African American	4 (9)
Asian Pacific Islander	3 (7)
Other	3 (6)

* Categories not mutually exclusive

      It was common for individuals to respond "no" to the questions of

experiences with health-related stigma but then to fill in their demographic

information. Of the 230 participants, 137 indicated that they or someone they know had an experience of health-related stigma, and 133 of those individuals provided narrative details of the experience. The 133 narratives provided during the recruitment phase represented the breadth of experiences that individuals have had with health-related stigma. Each story provided different perspectives of bullying, exclusion, rejection, blame, or embarrassment that they believed to be due to a physical or mental health condition. Some of the students suggested that I work with their organization that serves individuals who typically experience stigmatization such as an organization that specializes in helping individuals living with mental illness. Other individuals conflated health-related stigma with instances of discrimination or general bullying. The narratives were typed verbatim into a word file; as I entered them into the word file, I analyzed the narratives to determine if each was indeed an instance of health-related stigma as I described during my classroom visit. To be invited to take part in the interview process, the individual must have provided a personal experience of health-related stigma; examples of not meeting these criteria included discussing children being picked on in school or individuals suggesting I visit their nonprofit organization to recruit participants. The recruitment phase narratives provide a rich field for analysis that will be analyzed in later studies.

Fifty individuals met criteria for the interview process. To meet the criteria, the individual must have expressed interest in meeting for a one-on-one interview by providing their contact information, provided a personal narrative of health-related stigma, and they could not be student of mine—a requirement of

the IRB. The identifying numbers for the 50 individuals who met the criteria for

an interview were recorded in an Excel document as per the agreement with the

IRB, so they could be contacted for an interview.

This reflexive process of data entry occurred immediately following every

classroom visit. Engaging with the data and recording it at each collection point

developed an intimate knowledge of the data that being collected during the

recruitment stage, and it was useful to determine saturation. Additionally, the

recruitment phase and the in-depth interview phase overlapped; the recruitment

phase began on Jan. 23, 2014, and the final recruitment questionnaires were

collected on Feb. 27, 2014, while the interviews began on Feb. 3, 2014, and ended

on March 11, 2014. Building the phases upon each other was important to the data

collection process and echoed the reflexivity used throughout this study. The

process of reaching saturation is discussed further in the next section, which

describes the in-depth interview phase.

In-depth Interview Phase

Similar to the recruitment phase, data for this phase of the project were collected

using theoretical sampling in particular until a level of saturation was met. The process of

theoretical sampling collects samples and examines each sample for codes until no new

codes emerge from the data, thus saturating categories (Charmaz, 2006). Data collected

in this fashion uses a hermeneutic spiral that includes a circular process of data

collection, coding, analysis, writing, design, and additional data collection (Hood, 2010).

Saldaña (2009) described theoretical sampling as the collection of data that contributes to

the emerging themes and theory. The process of theoretical sampling is related to the

process—grounded theory—the method of qualitative data analysis used in this study. A fuller description the methods grounded theory used in this study is in the analysis section of this chapter.

To ensure that saturation would be reached, all 50 individuals who met criteria for an interview were contacted via email to schedule an interview. A random-list generator found at random.org was used to shuffle the order of the interview participant list, and each student was contacted in that order; randomizing the list was a requirement of the IRB. Wording for the initial email to interview participants appears in Appendix D. Twenty-two individuals followed up and scheduled an interview with me. Two additional interviews were conducted with individuals who learned about the study through word-of-mouth and then snowballed (Lindlof & Taylor, 2011) into the study.

In accordance with theoretical sampling, participants for the in-depth interview phase were invited to take part using a tiered process. As stated, the list of 50 individuals was randomized using a random-list generator, and the students then were contacted in that order, approximately five at a time, which began a process of contacting, scheduling, and interviewing. This reflexive process continued until saturation was met. Saturation was met at approximately interviews 20, but additional interviews were conducted to ensure that all of the voices who wanted to take part in the interviews were heard.

In all, 24 in-depth interviews were conducted with individuals who self-selected into this phase of the study. Participants ranged in age from 19 to 49 with a mean age of 26, the mean age was skewed higher in this phase of research. Sixteen individuals identified as female at birth and five male at birth. Nineteen of these individuals

identified as heterosexual and two identified as bisexual. They ranged in year in school and major. Ethnicity was represented as such: 15 individuals identified as white, non-Hispanic, five as Hispanic, one as American Indian, and one identified as other. Ethnicity was not collected as a mutually exclusive variable. Three interview participants did not provide demographic information; this includes the two individuals who snowballed into the study and one individual did not provide this information on their recruitment questionnaire. These descriptives are to provide a general sense of who took part in the interviews.

Interviews ranged in length from 30 to 75 minutes. Each was recorded on my computer using the Audacity software program and later was transcribed. I did not want to be typing during our conversation and instead focused on the relationship that was developing. Therefore, the interviews were transcribed as soon as possible after the interview, in most cases within 96 hours. Transcription was completed by March 21, 2014. Conducting and transcribing all of the interviews resulted in very intimate knowledge of these cases, which was helpful during data analysis. Taking part in every step of data collection created a bond between each participant and myself; these interviews and subsequently this dataset is truly a product of co-construction.

Interview procedures

Procedures for this phase were designed to be emergent. In accordance, the interviews were conversationally structured and encouraged comfortable interaction between the interviewer and the interviewee. Broadly, an interview is an engagement of two parties in a social interaction with a purpose of understanding a social reality (Lindlof & Taylor, 2011). The interviewer usually prepares a list of open-ended questions

that allows the interviewee to expand the discussion about the phenomenon in the way they deem appropriate (Lindlof & Taylor, 2011). The framework advanced by Pearce (2007) for the use of CMM in research studies was used in the design of the semi-structured interview guide used in this study. Pearce's framework is a pragmatic approach that follows a sequence of moves from a broader generalized understanding to questions of interpretation, critique, and action. Interviews were conducted in the form of a narrative interview, which allows for the entire story to be told (Lindlof & Taylor, 2011). The semi-structured interview guide moved the participant through stages that were designed to coincide with Pearce's model as well as to open up conversation; this included opening and building rapport between me and the interviewee, then moving into storytelling, developing depth, examining aspects of the interaction, discussing action steps for how to improve these types of interactions in the future, and finally, closing questions and debriefing. The semi-structured interview guide is available in Appendix E.

Twenty-three of the 24 interviews were conducted in my private research office on campus, while one was conducted in the interviewee's home. The use of space was important to these interviews. I wanted to make sure the interviewees felt comfortable, which meant trying to eliminate an institutional feel as much as possible. The research office was decorated with framed art and flowers and was scented to try to create a more comfortable environment. Each interview began with a greeting and rapport building. It was essential to build trust with the interviewee at the outset so they felt comfortable sharing their experiences. When interviewees arrived, they were greeted with a welcome, such as, "How is your day?" as they were directed to an office chair. Conversation usually progressed from there. At this time, points of identification began to emerge, such

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as the individual's interest in communication, the project, or health in general; finding areas of common ground was integral to building rapport and trust. After they were seated comfortably and opening conversation dwindled, I introduced the consent form and handed them a copy to read and sign. After they signed it, I signed the form. Once consent was obtained, the interview began.

At the start, I thanked them again for their participation and told them how valuable their input and experiences are to the research process. From there, I introduced the interview guide and the design of the interview. Interviews began with the storytelling process; this phase allowed for the interviewee to describe their experience(s) in detail. An open-ended question was used to begin the story, "Tell me a little bit more about why you decided to come here and talk to me?" This question allowed the participant to tell their story in detail: what happened, where it happened, and how it made them feel. Listening skills were key in the storytelling process in order to structure the rest of the interview. In this stage, I listened to understand their experiences and to ask clarifying questions or questions of curiosity that opened up the story. From there, the interview developed into depth of the story by discussing how these interactions made them feel, if these interactions influenced their health outcomes or impacted their self-image. The next set of questions was constructed to examine interpretation and began critiquing the experience(s). This included examining the positives and negatives of the episode(s) and what the experience might have looked like if the individual had the opportunity to respond differently. Moving through description, interpretation, and critique led nicely into questions of how we might improve these types of negative health interactions in the future. After we moved through the sequence of questions, I signaled the closing of the

interview by informing them that we had reached the end of the major questions. During this time, I introduced the word stigma as the label for the topic we had discussed throughout the interview. At this time, I asked if labeling the concept evoked additional feelings or experiences. Finally, as a clearinghouse question, I provided them the opportunity to add anything they might consider helpful to my research.

After each interview, I jotted down notes of importance so that I could compare the interviews and recognize emerging themes. These methods were used as a part of the theoretical sampling process, as they helped to develop initial findings and determine when saturation was met. Conducting all of the interviews provided me with a special perspective from which to analyze these data. I have an intimate knowledge and relationship with these individuals, their cases, and the data we co-produced, as I was present in every step of the process. Being so close to the data also made it easier as I moved into the full data analysis process. The next section details these analytical procedures.

Coding and Finalizing Themes

The process of theoretical sampling, which emphasized circularity—a back and forth between codes and data—was essential to coding, analyzing, and finalizing themes. The initial codes that developed using constant comparative method during the theoretical sampling process were expanded upon in this stage of data analysis. The next section provides an outline of the specific analytical procedures.

Analytical procedures

Methods of grounded theory have three general stages of data analysis: open coding and in vivo coding, integration, and dimensionalization. Data analysis began with

open coding. First, Open coding is a free reading of the data where the researcher writes down all codes that emerge from the data. It allows the researcher flexibility to identify all relevant themes as they appear in the data (Lindlof & Taylor, 2011). In the process of open coding, I engaged in a line-by-line reading of the interview transcripts as I read through the transcripts I wrote relevant quotes onto note-cards. The six research questions served as a guide as I read through the text to identify relevant codes. In total, 63 open codes emerged from the data, including codes such as agency, negative label, others changing their behavior to accommodate, questioning oneself, identification, words in quotes, embarrassed, patient-provider, the body, privacy, and the like. Open codes overlapped with the preliminary findings that were found through the process of theoretical sampling as well as illuminated codes not previously discovered. After the line-by-line reading of the data I transferred the written codes into a Word file. Using the word file I built matrices to organize the codes and pull additional quotes from the dataset to support existing codes.

From there, data analysis moved into the stage of integration in which the codes are organized into categories, referred to as axial codes (Lindlof & Taylor, 2011). Axial codes create categories that are used to collapse and bridge open codes (Lindlof & Taylor, 2011). The research questions helped in this process of organization, to make sense of the codes and categories and to determine their relation to one another. I did this by reading through the codes and organizing them by research question. Further I printed the matrices and cut them up by codes to check for points of overlap and relationships between the codes. After axial codes were developed I began the final step in the process, dimensionalization. This step provides a description of the themes and how the codes are

connected. The process of dimensionalization was concurrent with axial coding and the write-up of findings. As I wrote out findings, I examined my codes and revised their relationships to one another or the definition of the category as appropriate. The iterative process of integration and dimensionalization is consistent with the merits of qualitative research. Twenty-one themes and related 25 subthemes emerged from the data to answer the six research questions.

The coding process was more straightforward for some research questions than others. For example, codes relevant to RQ1, RQ2, and RQ6 were easier to identify than codes relevant to RQ3, RQ4, and RQ5. When coding for RQ1, I noted the health conditions discussed throughout the interviews—open coding—then grouped the health conditions in five themes—axial coding. Examples of themes for RQ1 are visibly recognizable physical health or internal physical health. A similar process was used for RQ2 to identify the kinds of communication episodes. Themes include settings such as the workplace or patient-provider interaction and instances that violate social norms, such as gender roles or othering. Codes relevant to RQ6 also emerged in a straightforward process. First the quotes relevant to the introduction of the label of stigma were pulled out of the data—open codes—then these quotes were organized to create meaning. Examples of themes that emerged in RQ 6 are discussing the stigma associated with their health condition or not identifying with the term.

Coding for RQ3, RQ4, and RQ5 was a more iterative process both defining codes to answer each research question and examining connection between codes that answer each research question. For example, open codes for RQ3 included negative labels, positive labels, comparison, and treating health conditions differently. These four open

codes were bridged into one axial code of labels. Dimensionalization helped to define

each and collapse comparison and treating health conditions differently. Additionally, the

theme of labels is related to the theme of othering, related to RQ2; this is an example of

the iterative process among research questions. An example of the coding process for

RQ4 is the theme lost of trust. The open codes of loss of trust, question oneself, and trust,

were collapsed into the axial code of loss of trust and the definition of the code includes

trust experiences with self and others. Another example of a theme for RQ4 is teachable

moments; this theme overlaps with a theme for RQ5. Finally, an example of coding for

RQ5 included different/open minded, diversity, acceptance, conversational spaces, and

awareness. These open codes were collapsed into one axial code of diversity, and

different/open minded and awareness were absorbed into the definition of the axial code.

The open codes of acceptance and conversational spaces remained as related subthemes.

  This section provided a brief overview of the coding process and provided

examples of some of the themes. The next chapter details all themes in the presentation of

research findings.

CHAPTER FOUR: FINDINGS

This chapter outlines the research findings for the present study. Findings answer the six research questions posited in the literature review. Twenty-one themes and 25 related subthemes emerged through the grounded analysis process detailed in the methods chapter. The four-stage DICA model, presented by Pearce (2007) as a way to use the coordinated management of communication (CMM) in research, provided structure for examining the facets of health-related stigma. Findings in this chapter are presented by research questions under the phases from the Pearce's DICA model that it corresponds to: description, meaning (interpretation), outcomes (critique), and action. The final section of these findings describes the interviewees' perspectives of the label of "stigma" and how they perceived stigma in relation to their experiences.

A majority of the individuals I spoke with during the in-depth interview stage were what Goffman (1963) would describe as "the own" group—that is, they were a member of the stigmatized group—while four individuals came from the perspective of "the wise," individuals who were not a member of the stigmatized group but were wise to the situation of the stigmatized group. The individuals who represented "the wise" were in significant relationships with "the own," such as mother, sibling, or best friend. However, speaking from the perspective of "the wise" was not exclusive to these four individuals. Several individuals who came to speak about their own experiences also discussed how they have witnessed others experience stigmatization. These cases were used either to exemplify their general awareness of health-related stigma or to reinforce their experiences. For example, individuals discussed their general awareness of the health-related stigma at different points of the interview. This often was not recorded or transcribed because individuals usually discussed this during the greeting or before they

departed from the interview. However, some individuals discussed general instances of health-related stigma within the body of their interview. For example, one individual who came to speak about her experiences living with depression said:

> I think that it's an interesting topic and I think that it's important . . . there is a stigma, but I don't really think people ask why. Or how to address it, especially such a broad thing. There are lots of different stigma and issues that can be addressed.

Similarly, another participant discussed how she found this topic to be personally relevant to her and her son living with autism:

> And think that's what…when you came into our class and said this is what you are studying, it's important to me that this gets out more because I want people to accept my son for who he is and not try to change him.

Individuals also reinforced their experiences by discussing how they have seen their friends, family, or others negotiate similar instances of stigma. For example one person came to discuss their experience living with depression discussed how moving away helped to manage their depression, and they noticed that friends living with depression were not able to manage it the same way. This person said:

> I think that was a much better choice [to move away] than some of my friends were just medicating through it all. It's a much better choice when you realize that the interactions that you're having are just not healthy.

One woman who discussed her experience living with a shoulder abnormality and the self-consciousness it has created for discussed how she has experienced her mother's

body image issues and she sees that relating to ideals that are set forth by others, in particular her mother:

> We grew up with them I guess, you just grow up as a little kid, it's just so sad because it is just a repeating cycle my mother for example is oh "I'm fat" and I'm like mom you're so beautiful. She's just starting to get gray hairs and wrinkles, and I love it. And she's really insecure about it. I read some article somewhere saying that a child sees their mother insecure they're going to have the same things running through their head. You're just born into a world of imperfection, and everyone's trying to be perfect.

Another individual who was disabled in a hit and run accident in which she was the pedestrian discussed how she witnessed experiences within the bureaucratic system she engages with for assistance and disability, " . . .I used to see people get walked over before, and I thought I'm not gonna be that person anymore." All of the voices that contributed to this study provided valuable insights into episodes of health-related stigma.

This chapter develops in five parts: description, meaning, outcomes, action, and examining the label of stigma. The six research questions posited in this study are answered by themes that relate to the each of the sections. Themes presented here build upon, reflect, and reinforce one another. As such, they are considered to be fluid, and some are not mutually exclusive, though they are presented in the model for clarity. Points of overlap are noted throughout the findings. Each section is a part of the greater system that contributes to understanding health-related stigma. The model provides a reverse-funnel format, beginning with a broad description and moving to a narrower focus of action steps for improving negative episodes of health-related stigma in the

future. Figure 1 below provides a visual of this. Explanation of the findings begins with description.

Figure 1. Reverse funnel for approaching the DICA model.
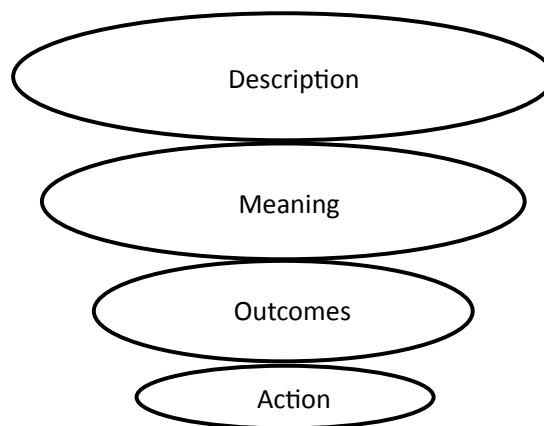
Description

Description is the first step in the four-stage process. The initial step aims to provide an explanation that provides a picture of the phenomenon as it exists in current social worlds. While descriptions of health-related already exist, as social constructions evolve over time, they must be described and re-described to provide accurate representations of concepts; RQ1 and RQ2 contribute to the description by providing a representation of aspects of the present state of health-related stigma. Findings in this

section explore what is happening—what mental and physical health conditions individuals identified as stigmatizing—and the kinds of communication episodes that produce health-related stigma. Describing these health conditions and their broader themes provides context for later themes that answer later research questions. Further, direct quotes will be used throughout to illustrate themes and to provide detailed descriptions of the experiences of health-related stigma that were captured in this study.

The first two research questions were proposed to provide a description of the current state of health-related stigma. RQ1 asked: What kinds of health conditions are attached to stigma? RQ2 asked: What kinds of communication episodes most commonly create conditions of health-related stigma? Five themes emerged to answer RQ1, and two themes and eight related subthemes emerged to answer RQ2. Both research questions contribute to the description of health-related stigma. An illustration of these findings begins with themes related to RQ1.

RQ1: What kinds of health conditions are attached to stigma?

The first research question examined the health conditions with which individuals have had stigmatization experiences. Five themes relating to the kinds of health conditions that are currently socially constructed by the participants of this study as stigmatizing emerged from interview narratives. The responses provided a range of physical and mental health conditions. These themes are: issues of mental health, visually recognizable physical health, physical health not always visually recognizable, internal physical health, and experiences with a violation of the body. The themes presented here were consistent throughout the interview narratives as well as with the recruitment phase narratives. After the five themes emerged, I re-immersed myself in the recruitment phase

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data to code for these themes and found that the recruitment narratives also can be

organized into the five themes presented here. These five themes and their contributing

conditions are organized in Table 2 below.

Table 2

Findings from RQ1: What kinds of health conditions are attached to stigma?

Themes	Examples
Mental health	Depression
	Anxiety/panic attacks
	Post-traumatic stress disorder (PTSD)/traumatic brain injury (TBI)
	Anti-social personality disorder
	Autism
	Learning disability
	Anger management
Visually recognizable physical health	Down syndrome
	Dwarfism
	Cerebral palsy
	Visible hearing aid
Physical health not always visually recognizable	Shoulder irregularity
	Hyperhydrosis – excessive sweating
	Cross-eyed
	Asthma
	Knee caps float around, leaves her inflexible and uncomfortable
Internal physical health	Autoimmune disorder that causes stomach problems
	Type 1 diabetes
	Type 2 diabetes
	Urinary tract infection (UTI)
	Tired/sick (unlabeled)
The body	Sexual assault
	Self conscious of body
	Applying for disability
	STD testing as a gay man

The first theme is issues of mental health. Mental health was the most widely

represented health condition in the interview sample. This theme included experiences of

living with depression, anxiety, post-traumatic stress disorder (PTSD), traumatic brain

injury (TBI), autism, learning disabilities, and anger management. When describing her experiences with depression, one individual described the experience as such:

> Sometimes it was subtle, and sometimes it was more noticeable. So like if they found out that you had depression, you know, I had to take anti-depressants. A lot of people would get really cautious around you and treat you like this baby bird . . . Or people would get really awkward and not know how to act around you and would just stop talking to you. They would be like, 'This person has a lot of issues, they're crazy' and not want to talk to you or be friends . . .. That's kind of the basics and people not understanding why you have to take a pill to be happy and why can't you just change your thinking . . .

PTSD also was identified as a stigmatized mental health condition. When explaining his experience living with PTSD and TBI after serving in the army, one man said:

> I don't wig out and start beating people up. It's more so like nightmares and unnecessary fears, I guess you would say, overly hypersensitive to certain situations. It caused problems for a long time. Like when I was first trying to learn how to cope with it, it caused me to lose a relationship to someone I had been with for six years because they didn't know how to cope with me, you know, and I was kind of like going through it all when it was a new thing in the military.

When speaking about her experience of living with a learning disability, one participant recalled the following story:

> Well, to start I was in special education from the time I was about 12, 13 years old because I do have a disability . . .. I would know at the beginning of every year, you are asked to go and talk to the teacher and make sure they got your paperwork

and that they know your needs. And what happened was it was the very beginning of the semester and I went up super quiet, and I said, 'Did you get my forms?' and she goes, 'Yeah! Go talk to your sponsor teacher!' I'm in a room of about 20-30 students, and what made it worse is I was in there with kids I went to special education with. And they all looked at me like they knew how badly this teacher had just screwed up. I'm humiliated, and I have to stay in that class for an entire year."

The second theme is physical health conditions that are immediately visually recognizable, such as dwarfism or Down syndrome. One woman discussed her brother's experiences living with Down syndrome:

His speech is slow, and you really have to concentrate to listen to him. So as my brother. . . me as his sister, I've noticed how people will stare because they don't really understand or they don't want to touch him—because they don't. . . I think they just don't understand. I've seen that growing up. We always try to treat him as normal as possible. We don't treat him any different than anyone . . ..

Another woman came to discuss her sister's experiences living with dwarfism, "Over the years, I would see people responding to how she looked. She's a really incredibly resilient person. She drives, she's like the primary caregiver for her 5-year-old son," she said. While there were only two cases of visually recognizable physical conditions in the interview sample, examples of this theme are expanded and reinforced by the narratives collected in the recruitment phase. For example, individuals provided narratives of living with cerebral palsy and a highly visible hearing aid. Additional instances of living with Down syndrome also were represented in the recruitment phase narratives.

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The third theme is physical health conditions that are not immediately visually recognizable but could be recognized over time or in the right moment, such as a shoulder abnormality or crossed eyes. One woman explained her experience with this type of physical health condition, saying:

I have something called Sprengel's deformity . . .. My left shoulder never descended in the womb or whatever so it kinda sticks out funny and it's a little weak. It's a silly thing. . .. So I've never experienced any sort of bullying from that. For me it's so noticeable and obvious, but it's always been a source of embarrassment or lack of self-confidence . . . wearing swimsuits or wearing tank tops, there's a bump on my back. It's been a process to say this is me.

Another individual explained their experience with a condition that causes excessive sweating, saying:

And so, so yeah, I get it from my mom's side of the family. It did just lead to a lot of embarrassment and keeping myself from doing certain things. And it was even things as small as not high-fiving kids in the hallway or bigger things such as not trying out for certain activities in school that would maybe have me be the center of attention such as trying out for school plays or getting more involved in certain after-school activities.

Another individual discussed his experience living with crossed-eyes:

So I was born cross-eyed, I had about three eye surgeries between birth and I'd say six or seven years of age. To where it corrected the cross-eyed part, but there was something in my brain, it wasn't a muscle thing, and after they would cut a piece of muscle out, cut it and reattach it my brain would push it back out. So I

focus with one eye at a time. I can't see 3D, I have no depth perception, and then whichever eye I look with the other will sort of do it's own thing. Some people will notice it right away, some people like my wife never really notices it, but that could have like a whole different context—that could be a whole beauty is in the eye of the beholder type of thing. But yeah, I was made fun of that for and glasses as a kid, and then as the years go on. . .. Then I was in the military they make fun of you for everything when you're in the military. And the construction industry. So I got razzed all the time for the eye. Or even strangers would do the "are you looking at me kind of thing?" and it was like, "of course I'm looking at you, you're the only one around." And so it gets old, it wears on you, and I think as you grow up you start to care a little less.

The fourth theme dealt with physical health that is internal, such as diabetes, Type 1 and Type 2, or urinary tract infections (UTIs). One man explained his experience with Type 1 diabetes: "I know it's not done out of any type of scorn. Most Type 1s that I talk to, they feel devalued, they wish that Type 1 had a little bit more recognition. That's definitely where it all stems from." Another person described the condition that impacts their internal health: "A few years ago I got diagnosed with a condition, and it's an autoimmune one, and it has to do with . . . guts problems and stuff like that." Two women discussed their experiences living with a UTI and the stigmatization they felt in particular from health care providers. One individual discussed her experience:

I had a doctor tell me it was just because I was drinking drinks with red dye. Just weird stuff. I felt like a lot of time they felt like I was just lying to them. A lot of time they would do the test and they would find that nothing is there, it just

always came back to nothing is wrong with you. Get out! It's just so like if there's

a problem, let's fix it, if there's not a problem. Get out."

The fifth theme considers experiences of the human body, in particular physical

and mental violations of the body. Physical violation refers to sexual assault and the

experiences thereafter. One woman recalled:

. . .We'll start with sexual assault because it's the easiest for me. It happened my

freshman year of college . . . and it was a very bizarre experience for me because

when I did tell my freshmen year adviser and I told a counselor and I told a sexual

misconduct advisor, all three of them told me not to report it. They told me to

report it for statistics, but to not bother to bring it to the court system—the school

court system—because it's not worth your time, you probably can't prove it, and

it will probably be even more emotionally damaging.

Mental violations of the body were interactions that produced mental distress, including

issues of body consciousness, such as being teased for being skinny or fat. One individual

said, "I have been bullied based on my physical appearance, specifically, my weight.

Growing up, I have been self-conscious about my body. That changed in high school. I

also suffer from anxiety." Another example of this theme was where a woman was turned

away from receiving disability because the disability office made an incorrect judgment

about her body. She had been hit by a car while running, due to this incident she was

hospitalized for months and needed to seek disability to help her pay for expenses:

When I went and applied for my disability, the first questions she told me she was

just kind of (looking up and down at legs) looking at me up and down, just kind of

looking at me judging me. Then toward the end of the interview, she goes, 'Well,

you don't look like you need any assistance,' and I said, 'Well, what does a person actually need to look like to apply for assistance?' And I said, 'What do people come in here looking like that need assistance?'

Some health conditions were more prevalent than others, which is seemingly consistent with the frequency of these conditions in the general population. There was also an interrelatedness of the conditions. Some narratives described the experience of managing several conditions at once and the ways their experiences intersect and diverge. Further, individuals consistently spoke about the cyclical nature of their conditions and how they found one health condition influenced another. For example, one woman described living with a condition that causes excessive sweating in conjunction with anxiety:

> I find that a lot of it is tied to anxiety. It's funny because I don't remember being very anxious when I was very young, but I remember becoming anxious because of this so I don't know if this started and I started to become more embarrassed and anxious and I kind of got more comfortable with myself, but the anxiety was still there. It's sort of been sliding back and forth.

Another individual discussed the circularity of depression and sexual assault: "Another thing that I noted was sexual assault. I think that the psychological effects that go into that are very, very interesting and how they play into depression and anxiety and how other people view you . . ." Participants also noted the influence of mental distress on physical health. For example, one woman explained her experiences:

> I never identified as that until my friend, she said, 'You're sickly . . .. So we've had lots of health problems. And I've felt that a lot of our health problems are

related to mental psychological problems. There's a word for it; I read it in a

book; I'm reading a book about the Hmong people—so there's a word for it—the

fact that it's not real pain necessarily, but it's pain that's being inflicted on your

body because it's up here [points to head], so that's what I thought of. In my

experience, it was never treated completely. Like Westerners don't look at you

wholly, they look at symptoms. . .. I've had reoccurring UTIs since I was kid. My

mom had them, my grandma had them. It's just a thing. I think it's weird that

doctors never looked into this because me experiencing all of this I can look back

on this and see there was something in common. I have a sister, so we both have

this . . .. We never got to fully develop. I've seen urologists; my sister has seen

urologists; it's just never gone away. It just had a ton to do with what was going

on at home."

Another woman explained the impact of depression on her body, in particular, how it

created stomach problems:

It was getting to a point that it was damaging my body. The reason that it lasted so

long is that I used to have anxiety attacks when I went to P.E., and so what we

discovered is that it wasn't the depression, but it exacerbated the issue because it

was anxiety attacks.

Another individual described the cyclical nature of their experience with anxiety:

Or you end up in the bathroom all hot and sweaty and drippy and stuff, and then

you know you come back to work and they're all, 'Are you OK? How you

feeling?' and you know it kind of re-spurs those feelings of like, "God, I hope it

doesn't happen again—further trying to figure out why it happened, and it can

spur more anxiety. People you work with, people start treating you different. Kind

of like at an arm's distance. She's 'crazy'.

In addition, individuals talked about the cycle of influence, how one generation

could influence another. One woman discussed her experience living with anxiety

coupled with her mother's experience living with a mental illness and at the end of the

interview she said:

What peaked my interest was the stigma of the parent be transferred to the child . .

. just thinking about it now. Family members treated me a certain way because of

her. I'm treated with the same gloves that they treated her. And I don't know if

the gloves are necessary at all.

Another, discussing her perspective on this idea, said: "Whenever people are children,

that's how they are raised and how they will raise their children . . .. I'm not blaming

them for their outlook, it would be a long way back, or maybe just society in general."

The quote provided previously of the woman living with the shoulder abnormality and

her relationship the example she provided about the relationship with her mother also

contributes to this theme. This alludes to the system of influence that individuals indeed

take part in and how family or society impact us.

The first research question asked with what kinds of health conditions are people

experiencing stigmatization. Five themes of health conditions emerged: issues of mental

health, visibly recognizable physical health, not always recognizable physical health,

internal physical health, and violations of the body. The second research question

addresses the kinds of communication episodes that produced feelings of stigmatization.

RQ2: What kinds of communication episodes most commonly create conditions of health-related stigma?

The second research question examined what kinds of communication episodes produce instances of health-related stigma. One of the dominant themes related to RQ2 is the sense that health-related stigma is not limited to one or a few interactions in a single context. Instead, individuals spoke about the variety of settings in which they manage health-related stigma. These communication episodes of health-related stigma build upon each other and create a narrative of stigmatization. This developed a general feeling of stigma they carry with them that influences various aspects of their life. In the design of this study, there was an assumption that individuals would be able to pinpoint one or two interactions of health-related stigma that impacted them, instead it was found that instances of health-related stigma build upon each other and are carried through contexts moving through the patient-provider interaction, classroom, the workplace, family, romantic relationships. It is important to note that this is a general feeling that one can carry with them in throughout interactions and the different contexts in which these experience occur.

Two overarching themes and eight related subthemes emerged from the data to address this question. They are displayed in Table 3 below.

Table 3	
Findings from RQ2: What kinds of communication episodes most commonly create conditions of health-related stigma?	
Overarching Theme	Related Subthemes
Settings These are the various settings in which participants discussed experiencing episodes of health-related stigma.	Public spaces This includes spaces such as the library, grocery store, or restaurants. Workplace Instances of stigmatization with co-workers and employers. Patient-provider Feelings of stigmatization that were produced in the patient-provider interaction such as the emergency room and with specialists. K – 12 education Bullying from peers and feelings of embarrassment from teachers or frustration from administrative policies. Institutions Large bureaucratic organizations such as universities or government offices.
Violation of norms Experiences where individuals were made to feel like they were not meeting expectations in some way.	Anticipated stigma Mental distress of the stigma that one might receive in an interpersonal interaction. Gender roles Concerns that one is not conforming to Westernized standards of gender. Othering Actions and language that made an individual feel outcast.

The first overarching theme that addresses RQ2 is the setting in which communication

episodes of health-related stigma most commonly occur. Five subthemes emerged: public

spaces, which were particularly related to individuals with a visibly recognizable physical

health condition; the workplace; the patient-provider interaction; K-12 education with

both peers and teachers; and bureaucratic institutions, such as universities and government agencies.

The first subtheme is the setting of public spaces, which was related directly to individuals with visually recognizable physical conditions. For example, one individual discussed experiences of eating at restaurants with her brother, who has Down syndrome. She discussed how some servers might look to her to give her brother's order instead of asking him directly. She said:

Even when we go to restaurants, he likes to order his own. So like when he's speaking, some people will focus their attention on me, and I will repeat it. And they're other people . . . will give their full attention, and they won't look at me. Those people I think maybe they know someone with a disability so they treat him nicer, I guess, maybe. Let me give you an example. We were at Cracker Barrel one time, and you know how they have the little gift shop. My brother was getting little gifts for his nieces and nephews because he has his own money, he wanted to buy them himself, the cashier, my brother was paying for them, she focused, giving him good eye contact. She was saying, 'Are you doing Christmas shopping?' and he said, 'Yes', and she said, 'It looks like you got them all done.' Just directly communicated with him. Never even looked at me. She was giving him her full attention; I really liked that because she would have done that with a 'normal' person. And I noticed other people, if they don't understand, they will look at me and give their attention to me. It's nice to know that other people might be familiar with other people with disabilities. They want to do things too; they want to be independent; they want to do things on their own.

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Another individual recalled a time when her sister living with dwarfism experienced stigmatization in a library:

> And what's really interesting. . .she can relate to them. . . sometimes children being children not being sensitive will have a crazy reaction. One time it was crazy this little boy at the library. . . he was like, 'oh my god look at that woman she's a freak' I was a teenager at the time I didn't know what to do. Then eventually the mother came over and reprimanded him quite harshly. . . in a way she expects these types of reactions from children.

The second subtheme of setting is feeling stigmatized in the workplace. Individuals spoke about being treated differently by their employers or co-workers. One woman discussed how her employer knew about her anxiety and tried to use it against her to cut her hours or fire her. She said, ". . . But he would purposefully poke at me to try and get me to have a panic attack so he could use a reason to fire me . . .." Another instance of negative interactions on the job were one man's experiences living with PTSD and interacting with others in the military:

> . . . My team was very supportive because we were all dealing with it, but once you go into the broader spectrum of the military, and you get to the people that don't have to see conflict, they kind of look at you different like, 'There's that group of 'crazy' people.' you know?"

Other individuals discussed how co-workers might tease them on the job, but they were able to overcome it, such as the woman living with asthma and working at a bar. She said:

. . . And at first, the bartender would be like, 'Aw, sweetie, let me carry all this

stuff, let me carry all the beers,' and I would be like, 'No, I've got it, like every

other girl has to do it, I can do it too.

This was noted as a sense of agency and will be explored further during the discussion of

outcomes. Another instance of stigmatization in the workplace setting is that of the

military. One individual said:

"They're gonna make fun of me for my eye, they're gonna make fun of him for

being a slow runner. It's not good by any means, but that's just what they do in

the military: They pick on each other's weaknesses. The small, cohesive unit

where I'm in, a six-to-eight-man team, and you might be dropped off behind

enemy lines, and you are together for weeks. You have to be tight; you have to

razz on each other. But you need to know each other's weaknesses too so you can

help that person with their weaknesses."

The third subtheme—experiencing stigmatization in the patient-provider

interaction—also was quite common. Individuals discussed feeling like their provider

was not listening to them or was patronizing. Another discussed how their less common

condition of Type 1 diabetes often is confused with Type 2 diabetes in the patient-

provider interaction and the frustration that can produce when their provider does not

know how to properly treat their condition and stereotypes him as someone with Type 2

diabetes. He said:

OK, it's usually nurses, though I have run into some emergency-care, family

doctors that have confused it too. It's usually nurses that get the two confused,

'Are you eating right? Have you been exercising right?' 'Well, it's not . . ..'' Other

individuals discussed how they felt when the provider made assumptions about them, which resulted in stigmatization.

One individual living with a condition in her knees that causes discomfort inflexibility said:

> So this doctor who is supposed to be just absolutely phenomenal was—pardon my French—an asshole. He was asking me questions, trying to get to know me, and I said I've always been in some type of theatre . . .. He said, 'You know, basically, you have to be really fit,' basically insinuating and getting further and further that you have to lose weight and exercise to actually be not in pain.

Two individuals discussed stigmatizing experiences with their provider when they sought care for their UTI. One woman said:

> Then the second thing is reoccurring UTIs and again I don't think that I'm particularly being bullied. But doctors definitely think . . . they give me a reason like it's because you're not going pee after you have sex and they give me a diagram of men's urine passage and women's urine passage. 'This is why you get them,' and I'm like, I haven't had sex in two years! This is not because of sex. I promise!

These quotes provide the range of experiences that individuals have had with health care providers and the ways that they have been made to feel devalued. However, a few individuals mentioned that they understand the perspective of the health care provider and the limitations put on the providers in their patient interactions. Often, these are structural limitations of limited time or the nature of the context, such as an emergency setting or a student health center.

The fourth subtheme of setting is primary education. Individuals spoke about feeling bullied, excluded, rejected, blamed, devalued, or embarrassed in K-12 settings. Instances of health-related stigma occurred with peers as well as with instructors. In interactions with their peers, individuals described how negative interactions made them feel bullied. One girl discussed her issues with a mental violation of her body that occurred in middle school:

> And I went to go walk across the court to the other guys that I started talking to, and one of the girls shouted, 'Keep walking you twig,' 'Yeah, you toothpick.' They were just naming me all sorts of stuff. I didn't look back. At that moment, I didn't care, I just laughed. . .. When I got home, that's when it really hit me. It stung, and I looked at myself in the mirror, and I told myself, 'Is that why they didn't like me?'"

Others felt stigmatized by their teachers. An example was the narrative described earlier of the individual asking her teacher if she had received her special education forms, which resulted in an embarrassing encounter. Another woman discussed how her teachers excluded her from participating in regular activities. "So it was just the whole getting excluded from things, not necessarily excluded from my peers. I didn't even get to choose if I got to go to P.E. or not," she said. In another instance of securing accommodations for one with a learning disability, one woman recalled her family's experience with teachers and with the primary-education system to arrange the right accommodations for her son living with autism. She said:

> So he got promoted through the fourth grade. We got to fifth grade, and the teacher that he had happened to be on the board for handling students with special

needs and immediately identified the issues, so it wasn't just I'm going to ignore

you. It was, 'I want you to prosper and learn.' That teacher changed our lives

because she cut out all of the red tape and said this is what you need to do to get

your son help. Although we were angry because we felt like we lost a year

because we felt if the fourth grade teacher, you know up until that point there still

kind of, they're all over the place, the kids. ADHD really seemed to fit as a

diagnosis, and we still think that he probably has some ADHD, but the underlying

cause of everything is this autism disorder."

The final subtheme for setting was bureaucratic institutions, which encompasses

interactions with structures such as institutions of higher education and government

offices. The setting of structures also was related to the previously established theme of

the body as described in the previous section. These communication episodes occurred

when individuals were constrained by structures and policy, including sexual assault

reporting and justice and filing for disability as illustrated previously in addition to

seeking STD testing.

An individual recalled his experience when seeking STD testing as a gay man and

how the structures in place constrained him:

So I went to the campus clinic and I explained to them my situation: I had never

been tested for anything. I wasn't exactly sure how anything happened. I just

wanted to know more information about testing, and I wanted to get testing done,

because I was aware that they did that at the clinic. And the male nurse who was

seeing me at the time, he said, 'Oh, well, if you are really interested in testing,

you can just get your blood drawn' and I explained that I wasn't aware that I was

able to get my blood drawn for donation because the school hosts blood drives. I

wasn't aware that I was allowed to do that because the last time I had heard

practicing homosexual males were not allowed to donate blood. But he kept

telling me, 'No, no, no, you should just go donate blood, it's the easiest way.' But

I kept telling him back, 'I can't donate blood, I'm not in that position.' So

eventually it reached the point where he flat out said, 'We won't do your testing

here; you'll just have to donate your blood" despite the fact that I was telling him,

'I'm unable to donate my blood. I need this testing done here, or I need a referral

for somewhere that will do my testing.'

The settings presented here represent the most common settings discussed by participants

where they had experienced vivid instances of health-related stigma. It is important to

note that individuals living with a stigmatized health condition feel it throughout settings

and their experience may vary depending on the context they are situated in. For

example, while an individual may feel stigmatized both in the classroom and the patient-

provider context, the experience, meaning, and outcomes will be varied due to inherent

differences of the setting and the accepted speech acts within.

The second overarching theme of RQ2 is related to episodes of communication

that call attention to the fact that an individual is somehow not conforming to norms of

society. That is, certain health conditions are deemed as socially acceptable, while others

are not. One individual illustrated this by discussing how their diabetes is considered to

be socially acceptable, while their depression is not. This is also a point of tangible versus

intangible that will be explored further during a discussion of interpretation. Three

subthemes contribute to the overarching theme: anticipated stigma, gender roles, and othering.

First, we will examine the subtheme of anticipated stigma. Anticipated stigma or self-stigmatization is the production of mental distress that one might be stigmatized. It is not the product of any direct interpersonal interaction. Instead, this type of stigma is anticipatory. For example, one individual who discussed his perspective on living with depression and avoiding the topic he said, ". . . The anticipation, you just avoided it at all costs before it even comes up." Another woman discussed her experience living with the excessive sweating condition, she said, " . . . Especially because I was so conscious of it, I was very conscious of it with other people, and I never saw anything or experienced anything with other people." The emergence of anticipated stigma is consistent with the literature. Even though this was consistent with the literature, it was initially an unexpected finding as this study aimed to look at interactions. However, the presence of anticipated stigma provides support for the idea that stigmatized feelings can be created through symbolic interaction with things such as the media or cultural norms.

Closely related to the concept of anticipated stigma is the second subtheme of gender roles, specifically, individuals indicating that they felt a sense of anticipated stigma if their condition prevented them from conforming to Westernized perceptions of gender. Women discussed their desire to be viewed as feminine. In particular, women discussed how health conditions, such as excessive sweating or issues of the bowels, might be more acceptable conditions for men. For example, one woman said:

I hate to sound like an ignorant feminist. I just think that it was perhaps more

accepted if a guy had it or because I didn't see it in anyone else, it just made it

that more awkward for people I thought when they did see it when I had it. Or

even guy's clothing kind of being made to handle sweat better than girls at some

point.

Instances like this, where women believed it would be more acceptable for a man to have

their condition contradicted the feminine image that these women desire to portray. One

woman said, "People expect things from you also, what you are born like. I really, that's

my personal thing. I really stick to those things. I try to be feminine as possible." Further,

one woman discussed the importance of portraying a sexy image when with romantic

partners and how her condition impedes this and "breaks up moments" between her and

her romantic partner. Similarly, men spoke about how men in general do not like to talk

about their feelings. When one participant was asked why he did not share his depression

experiences with others, he responded, "Maybe it's more of a guy, I don't want to talk

about my feelings . . ." Another male commented on this phenomenon prior to the start of

the interview when he asked me if any men were taking part in the interview process. He

was the first man to take part in my research so I told him that, and he said that's because

men don't like to talk about this kind of stuff—he implied experiences or feelings.

The final subtheme is the process of being othered. Individuals discussed the

phenomena of being othered as a way they were treated if they did not conform to the

societal definitions of "normal." For instance, individuals felt they were being othered in

the way they were treated, like they somehow could not navigate life by themselves or

that they needed others' assistance. One individual discussed how their sister, who lives

with a form of dwarfism, is treated in public:

People are nice, but people are overly nice sometimes . . . Someone will come up

to her at the grocery store and say, 'Can I get this for you?' and she appreciates it,

but also, no, 'I'm a really able-bodied person' able to do so much despite her

condition. Sometimes that would feel kind of condescending.

Another individual discussed her perspective on living with depression and how

individuals such as herself are represented in the popular media:

. . . They have these emotions . . .. They can't deal with society or the world, and

they're excused from their actions . . .. If they commit suicide, they are excused.

But that takes away their voice because this thing that they have impedes them

from making that decision—not held accountable for their actions . . ..

The title of this dissertation emerged from language that produces the feeling of

being othered—language that labels people in a negative way. When discussing these

labels, participants used an air-quote gesture to indicate that this was a label or stereotype

they do not ascribe to. Air quotes were used in conjunction with a variety of descriptors

such as "sick," "normal," and "crazy." With the word normal, one participant said, "I'm

not 'normal.' The word normal is so annoying, because what is normal? Just why! Why!

Does it have to be that way?!" When asked why he did not want to seek health care

during the early stages of his diagnosis with PTSD, one individual said:

Probably fear of ostricization. Stereotypes. Because like when PTSD came out,

even when you watched TV shows, they always portrayed the guy with PTSD as

some crazy guy that's gonna go kill a bunch of people. Are there people that have

done that? Yeah. It doesn't mean that I'm gonna go on a shooting rampage just

because I have PTSD, no. Because everyone has different symptoms, and I think

that I was kind of afraid that I was gonna be stereotyped as this 'crazy' guy.

The second research question asked what kinds of communication episodes do

these instances of health-related stigma occur? Two themes and eight related subthemes

emerged from the data to answer this research question. The first theme examined the

settings in which instances of health-related stigma are felt, this included five subthemes:

public spaces, primary education, the workplace, patient provider interaction, and

bureaucratic institutions. The second highlighted instances that somehow violate norms.

Related subthemes included anticipated stigma, gender roles, and othering. These themes

and subthemes provide context for instances of health-related stigma. The first theme and

its five related subthemes describe where these experiences are felt the most and the

second theme and three related subthemes more so provide evidence for why these kinds

of episodes occur. The next section, meaning, is the second step in the DICA model,

interpretation, that builds upon the representations presented the description phase and

moves toward developing more depth of understanding; specifically, the *meaning* made

in these interactions.

Meaning

This second step in the four-stage process is interpretation, which is constituted

through storytelling. This phase develops a fuller understanding of the stories provided in

the description phase. Specifically, this study examined the meaning made in these

communicative interactions and the feelings that communication episodes of health-

related stigma evoked. One research question addressed the interpretation of

communication episodes of health-related stigma, RQ3 asked: How do participants

interpret various interactions within communication episodes of health-related stigma?

The next section details the four themes and eight subthemes that emerged to answer the

third research question.

RQ3: How do participants interpret various interactions within particular cases of

health-related stigma-producing communication episodes?

Four major themes and eight related subthemes emerged that address the issue of

interpreting the meaning made in communication episodes of health-related stigma.

These are labels, emotions, identification, and media. The four themes and eight related

subthemes are represented in Table 4.

Table 4

Findings from RQ3: How do participants interpret various interactions within particular cases of health-related stigma-producing communication episodes?

Overarching Theme	Related Subthemes
Labels The process of naming.	As negative Labels make an individual seem "less than" in the eyes of society. As positive Labels can be useful to help develop understanding of one's experience. Used for comparison Comparing one label with another. Example: diabetes versus depression.
Emotions Strong feelings that were evoked through these experiences.	Exclusion Feelings of being coddled or othered. Frustration Overwhelming anger with a situation. Embarrassment Feeling of humiliation.
Positives Finding the positive meaning in negative communication episodes of health-related stigma.	Identification Finding common ground with others often through the use of humor. Support of God Looking to a higher power for strength or guidance.
Media Meaning made from media representations of illness and how these are produce and re-produced in society.	

First, I will explain the theme of labels, which describes the process of naming a health condition and the associations with that name. This overarching theme has three sub-themes: the negatives of being "labeled," viewing a label as a positive, and a comparison of different kinds of labels. Being "labeled" is generally understood as a bad experience. Individuals spoke about avoiding being labeled and what it means to be labeled. They consider the label to be a negative and that society will somehow consider them as less than. When asked if a stigma was attached to her condition, special

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education, one woman said, "People pay more attention to the label." Similarly, when speaking about her son's journey with autism, one woman said:

. . . He's labeled; he's got a label now. That's concerning to be me because that's something that I had to do to get him the help he needed, but at the same time I'm really worried, especially as an adult, how is that going to impact him . . ..

When speaking about her brother's avoidance of mental health services, one woman discussed his perspective:

Because he doesn't want that label of disabled, of being behind, of being needy. He doesn't want the label. We've actually talked to him about this. And we know there is medication that he can take. And he said, 'I don't want to be some doped-up druggy that can't think straight.' So he himself has a very negative stigmatization with that and doesn't want to be associated with."

Negative labels are associated with the experience of othering described previously. Another individual described the importance of putting the person before the label, the happiness she felt when an instructor told her class that when speaking or writing, to put the subject, the person, first and then the label. For example, one should say the boy who has Down syndrome as opposed to the Down's boy.

The next subtheme of labels is viewing labels as a positive. Individuals who spoke about this viewed the label as a useful point of reference to help others understand their experience. Individuals spoke about the importance of being able to label their condition and particularly how the label could be framed positively in their interactions. For example, the individual living with Type 1 diabetes uses the label of "Type 1 diabetes" to clarify that he is able to do certain health behaviors (e.g., eat foods sugary foods) because

he was Type 1 and not Type 2. Another individual discussed the frustration she felt when her doctors were not able to label her condition. She felt that labeling her condition of extreme fatigue would have made it easier for her friends and family to understand why she was physically too tired to socialize. She said:

> There was definitely something wrong with me, but they couldn't put it into words what it was, so rather than saying they were going to try to get to the bottom of it, they basically insinuated to my mom and to me that I was making it up.

Another individual discussed the importance of finding a diagnosis on the WebMD website for her condition of excessive sweat that she was able to use the label in conversation. She said, "I've used it a few times, whether or not I should, because I haven't necessarily been diagnosed. It just fit me really well, and it's nice to have a word." Another individual described her experience meeting with a teacher that taught her and her son what it means to have the label of autism:

> So ya, so one of the things…when I met who I thought was going to be his teacher, fortunately we did make, we're friends and so I'm able to go to him and tell him this is what I'm experiencing and he can help me. He was the first person to say "you know Simon, you have a really special brain and it works in a really special way and we're going to find out what it does really special so that you can do those things because that is what is going to make you happiest" and [he] was just like—ahhhh and just lit up.

What was particularly salient to the individual was that teacher also has autism so he was able to relate to her son in a way that no one else was able to do before. Instead of

making him feel like he was somehow disabled or less than they focused on what makes him unique. These instances of positive labels and the meaning that can be derived from viewing the positive in labels are essential findings to this study; looking at ways that negative instances can be reframed to have positive outcomes.

The third subtheme of labeling is that labels are used to compare one condition to another. The most prevalent comparison was that between mental illness and physical illness or tangible illness versus intangible illness. Individuals used conditions such as Type 2 diabetes to illustrate a point about their own condition. For example, when explaining the frustration she feels with her autoimmune disorder that causes disturbances with her bowels, she explained:

> I just think that people understand less. Because again, even if you have diabetes, maybe you cannot see it so much physically, you can see when they drop sugar, or eat at certain times, or take the sugar. And people understand it, and they work around that. But when you cannot—I could be faking it.

Another woman said that living with several conditions at once helped to crystallize her experiences. "I think that the sexual assault was a way for me to understand and really, really put words to people's psychological, physical, whatever kind of problems, they can be equal." These themes exemplify the different types of relationships that individuals can have with labels. What is particularly important about these findings is how labels can be viewed as positives.

The second overarching theme of RQ3 is the strong emotion that communication episodes of health-related stigma evoke. In particular, these emotions all have a negative

connotation. Three kinds of strong negative emotions emerged from these data: exclusion, frustration, and embarrassment.

The first subtheme, exclusion, explores the feeling of being excluded from social activity. In particular, individuals discussed being coddled by others, such as by authority figures or friends. This coddling made them feel excluded from activity and felt unnecessary to them. This is related to the previously discussed theme of being othered. One individual living with asthma characterized it this way: "I felt like teachers coddled me more. It was constantly like, 'Are you OK,' 'Is everything ok,' even like sometimes I wasn't necessarily OK, I would be like, 'I'm fine.' It was just a never-ending thing." Another had similar feelings about living with depression. Another discussed similar experiences living with depression: ". . . People who treat me really delicate, I try to express to them that I'm not a delicate flower, petal, that because of all these things, I'm actually a lot stronger than some people."

The second subtheme of emotions—frustration—was produced in communication episodes of health-related stigma. Many individuals discussed how their health condition and the interactions they've had have created feelings of frustration. Feelings of frustration were overwhelmingly created when an individual was constrained by organizational structures. For example, one woman discussed the process of getting an individualized education program (IEP) for her son, she said, "Now going through this process, I didn't expect it, and so I think frustration is probably something that I feel more than anything." Another woman discussed her experience trying to report her sexual assault through the university. She said, "[The university] is like its own little entity;. It's really aggravating . . .. It was so frustrating; it was the toughest semester I had

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in my life . . ..” Similarly, the narrative of the man seeking STD testing at a student health clinic produced frustration, and he said, “At that point I was *frustrated*, I thanked him for his time, and I left. I haven't dealt with the clinic since.” Another finding of the emotion of frustration is that it compelled individuals to give up. This theme is discussed in more detail in the next section.

The third subtheme of emotions produced in these instances of health-related stigma was embarrassment. This emotion was produced in two types of health-related stigma. These were interactions with others and instances of anticipated stigma. Individuals described their experiences of stigmatization as such:

It kills me inside to like, have to take an inhaler doing anything. Sometimes we're just like watching a movie chillin' and it's quiet and I can hear myself wheezing, and I know that he can hear me wheezing, and I'm just like, 'I'm not even doing anything right now, why can't I breathe?!' And so like I'll usually get up and go to the bathroom and use my inhaler. It's just like not sexy and it's embarrassing.

Another individual described interaction with their teacher as humiliating:

I was embarrassed. I wanted it to go away. And even though the next year, not a lot of kids had the same class with me, but it was something that I knew still happened, and every time I went to class, had to talk to her, I had to deal with— you embarrassed me in front of 20 students.

Embarrassment was closely connected to instances of self-stigmatization or anticipated stigma. In these cases, the individuals felt embarrassed by the potential of someone finding out about their condition. For example, one man said about his experiences with depression, “It's definitely like you do that all and you don't tell

anyone. It's just the embarrassment that I had to do this and move on. You just don't talk about it to anyone." The woman with Sprengel's deformity discussed how she felt embarrassed: "For me, it's so noticeable and obvious, but it's always been a source of embarrassment or lack of self-confidence . . .."

The third overarching theme of RQ3 is the positive meaning that can develop from these negative interactions. This includes finding points of identification or developing camaraderie often through use of humor. Examples are bonding with someone over living with depression and the medications associated with it. A woman living with a learning disability discussed her experience with identification as such:

> A nice thing about the school that I went to was a lot of kids went to special ed, so they understood. It was the kids who weren't in special ed that didn't understand what it is and how it works, that I got problems from.

Having others that understood seemingly made it easier for her. Another individual discussed how interactions around his physical condition—crossed-eyes—was used to develop camaraderie:

> . . . Like if it's a joking matter, like, 'Hey, '[he] can run a 21-minute three-mile, but his eye is jacked up, but this guy over here's running a 28 three-mile.' They're gonna make fun of me for my eye; they're gonna make fun of him for being a slow runner.

Every time individuals discussed finding points of identification with others, it was approached in a light-hearted manner. When asked about this concept, one person responded:

Or a lot of my friends haven't had the best childhood so we kind of bond over that

. . . then we chat about it, 'Do you take anti-depressants? Which ones are you

on?' It generally comes up pretty lightly. It's never a moment where [in serious

voice] 'I need to talk.

The second sub-theme of finding positives is searching for the support of a higher

power. When discussing her sister's journey, she said, "I think her faith has a lot to do

with that, looking to God for assistance." Another woman discussed the importance of

knowing they were created by a higher power and was designed:

. . . I'm a Christian, it's really helped me as I've grown up that I was created, I

was designed this way, it really helps a lot to not just drawing numbers out of hat,

to see if you are lucky with DNA, I'm a design, I'm a creation, I'm a piece of art

with imperfections, and that helps a lot.

The fourth overarching theme of RQ4 is representation in the media and how the

individuals respond to seeing their condition represented in mainstream media.

Individuals talked about how media can produce and (re)produce a society's perception

of illness and illness narratives. These were looked at both negatively and positively. The

majority of mentions examined the negatives of media, such as unrealistic female body

image or depression advertisements that they consider to be unnecessarily emotional.

About body image, one woman said:

. . . So many pressures on people to be perfectly beautiful, and of course the

media is destroying what normalcy is, like I was on Facebook and a friend posted

something from a glitzy magazine about a 'plus-sized model' and I was like,

'That's not a plus-size model!' It makes me angry!

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One person discussed how little people are portrayed in media: "You hear a lot just on television and on the media; people will say it or say it to her. Every now and then you will hear a midget and joke and I'm like, 'Little person, she's a little person!' (giggles)." This example discusses how the media can stigmatize and further how those stigmatizations are produced in society.

Conversely, individuals discussed how media can be useful to produce a positive message. One woman living with asthma described a radio ad she recently heard where children described what they felt it was like living with asthma. About the ad, she said:

I think it's so sweet. It's it so cute. It's like, um, little kids saying what they feel like, and there's this little boy who says, 'It's kind of like a fish out of water,' and it's so cute, because it is!

This is one example of how health conditions that are stigmatized can be represented positively. While these findings are not directly relevant to the present study, it is important to acknowledge the role that media play and how they can influence an individual's perspective. This concept also is discussed in the action stage.

This section examined findings from the third research question, which asked what meaning are made in these instances of health-related stigma? Four themes and eight related subthemes emerged from the data. The first theme of labels included three subthemes: negative labels, positive labels, and comparing labels. The second theme is the strong negative emotions experienced in these instances of health-related stigma: exclusion, frustration, and embarrassment. The third theme was finding the positive meaning including points of identification and the support of a higher power. The final theme was the role of the media in instances of health-related stigma. These meanings

provide support for the different ways that these experiences can be interpreted and how contribute to their story.

The next section, outcomes, is derivative of the second step of the DICA model, which asks critical questions to examine issues of outcome. Particularly, the choices individuals made in order to adjust for the meaning that was made in these communication episodes.

Outcomes

The third step in the DICA model is critical, which examines outcomes by asking critical questions of how meaning influences behaviors. This step examines "what we are making" and "how we are making." One research question aimed at taking a critical look at communication episodes of health-related stigma. RQ4 asked: What outcomes are created by participants' communication choices in these episodes of health-related stigma?

RQ4: What outcomes are created by participants' communication choices, in particular, cases of health-related stigma-producing episodes?

Four overarching themes and five related subthemes developed out of the data that address communication outcomes, two of which are positive: agency and life direction and two that are negative: hopelessness, and loss of trust. The findings for RQ4 are organized in Table 5.

Table 5

Findings from RQ4: What outcomes are created by participants' communication choices, in particular, cases of health-related stigma-producing episodes?

Overarching Theme	Related Subthemes
Develop agency Individual capacity to move through the world with confidence.	Teachable moments Enacting agency through interpersonal moments of education.
Life direction Negative communication episodes provided guidance for how to live their life.	Reframing The ability to reframe the situation and look at the positives that developed from it.
Hopelessness/giving up The communication episode became so dire that the individual decided to abandon the interaction all together.	Left the institution One way this was enacted was leaving the institution for another that they perceived to serve them better.
Loss of trust Trust was betrayed, thus the individual lost their trust in others and themselves.	Other Interactions made some individuals lose their trust in others.
	Self Loss of trust created self-doubt and lack of trust in one's self.

The theme of agency refers to individuals learning how to advocate for themselves in communication episodes that are related to their health condition. For example, individuals indicated that it has changed the way they interact in the patient-provider context, because they have had stigmatizing experiences. When speaking about seeking care for her UTI, one individual said:

> I think the urine infection one in terms of seeking health care, it's like I know that I have a urine infection. I don't want the doctor to tell me what to do. I'm like this is the antibiotic, this is the dosage I need; we don't need to discuss, we don't need to tell me I need to pee after sex; we just need to give me the prescription and go.

Others echoed this sentiment of entering the patient-provider context with knowledge to make their interaction work for them, but this was not always received well by health

care providers. The concept of agency also is important with action steps to improving health-related stigma. One woman who experienced stigma when applying for disability said, "I think voicing our opinions, not staying quiet. Let people know how we feel."

A subtheme of agency is teachable moments. These are moments that are used to teach others about one's condition or to correct misinformation or skewed perceptions. Teachable moments ranged from correcting language, such as asking others to not use the word "midget" or "retarded," to proving strength through action. For example, the woman living with asthma discussed running a 5K and how she felt a sense of pride and was able to show to her friends that she is capable of working out. The individual living with Type 1 diabetes said one of the best tools he has are those teachable moments. "If you're wanting to get society to a point of kind of understanding the difference, it kind of starts with you. I've had to take that responsibility. As frustrating as it is, I've taken that responsibility," this person said. The subtheme of teachable moments overlaps with themes identified later in the action stage.

The second overarching theme emphasizing positive outcomes is life direction. In managing instances of health-related stigma, individuals have determined how they can help others and prevent others from having the same experiences they have had. One individual who spoke about her experiences with special education discussed her plans for being a special education teacher:

> My plan is every year opening up about my disability and letting the kids know, I've been where they are. My plan is to turn what I've gone through into a positive. It's always something that's in the back of my mind, and it's not going to go away.

Another woman discussed giving a speech about body image and loving herself and the impact that it made on her classmates. A man living with PTSD and a TBI discussed helping others through the Wounded Warrior project. The Wound Warrior project is a nonprofit organization that provides assistance for U.S. veterans. He explained his volunteer role as such:

> I can go in there and be like, 'dude, I've been through this first-hand, I know what you're going through, I know what your family is going through, if you want me to talk to you, if you need your wife to talk to someone so your relationship doesn't end up like mine . . .. I more so try to do that kind of stuff like a shoulder for them there to be on.

This is a process of finding identity in agency and its contribution to their sense of self.

Related to positive outcomes is the subtheme of perspective or reframing. Many individuals discussed the importance of perspective, that is, that their health condition is a part of them, it helps to shape their identity, but it is not their identity. One man said about his not always recognizable health condition—crossed eyes:

> I have two arms and two legs, some people don't have that. I have friends that had that and they come back without it. So who am I to complain about something that may flare up every once in a while when there are people out there that have less than me, I would feel petty to get stuck on that.

One woman living with depression also discussed how she reflects on interactions: "I try to take all of the interactions that I've had as a positive even if they weren't positive at the time, but it helped me become a stronger person. . .." Another individual discussed reframing his experiences with PTSD/TBI:

And now, yeah I still see negative when you see people that can't pull themselves

out of whatever hole or rut they're in and go either until they're dead or in prison

or their lives have hit rock bottom. I think get more of the positive aspects of

seeing myself doing better and seeing people. . . people trying. It reassures my

faith in humanity to see people trying, people want to make the world a better

place, themselves better people, you know? Not everyone is a self-loathing

asshole that hates everybody.

These individuals were able to find the positives in their negative situations. This

provides us with hope for constructing these types of situations more positively in the

future. Further, they provide a model for positive social constructions. The next two

themes examine negative outcomes.

The third overarching theme of RQ4 is the concept of hopelessness or giving up.

This happened when individuals were pushed to the point that made it easier for them to

pursue some other course of action or inaction. For example, one woman recalled seeking

support from a rape crisis center for her sexual assault:

I never knew the rape crisis center existed. It happened to me in spring, in the

summer I found out in summer . . . It was really disappointing. The lady on the

phone, she told me, 'Well, honestly, too much time has passed. We really can't do

anything for you. If you want you can have someone sit with you while you do a

police report . . .'

The interviewee recalled that she ended up hanging up on the call. Another man said he

was not able to get the STD screenings he requested at his student health center and that

he gave up and will no longer seek services there. This phenomenon was particularly

relevant in patient-provider situations. Several individuals discussed giving up or avoiding seeking services because of a negative interaction they had with a provider. One woman provided a story:

> And one time, I was very depressed, I was like, 'I'm going to kill myself; there is no question about it.' Rather than killing myself, obviously, I'm still here. I was like I need to go to the doctor, so I got an appointment straight away, and I was like, look, 'I think I'm depressed. All I can do is think every time I turn around, I want to take pills; I want to jump off; I want to walk in front of a car; like, I don't know what to do. Help me. Help me, I think it's because I'm feeling ill. I even related it to that. The fact that I wasn't feeling very well, and the doctor said come back in a few weeks if you are still feeling the same. And I just felt so let down. I was like it's a good job that I'm actually kind of like being sensible about this, and I'm not actually psychologically damaged enough to actually hurt myself, and I was just completely astounded. That made it 100% worse.

Similarly, another woman said that after her negative experiences with an orthopedist, she will no longer seek orthopedic care: "I'm just bitter at him. And I never went to an orthopedist since, because he just made me believe that I was being ridiculous. And so if I was going to be ridiculous, why am I going to talk to anybody about it, why don't I just suffer through." In this instance not seeking care became a more attractive option than seeking care because the doctor made her feel bad about her condition.

The fourth overarching theme is loss of trust, somehow the individuals' trust was betrayed, which made it difficult to trust. Two subthemes of loss of trust emerged: loss of

trust in self and in others. When discussing her experience trying to secure

accommodations for her son's autism in the public school system, one woman said:

> I'm not as trusting as I was. I did go to the public school system. I did think that it
> was not the best, but it was adequate. I got what I needed. I don't have a learning
> disability . . . Now, going through this process, I didn't expect it, and so I think
> frustration is probably something that I feel more than anything.

Another individual discussed how losing trust in authority figures affected her:

> I guess it kind of affected me socially. I'm very closed off. Growing up, I didn't
> necessarily trust the people around me . . . and I mean doctors are supposed to
> help you; that's what you grow up with. It made me lose faith in humanity
> because these are supposed to be the best people, and they're not treating me very
> nicely, and I just lost my faith in humanity, and I just didn't think there were any
> nice people out there.

On the other side, another woman said the importance of hearing positive messages, such

as, "We don't use the word retarded," coming from an authority figure, reinforced her

trust in authority figures.

Another subtheme of trust is the self-distrust, which is questioning oneself.

Losing trust in oneself was a result of an interpersonal interaction that made individuals

question themselves. For instance, a woman discussed going home after a bullying

incident and looking in the mirror to question herself. "The most negative thing I thought

of was maybe 'How did this even happen?' and 'Why wasn't I like the other girls.'" A

man described the process of questioning himself in the health care provider context:

"That's always in the back of my mind: Because I'm gay, am I going to get the same kind of health care treatment that I would anywhere else."

Four themes and five related subthemes emerged to answer this research question: What outcomes are created by participants' communication choices, in particular, cases of health-related stigma-producing episodes? The themes included two positive outcomes and two negative outcomes. The positive outcomes were developing agency, with the subtheme of teachable moments, and providing life direction with the subtheme of reframing. The two negative outcomes were hopelessness and/or giving up, which often resulted in leaving the institution and loss of trust in both oneself and others. The first four research questions moved through the progression of description, meaning, and outcomes from the DICA model to develop a picture of what is occurring in communication episodes of health-related stigma. The next section, action, examines how these types of negative interactions can be improved.

Action

The action stage examines what measures can be taken to improve the social worlds as presented in the three previous sections. This section provides us with direction for the future and approaches for improving negative communication episodes. Further, this section moves toward answering the "so what" question of this study—it provides hope and direction for improving instances of health-related stigma, which can in turn improve our social worlds. The directions for improving negative interactions presented in this section One research question examined what can be done in communication episodes of health-related stigma to create more positive interactions. RQ5 asked: How can participants in health-related stigma episodes create positive social and health

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outcomes? Four themes and three related subthemes help to answer this research question.

RQ5: How can participants in health-related stigma episodes create positive social and health outcomes?

The four themes and three related subthemes emerged from this data to improve these kinds of negative health interactions addressed issues of education, diversity, supportive interpersonal relationships, and patient-provider best practices. Findings for RQ5 are organized in Table 6 below.

Table 6

Findings from RQ5: How can participants in health-related stigma episodes create positive social and health outcomes?

Overarching Theme	Related Subthemes
Education Providing others with knowledge about mental and physical health conditions that may clarify misunderstandings.	
Diversity Appreciating differences.	*Acceptance* Beyond appreciating making steps to accept individuals. *Conversational spaces* Creation of spaces where individuals feel free to speak about their mental or physical health condition without judgment.
Supportive interpersonal relationships Emphasizing the important role that social support provided significant others such as family and friends can have on one's experience.	
Patient-provider best practices How health care providers can improve their interactions with patients, with a special emphasis on communicative practices.	*Training* A focus on training individuals who are servicing in some professional capacity such as a health care provider or agent of the government.

The first overarching theme, education, was identified as an important aspect of

helping others to understand health-related conditions in order to create a greater general

awareness. Individuals discussed the importance of others having the education or

training to understand their condition and how it affects one's life. When asked what her

experiences might have looked like if they were more positive, one woman with asthma

said, "It would have looked like the people surrounding me in elementary school having

more education on what was wrong with me and maybe given me more responsibility

over something only I can say." Another woman emphasized the importance of education for discussion:

I wish that people could understand that depression is real, that it is very tangible, that it does affect your daily life. And it can affect more on some days than others, but it's still very present. I don't know how to make people get that. If I did, I would talk about it more.

Other individuals furthered these ideas and provided suggestions for education, particularly emphasizing type of education at the primary level. On that subject, one participant said:

I think education is really, really important. Even from a young age to like. I think if like starting elementary school age, if children were being educated on mental health, they have that on their mind from that age. People understand that it's serious.

Another participant was passionate about creating an educational program that traveled to schools across the country with a general message of acceptance:

If I had the money, I would make a thing that went from school to school, starting when they're in elementary school up to high school . . . Spread it just around the country . . . to try and teach the people the effects of what they say to people. That person may struggle with weight, but you don't know if they have a thyroid problem; you don't know if they're just genetically predisposed to be like that; you don't know if they have something going on at home that makes them turn to food, you know? So support everybody. I think if everybody just tried to support everybody, our generations to come would be better off to come, and they

wouldn't be, like you're the same age as me. They wouldn't be subjected to some

of the stuff that people our age had to go through with the ridicule and stuff. Even

with my professional life, with the ridicule. I think if we taught them as children

to be more open and understanding of people's personality quirks, physical

defects, limitations, whatever, that as adults, they would be more open to someone

who does have PTSD, someone who was bipolar.

In addition to large-scale education shifts, individuals discussed education at an

interpersonal level. Again, discussing those teachable moments and how engaging with

individuals at this level can improve awareness and connect health conditions with actual

people. This person's ideas overlap with the theme of diversity.

The second overarching theme is appreciating diversity, concepts encompassed in

diversity are appreciating diversity as well as opening up conversational spaces where

individuals feel safe to discuss their mental or physical health with others. This included

accepting, and one individual said, "And I would say, 'Oh, God, I thought I would never

say this, that it's OK to be different. There's nothing wrong with you for being different."

Another woman said, "I think just the open-mindedness, just knowing that people don't

all act the same, and they shouldn't, just that general idea. I know that I would have

thought about things differently . . ." If these qualities of accepting and appreciating

difference were common in society, it would be easier for individuals to begin

conversations about stigmatized health conditions.

The next overarching theme is supportive interpersonal relationships. As one

participant said, "When there are people that accept you, you don't stigmatize yourself as

much or hate yourself for being that way." While participants were able to offer

suggestions for improving such instances in general society, there was still an overwhelming skepticism to the reality of this. As an alternative, individuals suggested a focus on developing and maintaining strong interpersonal relationships among family and friends:

> . . . I think that bullies are going to be bullies forever. I don't think that will ever change. The only thing that we can change is being better friends and parents and looking out for the ones that are getting bullied and just making sure that they get some support and they don't—heaven forbid—kill themselves, shoot in a school or something.

Another individual discussed the importance of seeking out supportive relationships as opposed to toxic ones: "Make the choice to make your interactions better with better people as opposed to trying with some who's not going make it better." Many of the participants discussed the important role that significant others, such as partners or parents, play in their life: " . . . Having my boyfriend now, even if my goods are damaged or broke, it's OK. And so having him in my life has kind of changed the way I see myself with my mental illness, as being happy in the future." Another individual discussed the role of her parents: " . . . I was very lucky to have parents that basically told me my whole life that I was beautiful and I was powerful and strong and that I deserved the best from people." It's also important to note the difference that can be made by one person: "If I just had one person who could understand, or even not understand but say I don't understand, but I'm here to support you, would have been dramatically better. Like one person."

Related to developing strong interpersonal relationships is the fourth overarching theme of patient-provider best practices. For example, individuals discussed the role that the provider can play in the healing process and the desire for providers to show compassion in patient-provider interactions:

> . . . Trust and compassion are a big thing for me, so I guess because my family wasn't compassionate, they didn't really hug, but when you go to a doctor, they're not really compassionate. Holistic are, but doctors, they only have 15 minutes. It's kind of robotic just like chop, chop, chop and you're out. In health care, you should feel comfortable in your setting . . ..

Similarly, another individual discussed how her providers listening to her improved her care experience:

> In terms of seeking health care, I try and avoid seeking health care for that—I definitely got forced last time I fainted to go see someone . . . when I got admitted into ER. It was really annoying because I didn't have a choice, but at the same time it was very much because they listened to me. I was more open to doing tests even though it was a pain.

A subtheme to this is education and training for health care providers. For example, the individual who was denied STD screening believed that if the nurse had more training about testing and U.S. law, he might not have been turned away:

> . . . If he, the nurse, had understood or accepted you're a homosexual male, you cannot donate blood, so we will provide you the services. If he had made that connection. . . or accepted the fact that I was unable to do what he was asking of me. . . then the entire situation could have been avoided.

Similarly, the individual whose government disability assistance was not acknowledged believed that if the case manager she spoke with were better trained, she would have received the disability she deserved in a timely manner.

This section answered RQ5, which asked: How can participants in health-related stigma episodes create positive social and health outcomes? This research question was answered with four themes and three related subthemes. These are education, diversity, supportive interpersonal relationships, and patient-provider best practices. Each of these themes and their related subthemes provide directives for how to make negative interactions of health-related stigma more positive. These findings are the crux of this study and provide hope for improving negative interactions. The first four sections moved through the four steps in the DICA model, the final section, stigma, provides participants perspectives on the word stigma. This research question was included to understand how the label of stigma is perceived. The following section details how these perceptions and the process of incorporating stigma into the interviews.

Stigma

Another unique characteristic of this study is that the label of stigma was not provided until the end of the interviews. Additionally, questionnaires did not use the word stigma. Instead, stigma experiences were referred to as instances of "bullying, exclusion, rejection, blame, or embarrassment that they believe is due to a physical or mental health condition they possess." Further, the concept discussed during the interviews wasn't identified as stigma until the conclusion of the interview. To examine individuals' responses to labeling their experiences as "stigma," RQ6 asked: How do

participants perceive the concept of stigma? This method produced two themes and one related subtheme.

RQ6: How do participants perceive the concept of stigma?

The two themes and one subtheme that answer RQ6 are: Discussing stigma in the frame of their experience(s) with the health condition(s) they came to discuss, and not relating to the word "stigma." These themes and subtheme are represented in Table 7 below.

Table 7	
Findings for RQ6: How do participants perceive the concept of stigma?	
Overarching Theme	Related Subthemes
Stigma within the frame of their experience Explained the stigma that exists for the mental or physical health condition discussed in their interview.	
Not relating with the label "stigma" Stigma was not in their vernacular, which made it hard for them to relate to the word.	*Distaste for the label of "stigma"* Further several individuals expressed that they did not like the word stigma and its connotations.

The first theme was individuals discussing stigma within the frame of their experience. These individuals spoke about how they view their health condition as stigmatized by others. These are represented in Table 8. The perspectives provided here provide a range of health conditions and also provide support for the existence of these stigmas and how they are experienced.

Table 8	
Stigmas associated with specific health conditions	
Health Condition	Related Stigma
Asthma	"I think that it when people have asthma like I do when they carry an inhaler the stigma would be that that person is sick."
Dwarfism	"And, yeah, so I think stigma that it is a disability because people are less capable. And in some ways they're kind of funny. They're here for our entertainment, but we don't really think of them as real."
Mental health	"I think a lot in older generations there's a lot of stigmatization because they don't really understand. Like my generation now, there's more exposure about mental health issues, there's more articles on it. You can go to Yahoo and there's often articles on it or education about it."
Diabetes	"It's definitely relevant because they always tie obesity or being overweight to diabetes. I mean I'm not overweight so I don't get that as much, but there are some type 1s that are honestly not taking care of themselves and they'll get asked are you overweight because you're not taking care of yourself? So diabetes is stigmatized with being overweight"."
Excessive sweating	"Well yeah, just kind of the stigma of men sweating more than women and it being okay for men to sweat more than women."
Autoimmune disorder	"I don't know, like I really don't know. I just think that in general, stigma for people like us is the bathroom side." Should deformity, experience of internalized stigma: "You saying that made me realized, even though it's internal, it's still external there is that expectation that you're supposed to look like that. Even though it's never been expressed to me externally, I know their expectations and knowing that I'm different than the norm. Ya, stigma, I think that's appropriate."
Learning disability	"I don't really, I think I basically talked about it without meaning to. It was the way I was treated, it wasn't right. And the only thing is the negative connotation with special education, they don't understand it, and if they did, things would be a lot different."
Convergence of mental and physical conditions (Depression, sexual assault, and diabetes)	"I find stigma fascinating. Somehow with diabetes the stigma is that you had this terrible thing thrust upon you and everyone wants to help. Ignoring all of the things you can do for yourself. And the stigma for sexual assault and depression is that you somehow brought it upon yourself. And depression, I haven't figured out how to get out of that yet. I haven't figured out how to explain it to people, but sexual assault, I feel like I have to tools to be like, 'no, no I didn't' I can talk about it, I can talk about it until I am blue in the face. I think it's a huge power to be able to change that stigma."

The second theme was individuals who did not relate to the word stigma. Some of these individuals indicated that it was not a word in their vernacular. For example, when the concept of stigma was introduced, one participant responded: "Confusion. I've never heard 'stigma.' It's not something that's stuck with me . . .. When I read it, I look at the words around it for context clues . . . because I don't relate to stigma." Another said, "I guess that's all happened. It doesn't change it. Just because you put a label on it, it doesn't change it."

The subtheme of not relating to stigma was an expressed distaste for the label of "stigma." Most of these individuals were familiar with the term stigma and spoke about how they viewed the label. One individual said, "Stigma to me seems like a social word, like you are cast out to me, generalized. It's like you know you're categorized." Another participant was vocal about wanting to change the accepted usage of the word:

Yeah. We shouldn't tell people they have stigmas. Like I said, everyone has their quirks. I don't know you from Adam, but I'm sure you have things you struggle with just like you know that parts of my life, you don't know other things I may struggle with. I just think that everyone should feel like no matter what they have, no matter what their deficiency was, it's OK; it's not a stigma.

The themes outlined in this chapter highlight the most important emergent themes as discovered using methods of grounded theory. These themes provide a range of perspectives about the processes of health-related stigma and how to improve these types of negative communication episodes. The following chapter delves deeper into these findings to provide a rich discussion of the themes and their implications.

CHAPTER FIVE: DISCUSSION

The final chapter of this dissertation discusses in more depth the findings from the last chapter and their contribution to stigma literature. This chapter unfolds in five parts; first, a discussion of each of the findings for each research question; second, theoretical implications of the project; third, everyday implications; fourth, project limitations; and fifth, extensions of this work. The purpose of this study was to examine communication episodes of health-related stigma in order to understand what occurs in these types of communicative interaction and further learn how these negative interactions can be improved in the future. The theoretical framework of the coordinated management of meaning (CMM) was used to examine these processes. The DICA model—description, interpretation, critique, and action—advanced by Pearce (2007) as an application for the use of CMM was used in the construction of this project. The research questions for this study and subsequently the findings correspond to this model. Findings are presented in five areas: description, meaning, outcomes, and action, which correspond to the CMM model as well as stigma. This chapter begins by discussing findings.

Findings

This section discusses findings outlined in the previous chapter. Relevant literature is incorporated to reinforce the discussion. The discussion of findings is presented in six sections, one that corresponds to each research question.

Discussion of RQ1: What kinds of health conditions are attached to stigma?

The first research question examined the types of health conditions to which experiences of stigmatization are attached. Five themes emerged to account for the range of stigmatized health conditions including mental health, visually recognizable physical

health, not always recognizable physical health, internal health, and violations of the body. Many of the health conditions that emerged were consistent with previous studies, such as issues of mental health, Type 2 diabetes, and STD testing (Lupton, 2000; Smith, 2011; Weiss & Ramakrishna, 2004; Wahl, 1999). In addition to these commonly stigmatized conditions, the interview sample included narratives that discussed conditions not previously considered, such as hyperhydrosis, Type 1 diabetes, urinary tract infections, and body consciousness. Hearing the narratives associated with these instances, it is clear now that these are communication episodes of health-related stigma. These findings highlight the importance of considering all experiences that may produce feelings of bullying, exclusion, rejection, blame, or embarrassment. Further, this emphasizes promoting diversity in our social worlds as well as in research endeavors by being open to learning about the health conditions that impact people's lives.

The literature provides several classifications of stigma. However, many of these are dichotomous: internal versus external (Quinn & Chaundoir, 2009) existential or achieved (Falk, 2001). This study aimed to extend the literature to expose the gradient of health conditions and accompanying stigma experiences that exist in order to better understand those experiences. This allows for more precise categories to emerge that more accurately capture experiences. Previous studies such as Quinn and Chaundoir (2009) conflated concealable stigmatized identity—something that must be disclosed to the other such as mental illness or HIV status. So-called concealable stigmatized identities were well represented in this study, but were not lumped as one. Instead, the present study created more precise categories to accurately describe "concealable" stigmatized identities as a sexual assault is not the same at Type 2 diabetes.

Another finding of RQ1 was the circularity of health conditions particularly, how one exacerbates the other. Most often, this was a combination of a physical condition and mental distress. These findings prove that stigma creates a vicious cycle that impacts individuals physically and mentally. These findings help to extend the assertion that stigma can impact an individual both physically and mentally (Holland et al., 2010) and also that physical and mental health conditions can impact one another. An example is the narrative of the woman living with an unlabeled condition that made her sick and tired, coupled with feelings of depression; the doctors inability to provide her with a prognosis made her feel even more down.

Discussion of RQ2: What kinds of communication episodes most commonly create conditions of health-related stigma?

The second research question discussed the kinds of communication episodes that produced health-related stigma. Two themes and eight related subthemes emerged to answer this research question. First, is the theme of setting—which represents the settings in which these communication episodes most commonly occur. The settings that emerged were public spaces, the workplace, K-12, and institutions. To my knowledge, settings of health-related stigma have not been studied like this previously. The grounded, qualitative approach to this study allowed for a variety of contexts to emerge. Previous empirical studies (Quinn & Chaundoir, 2009; Smith, 2012; Smith & Hipper, 2010; Wahl, 1999) do not consider settings like this. There are inherent differences in setting and subsequently the experiences of stigmatization due to expected speech acts within that context (Pearce, 2007). This study starts this conversation, but this is a phenomenon that deserves further investigation to look examining exactly how experiences

What I found particularly relevant about these findings is that the four settings: the workplace, primary education, patient-provider interaction, and institutions, are structures that individuals must interact with on regular basis. Emphasis should be placed on these settings to create a safe environment when interacting with those structures. This is an issue at all levels of the structures, from larger governing policies to everyday interpersonal interactions within those structures. Another note about setting is that public spaces were directly related to individuals living with a visibly recognizable physical health condition. This is consistent with Smith's (2007; 2009; 2011) content cue of the "mark" that is that an individual is marked in a way that makes their health condition recognizable to others and indicates that this individual is different and therefore stigmatized. This is an interesting phenomenon I would like to explore in future studies.

The second theme that emerged to answer RQ2 is the violation of societal norms. These experiences made individuals feel like they were not meeting the expectations of society. This is consistent with the definition of stigma as a form of disgrace (Smith, 2007; 2011; 2012). This theme is also consistent with CMM specifically, the socialized self of CMM, in which an individual is becomes a tribe member (Pearce, 2007). In this socialization process individuals learn which speech acts are culturally acceptable. Findings from this study provide an example of individuals negotiating instances of health-related stigma they deem are not socially acceptable.

The subtheme of anticipated or internal stigma was also consistent with stigma literature (Quinn & Chaundoir, 2009). Anticipated stigma is an internal process that produces mental distress; it is about potential interaction, not about an actualized one. Individuals discussed how anticipated stigma influenced their choices and made them

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feel self-conscious in social interactions. The present study aimed to look interactions of health-related stigma, but anticipated stigma was directly related to stigmatizing experiences. What creates anticipated stigma and therefore influences interactions is a topic that deserves further investigation. This may be an issue of symbolic interactionism, which is one way that this study can be extended in the future.

The second subtheme is othering. Othering also was consistent with the literature (see Johnson et al., 2004; Shapiro, 2008; Van Breda, 2012). Findings from this study complement and extend literature on othering and its relationship with stigma. Individuals discussed actions and language that "other." This emphasizes the importance of communicative acts—actions and language. What I found particularly tangible and relatable with this concept was participants' use of the air-quote gesture when discussing labels that other them, such as "sick," "crazy," or "normal." These findings aim to complement and extend literature on language and language choices (Littlejohn, 2009). The air-quote gesture implies knowledge of the connotations that these words carry in social worlds. In particular these findings indicate that individuals experiencing stigmatization are conscious of these labels and in turn feel othered by this language. One explanation for this is that othering is used to ameliorate dissonance created by the human condition as Shapiro (2008) determined.

While anticipated stigma and othering were consistent with the literature, the subtheme of gender roles was not expected in relation to health-related stigma. As this subtheme began to emerge throughout the interviews, I began to see how not conforming to gender roles led to stigmatization, at least for those who desired to conform to traditional gender roles, in particular when gender roles are related to cultural

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implications (Pearce, 2007). Further, Lupton (2000) discussed the expectations of the

feminine body. Many of the narratives provided in this study helped to reinforce Lupton.

However, examining how the feminine body compares to the masculine body in relation

to health-related stigma and gender roles deserves additional investigation.

Discussion of RQ3: How do participants interpret various interactions within

particular cases of health-related stigma-producing communication episodes?

The third research question examined the meaning made in communication

episodes of health-related stigma. Four themes and eight related subthemes emerged. The

first theme: labels used to name these health conditions and the connotations of the

labels. Smith (2007; 2009; 2011) identified the label as the name given to a stigmatized

group, typically with a negative connotation. The first subtheme—negative labels—can

be used to describe stigmatized groups as "less than." Individuals discussed labels with

which they have experience, such as "special education" or "autistic," and the meaning

those words carry that may limit how an individual engages with society. Negative labels

are related directly to the process of othering, which was discussed previously. The

second subtheme looks at labels as positives. Individuals who spoke about positive labels

found that their label was a useful point of reference to help others understand their

experience. Viewing labels as a positive is something I believe is unique to this study.

Generally, labels are negative (Goffman, 1963; Smith, 2007; 2009; 2011; Smith &

Hipper, 2010) as described in the previous subtheme, but this subtheme is a reframe that

highlights the usefulness of labels and works to extend the literature through to include

this perspective on labels. Reframing labels is one approach to move toward social

change—that is, removing the negative connotation of labels and emphasizing the

positive aspects. For example, the label autistic would mean that a person living with autism thinks in a special way that others do not. This perspective would extend literature on labels. The third subtheme of labels and another extension of the literature was comparing one label with another. Mostly, this was a tactic used to explain the feelings associated with their health condition. Comparing tangible physical illnesses versus intangible illnesses or even uncommon physical health conditions was common. Many participants discussed that they felt that if their health condition was not something tangible—like Type 2 diabetes, which is generally understood, accepted, and accommodated for—makes them feel like their health condition will not be understood by others. Individuals living with other conditions that deal with issues of mental health or more uncommon health conditions, like the woman living with the autoimmune disorder that causes frequent bowel disruptions, might be accused of "making it up." Thus, a label that was more tangible was preferred to ease their interactions with others. This finding is also unique to this study; a good way to understand this concept is to use a lesser-of-two-evils perspective, where both are bad but one carries less burden.

The second theme of this research question is emotion. Smith and Hipper (2010) called for including emotion in models of stigma including the emotions of shame, guilt, and pride; while Link et al. (2002) discussed that stigmatized individuals might have feelings of being misunderstood, different, or even ashamed. This study provides additional emotions that an individual might feel and how they may affect outcomes. These interactions of health-related stigma produce three negative emotions: exclusion, frustration, and embarrassment. These strong negative emotions created a negative association with communication episodes that involved health conditions. Specifically,

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these emotions impacted outcomes, such as recalling instances of health-related stigma, behaviors in the health care context, and interpersonal relationship development.

The third theme is finding positive meaning in instances of health-related stigma. Individuals discussed the ways they experienced positives, such as identifying with others and finding support in a higher power. The subtheme of identification highlighted instances where participants found common ground with another person. Finding common ground was a positive experience that involved humor and developed camaraderie. Identification is important to the meaning that is made as well as to later suggestions for bettering these types of interactions through awareness initiatives that can use the concept of identification in the construction of the message discussed in RQ5. Findings from this study extend the conceptualization of stigma and provide direction for reconceptualizing what it means to live with a stigmatized health condition through positive communicative acts. Authors such as Link and Phelan (2001) and Smith (2011) discussed the imperative for better understanding stigma in order to improve stigma; this study answers that call in particular adding the positive reframe. Additionally, findings from this study serve to add to the literature about positive communication in health (see Pitts & Socha, 2013).

The fourth theme, media looks at the meaning that is made in media representations of illness and how these images are produced and (re)produced in society. Wahl (1999) discussed the role that media play in the stigmatization process for people living with mental illness. This study builds upon those findings and highlights instances of negative representations, such as little people being used as props for entertainment as opposed to being cast in lead roles, and builds upon positive representations, such as

radio ads that illustrate what it is like living with asthma. This finding—that the media influences society—is not novel (Lupton, 2000; Wahl, 1999). However, these findings upon current knowledge and provides additional instances of the media's influence, particularly in the context of health-related stigma. This phenomenon is not directly related to this study, as this study was predominately concerned with social interactions, however it was present throughout the interviews and deserved attention. Future research about this topic in relation to symbolic interactionism should be conducted.

Discussion of RQ4: What outcomes are created by participants' communication choices, in particular, cases of health-related stigma-producing episodes?

The fourth research question examined outcomes of the meaning made in the communication episodes of health-related stigma. Four themes and five related subthemes emerged. The first theme is the development of agency—capacity that helped the individual to move through the world with confidence. This concept has two subthemes: finding a sense of identity in the agency and using teachable moments. The subtheme of identity in agency is an example of a socially constructed personal identity as described by Ting-Toomey (2005). A part of that personal identity is engaging in the second subtheme of teachable moments. Individuals described their teachable moments as interpersonal interactions where they took a moment to provide education or correct misinformation about their health condition. The development of this personal identity is a positive outcome of health-related stigma experiences. These findings showed an integration of the stigmatized identity similar to the one found by Baumgartner and David (2009). In their study, Baumgartner and David (2009) found that the HIV identity is one several competing identities that one may possess, their "poz" identity does not dominate

their life. Similarly, in this study it was found that the health-related stigmatized identity is one of several identities that does not define the individual, instead it is one of several identities that contribute to the individual.

The second theme of outcomes is life direction. Life direction considers the concept of reframing and using their experiences as lessons for how they want to live their life. This included examples of their career choices or how they want to raise their children. This is a great example of growth born out of challenge, a tenet of conflict communication (see Littlejohn & Domenici, 2007).

The third theme of outcomes is hopelessness or giving up. This theme highlights communication episodes that became so dire that the individual decided that it was best to abandon their pursuits. The related subtheme was individuals who enacted "giving up" by leaving the institution for another, such as moving from one college to another or seeking health services through another health care provider. These findings are particularly salient for institutions and emphasize the importance of creating a safe environment where individuals want to be and are comfortable. Sayles et al. (2009) found that stigma limits individuals' agency and access to care. The present study found support for this in some cases such as the instances that made and individual give up, while in others it created agency as described previously.

The fourth theme of outcomes is a loss of trust in self and others. Somehow, the individuals' trust was betrayed, which made them lose that trust. The first subtheme—othering—accounts for instances where the individual lost their trust in an interpersonal interaction; this lack of trust caused them to close themselves off and become less trusting of the structures they interact with. The second subtheme of trust was a loss of

trust in oneself. These instances created self-doubt and can contribute in a negative way to personal identity.

Discussion of RQ5: How can participants in health-related stigma episodes create positive social and health outcomes?

The fifth research question examined how change can be made in social worlds to improve health-related stigma. Four themes and three related subthemes emerged as action steps for improving these types of negative interactions. These themes provide an extension of current literature and give concrete directives for future interventions. The first theme is education. It considers the importance of creating awareness and providing others with knowledge—this is tangential to teachable moments. Essentially, this theme expands upon the outcome of teachable moments and aims to expand upon teachable moments in a way that makes this a widespread practice. Further, education should be emphasized at the structural level providing large-scale education in places such as schools. Training is the related subtheme of education. This subtheme refers directly to individuals who provide service in a professional capacity to make sure consumers receive the best care possible.

The second theme of action is diversity. This theme is about appreciating each other's differences. The two related subthemes are acceptance and conversational spaces. The first subtheme, acceptance, moves beyond just appreciating differences to a place of acceptance where being different or "other" is socially acceptable. The second subtheme, opening up conversational spaces, refers to creating spaces where individuals feel free to discuss topics, such as those addressed in this study. Primarily, it is about accepting each other's humanity that people are different and unique, and that is important.

The third subtheme of action calls attention to the importance of creating strong interpersonal relationships through social support. Social support is the perception that one is being provided care, assistance, or comfort from a network of others when they need support (Albrecht, Burleson, & Goldsmith, 1994; Heaney & Israel, 2002; House, 1981). This theme discusses the importance of support in interpersonal relationships from family and friends. This is particularly salient to the development of support networks, and making individuals aware of the important role they can play in one another's life.

The fourth theme of action is patient-provider best practices. This theme is about the ways that health care providers can improve their interactions with patient to deliver the best care possible. This theme places special emphasis on communicative acts between the patient and provider. This theme deserves more attention in future research. One way of approaching this is through focus groups with mental and physical health care providers, which are discussed as one possible direction for future research.

Discussion of RQ6: How do participants perceive the concept of stigma?

The sixth research question examined the participants' perspectives on stigma. Two themes and one related subtheme emerged. First, identifying the "stigma" that is associated with the health condition discussed throughout the body of their interview; examples include discussing the association between being overweight and Type 2 diabetes, or individuals not understanding mental health. These findings are consistent with Lupton's (2000) assertion that stigmas are associated with certain health conditions, in particular those that have to do with regulation of the body.

The second theme was not identifying with the term "stigma." This theme accounted for individuals for whom stigma is not in their vernacular and also those that

do not care for the label of stigma. The related subtheme is expressing distaste for the word. These individuals made a point of discussing the negative connotations with the word and how they felt it was largely an unnecessary word. As far as I know this finding is unique to this study. At the outset three assumptions about the nature of stigma were advanced: it is a complex process, it is socially constructed, and it is a communicative concept. These assumptions in conjunction with the present findings provide support for attempting to mitigate usage of the word stigma. Stigma is a heavy word; its connotations are heavy. Moderating the use of "stigma" in everyday communicative acts (Cline, 2011) such as those social or structural settings would alleviate some of the burden that one living with the health condition might feel in situations like the ones described in this study.

The social construction of stigmatized illness is not novel. This study aims to further previous findings on health-related stigma as well as illuminate new perspectives on how to manage health-related stigma. This study provides two important overarching findings: (a) how we communicate matters—that interactions of health-related stigma are patterned through interaction specifically through cultural expectations of coherence and coordination (Pearce, 1989; 2005; 2007). Meaning that these patterns can be interrupted and reconstructed in a more positive and productive manner; (b) this study provides *how* to reconstruct these types of patterns through a positive communicative perspective. Specifically, examining how negative communication episodes can be reframed to emphasize the positive as opposed to the negative. One such reframe is viewing negative interactions as a learning experience, which direct the individual toward a better future such as findings ways to help others avoid the same type of negative experiences as the

ones that contributed to this study. Further, reframing includes viewing one's health condition not as something that makes them different or other, but instead unique or special and can contribute their uniqueness to the world. The next two sections discuss the theoretical and everyday implications of this study.

Theoretical Implications

This section discusses this study's contribution to theory. I see three ways in which this study contributes to communication theory and stigma theory: the usefulness of CMM, it furthers stigma as a communicative concept, and promotes a systems view of health-related stigma interactions.

First, the social approaches (Leeds-Hurwitz, 1995) used in this study provide a unique perspective to unpack experiences of health-related stigma in a way that honors the complex communicative system in which these experiences of health-related stigma are occurring. The grounded approach in the present study of health-related stigma incorporated narratives that allowed for individual's stories to be told. CMM provided the process for opening up the stories that contributed to this study's rich perspective on health-related stigma. The study of health-related stigma through the lens of CMM is novel to this study. CMM revealed facets of health-related stigma; specifically, the progression of description, meaning, outcomes, and action—corresponding to the DICA model (Pearce, 2007)—helped to support the argument that interactions of health-related stigma are socially constructed through patterned communication. Episodes of communication that build upon each other, and the acceptable speech acts within these episodes help to develop culture. This provides support for a move towards changing the narrative of acceptable speech acts, to be more supportive of diversity. Further, patterned

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social constructs, such as health-related stigma, can then be re-written through social interaction. This study provides directives for re-directing instances of health-related stigma in a more positive and productive manner. Approaching health-related stigma in this manner will help to ease the social burden of living with a stigmatized health condition and improve day-to-day interactions that may evoke stigmatized feelings.

Second, this study adds to the theory of stigma as a communicative concept (Smith; 2007; 2009; 2011) and emphasizes that health-related stigma is its own theoretical concept. Particularly, it examines what is being made through communication. This study examined the role of communication as object and theory (Pearce & Cronen, 1980) to develop a full understanding of health-related stigma processes such as: the impact of one health condition on another, how meaning such as language that others such as "sick" can impact health or social outcomes, or how teachable moments are considered an outcome of health-related stigma and also provide direction for improving instances of health-related stigma. Examining health-related stigma from a communication perspective considers that communication is a dynamic set of principles that are ever evolving and construct our social worlds (Pearce, 2007).

Third, findings supported the relationship between themes. This supports taking a systems view of health-related stigma. In this system the four concepts of description, meaning, outcomes, and action—derivative of the DICA model (Pearce, 2007)—reflect upon one another. Specifically, that these types of interactions are patterned—that is that the individual is influenced by interactions of health-related stigma. Improving these types of negative interactions through things such as education, training, diversity and focusing on creating deeply supportive interpersonal relationships can improve negative

interactions. Essentially, this is a re-frame. The next section discusses the everyday implications of this study—how the findings from this study can be applied in everyday interactions.

Everyday Implications

This study also promotes several practical implications for how to apply findings in ways that improve everyday social interactions. I see three ways that findings from this study can be practically applied: providing catharsis in interpersonal relationships, movement toward social change that begins on an interpersonal level, and promoting the characteristic of responsibility at four levels of interpersonal, community, organizational, and policy.

First, a project like this provides a cathartic outlet. More importantly, it provides individuals with the opportunity to have their voice and their narrative heard. Some individuals who took part in interviews shared with me that what they were telling me was something they had told very few people before. This exemplified the value of this project to me. I think that the lesson learned here is to create safe spaces in our interpersonal interactions where others feel comfortable enough to let down their guard and share (Littlejohn & Domenici, 2007). The challenge here is that research studies such as this one are inherently a safe space because of the structures in place to protect participants. Then the question is how do you we translate that same characteristic of safety to interpersonal interactions? One way that I created a safe space in the interviews was to find points of identification, such as discussing our shared interest in the topic, at the beginning of the interview. Sharing like this has worked for me in research interviews and my interpersonal relationships.

Second, many participants expressed their interest in the outcomes of this research and mentioned the value they saw in this project. Additionally, during the closing of the interview when I discussed that I will be writing a white paper to share with my interview participants each participant was enthusiastic about receiving the results. This supported the value of this project. Further, knowing that individuals are interested in these findings supports movement forward to begin the process of changing social norms. This project taught me that this begins at the interpersonal level. Another important point to make is that sometimes we are unaware that we are stigmatizing others through our actions or language. For example, when someone uses the word "retarded" they may not realize the negative impact their word choice has. This is a lesson learned from this project that was crystallized through a moment in the classroom when a student of mine unknowingly used the word "retarded" to describe their actions as dumb. It was clear in that moment that the student did not intentionally use the word to harm others, instead they were unaware of the impact that word may have on others (Cline, 2011; Littlejohn, 2009). Thus, it is important to build awareness about everyday interpersonal interactions (Cline, 2011) like this with friends, family, colleagues, students and the like, that produce feelings of stigmatization. For example, emphasizing teachable moments and what can be learned in those moments.

My final point about everyday implications that I learned from this project is the promotion of a sense of responsibility in individuals, communities, and organizations. I see these responsibilities as such: individuals should be responsible for their communicative acts—both language and action; communities should focus on creating safe welcoming environments; and organizations and policy should focus on removing

outdated policies or laws that produce instances of stigmatization—like the student health center blood drive policy that precluded the individual from getting STD testing. The next section looks at the limitations of the present study.

Limitations

At this point I would like to discuss a few limitations of this study. First, the perspectives provided in this study represent individuals at a particular time; these opinions may change over time. Additionally, social constructions like stigma have a temporal quality (Falk, 2001), which means that stigma of a particular health condition may dissipate over time. Thus, findings in this study should be considered a product of current—2014—social worlds. Finally, the study is limited in the sense that the individuals did not represent much diversity. The interview sample was predominately white, non-Hispanic and female. Despite these limitations this study provided a strong baseline for future studies. The next section provides suggestions for how this study can be expanded upon in the future both in this line of research as well as how it can be extended to other areas of communication.

Extensions

In addition to the findings, theoretical and practical implications this study provides direction for future studies. I see several directions for this line of research. This includes focus groups to discuss the findings of the current study with individuals who have experienced health stigmatization and health care providers, narrowing the lens of study, and creating health campaigns that emphasize action steps to improving health-related stigma.

First, I would like to conduct focus groups around the topic of health-related stigma with individuals who have experienced health-related stigmatization. I envision that the findings from this study would be points of discussion in future focus groups. The focus group discussions would incorporate the findings from the present study; and further, they will also be structured to open up conversational spaces for individuals who have experienced this type of stigmatization.

Second, I would like to conduct focus groups around this topic with mental and physical health care providers. I believe that incorporating health care providers would add another layer of perspective and understanding, particularly with instances of stigmatization in the patient-provider interaction. Similar to focus groups with individuals who have experienced health-related stigmatization, these focus groups would be structured to include findings from the present study as a point of reference.

Third, in future studies I would like to narrow the lens of study to one genre of mental or physical health conditions at a time. For example looking at instances of internal physical health in one study. A narrower focus would allow for me to be more directed in theoretical and practical application. This may be an approach that I take in new studies within this line of research or I may conduct additional analyses on the present dataset. Another way that I would like to extend this study in the future is to examine specific settings of episodes. For example, examining episodes of health-related stigma that occur in the patient-provider interaction or one's that occur in the student-teacher context. Selecting one setting would allow for the interview questions and subsequently the action steps for improving these types of interactions in the future, to be more effective and directed.

The fourth direction I see for the future of this research, developing health campaigns around the topic of health-related stigma. I have a background in strategic communication, thus I believe that my knowledge of this project married with my background in strategic communication would be the basis for an effective health campaign. Preliminary thoughts on this include an emphasis on action steps to improve instances of health-related stigma that provides education or emphasizing the importance of diversity and acceptance.

Further, I would like to work with a research team on this project. This research study provided a cathartic process to the participants, but this also led to researcher fatigue. This research involves hard conversations. Dispersing those hard conversations among a research team would lessen the burden of this project while also providing a catharsis to the participants. Future studies in this line of research would benefit from the strength of a research team to gather a variety of perspectives. This leads into the next section of future directions, which discusses projects that will build upon the current findings.

Finally, I would like to examine health-related stigma in different groups, as it was outlined previously one of the limitations of this study was that the sample was mostly homogenous. In future studies greater emphasis should be placed on diversity to examine the different lived experiences of health-related stigma. This includes examining the influence of historical trauma, political action, and social action in these types of experiences. An additional extension of this work may include examining the role that media plays in the health-related stigma in particular using social interactionism.

These are a few directions I envision for this line of research moving forward; I am proud of the work produced in this project from the conceptualization to execution. This project served as a baseline study to gain entry into the line of stigma research. In later studies I plan to expand upon what was created here. I believe that this study created a real impact with the communities that I aim to serve and I look forward to future endeavors with this topic.

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APPENDICES

Appendix A: Email to instructors

Appendix B: Script for classroom visit

Appendix C: Recruitment questionnaire

Appendix D: Interview invitation

Appendix E: In-depth interview guide

Appendix A

<u>Email to instructors to ask to visit their class</u>

Hi (name).

I am currently working on my dissertation, which includes engaging in conversations with individuals' about their experiences with health-related stigma. Specifically, I am interested in talking to individuals that have experienced an instance of bullying, exclusion, rejection, blame, or embarrassment that they believe is due to a physical or mental health condition they possess. The goal of my research is to learn about these types of negative communication interactions in order to find ways to better them in the future.

In order to conduct my research I need to recruit individuals to take part in my study. I plan on doing this by visiting a variety of courses to introduce myself and my study, and then asking those students to answer a short recruitment questionnaire. On the questionnaire I ask individuals about their experiences with health-related stigma, and if they would be willing to take part in a one-on-one interview to discuss their experiences further.

Would it be possible to schedule a time in the upcoming month (or so) for me to visit your class in order to disseminate my recruitment questionnaire? The classroom visit should take no more than 10 minutes of your class, and would assist me greatly in the recruitment process. Students will be instructed that their participation is voluntary; they may choose to answer or not answer any questions on the questionnaire. They can also choose not complete the questionnaire. Further questionnaires will be distributed in folders and the students will be instructed to stand their folder up on their desk to provide them with privacy as they fill out the questionnaire. After the students are given approximately seven minutes to fill out their questionnaire they will be instructed to put their questionnaire back into the pocket of the folder and pass it forward to be collected.

Please let me know if you are willing to allow me to visit your class, and when might be a good time to schedule my visit. My schedule is flexible and I am able to schedule my visit around most anytime that works best for you and the needs of your class. If you would like more information about my study before agreeing to let me visit your class, I am happy to provide it upon request.

In the meantime, I am attaching my script for the classroom visit and the recruitment questionnaire for you to review.

I look forward to hearing back from you.

Best,
Ashley Archiopoli

Appendix B

<u>Script for classroom visit/assent</u>

Hi all. My name is Ashley Archiopoli and I am a doctoral candidate in the Department of Communication & Journalism. I am currently working on my dissertation research and I am seeking out individuals who have had experiences with my research topic. Specifically, I am interested in talking to individuals who may have experienced an instance of bullying, exclusion, rejection, blame, or embarrassment that they believe is due to a physical or mental health condition they possess. For example an individual might feel bullied or devalued because of a learning disability or another might feel blamed for being diagnosed with cancer. These are just two examples, there are many reasons that one might feel bullied, excluded, rejected, blamed, or embarrassed due to a health-related condition, and that is what I want to learn from you.
The goal of my research is to learn about these types of negative communication interactions in order to find ways to better them in the future.

I am asking all of you to take part in my short recruitment questionnaire, filling it out should take no longer than 7 minutes. This questionnaire asks you a few questions about any experience that you might have had similar to the ones that I described previously. If you choose to fill out this questionnaire and return it to me you are agreeing to participate in this part of my study. Filling out this questionnaire is voluntary, and information you provide to me on this form will be kept confidential and anonymous. You may choose to skip any questions and/or to not complete it. (As the folders are being passed out). The questionnaires are being distributed in folders I am asking you to stand your folder up on your desk (demonstrate) to create privacy for you for the next seven minutes. You may choose to fill out the questionnaire or not. After approximately seven minutes I would like for you to put your questionnaire back into the pocket of your folder and pass it forward to me to be collected.

If you are willing to schedule a one-on-one interview with me to discuss your experiences further I ask you to indicate this to me by providing with your name and a good email address to reach you at on the form. If you elect to take part in the interview process our conversation will be kept confidential, that means any data I gather during our conversation will be stored on my password protected computer, and only myself and my advisor will look at the raw data. Any indentifying information that you provide to me during the interview will excluded from the data and reports. Finally, your name, if names are used, will be changed in any reporting of the data.
The interview itself will be conducted in a private place and we will schedule it around your needs. Additionally, if you elect to take part in the interview process you will be entered in a drawing to win one of two $25 Amazon gift cards.

Do you all have any questions? If you think of questions later or decide that you would like to have a one-on-one interview with me in the future here is my contact information amarch@unm.edu or 316/841.2820 (write on the board). Thank you for your participation!

Appendix C

<u>Recruitment Questionnaire IRB Study 13-833</u>

Have you or has anyone you know experienced an instance of bullying, exclusion, rejection, blame, or embarrassment that you believe is due to a physical or mental health condition?

If possible, please describe the situation…

Would you be willing to talk about this experience in a one-on-one interview? If so, please fill in your contact info below:

Name:

Email:

*Note: if more than 30 individuals volunteer to take part in the one-on-one interviews, individuals will be randomly selected for participation using a random number generator. Every individual who volunteers to take part in the interview process will be entered in the Amazon gift card drawing regardless if they are randomly selected for the interview or not.

Finally, please tell us about yourself:

a.   How old are you? _____

b.   Biological Sex (Check one)
         □ Male   □ Female   □ Transsexual

c.   Sexual Identity (Check one)
         □ Heterosexual   □ Lesbian   □ Gay
         □ Bisexual   □ Queer
         □Transgender   □ Other (Please write it)_____

d.   Year in school? (Check one)
         □ Freshman   □ Sophomore
         □ Junior   □ Senior
         □ Graduate Student

e.   What is your major field of study? _____

f.   What is your ethnic/racial group?   (Check all that apply):
         □ American Indian   □ White non Hispanic
         □ Hispanic/Latino   □ African American
         □ Asian/Pacific Islander   □ Other (Please write it)_____

<table>
<tr><td>By returning this questionnaire completed to the researcher you are agreeing to participate in this stage of the research process.

Thank you for your participation!</td></tr>
</table>

Appendix D

<u>Email to individuals that self selected into the interview</u>

Hi (name).

I am writing you to follow-up on your interest in being a part of my research study about instances of bullying, exclusion, rejection, blame, or embarrassment that may be due to a physical or mental health condition that you possess. You indicated that you would be willing to meet with me for a one-on-one interview to discuss your experience further. Would you still be available for this meeting?

Again, we will plan the interview around your schedule, and it will be conducted in a private place. All information that you provide to me in the interview will be kept confidential, that means any data I gather during our conversation will be stored on my password protected computer, and only myself and my advisor will look at the raw data. Any indentifying information that you provide to me during the interview will be excluded from the data and reports. Finally, your name, if names are used, will be changed in any reporting of the data.
Additionally, if you elect to take part in the interview process you will be entered in a drawing to win one of two $25 Amazon gift cards.

Are you still willing to take part in the interview process, and if so when would be a good time for you to meet?

Best,
Ashley

Appendix E

<u>Interview guide</u>

Portion of interview	Talking point/question
Opening	• *Rapport* • *Building trust*
Storytelling	• Tell me a little bit more about why you decided to come here and talk to me? • *Tell me more about your experience related to bullying, exclusion, rejection, blame, or embarrassment that are believed to be health-related.* • *Please feel free to take your time telling this story and include details that you may have left out on the brief questionnaire*
Depth	• How did you respond in that interaction (where you experienced bullying, exclusion, rejection, blame or embarrassment)? • How did this affect you? • Did it change your health behavior in any way? • Do you believe that this interaction had any influence on your health or health outcomes? How so? • Did it change your self-image in any way? How so?
Interaction	• Looking back on that interaction do you believe that it was a negative or a positive experience? Why?

	• Reflecting on the interaction – do you wish that you responded in a different way? What would you have done differently? • If the other person responded differently – how would you have liked them to respond? • (If the person indicates that they have had other similar experiences) Have you had similar experiences since this initial experience? And if so, how did you respond differently?
Better	• If you could imagine a different way that this interaction could have gone, what would that have looked like? • In what ways could interactions like yours be improved?
Closing	• *Let me tell you more about my research…* • The concept that we have been discussing is stigma – now that we have identified it was stigma is there anything else you would like to add about your experiences with stigma *and the negative feelings that may be associated with that word*? • Anything else that you would like to add that would help me with this research question • *Offer a white paper in the closing to see if there are interested in the production of it – offer to send via email when it is completed.*

Debriefing	• *After taking part in this interview you might also want to discuss your experiences further, if so you can contact the UNM Student Health & Counseling Center at (505) 277-3136 to schedule an appointment with a counselor.*