

THE MANAGEMENT OF STIGMA WITH SOCIAL SUPPORT INTERACTIONS
AND INFORMATION AND COMMUNICATION TECHNOLOGY, IN THE
CONTEXT OF INVISIBLE DISABILITIES

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THE MANAGEMENT OF STIGMA WITH SOCIAL SUPPORT INTERACTIONS
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In this dissertation, I explore how individuals manage stigma with information and communication technologies (ICTs) in the context of invisible disabilities. The studies in this dissertation address social support interactions as a mechanism for managing stigma from several stakeholders' perspectives. Study 1 examines how individuals with an invisible disability try to manage their chronic illness through social support interactions and the effects of such communication on their psychological adjustment to pain. Study 2 is an empirical study that investigates the decision-making process of young adults of providing support or not to distressed posters and their posts they see on social networking sites. Study 3 explores the experiences of individuals who experience courtesy stigma (also known as secondary stigma), which is stigma by affiliation. It examines how hearing parents of d/Deaf¹ children strategically utilize different information and communication technologies to obtain information about cochlear implants. Together, these chapters illuminate how social support interactions are a mechanism in which individuals manage stigma from different perspectives and

¹ d/Deaf (with both the lowercase and a capital "d") will be used to refer to the d/Deaf label as both a pathological and a cultural trait. Lower case "deaf" refers to deafness as a disability, while "Deaf" denotes a cultural trait (Senghas & Monaghan, 2002).

roles as well as how individuals use information and communication technology as a tool to manage stigma.

BIOGRAPHICAL SKETCH

Pamara Chang received her Bachelor of Arts degrees in Communication and Community Health in 2010 from the University of Illinois, Urbana Champaign. She graduated with highest honors on the Dean's List and was inducted into the Lambda Pi Eta National Communication Association Honor Society. She received her Master of Science degree in Communication at Cornell University in 2015.

She has been the recipient of the Glass Family Fellowship and the Anson Rowe Advanced Student Award. Pamara was the President of the Communication Graduate Student Association and the Graduate Student Representative on Faculty Search Committees. Because of her interest in interdisciplinary and translational research, she has been an invited speaker at several conferences; these events include the College of Human Ecology Career Development Series, the keynote speaker at the *Translational Research Institute for Pain in Later Life's Mobile Health Technologies Conference*, a guest speaker at the College of Agricultural and Life Sciences Alumni Association Board meeting, and a guest speaker in many Communication classes. Pamara has presented her research at conferences such as the International Communication Association, National Communication Association, the ACM conference on Computer-Supported Cooperative Work and Social Computing, the International AAAI Conference on Weblogs and Social Media, Society for Research on Adolescence, and the Gerontological Society of America Annual Scientific Meeting. Her work has been published in major journals in the Communication and Health field such as *Health Communication*, *Journal of Broadcasting and Electronic Media*, *Journal of the American Medical Informatics Association*, *Patient Education and Counseling*, and *The Clinical Journal of Pain*.

This upcoming Fall 2016, Pamara will be an Assistant Professor in the Department of Communication at the University of Cincinnati.

To Mom and Dad

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CHAPTER 1

INTRODUCTION AND THEORETICAL OVERVIEW

The construct of stigma has generated extensive theoretical and empirical research across several multidisciplinary fields such as communication, psychology, and sociology (e.g. Goffman, 1963; Jones et al., 1984; Link and Phelan, 2001, Smith, 2011). Stigma refers most commonly to “an attribute that is deeply discrediting,” and most scholars use the definition of a stigmatized person as a person who is “reduced from a whole and usual person to a tainted, discounted one” (Goffman, 1963, p.3). Research on stigma has primarily focused on the individual (i.e. effects of stigma on the “target” or the “perceiver”)², but has gradually progressed to encompass the social aspects of stigma (i.e. relationships between the “target” and “perceiver”) (for review, see Major & O’Brien, 2005; Smith, 2011).

Scholars have found that stigma particularly affects social interactions, mostly between the perceiver and target (Harris et al., 1992; Sibicky & Dovidio, 1986); and during a stigma interaction, many individuals may feel anxiety, discomfort, tension, or embarrassment, whether they are the target or perceiver in the interaction (Hebl, 1997). These social interactions between perceivers and targets are called “mixed interactions” (Goffman, 1963), where at least one person feels stigma (i.e. the target) and one person is the ‘stigmatizer’ (i.e. perceiver). For example, a person with chronic pain communicating with a person who does not have chronic pain is considered a

² “Perceiver” refers to those who are stigmatizing others. Some researchers have referred to these individuals as “nonstigmatized” or “normals.” “Target” refers to the individual who is stigmatized. Although imperfect terms, I will use these terms in this dissertation since they are consistent with existing stigma literature (Heatherton, Kleck, Hebl, & Hull, 2000, p. 10).

mixed interaction. No matter the role an individual embodies in these mixed interactions, individuals attempt to manage stigma.

Goffman (1963) proposed a framework on the management of stigma emphasizing that individuals, who experience and feel stigma, strategically manage their stigma information and their identity. This management of information and identity is referred to as “techniques of information control” (p. 42). There are several strategies of techniques of information control (i.e., in-group alignment, selectively disclosing stigmatized information, etc.), but one mechanism that researchers have consistently found to be an important factor in understanding techniques of information control is how people seek, engage in, provide, and receive social support in communicative interactions.

In this dissertation, I explore how individuals manage stigma with information and communication technologies (ICTs) in the context of invisible disabilities. Invisible disabilities are disabilities that are hidden or not immediately noticed by an observer except under unusual circumstances (e.g. chronic pain; Matthews, 1994). The studies in this dissertation address social support interactions as a mechanism for managing stigma from several stakeholders’ perspectives. Study 1 examines how individuals with an invisible disability (i.e., the target) try to manage their chronic illness using mobile devices. Study 2 is an empirical study focusing on the perspective of individuals who observe stigma messages (i.e. the perceiver), and Study 3 explores the experiences of individuals who have courtesy stigma (also known as secondary stigma), which is stigma by affiliation.

The structure of this dissertation is organized in the following way: The next section of this introduction will explore the theoretical overview of stigma and discuss the inter-relationship between stigma and social support. Chapter 2 (Study 1) explores how older adults with chronic pain engage in social support interactions using mobile technologies. Chapter 3 (Study 2) is an empirical study that investigates the decision-making process of young adults responding or not responding to distressed messages they see on social networking sites. Chapter 4 (Study 3) examines how hearing parents of d/Deaf³ children strategically utilize different information and communication technologies to obtain information about cochlear implants. Together, these chapters illuminate how social support interactions are a mechanism in which individuals manage stigma from different perspectives and roles as well as how individuals use information and communication technology as a tool to manage stigma. Finally, Chapter 5 provides a general discussion of these empirical findings and highlights opportunities for future research on stigma and social support. To do this, I first turn to a theoretical overview of stigma and social support as well as a discussion of the contexts I study to research stigma communication.

Theoretical Overview

There are several angles, perspectives, and approaches to studying stigma and its social aspects. I will first focus on the origins and evolution of how stigma was defined and conceptualized, as well as the multiple social components that stigma researchers have identified. Then I will cover various types of social stigma

³ d/Deaf (with both the lowercase and a capital “d”) will be used to refer to the d/Deaf label as both a pathological and a cultural trait. Lower case “deaf” refers to deafness as a disability, while “Deaf” denotes a cultural trait (Senghas & Monaghan, 2002).

interactions (i.e. mixed interactions). This overview will be beneficial to better understand the different contexts covered in this dissertation (i.e. chronic pain, d/Deaf communities, and distressed behaviors), especially for pulling apart various components of stigma. These contexts can also help further illuminate or de-emphasize certain characteristics of stigma specifically in ICT interactions and experiences.

Conceptualization of Stigma

Stigma is a complex phenomenon, and many experts in the field of stigma agree that there should be an allowance of variation in the definition, as long as researchers are clear as to what they mean by stigma when the term is used in different studies and contexts (Link & Phelan, 2001). The variation in the definitions of stigma also informs us on the emphasis that different scholars and researchers place on the social elements of stigma.

Goffman's conceptualization of stigma. Goffman's (1963) seminal work on stigma is frequently referred to and is considered the classic definition of stigma. He defines stigma as "an attribute that is deeply discrediting" and proposes that the stigmatized person is reduced "from a whole and usual person to a tainted, discounted one" (Goffman, 1963, p. 3). This definition focuses on the individual who is perceived as stigmatized, also known as the "target." Goffman emphasizes the processes of social construction as critical to understanding stigma, and describes stigma as a "relationship between an attribute and a stereotype" (p.4). Furthermore, he explains that stigma is a product of the discrepancy between a "virtual social identity", which is how a person is characterized by society in relation to what is considered 'normal,'

and an “actual social identity,” which are the attributes an individual actually possesses (p.41).

Jones and Colleagues’ (1984) dimensions of stigma. Another conceptual framework of stigma was developed by Jones et al. (1984) and was first introduced in *Social Stigma: The Psychology of Marked Relationships*. These scholars emphasize Goffman’s idea of stigma as an attribute. They coined the term “mark” and used it to describe a range of deviant conditions that might influence society’s perception that an individual is flawed; consequently, these “marks” might initiate the stigmatizing process. Jones et al. (1984) describe that the social environment and context define what is considered to be deviant and what is not deviant. Jones et al. (1984) propose six dimensions of stigma: 1) concealability, 2) course, 3) disruptiveness, 4) aesthetics, 5) origin, and 6) peril. Concealability concerns the visibility and detectability of the “mark.” Concealability varies in degree, but individuals who are able to conceal their condition, such as individuals who have chronic pain, oftentimes choose to conceal it. Course refers to the alterability of the “mark;” and the more irreversible a condition is (e.g. HIV/AIDS, mental illnesses), the more negative attitudes the individual may receive compared to individuals with conditions that may be altered (e.g., body modification). Disruptiveness is defined as the degree to which the “mark” and/or others’ reactions to it affect social interactions and relationships (e.g., the fear of unexpected behaviors from an individual with bipolar disorder). Aesthetics is another dimension of stigma and refers to the extent in which a “mark” elicits an affective reaction. Origin refers to the responsibility attributed for the “mark.” The degree of stigma may vary whether ‘perceivers’ think the stigma originated from birth, is

accidental, or deliberate. Peril is the last dimension of stigma in Jones et al.'s framework, and it is defined as feelings of danger or threat that the "mark" induces. It can also include feelings of discomfort and vulnerability because of the possibility that the stigmatized condition may physically, socially, or even morally affect others.

Crocker, Major, and Steele's (1998) definition of stigma. Crocker, Major, and Steele (1998) frame stigma as a characteristic of the individual. Specifically, they define stigma as occurring when an individual possesses an attribute or feature that conveys a devalued social identity within a social context, which is similar to Goffman's conceptualization of stigma. They also emphasize that a stigmatized identity is socially constructed. Another key point and difference from the definitions of stigma above is that in Crocker et al.'s discussion of stigma, the concept of power plays a role in whether stigma is enacted or not, since they argue that power can determine an individual's susceptibility to feeling stigmatized as well as influence how that individual may respond to stigma.

Similarities, gaps, and criticisms of existing stigma conceptualizations. The aforementioned definitions of stigma and the components that make up the conceptualization of stigma mostly focus on the individual, and tend to emphasize the cognitive processing of information rather than on the complex processes that the 'target' may experience (Sayce, 1998). The social psychological definitions mentioned above have similar underlying components. First, these definitions emphasize that there is an attribute that is different compared to the societal norm, and this attribute leads to devaluation of the social identity. Also, the conceptualizations of stigma thus

far have focused on stigma as a social construction, where it is dependent both on relationships and the social context (Major & O'Brien, 2005).

Although these perspectives on stigma have put forth a foundation for the conceptualization of stigma, many of these have also been challenged for neglecting the viewpoint of the 'target' and for focusing too narrowly on individuals, rather than expanding the focus to the various societal factors that may or may not shape exclusion from social life (Parker & Aggleton, 2003). Therefore, Link and Phelan (2001) more recently proposed a definition of stigma in which the stigma concept encompasses interrelated stigma components mentioned above in addition to some newer ones; and this will be the framework for this dissertation when referring to stigma.

Link and Phelan's (2001) conceptualization of stigma. Link and Phelan's (2001) definition of stigma is similar to the aforementioned definitions in that they have similar components such as labeling, stereotyping, and cognitive separation. Emotional reactions is the fourth component that was later added to the conceptualization of stigma (Link, Yang, Phelan, & Collins, 2004). These components identify the social processes of stigma that could be observed. However, Link and Phelan also propose to add the components of status loss and discrimination, in order to capture an even more social and holistic perspective on stigma. In this conceptualization of stigma, stigma exists only when these interrelated components converge and interact.

The first component in Link and Phelan's (2001) definition is labeling. In previous definitions, scholars have used terms such as attribute, condition, or mark.

However, Link and Phelan put forth the term “label” to replace these aforementioned terms because an attribute, condition, or mark refers to a characteristic in the ‘target’, and so differences that are a product of social processes can be ignored. Labeling can be discussed from both the perspective of the perceiver and target. Labeling is the process in which individuals distinguish and label human differences. There is a degree of social salience for certain differences and the selection of these characteristics and the creation of labels for them are socially constructed, which is why this is an essential component to stigma and can differ depending on time and place.

The second component is stereotyping. Stereotyping refers to the process in which the labeled difference is linked to negative attributes and associations for either the ‘perceiver’ or ‘target,’ hence a stereotype.

The third component is cognitive separation. This process occurs when social labels create a separation of “us” from “them” (Morone, 1997). When the “us” and “them” groups are particularly set apart, members of the stigmatized group may start to accept societal stereotypes about themselves and view themselves as different and as inferior to the other group. This separation of groups may also stem from other components of stigma. For example, linking labels to negative attributes may be a justification or even a rationale for believing that individuals with a certain label are fundamentally different from those who don’t have that label. It’s important to emphasize, however, that the cognitive separation can be driven by either or both groups of perceivers and targets.

The fourth component is emotional reactions. Although this component was added later, it is a critical addition to the conceptualization of stigma because it helps us better understand the behaviors of both the perceiver and the target. As a result of labeling, stereotyping, and separation, the perceivers may feel emotions of anger, irritation, anxiety, pity, and fear (Link, Yang, Phelan, & Collins, 2004). This can consequently affect the interaction between the perceiver and target because the target may then detect these emotions.

The fifth and most recent addition that is a component of stigma is the combination of status loss and discrimination. Perceivers experience stigma when all the aforementioned components occur, consequently leading them to feel status loss and discrimination. Status loss refers to the downward placement and perception of a person in some type of social hierarchy, so that the perceiver reduces the target's status. Subsequently, discrimination refers to the attitudes and beliefs influencing the behavior to stem from the perceiver toward the target. For example, individuals (the perceivers) may discriminate against targets, such that they may turn away targets for job openings (Schnittker & John, 2007).

Link and Phelan's (2001) conceptualization provides a more holistic and social perspective on stigma. They also emphasize in their definition that these components are interrelated and stigma can only occur when they interact. This definition of stigma will be the foundation of this dissertation; therefore every reference to stigma from this point forward will be in regards to Link and Phelan's (2001) conceptualization.

Social Components of Stigma Research – the Target, the Perceiver, and the Interaction between the Target and Perceiver ('mixed interactions')

Parallel to the evolution of the conceptualization of stigma, as discussed above, there has been a co-occurrence of empirical studies on stigma interactions. The social psychology research mostly focuses on the social identity, resulting from the cognitive, behavioral, and affective processes, of the target (Yang, Kleinman, Link, Phelan, Lee, & Good, 2007). Social stigma, however, captures the perspective of the interaction of the target and perceiver. Social stigma is complex in that it can be a catalyst for other components of stigma to factor into the cycle of stigmatization. For example, targets can further internalize social stigma, which then becomes what is often called self-stigma (Crocker, Major, & Steele, 1998). To understand a more holistic viewpoint on social stigma research, it is critical to understand the findings from research on targets, perceivers, and the interaction between the two.

Social stigma and the perceiver. This section will focus on stigma with the focus on the perceiver. Perceivers' reactions to targets who have a condition associated with stigma can have a range of reactions in both intensity and quality, ranging from affective (i.e., sympathy and discomfort) to behavioral dismissal (i.e., labeling and social distancing). Furthermore, cultures and subcultures can define which characteristics are considered stigmatized and which are not (e.g. Crocker et al., 1998; Pfuhl & Henry, 1993). For example, body modification can be accepted and a norm in some cultures but stigmatized and even looked at as deviant in others (Goffman, 1963, p.43). In this section, there will be a discussion of the most prevalent types of research on perceivers and stigma, including why perceivers may stigmatize

(e.g., Stangor & Crandall, 2000), how stigmatization serves as a response to factors that threaten the perceiver, and to what extent perceivers stigmatize targets.

There are several reasons why perceivers may stigmatize targets. Perceivers may stigmatize targets partially to reduce the complexities of understanding “them” (e.g., Allport, 1954; Hamilton, 1981; Fiske & Neuberg, 1990; Macrae, Milne, & Bodenhausen, 1994), to feel better about themselves (e.g. Ehrlich, 1973; Fein & Spencer, 1997; Wills, 1981), to feel better about the groups that they belong to (e.g. Tajfel & Turner, 1986), to justify their preferential status in society (e.g. Jost & Banaji, 1994; Lerner, 1980; Major, 1994), and/or to validate an important world view that they view as the societal norm (e.g. Greenberg et al., 1990). Stereotyping and separating, both conceptualizations of stigma, are major factors in explaining why perceivers may stigmatize targets. Stereotypes can serve as an explanation for why perceivers stigmatize, since stereotyping provides explanations for others’ behaviors, supports the perceivers’ motivation, satisfies needs for cognitive closure (Jost, Kruglanski, & Simon, 1999), and enhances personal and collective self-esteem (Stangor & Schaller, 1996). For example, stereotyping and separating (i.e., comparisons between in-groups and out-groups) can enhance self-esteem for the perceiver, as a result of downward comparison (Brewer, 1979; Fein & Spencer, 1997). Dunning (1999) and Tajfel and Turner (1979) also found that stereotyping helps perceivers achieve a flattering self-image; and separating helps strengthen a sense of positive group distinctiveness. Stereotypes do not necessarily have to only involve negative perceptions (i.e., dislike of devalued identity); it can also specify a set of

characteristics assumed to exist among people sharing the same stigma (i.e., the stigma evokes a social identity for targets).

Protection of the self from threat, another component to stigma often known as ‘peril,’ (Jones et al., 1984) may be another explanation for the development of stigma. There are two types of threats that perceivers react to which influence the stigmatization of targets. The first is that perceivers may feel instrumental threat, which is when they feel as if concrete factors such as health, safety, or social position are threatened (Schaller, 1999). The second type of threat that may influence stigmatization is symbolic threat. Symbolic threat refers to a perceived threat to beliefs, values, ideology, and an understanding of a worldview. If these factors are not in sync, then perceivers may stigmatize targets because they themselves may feel anxiety or fear.

Social stigma and the target. Outcomes and/or effects of stigma form a substantial portion of the stigma literature, especially studies describing how stigma negatively affects targets (e.g., Hinshaw, 2005) and how these individuals cope with stigma (e.g., finding camaraderie and social support online to cope with stigma; Chang & Bazarova, 2016). Specifically, targets can internalize stigma, and this internalization consequently can lead to feelings of guilt and inadequacy about their identity. Furthermore, social stigma can have deleterious effects on the individual’s self-esteem and self-efficacy, which then may or may not lead to altered behavioral presentation (Corrigan, 2007). The interplay between labeling, anticipation of stigmatization, and actually being stigmatized influences psychosocial well-being (e.g., modified labeling theory; Link, Cullen, Struening, Shrout, & Dohrenwend, 1989). Additionally,

stigmatized beliefs may provoke an emotional response in the target, including embarrassment, isolation, and/or anger. Following are empirical studies on social stigma from the perspective of the target.

Self-esteem effects. Numerous studies have demonstrated a strong connection between feelings of stigma and well-being. Scholars have found that stigma affects self-esteem and depression (Link, 1987; Wright, Gronfein, & Owens, 2000).

Stigma and effects on social networks. There are also studies examining how stigma affects social networks. Labeling is likely to provoke stigma and have negative consequences for social networks. For example, studies show that individuals with more severe and perceptible symptoms of mental illnesses are more likely to experience and perceive rejection (Cormack & Furnham, 1998), especially because conditions that are more easily ‘labeled’ as a mental illness lead to harsher social reactions by perceivers (Link et al., 1999). Another perspective on social networks is considering the social distance that both perceivers and targets create because of stigma. Martin, Pescosolido, & Tuch (2000) found that the majority of the public in the U.S. want social distance from individuals with mental illnesses because they are concerned about working, living, and socializing with these individuals. Other studies on social networks and stigma focus on positive effects on social networks based on the degree of stigma of the condition. The more severe and perceptible symptoms of mental illness are, the greater the likelihood of an increase in support and positive affect in social networks (Parson, 1951). Additionally, there are studies investigating the severity and perceptibility of illnesses and the quantity and quality of social networks. Perry (2008) found that more extreme mental illnesses with more

perceptible symptoms have more likelihood of positive effects on core networks, but will provoke stigma and have negative consequences among peripheral outsiders. Overall, relative to those with less severe disorders, individuals with severe diagnoses and more visible symptoms of mental illnesses have larger and broader functional networks, as well as more supporters who are aware of and sympathetic toward the illness situation. However, those with more severe diagnoses are also vulnerable to rejection and discrimination by acquaintances and strangers.

Courtesy Stigma. Courtesy stigma refers to stigmatization by affiliation; it is also known as secondary stigma (Goffman, 1963). Although courtesy stigma can occur in a variety of different relational ties, there has been a growing trend of interest in courtesy stigma for parents of children. In this dissertation, chapter 4 examines how parents who experience courtesy stigma because of their d/Deaf child seek and interpret biased information from various ICT sources.

Anticipated stigma and its effects. Anticipated stigma refers to one's expectation to experience prejudice, discrimination, and stereotyping from others, specifically perceivers, in the future (Earnshaw & Chaudoir, 2009; Quinn & Earnshaw, 2011). People living with stigmatized identities who anticipate great stigma are more likely to have experienced enacted stigma (i.e., experiences of prejudice, discrimination, and stereotyping directed at them from others) and to have internalized negative stereotypes about people living with chronic illnesses and applying them to themselves (Earnshaw & Quinn, 2011; Steward et al., 2008). In addition, anticipated stigma has been linked to negative health outcomes, including increased psychological distress (Meyer, 1995; Quinn & Chaudoir, 2009), diminished mental health (Link,

1987), decreased well-being (Mendoza-Denton et al., 2002), and increased physical illness symptoms (Quinn & Chaudoir, 2009). Anticipated stigma has the potential to be perpetually present and constantly weighing on the mind (Earnshaw, Quinn, Kalichman, & Park, 2013). It can also play a unique role in determining targets' behaviors, as they may expect to be treated poorly, may avoid others, or may approach interactions in such a way that results in negative intra- and interpersonal consequences (Henry et al., 2010; Pinel, 2002).

Interaction between perceiver and target. Scholars have found that stigma affects social interactions, particular between the perceiver and target (Harris et al., 1992; Sibicky & Dovidio, 1986). During a stigmatized interaction, many individuals may feel anxiety, discomfort, tension, or embarrassment, whether they are the target or perceiver in the interaction (Hebl, 1997). These social interactions between perceivers and targets are called “mixed interactions” (Goffman, 1963). This dissertation primarily focuses on the different aspects of why and how mixed interactions occur and how ‘targets’ manage stigma through social support interactions in mixed interactions. For example, Chapter 2 investigates communication interactions of older adults with chronic pain and other individuals in their lives, and the effects of such mixed interactions on their affect and psychological adjustment to pain. Another study, chapter 3, examines how perceivers undergo a decision-making process of engaging or not with targets on Facebook.

Disruptiveness influencing mixed interaction. Disruptiveness, a focal component of Jones et al.'s (1984) conceptualization of stigma, may be a reason why mixed interactions are uncomfortable for both the perceiver and target, in that it strains

the interaction between individuals. McGuire (1998) found that perceivers have strengthened stereotypes of individuals who possess disruptive stigmas compared to those who possess less disruptive stigmas, which would then result in more aversive reactions in social interactions.

Anxiety and avoidance. There are two common themes that emerge as a result of mixed interactions. The first theme is anxiety, and here it is defined as a physiological with the uneasiness concerning an impending negative outcome, that the person believes is unavoidable (Leary, 1983). Anxiety is also directly associated with additional feelings of discomfort, tension, and strained interactions (e.g. Ickes, 1984). Perceivers may expect mixed interactions to be difficult or negative, because they involve interaction with a target. Consequently, the target may feel the perceiver's anxiety and as a result also feel anxious during the interaction. Anxiety can occur when only one interactant experiences discomfort, or it can occur when both feel anxious. The second theme that is apparent is avoidance. Both perceivers and targets can purposely and strategically arrange their interactions so as to minimize or altogether avoid mixed interactions.

These social interactions including 'targets' and 'perceivers' can oftentimes turn into social support interactions in order to manage stigma, to cope with social elements of stigma (i.e., anxiety, avoidance, etc.). So, now I turn to a review of social support and its effect on stigma communication.

Social support, stigma communication, and ICTs

Research demonstrates that social support is related to and beneficial to both physiological and psychological well-being (Berkman & Syme, 1979; Herbert &

Cohen, 1993; Wills, 1985). It is especially tied to these fields because social support is a process “inextricably woven into communication behavior” (Albrecht, 1987, p. 14). In the contexts where an individual experiences stigma, individuals actively seek, engage in, provide, and receive varying types of social support in communication interactions. These social support interactions can occur in face-to-face contexts, small group interactions, and/or selective groups, but with the rise in ICTs, these individuals are increasingly turning to online and mobile platforms to make salient decisions, communicate with similar others, and manage their condition in an effort to improve their overall health and well-being. First, I will discuss a general overview of social support and its effects. Then, I will turn to social support interactions with the use of ICTs for individuals who experience stigma.

Social support affects health and well-being (Cassel, 1976; Cobb, 1976). There has been an emphasis on the complexity of social support as a phenomenon and the typologies of social support. The functions of social support have been identified across studies in the literature and include tangible support, informational support, emotional support, and appraisal, which all are interrelated to influence the reduction of uncertainty, decrease in perceived personal control and stress, and increase in information (Albrecht, 1987; Barnes & Duck, 1994). Building off that, Cohen, Underwood, and Gottlieb (2000) argue that social support is a process in which social relationships can promote health and well-being. Cutrona and Suhr (1992) proposed a typology of social support that is oftentimes used in social support behavioral research (e.g. Braithwaite, Waldron, & Finn, 1999; Coulson, 2007; Coursaris & Liu, 2009; Loader, Muncer, Burrows, Pleace, & Nettleton, 2002; Winzelberg, 1997). This social

support behavior code is a list of 23 mutually exclusive social support behaviors, but is categorized into five major components including information support (i.e. advice and suggestions), tangible assistance (i.e. instrumental support like taking someone to a doctors appointment), esteem support (i.e. compliments and validation), network support (i.e. interpersonal social support and companionship), and emotional support (i.e. sympathy and affection). These components of social support will be referred to throughout this dissertation.

Communication is a critical component of social support (Albrecht, Burleson, & Goldsmith, 1994); and studies examining social support in interactions or exchanges that frequently occur in the context of communication have flourished (Burleson, Albrecht, & Sarason, 1994). Social support research, especially in regards to supportive relationships, demonstrates that an increase in support can reduce pregnancy complications, aid recovery from illness, protect against depression, decrease deviant behavior, and decrease psychological and physiological stress (see Slater & Depue, 1981). There are several conceptualizations of social support, but for this paper, references to social support from this point forward will refer to Albrecht and Adelman's (1987) definition of social support: "social support refers to verbal and nonverbal communication between recipients and providers that reduces uncertainty about the situation, the self, the other, or the relationship, and functions to enhance a perception of personal control in one's life" (p.19). Although traditional social support research has been in face-to-face contexts, most recent research examines social support in technologically mediated contexts (Walther & Boyd, 2002). This next section will specifically address ICT social support, especially because individuals

who manage stigma are increasingly turning to ICT platforms to engage in these social support interactions.

Stigma and social support on information and communication technology platforms. The Internet plays an important role for individuals who feel stigma and who seek support from others. Computer-mediated support groups offer a venue for people who feel stigmatized, especially when they have a disability, to disclose personal information with a sense of safety (Braithwaite, Waldron, & Finn, 1999). These computer-mediated support groups are also known as online communities. Online communities are groups of people who meet and interact with others, are connected by a specific interest, are brought together by a technological platform, and can develop social relationships and a sense of belonging to the group (e.g. Preece, 2000; Blanchard and Markus, 2004; Rheingold, 2000; Haythornthwaite, 2007). Many individuals who have a chronic illness or health problem seek online support communities because of the social and psychological challenges they face or anticipate in face-to-face contexts (Bury, 2000; Charmaz, 1991; Charmaz, 2000). Researchers found that individuals on these sites believed that the biggest advantage of these groups was the perception that there was less stigma attached to their own condition by other group members because of the anonymity on these sites (Wright, 2000). The online context provides many benefits for individuals who feel stigma.

There are several benefits to social support groups being online including relevant and accessible information from peers and from professionals (Frost & Massagli, 2009; Lasker, Sogolow, & Sharim, 2005; Preece, 1998), experience-based information about treatments and behavioral strategies to coping with specific

conditions, connection with others in similar circumstances, ability to communicate anonymously, reciprocity of social support, and capability of communicating in a judgment free space (Hwang et al., 2010). Furthermore, the affordances of technologically mediated venues allow for opportunities for individuals to interact with others who they consider to be a weak relational ties (Turner et al., 2000), be free of space and time constraints (Maloney-Krichmar & Preece, 2005), and be able to communicate anonymously (Wright, 2000, 2002). Online communities also allow for individuals to simultaneously hide elements of stigma information and identities offline and reveal them online, and also to parse out and separate ways in which people can experience stigma.

The rise in e-health leads to various types of communities where individuals with similar conditions gather virtually to share experiences, ask questions, or provide and request emotional support. This is oftentimes called ‘peer-to-peer’ online communities (e.g. Alemi et al., 1996; Houston, Cooper, & Ford, 2002; Lieberman et al., 2003; Quick, 1999). Participants in these peer-to-peer online communities usually communicate and engage in supportive interactions through bulletin boards, chat rooms, Listservs, and individual exchanges (Rapaport, 1991). This is different from adjunct online communities, which are online communities created by and/or sponsored by health organizations, facilitated by professional health moderators, or part of a larger intervention (e.g., Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004). Additionally, although online health communities are defined above, I’d like to put forward another definition of virtual communities, which is similar to online health communities but further emphasizes social networks within these communities.

Virtual communities are social networks formed or facilitated through electronic media; virtual communities are also defined as communities through computer communication networks, like the Internet, where individuals with similar or common interests interact and communicate, consequently allowing for social networks to build over time and over distance (Wellman, 1997). These peer-to-peer online communities and virtual communities are contexts in which the stigma-related theoretical questions are asked in throughout this dissertation.

There is also a burgeoning interest in mobile health and social support research. According to the Pew Research Internet Project (2014), almost 90% of adults have cellphones, 58% have smartphones, 32% have e-readers, and 42% own tablet computers. The benefits of mobile health applications and interactions as a provision of social support are thoroughly discussed in Chapter 2, exploring how older adults with chronic pain interact and exchange social support via mobile devices, as well as the effects of such communication interactions on their psychological adjustment to their chronic pain and overall well-being.

There also needs to be further inquiry about the process of social support, the medium in which the social support occurs (i.e., computer-mediated, fluid between offline and online), and the context of these supportive interactions (i.e., health conditions, expectations). The mediated technologies offer social support to be more available, accessible, instantaneous, anonymous, and person-control driven (i.e. seeking and giving support, privacy). The mediated technology platforms and sources of support can transcend problems with traditional face-to-face social support interactions, but because each context poses different challenges to the

conceptualization of social support, it is important to parse out which components of social support is more or less pertinent and effective in different health and stigma contexts. This dissertation, specifically with the three empirical studies, attempt to address these aforementioned inquiries. Specifically, I parse out how ICTs may or may not affect or change the experience and enactment of social stigma, because new technologies can disambiguate and separate the ways in which people can communicate their stigmatized condition(s).

Taking what we know about social support, stigma communication, and ICTs as a platform for hosting these social support and stigma interactions, we can see how ICTs facilitate techniques of information control. Because stigma is highly contextual, stigma cannot be eliminated; rather, individuals can manage stigma information and identities in various ways on ICTs. One strategy of techniques of information control is whether or not an individual would disclose or conceal this stigma information and identity, and to whom and in what context they would disclose in order to manage their information, rather than eliminating stigma all together. One way to implement this strategy is to create two groups: one group to which an individual tells nothing, and a second, more selective group to which the individual tells everything and relies upon (Goffman, 1963). This selectivity can further be enabled by ICT contexts. For example, older adults can seek social support online communities for older adults with chronic pain to cope with associations to stigma such as *stereotypes* attached to chronic pain like weakness, *discrimination* against older adults with chronic pain, and *negative emotional reactions* that targets have in reaction to perceivers' attitudes and behaviors toward them. Techniques of information control on ICTs illuminates how

individuals who experience stigma because of an invisible disability can express stigmatized opinions and avoid *stereotypes and discrimination*. This example demonstrates the interrelationship between stigma components (i.e. stereotypes, discrimination, negative emotional reactions), social support as techniques of information control mechanism, and benefits of ICT as a platform to have these interactions.

Another example that illuminates a component of stigma through techniques of information control is *separating* with the use of ICTs to manage stigma. The separation of groups of “us” and “them,” in this case, is driven by social support interactions that encourage camaraderie. This adds a new dynamic to stigma management, particularly online, because the fluidity and the movement between online to offline could be mechanisms through which *separating* occurs. This is an example of how the online experience pulls apart the conceptualization of stigma because the process of *cognitive separating* is illuminated here whereas negative *emotional reactions* may be de-emphasized in this context (e.g. Chang & Bazarova, 2016).

As we apply this stigma conceptualization to a unique context, we see that these socially constructed contexts challenge some of the components that make up stigma and it illuminates some and de-emphasizes others in the process of management of stigma on ICT platforms. Additionally, the discussion of social support interactions sheds light to mechanisms through which stigma management occurs. This dissertation explores various invisible disabilities (i.e., chronic pain – Chapter 2, distressed interactions on social networking sites – Chapter 3, and d/Deaf

communities – Chapter 4), and how individuals with these invisible disabilities manage stigma in different ways using ICTs and engaging in social support interactions.

CHAPTER 2

STUDY 1 – CHRONIC PAIN MANAGEMENT AND SOCIAL SUPPORT INTERACTIONS AMONG OLDER ADULTS

Chronic pain is a widespread and complex experience, defined as any pain lasting more than 12 weeks that may arise from an initial injury or an ongoing chronic illness, as well as instances where there may be no clear cause (The British Pain Society, 2013; NIH Medline Plus, 2011). It is also considered a condition influenced by a wide range of psychosocial factors, including emotions, social and environmental contexts, sociocultural backgrounds, the meaning of pain to the person, and beliefs, attitudes, and expectations, as well as physiological factors. While anyone can experience chronic pain, it is particularly prevalent among older adults, with epidemiological surveys showing that the likelihood of chronic pain increases with age (Tsang et al., 2008). Among adults 65 years and older, approximately 60-75% report chronic pain (IOM, 2011; NIH Medline Plus, 2011).

Chronic pain can have deleterious consequences on psychological, social, emotional, and interpersonal well-being (Penny, Purves, Smith, Chambers, & Smith, 1999; Romano & Turner, 1985). Older adults with chronic pain often experience social isolation and loneliness in their everyday lives (Clarke & Iphofen, 2008), which can affect their psychological and social well-being. Furthermore, they worry about being a burden to their close friends and family and may fear being labeled as a complainer (Goodman, Hiniker, & Paley, 2003). With the increase in chronic pain intensity, it becomes more challenging for older adults to maintain existing

relationships in part because pain interferes with visitation with friends and family (Kivett, Stevenson, & Zwane, 2000). Due to this increased isolation, older adults with chronic pain have a unique need and desire for communication, which may potentially be addressed with the help of information and communication technologies (e.g. Mynatt, Essa, & Rogers, 2000; Riche & MacKay, 2010; Rogers & Mynatt, 2003).

Indeed, in recent years there have been efforts to build information or communication technologies (ICTs) and mobile applications (apps) to enhance lives of older adults with chronic pain (e.g. Philip et al., 2015). In turn, older adults have been increasingly embracing ICTs, specifically mobile technologies and chronic pain apps to manage pain-related experiences (Currie, Philip, & Roberts, 2015; Parker, Jessel, Richardson, & Reid, 2013). There are currently about 220 chronic pain mobile applications (Wallace & Dhingra, 2014), the primary purposes of which are pain education (24.1%), pain self-management (62.3%), and a combination of these two (13.6%) (Rosser & Eccleston, 2011). Many of the studies on chronic pain management on ICTs and mHealth focus on the usability of these specific apps, attitudes toward mHealth applications, and design implications for older adults with chronic pain (Grindrod et al., 2014).

While mobile technologies for fostering management of chronic pain are important, researchers have increasingly recognized the role of communicative practices and social support interactions surrounding these applications. Specifically, there has been a push to design technologies to enhance social interactions between older adults with chronic pain and their family and friends (e.g. David et al., 2011), as well as create social support interventions delivered through SMS-text messaging (e.g.

Guillory et al., 2015). These studies show the promise of new technologies for enhancing social, emotional, and interpersonal components of older adults' lives.

In order to further leverage rewarding social interactions to motivate self-management and health-promoting behavior through ICTs, it is important to better understand how older adults with chronic pain perceive social support and how social support networks and interactions affect their overall well-being. This mixed-method study seeks to understand how older adults communicate about their pain and how they exchange social support, as well as the effects of such interactions on their well-being and psychological adjustment to pain. Specifically, we aim to investigate 1) how older adults with chronic pain perceive social support and partner responsiveness in pain-related interactions, 2) types of interpersonal resources and support networks used by older adults with chronic pain, as well as how these networks are specifically accessed through different communication technologies, 3) content types (e.g., pain-related experiences and emotions) they share in pain discourse, 4) pain-related content interactions on mobile devices, and 5) effects of pain-related discourse on affect and psychological adjustment to pain. This study utilizes the lens of pain catastrophizing and the communal coping framework (Sullivan et al., 2000), as well as staccato social support (Adams, Baumer, & Gay, 2014) to examine these processes. Together, these analyses provide important insights into communicative dynamics of pain-related discourse and their potential effects on older adults with chronic pain.

Management of Chronic Pain with Social Support Interactions

Social support and older adults. Social support enhances health and increases well-being (Cohen & Wills, 1985; Pierce, Sarason, & Sarason, 1996;

Sarason, Sarason, & Pierce, 1990). Social support among older adults in particular is an essential issue, as their support networks change, both in quality and quantity, and there is an increase in age-related support needs (Berkman, Glass, Brissette, & Seeman, 2000; Unger, McAvay, Bruce, Berkman, & Seeman, 1999). Higher levels of social support among older adults are associated with better physical health (Auslander & Litwin, 1991; Cutrona, Russell, & Rose, 1986), improved life satisfaction (Aquino, Russell, Cutrona, & Altmaier, 1996), less loneliness (Russell, 1996), and lower depression (Dean, Kolody, & Wood, 1990; Kogan, Van Hasselt, Hersen, & Kabacoff, 1995). Furthermore, poor social connections, fewer social activities, and social disengagement in older adults above the age of 65 have been shown to predict greater risk of cognitive decline (e.g., Zunzunegui et al., 2004).

The benefits of social support, however, are most strongly linked with perceptions of social support (Barrera, 1986; Wethington & Kessler, 1986), such that individuals who believe that they have a high level of social support, regardless of how much support they actually receive, have higher levels of overall well-being (Auslander & Litwin, 1991; Newsom & Schulz, 1996; Stephens, Alpass, & Stevenson, 2011). Subjectively perceived support is defined as a person's belief that the members of his/her network are constantly available and actually supportive in various ways (Berkman et al., 2000). This perceived support is shown to have a more significant effect on health and overall well-being compared to social network size or composition alone. Antonucci, Fuhrer, and Dartigues (1997) found that compared to the size and composition of a social network, perception of social support and satisfaction with social relationships better predict mental health and well-being.

However, perceived social support and social network composition are conceptually and empirically related, so it is also important to consider older adults' social networks.

The relationship between the perception of social support and social network composition is critical, especially as older adults' support networks become smaller over time. This may be due to an intentional 'downsizing' on their part, as older adults reduce energy spent on maintaining contact with peripheral social partners and more energy on closer partners (e.g., Carstensen, Isaacowitz, & Charles, 1999; Chang, Choi, Bazarova, & Loeckenhoeff, 2015). Socially, older adults become more selective in whom they spend their time with and who they communicate with over time (S.L. Brown, Asher, & Cialdini, 2005). Older adults attach less significance to the number of social relationships in their networks and emphasize relationship quality over quantity (Heylen, 2010). The interrelationship between actual received social support, perceived social support, and social support networks affect health outcomes of older adults (Grenade & Boldy, 2008); but the combination of these aforementioned factors becomes even more complex in older adults with chronic pain.

Social support and interactions among older adults with chronic pain.

Chronic pain further complicates older adults' social interactions, and consequently, their social support interactions. Older adults with chronic pain constantly face the constraints pain places on social interactions and availability (Miles, Curran, Pearce, & Allan, 2005). They even take deliberate steps to self-isolate and to conceal their chronic pain in order to avoid negative social consequences, such as exposure to stigma and misunderstanding (International Association for the Study of Pain, 2011).

In turn, concealing chronic pain experiences dramatically reduces opportunities to discuss pain experiences with others and can lead to social withdrawal. On the other hand, revealing pain may also result in negative consequences such as feeling and/or experiencing shame, stigma, negative emotions, and discrimination (Werner & Malterud, 2003). The negative consequences that may occur after revealing or concealing chronic pain may illustrate one of two feedback loops. If a person experiencing chronic pain perceives negative consequences based on concealing their chronic pain, this can lead to further withdrawal from social situations, which can then lead to further isolation from social contacts and in turn can increase levels of chronic pain. If the person fears perceived negative consequences based on revealing about chronic pain, they experience negative emotions associated with telling others, which can lead to isolation, and then more pain.

These feedback loops have negative outcomes, as perceived social support for individuals with chronic pain is associated with long-term health outcomes. Evers et al. (2003) found that high levels of perceived social support assessed early in chronic pain diagnoses can affect long-term functional disability and lower perceived levels of pain for individuals with rheumatoid arthritis in both three-year and five-year follow-up surveys compared to individuals who had lower levels of perceived social support. Furthermore, in one-year-long longitudinal studies, lower levels of perceived social support have been shown to be related to more general interference (disruptiveness in daily activities) and pain interference⁴ in chronic pain patients (Smith & Wallston,

⁴ Pain interference is similar to general interference where there is disruption in daily activities. Pain interference is defined as the “extent to which pain hinders engagement with social, cognitive, emotional, physical, and recreational activities” (PROMIS, 2015, p.1).

1992), increased pain (Waltz, Kriegal, & van't Pad Bosch, 1998), and functional disability (Evers, Kraaimaat, Geenen, & Bijlsma, 1998).

Although there is strong evidence supporting a positive link between social support and health outcomes or well-being for older adults with chronic pain, the findings are more mixed when evaluating the effects of perceived social support from family members and friends. Some studies find that patients who have high levels of perceived social support from family members report less pain intensity, more satisfactory social activity, and fewer instances of pain interfering with their daily routines and behaviors than those who perceived their family support to be inadequate (Jamison & Virts, 1990). In contrast, other studies show that positive attention from spouses to pain displays of older adults with chronic pain is associated with higher pain intensity, increased pain behavior frequency, and greater disability (e.g. Turk, Kerns, & Rosenberg, 1992).

In regards to social interactions with friends, Roberts et al., (2015) found that older adults with chronic pain are aware of the changing nature of their social interactions, partly due to chronic pain experiences. In particular, they identified two prevalent themes around older adults with chronic pain and their interactions with friends: 1) older adults with chronic pain perceive that their friends are embarrassed when talking about chronic pain because they don't know what to say, and 2) during periods of intense pain, older adults with chronic pain feel reluctant to talk or communicate with their friends; they are concerned that social withdrawal due to pain might be detrimental to close relationships because they believe that social interactions are an integral part of their values. Older adults with chronic pain value their close

interpersonal connections with friends and consider their chronic pain to be a barrier to enhancing these relationships, because they constantly battle whether or not to discuss their pain with others (Roberts et al., 2015). Often, they do not want to bring up their chronic pain, as they don't want to be viewed as a negative or 'complaining' person, while simultaneously not wanting to hide their pain-related feelings and experiences from their friends (Benjamin et al., 2012). Perry and Watt-Watson (2010) concluded after a literature review of chronic-pain-related studies that peer support had positive effects on improved self-efficacy, increased activity levels, and reduced pain severity for people with chronic pain. Therefore, we predict that the pain-related discourse that older adults with chronic pain have with their close relations is associated with feeling cared for and feeling understood by communicative close partners:

H1: The pain-related discourse that older adults with chronic pain have with close relations is positively associated with older adults with chronic pain a) feeling cared for, and b) feeling understood.

Furthermore, we ask the following research question to investigate who older adults with chronic pain talk to specifically when they are experiencing pain and/or pain-related emotions:

RQ1: Who do older adults with chronic pain interact with most frequently when experiencing pain and pain-related emotions?

Pain Catastrophizing, the Communal Coping Framework, and Perceived Social Responses for Older Adults with Chronic Pain

Pain catastrophizing and perceived social support. Another perspective on social support interactions particularly applicable to older adults with chronic pain is the process of reinforcing pain behaviors and their effects. Pain catastrophizing is a negative cognitive-affective process that includes elements of magnification, helplessness, pessimism, and rumination on pain, which, in turn, drives pain-related outcomes (Sullivan et al, 2001). Specifically, pain catastrophizing can exacerbate negative emotional and physical outcomes, such as heightened and intense pain (Sullivan et al., 1995), increased pain behavior (Keefe et al., 2000), reduced involvement in daily activities (Keefe et al., 1989), and disability (Burton et al., 1995). Therefore, pain catastrophizing is hypothesized to be a maladaptive way of coping with real or anticipated pain.

Individuals with chronic pain who are categorized as high catastrophizers show more sustained communicative pain behaviors and fewer pain management behaviors (e.g., taking medication) when an observer is present, compared to when they are alone (Sullivan et al., 2004; Sullivan et al., 2006). Cano (2004) found that within married couples, pain catastrophizing was positively associated with less perceived spousal support in longer durations of chronic pain. In short pain durations, spouses may reinforce the pain catastrophizing by providing emotional and pain-specific support because they believe that the spouse with chronic pain is making a reasonable request for help (Cano, 2004). However, as the pain duration prolongs, the spouse may withdraw from or react negatively to pain catastrophizing after helping attempts are

unsuccessful and become frustrating. This negative effect derived from spousal support for older adults with chronic pain can be explained by the operant model of social support (Fordyce, 1976; Fruzzetti & Iverson, 2004). The operant model of social support, specifically in the context of pain, posits that pain behaviors are often communicated to close others, but that the responses may reinforce or punish those behaviors because reassurance and emotional validation of pain behaviors can reinforce further verbal pain behaviors, fueling this cycle (e.g. Block, Kremer, & Gaylor, 1980). Furthermore, pain catastrophizing in older adults with chronic pain is significantly and positively associated with patient-perceived punishing spousal responses (Cano, 2004).

To reflect the increasing focus of research on the effects of pain catastrophizing on perceived social responses, the conceptualization of catastrophizing has shifted to the interpersonal nature of the construct, both as a communicative practice and as a mediating variable on social interactions. The aggregation of research findings suggests that individuals with a propensity to catastrophize express more pain behaviors in social contexts, and that rather than serving a palliative function, these catastrophizing behaviors are mechanisms to communicate information about perceived pain to others (e.g. Cano, 2004; Giardino et al., 2003; Sullivan et al., 2000, 2001; Thorn et al., 2003). Therefore, in line with the pain catastrophizing findings reviewed above, we predict that older adults with chronic pain who have higher levels of pain catastrophizing talk more about their pain with close relations:

H2: Pain catastrophizing in older adults with chronic pain is positively associated with pain-related discourse with close relations.

The communal coping model of catastrophizing. The interpersonal and social approach to understanding pain catastrophizing and its effects can be most clearly seen through the lens of the communal coping model (Coyne and Fiske, 1992; Sullivan et al., 2006). The communal coping model of catastrophizing is a framework that theorizes how catastrophizing represents a social-goal-oriented process as part of a broader interpersonal orientation to coping with pain-related experiences. This framework operates under the assumption that individuals with chronic pain communicate distress and try to gain support from close others in particular (Sullivan et al., 2000; Thorn et al., 2003). Pain catastrophizers tend to engage in exaggerated pain-related emotions in order to solicit empathic responses from their social environment (Coyne & Fiske, 1992). Consequently, pain catastrophizers may be expected to engage in behavior aimed at maximizing the probability that their pain-related emotions will be evident to their close others in their social environment. This framework posits that the provision of reinforcing responses such as expressions of sympathy may be more important to chronic pain patients than reductions in pain intensity or disability, which are considered practical-pain related behaviors (Keefe et al., 2000). To summarize, catastrophic thoughts predicate exaggerated displays of pain-related emotions, which serve a communicative function (i.e. explicitly expressing emotional needs, garnering sympathy) within a social context, specifically one that occurs as an outcome of the interaction between the pain catastrophizer and

their close partner/responder (Keefe et al., 2000). Taking Sullivan's communal coping hypothesis and its assumption that pain catastrophizers communicate with close relations, we predict that older adults, who are categorized as high pain catastrophizers, verbalize more pain-related emotions and less pain-related practical issues in pain-related discourse:

H3: The pain-related discourse that older adults with pain who are categorized as high pain catastrophizers have with close relations is a) positively associated with content of pain-related emotions and b) negatively associated with pain-related practical content.

The discussion of management of chronic pain with social support interactions thus far has been in the context of face-to-face social contexts and mostly within the context of pain catastrophizers. As many older adults with chronic pain have increasingly been turning to mobile technologies, we now consider the types of social support interactions afforded uniquely by mobile technologies and their role in chronic pain management.

Mobile Health (mHealth), Social Support Interactions, and Chronic Pain Management of Older Adults

mHealth and chronic pain in older adults. mHealth is a rapidly emerging field with the potential to assist older adults in the management of chronic pain by enhancing communication with providers, monitoring treatment-related side effects and pain levels, and increasing access to pain care resources. Older adults with chronic

pain in particular are interested in and willing to use these mHealth applications to assist in the management of their chronic pain (Parker, Jessel, Richardson, & Reid, 2013). There are different types of mHealth pain application, including but not limited to educational apps with general information about chronic pain, its symptoms, and treatment options, tracking apps where individuals with chronic pain can track symptoms and medication use, reminder apps that send appointment and medication reminders, and intervention apps for pain management (Rosser & Eccleston, 2011).

One of the most prevalent types of mHealth applications for older adults with chronic pain is intervention apps. This prevalence may be due to the transferal ability of Internet-based interventions to smartphones. These interventions can include different types of cognitive and behavioral therapy techniques, moderated peer support forums, and tailored and automatic messages to improve pain-related outcomes (Bender et al., 2011). For example, older adults with chronic pain have an affinity for relaxation technique interventions delivered through mobile technologies (Currie et al., 2015). Many of these Internet-based interventions transferred to mobile health applications consist of interactive components designed to promote communication, distraction, information, self-expression, and social support (Holden et al., 2003).

mHealth and social support interactions for older adults. There is a momentum to increase intervention mHealth applications for older adults with chronic pain, especially social support interventions. For example, Guillory et al.'s (2015) study found that delivering social support text messages as an intervention reduced perceived pain, decreased pain's interference with general activity, increased relations with others, and increased sleep for older adults with chronic pain. mHealth

applications are increasingly focusing on these social and interpersonal components. Drawing from the social support and chronic pain frameworks, many mHealth applications are designed to enhance social support interactions to ultimately better pain-related outcomes. These mHealth applications and new technologies support chronic pain management by creating tools to connect with family and friends (e.g. Benjamin et al., 2011) and even to communicate with health care providers (Hall et al., 2012). For example, Benjamin et al. (2011) developed a creative technology to enhance communication between an older adult with chronic pain and their family. The researchers created a touch screen computer fitted into a wooden picture frame; and this device displayed photos of the older adult with chronic pain and their family or friends. When the older adult with chronic pain would touch a photo, an email was sent to those in the photo, encouraging them to send the older adult with chronic pain a video. This is just one example out of many novel technologies to foster social support interactions among family and friends and older adults with chronic pain. These interactions are further encouraged because peer support and interpersonal social support have beneficial effects on health (Boothroyd and Fisher, 2010).

These types of interactions are more commonly supported on mobile devices, as they can now be delivered through mobile technologies like text messages, phone calls, mobile applications, etc. (e.g. Guillory et al., 2015; Penttinen et al., 2002). Specifically, older adults in particular use various ICTs if they feel comfortable and confident using new technologies, like smartphones and tablets (Mitzner et al., 2010; Joe & Demiris, 2013) that can foster support interactions. The peer-support-based mHealth applications help better health outcomes through enhancing positive health

behaviors through social interactions (e.g. Consolvo et al., 2006), and encouraging meeting health goals through social support (e.g. Grimes et al., 2008). In the context of chronic pain, patients who exchange experiences with people with similar symptoms on mHealth platforms show significant reductions in pain levels, disability, and distress (Holden et al., 2002). Combining these findings, we predict that older adults with chronic pain who are more comfortable with technology have more pain-related discourse on their mobile devices:

H4: The self-efficacy and comfort level of using ICTs for older adults with chronic pain are positively associated with pain-related discourse on mobile devices.

Staccato social support afforded by mobile technologies. Social support on computer-mediated communication platforms have primarily been in the form of online discussion forums, bulletin boards, and listserves; and there has been a wealth of research showing the benefits of these social support CMC environments (e.g., Walther & Boyd, 2002; Sapp & TrenthamDietz, 2003; Newman et al., 2011). However, with evolving CMC platforms and mobile technologies in particular there has been a focus on short and rapid interactions driven by online contacts, and these ‘bursty’ interactions are characterized as social awareness streams that are consumed on mobile devices (Naaman et al., 2010). Drawing from this concept of social awareness streams, there is a particular style of social support that mobile devices afford referred to as ‘staccato social support’ (Adams et al., 2014). Staccato social support is enacted in mobile environments designed for brief, rapid social sharing and

support interactions (Adams et al., 2014). Staccato social support, unique to mobile devices, is associated with a high prevalence of esteem support, which increases confidence. It also fosters informational social support in the form of advice giving (e.g., compliments and short validations) (Adams et al., 2014). Given the framework of staccato social support and its effect on interactions, we predict that older adults who have pain-related interactions focused on practical issues on mobile devices feel cared for, feel understood, and perceive social support. We also predict that having pain-related discourse on mobile devices is associated with positive affect and better psychological adjustment to pain:

H5: Communicating practical pain-related content on mobile devices is associated with a) feelings of being cared for, b) feelings of being understood, and c) perceiving social support for older adults with chronic pain.

H6: Communicating about pain on mobile devices is associated with a) positive affect and b) better psychological adjustment to pain for older adults with chronic pain.

Methods

This study used a mixed-method approach to understand how older adults with chronic pain communicate about their pain and exchange social support, as well as the effects of such interactions on their well-being and psychological adjustment.

Specifically, we conducted an explanatory sequential mixed-method study (Creswell et al., 2003; Steckler et al., 1992; Morgan, 1998; Tashakkori & Teddlie, 2003) using

surveys through experience sampling, also known as ecological momentary assessment (EMA) (Stone & Shiffman, 2002) and semi-structured interviews. We used surveys with EMA to collect in situ data and conducted semi-structured interviews to seek a more in-depth understanding of the communication patterns of older adults with chronic pain. Once we received institutional review board (IRB) approval, we collected data between November 2014 and December 2015.

Participants

For this study, we recruited 25 older adults with chronic pain who were 55 years and older, and owned a smartphone. We strategically set the age of participants to 55 years and older because although most countries have accepted the age of 65 years old as the definition of an “older adult” (World Health Organization, 2016), the age range of 55-65 is considered as the ‘younger older adult’ population (WHO, 2016). Also, 39% of individuals in the 55-65 age group and 18% in the 65+ group owned a smartphone in 2013 (Smith, 2012; 2013), and this number has been dramatically increasing over time. This was an important factor to consider, as our participants had to own a smart phone so we could deliver the survey measures to them every day three times a day at randomized times. Participants were recruited through flyers posted in public places around a Northeast city in the U.S. (e.g., libraries, bulletin boards in cafés, community centers, and chronic pain clinics, etc.), with the permission of administrators, shop owners, and clinicians at these chronic pain clinics, as well as through snowball sampling.

The participants ranged in age from 56 to 86 years old ($M = 72$, $SD = 7.65$). Participants were 91.5% Caucasian, 4.2% African American, and 4.2% Asian/Pacific

Islander, and the sample categorized themselves as 58.6% married, 20.3% widowed, and 21.1% divorced. Participants reported between 1 and 6 chronic conditions ($M= 3$, $SD= 1.83$).

Phase 1: Surveys

At an initial face-to-face meeting, participants signed the informed consent form and downloaded a customized mobile application called Ohmage (Estrin et al., 2009), which would deliver survey questions to the participants throughout the study. We would then walk the participant through using the mobile application and practice with them a few times until the participant felt comfortable. They also filled out a baseline questionnaire that contained measures explained below.

The data was collected using an experience sampling method (Hormuth, 1986) via the Ohmage smartphone application, which would prompt participants to answer survey questions three times per day at randomly scheduled times in a 12-hour time window (once in the morning, afternoon, and evening) during one week. Experience sampling allowed the team to collect in-situ data, which helps with reducing recall bias and reporting errors. Mobile health applications have been used successfully for experience sampling by allowing patients to track pain experiences via diary methods, and there has been an increasing popularity of mobile applications for pain management (Rosser & Eccleston, 2011). Filling out the survey questions at each prompt took approximately five minutes. The app displayed survey questions described below. Next, we elaborate on the survey measures in the baseline questionnaire as well as the survey questions we asked through the mobile application.

Measures in the baseline questionnaire

In addition to the demographic information reported above, we also asked the following in our baseline questionnaire.

Self-rated health. We assessed the self-reported number of days in the past 30 days that participants experienced poor mental and physical health. We asked them to rate their mental and physical health on a 5-point scale, 1 = “poor” and 5 = “excellent.” We also asked participants to provide a rating of their overall health on a 5-point scale from 1 = “poor” to 5 = “excellent.”

Duration of use and comfort with different technologies. To gauge the amount of time participants spent with different information and communication technologies, we asked them to indicate how frequently they use computers, email, online social networking sites, the Internet (not for email but for games and online shopping), videochatting, and mobile devices for communication like texting and phone calls, with 1 = “never,” 7 = “several times a day.” We also asked participants to rate how comfortable they felt using each of these ICTs on a 5-point scale, with 1 = “very uncomfortable” and 5 = “very comfortable.”

Social connectedness. To gauge participants’ social connectedness to others, they were asked to answer questions from Lee and Lee’s (2001) social connectedness scale, which was measured on a 5-point scale, 1 = “strongly agree” and 5 = “strongly disagree.” For example, “Even around people I know, I don’t feel that I really belong,” or “I feel distant from people,” with 5 indicating the highest degree of social connectedness.

Perceived social support. Participants were asked to rate perceived social support in their everyday lives using Zimet, Dahlem, Zimet, and Farley’s (1998) scale

of perceived social support, which is on a 7-point scale, with 1 = “very strongly disagree,” and 7 = “very strongly agree.” For example, participants were asked to indicate how they felt about statements such as “I count on my friends when things go wrong” or “I get emotional help and support from my family”, with 7 indicating the highest degree of perceived social support.

Social constraints related to expression of chronic pain. Participants were asked to rate how socially constrained they felt when expressing their pain to others. We used Herbert & Rimé’s (2004) measure. Participants answered questions on a 5-point scale, with 1 = “almost never” and 5 = “almost always.” For example, “Do you keep your feelings about your pain to yourself because they make other people feel uncomfortable?” A higher number indicates a higher degree of feeling socially constrained.

Pain-related social support and attitudes. Participants were asked on a 5-point scale, with 1 = “very untrue” and 5 = “very true,” to indicate how much or how little they felt supported in relation to their chronic pain. We used the social support and pain attitudes (SOPA) scale (Jensen, Turner, Romano, & Lawler, 1994). For example, participants were asked, “When I am hurting, I deserve to be treated with care and concern” or “When I hurt, I want my family and friends to treat me better.”

Perception of credibility of health conditions. The next measure assessed the extent to which participants thought that their pain experience was recognized as credible by their social environment. To measure it, we used Herbert & Rimé’s (2004) 5-point scale, with 1 = “not at all” and 5 = “to a great extent,” asking questions

such as “to what extent do you think your social environment understands the origin of your pain?”

Pain catastrophizing. To gauge the more social aspects of pain catastrophizing, we used the Pain Anxiety Symptom Scale (McCracken, Zayfert, & Gross, 1992). We asked participants to rate each item in terms of frequency on a 5-point scale, with 1 = “Never” and 5 = “Always.” For example, “I worry when I am in pain”, with a higher number indicating higher pain catastrophizing.

Measures delivered through Ohmage Experience Sampling Method

Pain severity. Participants were instructed to rate the severity of the pain they felt. Pain severity was measured through the Brief Pain Inventory (Cleeland, 1991), a commonly used scale to measure chronic pain patients’ pain. It gauged participants’ pain level by asking them to mark the number that best described their pain on a scale of 1 = “no pain” to 11 = “pain as bad as you can imagine.”

Communication contact and nature of relationship. We asked the participants an open-ended question through the mobile application of who their most recent communication contact was and through which communication channel they used to communicate with them. Participants were asked to choose one of the options for their relationship with the recent contact: spouse, child, sibling, friend, neighbor, doctor, other relative, group setting/several people, and other. Participants who chose ‘other’ were given an open-ended space to enter the type of relationship. Then we asked them the nature of the relationship with the interaction partner, which was gauged using Vangelisti & Caughlin’s (1997) relational closeness scale measured on a 7-point scale, with 1 = “not close at all” and 7 = “very much.” An example of a question was, “How

much do you think you confide in each other?” or “How important is your relationship?” We also asked on which technological medium the interaction took place, asking them to choose from among face-to-face, landline telephone, mobile phone, texting, email, videochatting, Internet like social networking sites, and other. Participants chose ‘other’ if none of the options was applicable, and they could type in an explanation in a designated open-ended space.

Verbalization of pain and pain-related emotions. Disclosure of pain and pain-related emotions was taken from the ratings of discussion content for verbalization of pain and factual and emotional issues related to pain (Herbette & Rimé, 2004). We asked participants to indicate the content of their discussion on a 5-point scale, with 1 = “never,” and 5 = “very much.” For example, we asked “Was the discussion focused on practical issues (such as medical ones, examinations, medical treatment)?” or “Was the discussion focused on emotional issues (such as hopes, fears, worries associated with chronic pain)?”

Interaction satisfaction, partner’s perceived responsiveness and social support. We asked participants to reflect on their interaction. In order to gauge interaction satisfaction (Herbette & Rimé, 2004), we asked participants to rate how satisfied they were with each conversation on a 5-point scale, with 1 = “very unsatisfied,” and 5 = “very satisfied.” Participants were also instructed to indicate to what extent each discussion was beneficial (5-point scale, Not at all: To a great extent) (Herbette & Rimé, 2004). The extent to which the participant felt perceived responsiveness and social support by their partner was measured by Laurenceau, Barrett, and Rovine’s (2005) scale (5-point scale, Very little: A great deal). For

example, participants were asked to rate “The degree to which you felt understood by your interaction partner,” or “The degree to which you felt cared for by your interaction partner.”

Affect and psychological adjustment to pain. We asked participants to rate how positive or negative they felt at the moment. In order to gauge affect, we asked participants to rate how positive or negative they felt right now, with 1 = “very negative” and 7 = “very positive,” with a higher number indicating more positive affect and a lower number indicating negative affect. We also used Linkowski’s (1971) scale to measure psychological adjustment to pain. We asked participants to rate how psychologically adjusted they felt to their pain at the moment on a 5-point scale, with 1 = “agree” and 5 = “disagree.” For example, participants were asked to rate “I have a hard time adjusting to the limitations of my pain,” such that a higher number indicated better psychological adjustment.

Quantitative Data Analysis

The analyses utilized multilevel modeling in the SPSS MIXED procedure to control for a potential nonindependence of residuals resulting from participants reporting on multiple communication interactions (Hayes, 2006). We controlled for age of participant, gender, and other factors taken from the baseline questionnaire such as number of pain conditions. The summary of all the hypotheses and the results are presented in Table 1.

Phase 2: Semi-structured in-depth interviews

After one week of filling out questions delivered through the smartphone mobile application, the first author and/or research assistant met again with each

participant for an in-depth interview. The purpose of the interview was to gain a more in-depth understanding of the communication patterns, especially because we collected data for only one week, and older adults with chronic pain in particular may have more variation in their social interactions. The interviews lasted between 30-180 minutes. The interviews allowed for flexibility to avoid limiting the field of inquiry and for the interview to take form naturally (Lofland, et al., 2006). The semi-structured interview may stray away from any a priori categorization that may limit the research questions or field of inquiry (Charmaz, 2000). All interviews were conducted face-to-face in public places (e.g., participant's offices, coffee shops and bakeries) and audiotaped. Once the interviews were completed, participants were compensated for their time with \$20.00.

Qualitative Data Analysis

The audiotaped interviews were transcribed verbatim and edited to remove any identifiers. Additionally, confidentiality of all the participants was maintained by omitting from the transcripts all personal references that may have identified the participants. Each participant was given a number that corresponded to the interview transcript (Pn). After reading through the interview scripts multiple times to become acquainted with the data, I imported the transcripts into Atlas.TI, a qualitative data analysis software package that helps with categorizing and comparing findings. Atlas.TI enables creation of a user-defined personal computer based coding system that organizes all the transcripts within one unit and allows easy text searching, tagging, and comparison. There was a close reading of each of the units. Taking themes that arose iteratively from the data, the author and a research assistant then did

a full coding of all the transcripts applying these codes. They grouped excerpts with similar codes and wrote a series of memos analyzing those responses during all phases of analyses to highlight key questions about relationships in the data, to refine categories, and to ensure a close association between participants' responses and emerging analyses. The author and research assistant then did another round of coding, which resulted in Cohen's Kappa = .88. The three main strategies for analyzing the data were coding, memo writing, and iterative coding.

Results

Perceived social support and partner responsiveness of older adults with chronic pain in pain-related interactions. Hypothesis 1a predicted that pain-related discourse between older adults with chronic pain and their close relations was positively associated with their feeling of being cared for by their communicative partner. The null model to evaluate variance in the dependent variable had an estimated residual variance of 0.77, and an estimated variance of random components of 0.13, with the interclass correlation (ICC) of 0.14. Consistent with Hypothesis 1a's prediction for pain-related discourse with close relations and older adults with chronic pain feeling cared for, the association was significant, $F(1, 489) = 21.98, p < .001$, showing that more pain-related discourse was associated with feeling cared for by a communication partner, $B = .03, SE = .01, p < .001$. Further, the difference in deviance scores between the two models, the null model and the model with predictors, was also significant, $\chi^2(1) = 41.865, p < .001$, leading to a rejection of the null hypothesis of no relationship between the two variables. Additionally, consistent with H1b, which predicted that pain-related discourse was positively associated with feeling

understood, the association was significant, $F(1, 487) = 26.87, p < .001, B = .03, SE = .01$. The more older adults had pain-related discourse with close relations, the more understood they feel by their communicative partner. The changes in deviance scores for the models was also significant $\chi^2(1) = 52.812, p < .001$. Thus, when older adults with chronic pain communicate with close relations they feel cared for and feel understood.

Types of interpersonal resources, support networks, and preferred communicative partners of older adults with chronic pain; and the use of different communication technologies to communicate about pain. Probing further into pain-related communication, we further examined types of preferred partners and interpersonal resources older adults with chronic pain drew upon to talk about their pain (RQ1). Surprisingly, despite the positive effects of pain-related discourse identified in the analyses for H1a and H1b, qualitative analyses revealed that in general, older adults with chronic pain did not feel like communicating with anyone when they were experiencing pain and/or pain-related emotions. Many informed us that they actively self-isolated and avoided any communication, as the following excerpts illustrate:

“I avoid people. If I could avoid myself I would. If I could get out of my own skin I would run. I don’t even like to be around me. The mood usually follows the pain.” P005.

“When I am actually having a lot of pain, if I’m alone, I tend not to reach out. I won’t actively get my phone or try to talk to someone. If I don’t talk to people face to face when I’m in pain why would I possibly go get my phone to talk to someone?” P001.

However, when older adults with chronic pain did want to talk about their chronic pain, they preferred talking to others who also have chronic pain, compared to

their close relations like their spouses or close friends who do not have chronic pain.

The participants expressed that they would rather talk to others who can understand their chronic pain than close family and friends because they do not want to worry the latter. For example, one of the participants shared her experience:

“There is solidarity with others who also have pain. You don’t want to talk about it with others who don’t know about it or haven’t experienced it. They have nothing to add to the conversation. You’re sharing information or experiences so those who will get you the most are people who also have chronic pain. Plus I don’t want to burden or worry my family and close friends.” P011.

We further explored the different types of technologies older adults with chronic pain were using when they did happen to have pain-related discourse with others. Figure 1 reports percentages of each information and communicative technology used in their pain discourse throughout the week by technology-type. Across all the participants’ interactions, most of them occurred 67.2% percent in face-to-face settings, followed by 11.3% on email, 9.3% on mobile phones, 3.6% on the Internet (e.g. online communities and information-searching), 0.6% on the landline telephone, and 0.2% on videochat. Thus, in answer to RQ1 we found that older adults with chronic pain prefer to talk to other individuals who also have chronic pain, and although there are various communication channels they use to have these pain-related interactions, they talk mostly in face-to-face contexts, followed by email and mobile phones.

Pain catastrophizing and pain discourse. Next, we examined the role of pain catastrophizing in pain talk to test H2 predicting that pain catastrophizing in older adults with chronic pain is positively associated with pain-related discourse with close relations specifically (H2). The association was significant, $F(1, 484) = 10.59, p$

<.001, showing that older adults who are categorized as pain catastrophizers have more pain-related social interactions, $B=.03$, $SE=.02$, $p<.001$. The change in deviance scores between the null model and the model with the fixed predictor was also significant, $\chi^2(1)=22.748$, $p<.001$. Thus, older adults, who are categorized as pain catastrophizers, have pain-related discourse with close relations.

Content types (e.g., pain-related experiences and emotions) older adults share in pain discourse. Hypothesis 3 predicted that in interactions with only close relations, high pain catastrophizers' discourse is a) high in pain-related emotions and b) low in pain-related practical content. There was a significant relationship for content of pain-related emotions, $F(1, 52)=5.14$, $p<.05$, $B=.07$, $SE=.03$, as predicted by H3a, meaning that the more older adults with pain who are categorized as high pain catastrophizers have pain-related discourse, the more they discuss pain-related emotions. The change in deviance scores between the null model and the model with the fixed predictor was also significant, $\chi^2(1)= 23.642$, $p<.05$. Hypothesis 3b was not supported, however, $F(1, 38)=3.23$, $p>.05$, $B=.05$, $SE=.03$. The change in deviance scores for the models with pain catastrophizer's pain discourse and content of pain-related practical issues was also not significant, $\chi^2(1)=6.977$, $p>.05$. Thus, older adults, who are high pain catastrophizers, have pain discourse with close relations about pain-related emotions, but not pain-related practical content.

Pain-related content interactions on mobile devices and the effects of such interactions on mobile devices. Next, we examined communication patterns of older adults with chronic pain and their use of mobile devices to have these pain-related interactions. Consistent with Hypothesis 4's prediction that there is a positive

association between pain-related discourse on mobile devices and participants' comfort level and confidence with using ICTs, the relationship was significant, $F(1, 22) = 4.87, p < .05$, showing that the more confident and comfortable older adults were using ICT, the more pain-related social interactions they had on their mobile devices, $B = .31, SE = .14, p < .05$. The change in deviance scores for the models were also significant, $\chi^2(1) = 12.753, p < .05$. Thus, the more comfortable and confident older adults are using ICTs, the more pain-related discourse they have on their mobile phones.

The next hypothesis predicted that communicating practical pain-related content on mobile devices is associated with older adults a) feeling cared for, b) feeling understood, and c) perceiving social support. There was a significant relationship for older adults feeling cared for, $F(1, 492) = 42.76, p < .001, B = .26, SE = .04$, as predicted by H5a. The change in deviance scores between the null model and the model with the fixed predictor was also significant, $\chi^2(1) = 38.119, p < .001$. The results also show an association between communicating practical pain-related content on mobile devices and older adults with chronic pain feeling understood, $F(1, 480) = 29.25, p < .001, B = .20, SE = .04$, as predicted by H5b. The change in deviance scores for the models was also significant, $\chi^2(1) = 52.503, p < .001$. Finally, there was a positive association between communicating practical pain-related content on mobile devices and feeling perceived social support, $F(1, 488) = 29.82, p < .001, B = .14, SE = .03$, as predicted by H5c. The change in deviance scores for the models were also significant, $\chi^2(1) = 58.249, p < .001$. The results show that having practical pain-related

content interactions on mobile devices is positively associated with older adults with chronic pain feeling more cared for, understood, and perceive social support.

Although our results show that practical pain-related discourse on mobile devices is associated with feeling cared for, feeling understood, and perceiving social support, our participants further expressed the specific type of response they anticipated from their communicative partner in pain discourse. Participants primarily wanted to vent to someone who would listen to them and validate their pain-related expressions, and if this occurred then they would feel understood. However, participants discussed feelings of frustration when receiving unsolicited advice or responses:

“I just want to vent. I don’t want advice. I don’t want to be told what to do. I just want to get this pent up negative energy out. I just don’t want a response back especially because most of the time when I do get responses it’s not the one I want. It makes me feel worse sometimes!” P014

“If I ever do get a response I just want validation that what I am saying is right. Factual validation. Like if I say that the weather is affecting my pain, I want someone to say, yes weather definitely affects pain, nothing else.” P019

Another theme that emerged from the interviews that supplement the results of pain-related content interactions on mobile devices is how participants used mobile devices as a tool to facilitate face-to-face pain-related interactions. Participants who used mobile technology for in pain-related interactions discussed how mobile devices would act as a tool for connecting with others and arranging face-to-face interactions with them. They expressed that they did not want to text or communicate via mobile devices about their actual pain, but that they did text to reach out to friends who also had chronic pain to briefly check-in on them to see how they were doing. If they were

doing well, they would not continue communicating via text message. If they were not doing well, they would decide to meet face-to-face. One of the participants shared her experience(s):

“We have code words and phrases like with my friend [removal of name], we text each other at least once a day and we ask ‘NB or HP?’ That’s never better or help please. It’s a way we check in with each other without getting into the emotional mushy gushy parts of pain. If it’s NB that’s that, done. If it’s HP then we meet and walk together or talk more about mushy gushy stuff in person. It’s nice to know that I can do this any time, she’s always there.” P025.

Effects of pain-related discourse on mobile devices on affect and psychological adjustment to pain. Hypothesis 6 predicted that communicating about pain on mobile devices is associated with a) positive affect, and b) psychological adjustment to pain. There was a significant relationship for positive affect, $F(1, 493)=11.06, p<.001, B=.14, SE=.04$, as predicted by H6a, suggesting that the more older adults with chronic pain communicate about pain on their mobile devices, the more positive affect they feel, even when controlling for the level of pain the older adult felt at the time of communicating about their pain, $F(1, 397)=119.19, p<.001, B=.34, SE=.03$. The change in deviance scores between the null model and the model with the fixed predictor was also significant, $\chi^2(1)= 31.329, p<.001$. Hypothesis 6b was also supported for the association between communicating about pain on mobile devices and psychological adjustment to pain, $F(1, 489)=44.03, p<.001, B=.18, SE=.03$. The change in deviance scores between the null model and the model with the fixed predictor was also significant, $\chi^2(1)= 60.966, p<.001$. Thus, older adults with chronic pain that communicate about their pain on their mobile devices feel more positive affect and have better psychological adjustment to their pain.

Discussion

The goal of this study was to better understand how older adults with chronic pain communicate about their pain and exchange social support, as well as the effects of such interactions on affect and psychological adjustment to pain. We also aimed to investigate pain-related interactions on mobile devices. The integration of our quantitative and qualitative analyses revealed that pain-related discourse that older adults with chronic pain have with close relations is associated with feeling cared for and feeling understood by their communicative partner. The findings also show that older adults with chronic pain prefer not to communicate about their pain, and instead seek to actively self-isolate when experiencing pain and pain-related emotions. However, when they talk to others about their pain-related experiences and emotions, they sought out other individuals who also have chronic pain. Furthermore, they primarily had pain discourse face-to-face, followed by email, then mobile phones, and then the Internet (e.g., online communities and information-searching). Findings also show that older adults who are classified as pain catastrophizers talk to their close relations about pain-related emotions, but not practical pain-related content. Finally, the results show that older adults who are more comfortable and confident using ICTs have more pain-related discourse on mobile devices, and, in doing so, feel cared for, understood, and perceive social support. In general, when older adults with chronic pain have pain-related discourse on their mobile phones, they experience more positive affect and better psychological adjustment to their pain. In the following, we discuss theoretical implications and future directions suggested by the findings from this study.

Theoretical Contributions and Implications

Interpersonal dynamics of pain-related discourse for older adults with chronic pain. The first two aims of the study focused on pain-related discourse between older adults with chronic pain and their communicative partners, and the interpersonal dynamics that stemmed from these interactions. The first goal of the study was to investigate perceived social support and partner responsiveness of older adults with chronic pain in pain-related interaction. Our study found that when older adults with chronic pain have pain discourse with those they consider relationally close, they feel cared for and understood. This validates the effects of peer-to-peer support within close relationships, as interactions with close relational others yield positive effects for individuals with chronic pain. Specifically, these peer-to-peer interactions improve self-efficacy, increase activity levels, reduce pain severity, and increase perceptions of relational closeness (Perry & Watt-Watson, 2010).

The second goal of the study was to investigate the types of interpersonal resources and support networks used by older adults with chronic pain to communicate about their pain. Although there are positive effects of talking about pain to close others, our study found that most of our participants actively self-isolate and avoid communication when experiencing pain and/or pain-related emotions, which is consistent with previous studies on older adults with chronic pain and isolation due to pain (e.g., International Association for the Study of Pain, 2011; Miles, Curran, Pearce, & Allan, 2005). The interviews show that when older adults with chronic pain do have pain-related interactions, they prefer talking with others who also have chronic pain more than they do with those they consider relationally close.

Participants expressed that they prefer talking to others who also have chronic pain because they feel better understood. In contrast, they avoid talking to close relations who don't have chronic pain because they do not want to burden or worry them. Our results are consistent with Gonzalez-Polledo's (2016) study that found that individuals with chronic pain seek similar others, and actively seek other individuals who also have chronic pain using ICTs when this type of social network is not available in their face-to-face environment. Furthermore, our finding that older adults with chronic pain prefer communicating with others with chronic pain can be better understood through the lens of Cohen and McKay's (1988) matching model, which states that under stressful situations, individuals seek others with similar social characteristics, attitudes, personality, and negative experiences who can relate to their distressed state. Consistent with this model, participants in our study preferred communicating with similar others about their pain-related experiences and emotions.

Furthermore, the results of our study show that when older adults with chronic pain share pain-related experiences and emotions with others, they favor validation over any other type of response. Validation is a mechanism for a type of social support referred to as esteem social support (Tichon & Shapiro, 2003). Thoits (2011) argues that esteem support, in the form of validation, is one of the more effective mechanisms for linking social interactions and support to physical and mental health. When our participants did not receive validation of their pain-related experiences and emotions from their communicative partner, they felt frustration and anger. This finding illuminates the importance of validation in chronic pain discourse, as validation increases the recipient's feelings of competence (Braithwaite et al., 1999) and is a

common strategy in social support processes (Chan et al., 2001; Murray, 2002; Simich et al., 2003).

High pain catastrophizers and their pain-related discourse. The third aim of the study was to examine content types (e.g., pain-related experiences and emotions) that older adults with chronic pain share with others. We specifically investigated content types of pain catastrophizers, as they tend to share more pain-related experiences compared to non-pain catastrophizers (Sullivan et al., 2000; Thorn et al., 2003). Our quantitative results indicate that being a pain catastrophizer is positively related to talking more about pain experiences with close relations. This suggests that pain has a communicative function in close relationships, which is consistent with the communal coping model, which states that pain catastrophizers share pain-related experiences with close relations. (Sullivan et al., 2000; Thorn et al., 2003). Pain catastrophizers may continue to share pain-related experiences with close relations as a coping function to elicit emotional validation (Block et al., 1980) as well as to receive sympathy (Keefe et al., 2000). Furthermore, we found that older adults with chronic pain who are categorized as high catastrophizers talk about emotional pain-related content, but not practical pain-related content. This finding is consistent with previous research about pain catastrophizers' discourse exaggerated pain-related emotions (Coyne & Fiske, 1992) because they are met with sympathy and attention, which are more important to older adults with chronic pain than practical pain-related help (Keefe et al., 2000).

Pain-related discourse on mobile devices. In light of pain-related discourse and positive effects of such interactions, older adults with chronic pain oftentimes use

ICTs. They use ICTs so they can communicate with similar others, who can identify with their experiences. Specifically, ICTs provide a way for older adults with chronic pain to connect with others who ‘speak their own language (Biro, 2012; Ginsburg, 2012). Older adult’s use of ICTs are reflected in our findings that show that after face-to-face interactions, older adults communicate about pain-related content on email and mobile devices.

Quantitative results show that older adults with chronic pain who felt more comfortable and confident using ICTs had pain-related discourse on their mobile devices, and when they did so, they felt cared for, understood, socially supported by their communicative partner. The qualitative analyses supplement this finding by showing that older adults with chronic pain reach out to other friends who have chronic pain to briefly ‘check-in’ on them. These participants would also come up with code words and phrases that they would use in mobile communication. These ‘check-ins’ and ‘code words’ that older adults with chronic pain use may be unique to mobile technologies and represent a novel form of social support in which older adults with chronic pain seek and engage in through mobile technologies. This type of support is consistent with the *staccato social support*, or short, rapid, and ‘bursty’ support interactions afforded by mobile technologies(Adams, Baumer, & Gay, 2014). Findings from a previous study show that staccato social support fosters information social support in the form of advice giving, compliments, and short validations (Adams, Baumer, & Gay, 2014). However, this study further extends staccato social support to the context of older adults with chronic pain suggesting that it can also happen in a different form of ‘bursty’ support, such as ‘check-ins’ or ‘code words’ that

encourage further communication between partners. As our qualitative findings indicate, older adults with chronic pain use mobile devices, and the staccato social support that they facilitate, as a tool to connect with others who also have chronic pain in order to meet face-to-face.

This study also provides an important contribution to the effects of pain-related discourse via mobile devices on affect and psychological adjustment to pain for older adults with chronic pain. We found that older adults with chronic pain who used mobile devices to talk about pain experienced more positive affect and better psychological adjustment to their pain, even after controlling for current pain levels. This finding implicates that mobile devices could be leveraged to encourage pain-related interactions with similar others, ultimately to increase positive affect, better psychological adjustment to pain, and feelings of being cared for, understood, and supported.

Future Directions

Social support networks have been called “the future for health care delivery” (Griffith et al., 2012), and it is critical to understand their impact on social support and well-being. Older adults are the fastest growing group of individuals using ICTs in general and mobile technology in particular (Smith, 2013; Zickuhr, 2014). Therefore, these technologies could be leveraged for delivering behavior change interventions for older adults with chronic pain. One promising future direction would be to translate these findings into an intervention study of social reminders and feedback through mobile devices, and test the efficacy and effectiveness of social support interventions. Specifically, an intervention could send social reminders or text messages to members

of support networks reminding them to connect with others who have chronic pain. This approach could take into account types of relationships, types of support, and types of communication channels to ensure that social support is effective.

Another future direction could be to examine the effects of staccato social support over an extended period of time, and further investigate the effectiveness of this type of social support for older adults with chronic pain. A further study could also examine the specific mechanisms that influence positive effects of pain discourse. Although our participants expressed not wanting to talk to others when experiencing pain, we did find positive effects of feeling cared for and understood when older adults with chronic pain had pain-related discourse with close relations. Understanding which communicative mechanisms in these pain-related interactions lead to older adults feeling cared for and understood would allow close relations to communicate more effectively with friends or relatives who have chronic pain. Furthermore, as these pain-related interactions are increasingly taking place via mobile devices, future studies could investigate the different types of social support interactions that occur on various ICTs and the effects of such interactions. Better understanding how ICTs are being used by older adults with chronic pain can help guide designers to better consider the needs of older adults with chronic pain.

Limitations

This study has a few limitations. The first limitation pertains to the sample size and representation because participants were primarily female, and came from a geographically limited area, which could potentially limit the generalizability of our findings. Future work could replicate this study with larger samples from varying

geographic areas, with different clinicians, different health care access, and different familiarity with ICTs. Furthermore, this study collected experience sampling data for one-week period, so future studies could use more extensive longitudinal methods to capture communicative and social support interactions of older adults with chronic pain. Finally, there are opportunities for future studies to investigate the social context of pain, such as how existing interpersonal relationships shape pain-related preferences for social support and pain outcomes, and how pain outcomes may differ based on support provided by different friends or family members.

Conclusions

There are various pain management strategies for older adults with chronic pain. However, with a growing number of ICTs that support pain-related interactions in particular, it is important to understand the effects of pain-related discourse for older adults with chronic pain. This study examined communicative dynamics of pain discourse and its effects on older adults with chronic pain, with a focus on pain discourse that occurs on mobile devices. Findings show that even though older adults with chronic pain prefer self-isolation and avoidance of interactions when in pain, pain discourse with close relations has positive effects. These findings provide significant insight into pain-related interactions among older adults with chronic pain, with the promise that ICTs will make it easier than ever to reach out to and foster social support and pain management techniques to older adults with chronic pain.

CHAPTER 3

STUDY 2 – ‘TO RESPOND OR NOT TO RESPOND, THAT IS THE QUESTION:’ EXAMINING THE DECISION-MAKING PROCESS OF PROVIDING SOCIAL SUPPORT TO DISTRESSED POSTERS ON FACEBOOK

Young adults are at high risk for psychological distress because of the neurological and physiological changes that are common to this period, as young adults face challenges of transitioning from home to novel environments (Egan & Moreno, 2011; Hunt & Eisenberg, 2010; Moreno et al., 2011; Tandoc, Ferruci, & Duffy, 2015). To cope with stressful situations and distress, young adults often turn to peer networks for social support (Galaif, Sussman, Chou, & Wills, 2003; Oh, Lauckner, Boehmer, Fewins-Bliss, & Li, 2013). Although not necessarily helpful in offsetting psychological distress, peer support exchange is an important resource in youth’s daily life (Wright et al., 2013), and understanding how peer networks respond to distressed social media messages will inform prevention and intervention efforts.

The availability and use of social media have dramatically changed social support interaction landscapes by offering new ways of expressing oneself and of tapping into peer support networks (Akbulut & Gunuc, 2012). Social network sites (SNSs) have become a part of daily communication venue for young adults, who access it every day and use multiple sites. For example, recent statistics show that 86% of college students 18-24 years old use SNSs and are the most frequent social networking users of all age groups (Duggan, 2015; Smith, Rainie, & Zickuhr, 2011). They use SNSs to share their everyday experiences, which include negative and

distressed emotions (Moreno et al., 2012), and to seek social support and validation from their networks (Bazarova & Choi, 2014; Bazarova, Choi, Sosik, Whitlock, & Cosley, 2015). This makes SNSs a useful and unique channel for exploring how social support transactions transpire in this online environment, especially with regard to how students notice, interpret, and respond to peers' distressed messages on SNSs.

Most research on social support exchanges on SNSs focuses primarily on help-seeking behaviors (e.g., Blight, Jagiello, & Ruppel, 2015), perceptions of social support (e.g., Wright et al., 2013), and effects of receiving social support (e.g. Wright, 2012). For example, research on variation in help-seeking behaviors within SNSs (e.g., indirect sharing but no clear request for help, direct request for support, use of quotes such as song lyrics to describe state of mind, and vague requests) found that while perceived offline support is positively associated with perceived online support, responses such as 'likes' from non close relations on Facebook is less helpful (Blight, Jagiello, & Ruppel, 2015). Another study examined the effects of relational closeness on the perceived value of social support and found that individuals who post status updates on Facebook perceived that relational closeness of the responder (e.g. whether the responder was a close friend or family member or someone only known through social media) made no difference in the perceived value of social support offered; social support from any respondent was helpful. This suggests that there is something about the medium itself which facilitates perception of support from the poster's perspective (Rozzell et al., 2014). Taken as a whole, these studies suggest that young adults do use SNS to communicate distress, and that a) perceived social support does not differ based who is providing the support, b) perceived social support on and

offline are positively correlated, and c) simple on-line communications of support such as “likes” is not perceived as helpful to the support seeker.

While what has been documented is very useful in understanding how social media venues affect the experience of posting distressing posts, much less is known about the *viewers’* experience in SNSs, particularly in regard to factors that influence how viewers notice, interpret, and respond to potentially distressed posts. Since viewers’ responses – or lack thereof – largely determine actual outcomes, such as fulfillment of disclosers’ goals (e.g., Bazarova et al., 2015), subsequent disclosure production of content (e.g., Jiang, Bazarova, & Hancock, 2011), and well-being (e.g., Reis & Shaver, 1988), understanding their experience is important. One study experimentally examined the relationship between technological features (e.g. pictures, text, information) used to signal distress in SNS and viewers’ willingness to provide social support to the distressed poster and found that viewers were less willing to provide social support as number of features signaling distress increased. Authors speculated that this was because displaying distress and negative affect was inconsistent with social norms of positive postings on Facebook (High, Oeldorf-Hirsch, & Bellur, 2014). Another study, drawing on and supporting the classic bystander effect (Darley & Latane, 1968), found that the total number of viewers in the audience exposed to a distressed post was inversely related to the likeliness of a single individual’s responding to it, and it took people longer to respond when other viewers were mutual friends of the discloser and the viewer (Robbins & Affifi, 2014).

Another salient factor influential to viewers’ decision to respond to distressed posts is the offline relationship closeness between poster and viewer. In general, the

more relationally close the poster and viewer are the more likely the viewer of the post will respond using one-on-one channels, such as face-to-face, phone call, or email (Egan, Koff, & Moreno, 2013). Similarly, viewers respond based on the perceived level of immediate crisis or need for action, with distressed posts interpreted as a “call for help” more likely to receive immediate response than those interpreted as attention-seeking (Egan et al., 2013). Finally, individuals are less willing to respond to non-close friends than to close friends because of privacy invasion and social norm concerns (Egan et al., 2013). These factors suggest that a complex array of factors: contextual factors, such as social norms, relational closeness, and audience characteristics may be at play in viewer interpretations of distressed posts and subsequent decisions about how to best respond.

Despite the progress made in identifying some of the factors that influence viewers’ interpretations of and decisions to respond, there exist gaps in our understanding of the full array of factors, which govern viewer interpretation and decisions to respond. Nor is there a unifying framework for connecting these disparate factors in a way that may guide both research and intervention development in this area. Using a phenomenological approach, the overarching goal of this study was to address these gaps and to propose a conceptual framework of a viewer’s decision to respond to distressed messages encountered on SNS. More specifically, this study was intended to comprehensively examine the decision-making process that young adults in a college setting undergo when deciding whether and how to respond to distressed posts on social networking sites.

Methods

Participants

Participants were recruited from a large northeast U.S. University in the Fall of 2014 and Spring of 2015, in return for extra credit for participation in the study.

Overall, we had 27 participants all of whom were social networking site users, 7 male and 20 female, aged between 19-22 years old ($M= 19.78$, $SD= .85$), of which 51.9% were sophomores in college, 33.3% were juniors in college, and 14.8% were seniors in college. The sample consisted of 52.22% Caucasians, 22.78% Asians, 4.75% South or Central Americans, 6.3% African Americans, and 13.92% who did not identify their race or ethnicity.

Data Collection

The overarching goal of the study was to elucidate factors salient for viewers of a distressed social media post in deciding whether and how to respond. To examine this, study participants were invited into a lab setting for an interview and asked several questions from their personal experiences about how people request social support, how they themselves interpret these posts, and what kind of responses they provide or do not provide. Specifically, they were told to refer to these questions in the context of distressed posts that they have seen on social media. They were asked to give as many examples of distressed posts they have personally seen and their reactions and experiences with them, such as which SNS they saw the post in, how often they see these types of posts, and specific content of these distressed posts.

Semi-structured interviews were used to surface and explore key elements in the process of deciding whether and how to respond to the distressed post. The interviews included items intended to elucidate factors and mechanisms associated

with two broad areas: a) the participant's perception of the poster's motivation for making a distressed post (e.g. "What do you think people are looking for and why do you think they are making these distressed posts?"), and b) identification of the perceived factors which most influenced responses (e.g. "When you decide to respond or not, how does your relationship with that person come into play?" "Does the location of the distressed post influence your response or not?"). Interviews ranged from 13 to 48 minutes ($M= 23:19$, $SD= 9:02$). Interviews were audio-recorded, transcribed verbatim, edited to remove identifiers and other references that may identify the participants and/or anyone they mentioned during the interview, and imported into Dedoose, a qualitative data analysis tool.

Data Analysis

Because we were interested in developing an overarching theory for understanding factors and the relationships between factors which govern SNS viewers' decisions about responding to a distressed SNS post, data analysis was conducted using grounded theory (Glaser & Strauss, 1967) to identify key factors and mechanisms in each area. Each transcript was initially read closely at least 2 times to identify key themes. Once key themes and subthemes were identified and agreed upon, a three-stage analytic coding strategy that included open coding, axial coding, and selective coding (Corbin & Strauss, 1990; Strauss & Corbin, 1990) was employed to systematically analyze the findings. First, a research assistant and I independently identified themes through a close reading of the transcripts as part of an open-coding process in which distinct concepts and categories were identified. We met several times to discuss and reconcile these codes to create a master codebook which were

then systematically applied to each interview by each of us independently. Interrater reliability was strong ($\kappa = 0.88$). All discrepant cases were discussed until agreement was reached.

Axial coding was used to examine the relationships between themes and to refine categories as well as to ensure a close association between participants' responses and emerging analyses. The axial coding process allowed organization of the codes based on the relationship between the codes and themes that connected them; existing theories were used to inform the organization and interpretation of the themes.

The final stage of analysis, selective coding, was used to develop a theoretical framework through identification of core themes, which linked all identified codes. Selective coding was accomplished through memos (Strauss & Corbin, 1990) written throughout the open coding and axial coding process. These memos reflected emerging research questions, speculations about participants' variations in response to the phenomena, comparisons with theory, recurring themes, and possible relationships among major categories.

Results

Using Strauss and Corbin's (1998) model of processes, themes were used to create a parsimonious framework that explains the processes participants used in deciding whether to respond to distressed posts viewed on Facebook (Figure 2). The contextual condition in which this figure is placed is the SNS Facebook because this was the primary SNS platform that participants discussed their viewer behavior. Direct quotations reflecting each category are shown in Table 2.

Relationship closeness as key driver of responding to distressed posts on SNSs

Almost all participants in the study noted that the first and most heavily weighted factor underlying their decision about whether to respond to distressed posts was the degree to which they felt relationally close to the poster. Most participants explained that having an existing close relationship with the poster would prompt an immediate decision to reach out to the poster, usually by sending him/her a private message using a more private platform, such as instant messaging, phone or text message:

“It depends on how close I am with the person, if I talk to them on a daily basis, if I feel comfortable responding to them, um, the closer I am to the person the more likely I’d be to respond, but I probably wouldn’t respond via the actual like under the message (on Facebook), probably send them an individual message to ask if they needed help. . .so yea always respond if I’m really close to them but privately and then think about it a ton if I’m not that close to them”

In cases where the viewer perceives a non-close relationship, many factors were considered in their likelihood of responding to the poster. This next section describes each broad category of factors identified by respondents as influential in shaping their decision about whether to respond or not to respond.

Decision-making process and intervening conditions that affect the likelihood of responding to distressed posts or not on Facebook in non-close relationships.

When the viewer of the distressed post was not close to the poster, several intervening conditions that affect the response process emerged from the interviews. The primary reasons suggested by the interviewees for the likelihood of not responding to distressed posts include posting patterns of the poster (e.g. frequent posts indicate non-seriousness of content and desensitizes the viewer; frequent posts

influence the viewer to attribute the poster to be a generally sensitive and emotional person), viewer's inferences about poster's motivation for distressed post is attention-seeking behavior leading the viewer to not respond, others' responses influence behaviors because they have a fear of judgment and negative evaluation from others which leads them to displace their responsibility and not respond. Conversely, the factors that influenced viewers to respond to the distressed posts included: high levels of acuity and seriousness of content, posting patterns (e.g. silence followed by an extreme distressed post), feasibility and self-efficacy of viewer of providing support, history of reciprocity across social networking sites, and commiseration and empathy. These factors are demonstrated through participant quotes in Table 2 and are summarized into a connecting framework in Figure 2. This next section elaborates on each theme in greater detail.

Acuity and seriousness of content.

A prevalent reason that increases the likelihood of responding has to do with the high acuity and extreme seriousness of the post content on Facebook. For example, viewers are more likely to respond to posts about a medical complication than to a post about a break up, as posts about break up's are more prevalent on Facebook. When the content of the distressed post reaches a certain severity threshold (e.g. medical emergency; contemplation of suicide; self-injury), the viewer will respond to the poster in non-close relationships. (see Table 2, Quotation1 and Quotation2; referred to as Q# moving forward).

Posting Patterns

In addition to the high level of seriousness of the distressed post, participants consider the different types of posting patterns of the individuals who make the distressed post in their decision-making process of how likely it is that they will or will not respond to the poster. Different types of posting patterns that lead to different levels of likelihood of responding are explained next.

Frequent posts indicate non-serious content and desensitizes the viewer leading the viewer to not respond to the poster. A viewer's likelihood of responding to the poster decreases if the viewer knows that the poster discloses constantly. If participants know that the poster discloses 'distressed' information frequently online, they are less likely to respond because the viewer becomes desensitized to this type of content (see Table 2, Q3 and Q4).

Frequent posts indicate poster to be a generally 'sensitive and emotional' person leading the viewer to not respond to the poster. Additionally, the viewer tends to attribute certain characteristics to posters who make distressed posts on SNSs. Participants expressed that individuals who post frequently about distressed content are 'sensitive' and 'emotional' (see Table 2, Q5). This attribution towards the poster leads viewers to not respond because they don't know how accurately to interpret the distressed post.

Frequent posts followed by silence followed by an extreme distressed post indicate the extreme nature of distress increasing the likelihood that the viewer will respond to the poster. Participants observed that posters who frequently post and then abruptly deactivate their Facebook or stop posting are the ones who may be in serious distress. This inconsistency and discrepancy of the timing of the posts demonstrated to

the participants that the poster was really in distress and that their ‘total silence’ is a sign of a real ‘crisis’ (see Table 2, Q6 and Q7). Participants elaborated on their personal experiences with depression, whether they experienced it themselves or whether they saw their close friends experience depression, and how when an individual is really depressed it’s a pattern that they avoid social media. A participant best demonstrates this point by saying, “Silence for a while and then a *really* distressed post is a bad sign” (see Table 2, Q7) and how this silence followed by an extreme distressed post would influence the viewer to respond.

Feasibility and self-efficacy of providing support increases likelihood that viewer will respond to poster.

Non-close relations expressed that they do not respond to distressed posts because they feel that no matter how or what they respond with they will not be able to make a difference nor help the poster feel better. The participants from this study expressed that they will respond only if they can provide instrumental support to the poster and feel that they can provide effective social support to the poster (see Table 2, Q8). So, the viewer will respond to the poster if they feel higher levels of self-efficacy to provide support to the poster.

History of reciprocity across SNSs increases likelihood to respond to posters

Reciprocity is another factor that we found to be a prevalent theme that participants take into consideration in their likelihood to respond or not to non-close relations. If the poster and the viewer respond frequently to another’s posts either by “likes” or comments on at least one platform or the combination of several platforms (e.g. Facebook, Instagram, and Twitter), then the viewer is more likely to respond

regardless of the content of the distressed post (see Table 2, Q9). The reciprocity of responding to one another's posts is perceived as an 'unwritten contract' between posters and viewers on these SNSs, such that the more past interactions that occurred between the poster and viewer across SNSs, the more likely it is that the viewer will respond to the poster.

Higher levels of commiseration and empathy increase the likelihood for viewers to respond to posters

The findings also show that when the viewer's inference about the poster's motivation for making a distressed post is commiseration, then the viewer is more likely to respond. Participants explained that sometimes they interpret a poster's distressed posts to be a cathartic mechanism since they can reach out to many people at once and look for someone who had similar experiences from a larger pool of people. The participants perceive that the distressed poster is looking for 'commiserating buddies,' and so when the viewer can empathize with the content of the post and is that sought after 'commiserating buddy,' then the viewer will respond (see Table 2, Q10).

Perceived attention-seeking behavior of poster decreases likelihood of viewer to respond

An emergent theme from the data was that viewers inferred posters' motives for sharing distressed posts. One of the commonly inferred motivations for distressed posters is to seek attention. Participants expressed that they find posters to be 'attention-seeking' or want to be 'in the spotlight' when posters make extreme statements like calling the police at parties quite frequently on their SNSs (see Table 2,

Q11). Another perspective on why participants think posters are attention-seeking is that viewers believe the act of posting a distressed comment on a public platform like Facebook makes the actual content of the post less serious (see Table 2, Q12).

Others' responses and its influence on viewer and their likelihood of responding to poster

Also, when participants were asked about their reactions to other viewers' responses to distressed posts, their responses suggested a displacement of responsibility when others had already stepped in. In particular, they thought that the responsibility has already "been covered" and there was no need to respond themselves when many others had already reacted to a distressed post (see Table 2, Q13 and Q14). So, when the viewer would see many other responses, the likelihood of responding decreases. Another influential factor that led participants to not respond to distressed posters was the fear of being judged from others. Participants worried about other viewers making judgments on the responses they would make (see Table 2, Q15) and they would also actively think about crafting "well-worded" responses in fear of future repercussions ultimately leading viewers to not respond (see Table 2, Q16).

Discussion

This study provides insights into college students' process of deciding whether and how to respond to distressed posts they see on SNSs. It emphasizes the complexity associated with the decision-making experiences of young adults on SNSs like Facebook. Our study not only elucidates factors salient for viewers to make a decision of how and why they respond to distressed posts, but also leads to the

development of a parsimonious framework represented in Figure 2 that explains the relationships between these factors that govern SNS viewer decisions about responding to a distressed SNS post.

The following communicative characteristics illuminate the theoretical model represented in our framework. First and foremost, the study reveals the importance young adults place on their relationships such that the key driver underlying viewer's decision of responding or not to the distressed post is based on relationship closeness. If there is a close relationship with the poster, then the viewer will immediately respond to the poster regardless of other considerations. However, if the responder is not close to the poster, there are several intervening conditions that affect the response process.

In nonclose relationships, the factors that contribute to the viewer's decision to respond to distressed posters include the following. First, when viewers interpret that the content of the distressed post is serious and of high acuity, they will respond. Secondly, participants reported that when the posting patterns of distressed posters are silent and then followed by an extreme distressed post, viewers are more likely to respond. Third, the viewer's self-efficacy level of providing instrumental support to the distressed poster affects the response decision, such that if the viewer thinks they can provide concrete support, they will respond. Finally, the last factor in nonclose relationships that lead to responding to distressed posts is high levels of commiseration and empathy. Our study found that when the viewer thinks the distressed poster is looking for someone to genuinely empathize, then the viewer will respond.

Also in nonclose relationships, our study shows there are more prevalent and pressing factors that influence viewers to not respond. These conditions include: perceived attribute of poster such that the viewer is desensitized due to the poster's posting frequency and perceived sensitivity of the poster; frequent and high posting patterns; perceived attention-seeking of poster; displacement of responsibility; and fear of judgment of other viewers.

The themes emerged from this study indicate the emergence of a unique framework that explains the decision-making process of providing social support to distressed posters on SNSs, but also represents forms of social influence of normative behavior. For example, descriptive norms, which are people's perceptions about the prevalence of a behavior that affect individuals' own behaviors (Rimal & Real, 2005), help explain why viewers of distressed posts who have close relations with the poster respond immediately and privately (via text message or phone call) because those who have close relationships may act similarly both offline and online due to normative conducts of that close relationship. Furthermore, viewer's decision-making process to respond or not to respond when the poster is a non-close relation can be better understood through the lens of the theory of normative social behavior (Rimal & Real, 2005). The theory of normative social behavior posits that there are three mechanisms that influence behavior, which include injunctive norms, outcome expectations, and group identity, all of which explain different components of our framework.

Injunctive norms refer to the extent to which individuals perceive that influential others expect them to behave in a certain way, with the assumption that if they do not behave in this way, there will be social sanctions for nonconformity

(Rimal & Real, 2005; Schachter, 1951). Our finding that nonclose relationships is a key driver to determine a viewer's decision to not respond to the distressed post is line with Egan et al.'s (2013) study, and also reflects an injunctive norm that what ought to be for a nonclose viewer is to not respond as the viewer may feel less comfortable responding because they may view it as an invasion of privacy, awkward, and breaking a norm for nonclose relationships. Additionally, in nonclose relationships, viewers of distressed posts may not respond to posters as a form of social sanction to poster's not following injunctive norms of SNS behavior. For example, this study found that perceived attribute of the poster such as desensitization due to posting frequency and perceived sensitivity or emotionality of the poster influenced viewers to not respond. Fox and Wood (2012) found that the frequency in which individuals disclose is important in influencing social outcomes like responses; and our study shows that viewers become desensitized to distressed posts when they see the same individual posting frequently consequently leading to viewers labeling or categorizing that poster to be an 'emotional' and 'sensitive person leading the viewer to not respond. This has unique repercussions for the poster because then we can imply that the high frequency of these types of posts would be breaking injunctive norms and could moderate the extreme nature of the distressed post leading the viewer to not respond. Our participants also explained that if they thought the poster was displaying attention-seeking behavior and were constantly looking for responses from peers, they attributed the poster to be 'dramatic' and 'overreact to situations,' ultimately leading the participant to not respond, which would be a demonstration of social sanctions to frequent types of distressed posts.

Now, another component of the theory of normative social behavior that explains the remaining factors driving viewers to not respond is group identity. Group identity refers to the desire to be similar and to aspire to be part of the reference group. An emergent finding from our study is that because of viewer's fear of judgment from others on their SNS network, viewers displace the responsibility of responding to other people. Group identity enforces individuals to follow the norms of others for social approval. Robbins and Affifi (2014) found that viewers took longer to respond when they knew other viewers were also responding to the same distressed post, indicating that there are identity concerns causing the hesitation in response decisions. This fear of judgment of viewer's own responses is married to the fear of negative evaluation which is a primary inhibitor of helping behaviors (e.g. Karakashia et al., 2006; Latane & Darley, 1970; Zoccola et al., 2011), which is further explained by group identity as a mechanism for social approval and following normative social behavior.

Finally, outcome expectations as a component of the theory of normative social behavior explain why nonclose relations do respond to distressed posters. Outcome expectations refer to the beliefs that an individual's actions will lead to benefits to oneself, benefits to others, and anticipatory socialization. In nonclose relationships, viewers responded to distressed posters if the content of the distressed post was extreme; and this emergent can further be explained by Egan et al.'s (2013) finding that viewers who perceived status updates to be 'serious' perceived viewers to perceive posters as someone having a mental illness or having a serious call for help. Participants from our study discussed that responding to serious distressed posts would put the viewer's mind at ease and would feel better knowing that they

responded to such serious content. Responding to the distressed post is perceived as benefiting both the viewer and the poster from the perspective of the viewer. Similar to this first theme, participants reported that when the posting patterns of distressed posters are inconsistent, the viewer interprets the poster is in serious distress, leading the participant to respond. When individuals have symptoms of being distressed, individuals tend to self-isolate and avoid social interactions (Whitmer & Gotlib, 2011). It seems that viewers in our study have observed this trend in distressed posters leading them to respond in hopes that they are actually helping the poster in distress. Third, the viewer's feeling of being able to provide instrumental support to the distressed poster leading to responding, in line with the findings from Casey and Ohler's (2012) study, illuminates outcome expectations in that the viewer will respond if they can tangibly benefit the poster. The history or reciprocity across multiple SNSs led to viewers responding and this theme is reflective of outcome expectations in that viewers respond for the sake of anticipatory socialization. Finally, we found that when the viewer thinks the distressed poster is looking for someone to genuinely empathize with and the viewer can commiserate with the poster, the viewer will respond, which highlights all three components of outcome expectations. This final theme could also be understood through the lens of perceived homophily theory where individuals with same experiences feel more confident and comfortable in interactions which lead to an increase in support interactions and satisfaction of interactions, all of which they feel is valuable. This theme of commiseration that leads viewers to respond is demonstrative of perceived homophily theory (McCroskey, Richmond, & Daly, 1975).

Taken together, the themes that emerged from our study explicate a framework that provides insight into the decision-making process of providing social support or not to distressed posters on SNSs. Furthermore, this model is better understood through the lens of the theory of normative social behavior to parse through the model's unique themes and how they are all connected.

As with all studies, this study has limitations. One notable limitation is the sample size of our study. Opportunity for future research is to expand on the forms of social support provided in SNSs (i.e. quality and quantity of responses). This study only examined if the participants responded or not so it would be interesting to investigate the content of responses provided.

Finally, from these findings, we hope to improve our understanding of how to best counsel, advise, and intervene with these support seeking-and-providing communication interactions. As more studies are being conducted to increase knowledge on mental health and help seeking among young adults, we will seek to translate these into practices and policies that emphasize the effective and efficient use of SNSs. For example, we will continue to collaborate with technology design research teams to test the effectiveness of 'flagging' or 'intervention tools' on SNSs. We can also implement and manipulate technology features like anonymity to help empower viewers to respond and make it a permanent feature in SNSs where there are frequent support seekers. It is demonstrated that peer interventions in college populations are successful (e.g. Charandabi, Vahidi, Marions, & Wahlstrom, 2010; Marick, 2002; O'Grady, Wilson, & Harman, 2009). However it is unknown if these similar peer interventions involving SNSs would be equally successful or differ in

outcomes; this would be a valuable topic for future research. This process young adults undergo provides a comprehensive understanding of adolescent's experiences of reacting to and behaving towards distressed posts on SNSs. The results of this study shed light to intervening conditions that can be manipulated to develop tools and peer interventions that will allow young adults of SNSs to better offer social support.

CHAPTER 4

STUDY 3 – EXPLORING THE COMMUNICATIVE DYNAMICS OF PARENTS WHO HAVE d/DEAF CHILDREN AND THEIR ONLINE ACTIVITY

Introduction

Two out of 1,000 children in the United States are born deaf or hard-of-hearing (NIDCD, 2014). Since 1984, many individuals who are born deaf or hard-of-hearing have had the option of getting cochlear implants. According to the Food and Drug Administration (FDA), approximately 324,200 people globally have received these implants, including about 58,000 adults and 38,000 children in the United States (NIDCD, 2014).

A cochlear implant is a surgically implanted device designed to help individuals who are sensorineurally deaf to perceive varying levels of sound. The device, approved by the FDA in 1984, works by connecting a nerve-stimulating electrode to the inside of the cochlea (Fryauf-Bertschy et al., 1997; Yaremko, 1993). The cochlea is the hearing nerve inside of the ear. The cochlear implant is “the first man made device that successfully interfaces with the human brain” (Bonn, 1998, p. 1837). In combination with therapy, it can restore a great deal of hearing (Niparko, 1995).

The benefits of getting a cochlear implant are maximized when the surgery is performed before the age of five years old (Fryauf-Bertschy et al., 1997; Yaremko, 1993). In 2000, the FDA lowered the age of eligibility for implantation to one year old because it is safest to receive the implant at a younger age (Mindess, 1999). Since

early implantation leads to better results and fewer complications (Nikolopoulos et al., 1999; O'Donoghue et al., 2000; Miyamoto et al., 2005) parents are under time pressure to make this decision.

Research on cochlear implants has focused on multiple perspectives (e.g. parents, medical professionals, d/Deaf⁵ communities). There are two dominant viewpoints: 1) the 'd'eaf community, which tends to be more pro-cochlear implant and believes that the implant is advantageous (NIH, 1995), and 2) the 'D'eaf community, which tends to be more critical about the cochlear implant believes that cochlear implants represent a form of cultural genocide (Apicella, 1994; Brauer, 1993; Sparrow, 2010).

While extant research covers the technological history and medical implications of cochlear implants, it overlooks the important role parents have in making this decision for their child(ren). Parental decisions about cochlear implantation are particularly challenging because the implants vary widely in outcomes and effectiveness (Thoutenhoofd and Archbold, 2005; USDA, 2014). So, many parents of d/Deaf children who want to make a decision about cochlear implantation for their child refer to information that they actively seek on the Internet, as one of their information sources (A.Young, Grealley, and Nugent, 2003). Parents are enthusiastic about the ability to obtain information online quickly, conveniently, and privately to help with their decision-making process (Chang, under review), but little is known about the level of the use of the Internet to acquire health information, what

⁵ d/Deaf (with both the lowercase and a capital "d") will be used to refer to the d/Deaf label as both a pathological and a cultural trait. Lower case "deaf" refers to deafness as a disability, while "Deaf" denotes a cultural trait (Senghas and Monaghan, 2002).

types of online venues parents utilize, how they interpret the interactions that occur on these venues, and the effects of using such online communication platforms, particularly for parents of d/Deaf children seeking information. One study found that the most common type of information for parents online is the topic of cochlear implants, how they work, and where to get the surgeries (Zaidman-Zait and Jamieson, 2004). However less has been focused on the types of online communities parents seek and engage in, why they seek the information on the Internet, and the communicative components parents experience on the Internet that influences their decision. Therefore, the aims of this qualitative study are to explore: A) what online platforms parents seek and value, B) how parents interpret the different information sources online, and C) what types of communities online parents are involved with and why. Combined, these three components in the decision-making process will provide a lens through which we can better understand the utilization of the Internet and its specific platforms and communities that may influence parents decision-making process, each of which comes with a set of unique pressures, norms, and motivations.

Methods

Participants

Study participants included 26 parents of d/Deaf children. The sample included parents who at one point considered the cochlear implant for their child(ren) and decided for or against the cochlear implant and sought information online. Participants were recruited through Schools for the Deaf across the United States, including schools from the West Coast, Southwest, Midwest, and the Northeast, as well as

through the American Society of the Deaf. All the participants of the study were mothers. 7 of the participants were recruited via snowball sampling. 21 of the participants were hearing, 3 of the participants were d/Deaf and had no cochlear implant(s), and 2 of the participants were d/D and had a cochlear implant(s).

Data collection

After receiving approval from the Institutional Review Board, I mapped out potential schools and d/Deaf organizations that could help with the recruitment of participants for interviews. Some of the Schools for the Deaf required the completion of confidentiality forms, which I completed. A research assistant and I emailed and/or phone-called Schools for the Deaf across the United States as well as reached out to national organizations such as the American Society for Deaf Children to see if they would be willing to post the recruitment letter on their website, any weekly e-blast, monthly packages for parents of schools, or refer us to any other school or organization that would be willing to help reach out to parents. People interested in participating in the study were encouraged to contact me to schedule an interview. Participants were also recruited through snowball sampling.

Data were obtained from in-depth semi-structured interviews for this study. The interviews took place from August 2015 to February 2016 and lasted between 32-150 minutes. These interviews allowed for flexibility to avoid limiting the field of inquiry and for the interview to take form naturally (Lofland et al., 2006). The semi-structured interview may stray away from any a priori categorization that may limit the research questions or field of inquiry (Charmaz, 2000). All interviews were conducted over the phone or over Skype. Because some of the participants were

d/Deaf and/or had cochlear implant(s) and preferred to use American Sign Language, a Video Relay Service (VRS) was used.

Data analysis

The interviews were audiotaped and transcribed verbatim and edited to remove any identifiers. Additionally, confidentiality of all the participants was maintained by omitting all personal references that may have identified the individuals with the interview transcripts. Each participant was given a number that corresponded to the interview transcripts (Pn). After reading through the interview scripts multiple times to become acquainted with the data, I imported the transcripts into Atlas.TI, a qualitative data analysis software package that helps with categorizing and comparing findings. Atlas.TI enables creation of a user-defined personal computer based coding system that organizes all the transcripts within one unit and allows easy text searching, tagging, and comparison. There was a close reading of each of the units, identifying key themes such as the types of online platforms parents seek and use, how parents interpret different online sources, and types of online communities parents are involved with and why. Taking themes that arose iteratively from the data, I then did a full coding of all the transcripts applying these codes. I grouped excerpts with similar codes and wrote a series of memos analyzing those responses during all phases of analyses to highlight key questions about relationships in the data, to refine categories, and to ensure a close association between participants' response and emerging analyses. The three main strategies for analyzing the data were coding, memo writing, and iterative coding.

Results

Participant's interviews regarding the utilization of various online sources, online communities, and social networking sites highlighted a range of experiences. The findings are organized to address each aim of this qualitative study and illuminate themes that emerged from the data. Direct quotations reflect each theme.

Online platforms that parents seek and value in regards to cochlear implantation information

There seems to be a clear set of online venues that parents seek and value in regards to cochlear implantation information for their d/Deaf child. Several parents discussed how there are sets of websites that are known specifically to hearing parents to get information about cochlear implantation. These websites are primarily objective medical websites. When seeking information about cochlear implants, hearing parents sought websites that have objective facts and avoided websites that had discussion forums or blogs from other parents and what they know about cochlear implants, as these are harder to sort through the biases that stem from the pro-cochlear and anti-cochlear implant groups:

“It's great to hear about other parents experiences, especially those parents who have already gone through with making the decision for their child. Sometimes we got to even meet the children and interact with them too. The difference between these interactions and the ones online is that when I look online I can gather facts. One of the best resources for me was to hear about other parents' experiences, but the second best resource was objective information based websites. This is because sometimes I feared I would be swayed by emotions of the families. So, mostly, I used to go to medical-based websites. The NIDCD [National Institute on Deafness and other Communicative Disorders], ASHA [American Speech Language Hearing Association], and whatever links were attached to these websites to learn everything I could about cochlear implants.” P015

“I need pure information. All the websites online are biased because there is a huge divide in what people think about cochlear implants. So the best type of information I can get for me and my kid is the pure kind from medical websites.” P003

Another prevalent type of online venue that parents went to that emerged from the interviews was the use of social networking sites, specifically Facebook groups. Parents expressed that they used social networking sites for troubleshooting purposes. It was a good venue to go to for parents who wanted to learn more about technical difficulties or negative effects of cochlear implants:

“Facebook groups are more about problem solving and trouble shooting. [Child’s name] got an infection on his head where the magnet goes so I posted about it and got like 20 responses back. There is a lot of support there. They said, ‘he probably has a skin infection and needs to do antibiotics.’ Sometimes I find it even more helpful than waiting to go to the doctors since I’m talking to other parents about the same problems they might have if their child has an implant.” P10

“Twitter is great. Twitter is basically a quick search engine I can use if something is wrong with [Child’s name]. Like one time there was something wrong with turning the implant on and off so I went on Twitter to see what we could do to fix it. Every parent with a d/Deaf child should use Twitter.” P17.

Interpretation of different information sources online

In addition to the online venues that parents seek and value, participants had different strategies that they implemented to interpret whether the websites were biased or not, in which direction they were biased, and if the information was reliable. One of the more prevalent strategies that parents used was to look at who was sponsoring the website and to sort through ‘clues’ the websites had to interpret the type of information source. One participant said:

“The first thing I look for when I find a new website is scroll all the way to the bottom of the page to see what group sponsors or hosts the website. If there is no information on the bottom then I will go to the ‘about’ section of the website. Seeing who is hosting it says a lot about the content that I would see on the website. You can piece together clues like if they use the big ‘D’ or little ‘d’ when writing the word d/Deaf, which way the website is biased. If a medical cochlear implant company is sponsoring it that would probably mean that they are more pro-cochlear and there is a cochlear

brand attached to the website too. You get to be a pro at it really after looking for the right clues on the websites.” P05

Another strategy parents used to interpret the type of information on these websites was to look at the links associated with the website. One participant explains:

“It’s really easy to tell which camp the website belongs in if you look through the other links. I was on a cochlear implant brand website and on the side of the website I saw a list of other community boards. That’s how I knew that brand and company catered to mostly hearing parents. All the links were geared toward hearing parents who had to make a choice. The links included ones like alldeaf.com CIHear. These websites grouped together hearing people and hearing parents who are interested in cochlear implants and are not against it.” P01

Types of online communities that parents are involved with and why

There are an increasing number of social support groups online that parents join, and there are various reasons why parents are involved with these online support communities. One prevalent reason that emerged from our interviews was that parents like to connect with other parents who have similar lifestyles as them. Although the main topic of these social support websites is about their d/Deaf child(ren), a lot of parents connect about different topics and engage in other types of social support interactions:

“It is nice to talk with other parents who live a similar life that you do. Conversations go beyond the kids to other difficulties you face because you have a child who is d/Deaf. For example I’m a single mom. I know that there is some high statistic of how many parents get divorced when they have a child with a disability. I’m living proof. There are a lot of other single moms I have met on these online support groups. It’s nice to know that there are other single moms who go through the same situation as I do. This website helped me make friends so it’s not just a website where I talk to strangers about their children” P014

Another theme that permeated the interviews was that a lot of parents liked the accessibility to other parents of d/Deaf children, especially if they lived in rural areas of the U.S. For example, one participant expressed:

“My son and I live in Ohio. We had to go to North Carolina to get his implant and I know that most schools for the Deaf and all the best resources are on the coasts. It makes sense but we can’t move because most of our family also lives here. We’re lucky that we can commute and my son can go to a School for the Deaf here but where we live is considered rural. These online communities are so easy to access that it doesn’t matter as much that I live in a rural area where I don’t have the same type of network I might have on the coasts to connect with other hearing parents. The Internet helps with connecting with other parents despite my location.” P04

Another interesting theme that many participants talked about in these interviews was the benefit of being able to avoid hostile situations regarding the topic of cochlear implants. In face-to-face situations, parents might not be able to avoid disagreements but in online settings parents can exit the community if they feel any hostility or anger directed towards them. One of our participants illustrated this point by saying:

“I’ve had nasty experiences with parents who think that I destroyed my child because I gave her an implant. They point at me and they point at my kid sometimes. It’s a horror film that we live in. People are just mean, very mean. The great part about using the Internet and being a part of these online support groups is that I can enter and exit whenever I want. If a parent disagrees with me let’s say on CICircle [a cochlear implant based listserv], then I can just ignore them or leave that discussion. I don’t have to stand the hostility. I like the freedom of being able to be as involved or as detached to these groups. It’s just different offline.” P21

Discussion and Conclusion

Discussion

This study provides new insights into the experiences parents of d/Deaf children and their information-seeking strategies and online activity. This series of in-depth interviews highlight a range of online activity that parents engage in ranging from the specific types of websites they go to and online platforms they purposely seek such as online social support communities. Three main themes that emerged from the data include the types of websites parents actively seek to get information, how

parents interpret certain websites to parse through biases, and finally, benefits and advantages from online social support communities.

The parents described that when seeking information about cochlear implants there are two types of websites they most often visit. One type is objective information-based medical websites such as the NIDCD (National Institute on Deafness and Other Communication Disorders) and the ASHA (American Speech, Language, and Hearing Association). Parents expressed their desire to avoid websites that have discussion forums or blogs when information-seeking because they are harder to sort through biases that stem from the longstanding pro-cochlear v. anti-cochlear debate. This theme is consistent with mothers' preferences for online information that are presented by clinical professionals v. online advice from other parents (Bernhardt and Felter, 2004). The second most frequently visited type of website was social networking sites like Facebook groups or Twitter accounts specific to cochlear implants, as they provided a platform for parents troubleshooting. These two specific types of websites parents sought reflect parents' feelings of responsibility to be the most objectively well informed (Schaffer, Kuczynski, and Skinner, 2008). This finding regarding the types of websites and online platforms parents actively seek is consistent with information seeking behavior in which "the purposive seeking for information is a consequence of a need to satisfy some goal" (Wilson, 2000). In particular this finding demonstrates that parents seek information with the goal of understanding how to effectively care for their d/Deaf child. This can be better understood through the lens of Dervin's Sense-Making approach (1983), which describes a situation (the context of the information need, or problem), a gap between

the current situation and the desired situation, an outcome, and a bridge linking the situation and outcome (closing the gap). In terms of the Sense-Making model, parents of children with disabilities often find themselves in situations where there is a gap between their knowledge and understanding of how to care for their children and possibly better methods and solutions. There is a number of ways parents bridge that gap and in this context it seems that it is to seek as much objective information as possible through medical based websites and social networking site groups.

A prevalent theme that continued to emerge in our data was how parents interpret the credibility and general position of websites they visited. Bernhardt and Felter (2004) found that mothers of young children expressed serious concerns regarding the reliability of health information they access online. Some of the strategies the mothers employed to determine their trust in the information retrieved included exploring the motives of the Web sites' owners, evaluating the source of information, and looking for information repetition and convergence. This is in line with our finding that parents would actively look for language cues on the websites, such as the use of the little 'd' or big 'D' spelling of the word d/Deaf. We also found that one of the first strategies parents implement when looking at a new website is to look at the host of the website. The other frequently implemented strategy that parents used to determine the credibility of websites was to look at other hyperlinks the website suggested. Parents expressed that by looking at the links that the website suggested they would be able to determine the type of group the website is associated with as well as what kind of information that website would display. Fox and Rainie (2002) imply that parents are 'responsible searchers' because they found that parents

are most likely to spend time online during a specific information-seeking search, visiting at least four sites related to the original website. Parents are also inclined to do further research on the links and information they uncover.

The final and prevalent theme that emerged from our study was parents perspective on the advantages of social support communities online. Virtual social support communities are defined as “a group of people with similar concerns who communicate via information technology” (du Pre, ' 2000). These communities typically consist of smaller discussion groups in which people can engage in communication about specific issues (Wright, 2002). The goals of on-line support groups include collaboration between participants, information sharing, social and emotional support, and personal empowerment (Bowers, 1997; Roberts & Fox, 1998; Sharf, 1997; Winzelberg, 1997). Participants in our study expressed that one of the most beneficial aspects of online support communities was that parents could go beyond talking about cochlear implants, but also engage in social support interactions about other topics, as many parents of d/Deaf children could have similar lifestyles. Other parents with disabilities are the most common social support sources for parents of children with disabilities, compared to family, friends, or specialists (Mackintosh et al., 2006; Tsibidaki and Tsamparli, 2007), and parents in our study found this type of social support online. Additionally, participation in online support groups allows parents to connect with other parents who are going through similar experiences to themselves (Leonard et al., 2004), as our participants discussed lifestyle similarities (i.e. being a single mom). Furthermore, Chenoweth and Stehlik (2004) posited that these similar types of social contacts are considered valuable to individuals because

there is less risk of social rejection, and they “know what it’s like.” Also, sharing problems with parents that have similar experiences reduces the feelings of isolation and provides families with various models of coping and caring (Christiansen & Leigh, 2002; Cooper & Allred, 1992; Freeman, Carbin, & Boese, 1981; Zaidman-Zait & Jamieson, 2004). Ultimately this online source of parental social support has been frequently cited in the literature as parent-to-parent support (eg, Most & Zaidman-Zait, 2003; Nunez & Ceh, 2001), which can, in turn, lead to a feeling of well-being (Dromi & Ingbar, 1999; Dunst & Trivette, 1990; Shonkoff, Hauser-Cram, Krauss, & Upshur, 1992). Another theme that parents discussed was the benefit of online communities, especially because many parents live in rural areas or areas that do not have a big d/Deaf community presence. Parents expressed that they find solace in these online social support communities that they cannot find offline because of their geographical constraints. Geographical boundaries and social barriers are removed online and many of the difficulties parents encounter attending face-to-face groups are absent as well (Gary & Remolino, 2000; White & Dorman, 2001). Our findings reflect the community-building function that some sites provide that is perceived as vitally important by some families, especially those living in rural areas, where contact with other families with d/Deaf children may be minimal or nonexistent. Lastly, an advantage of these online social support communities for parents was the flexibility of avoiding confrontation and being able to enter and exit these communities at any point in the interaction. In face-to-face situations, parents may inevitably experience confrontational interactions with parents who multiple viewpoints or even hostile situations. Online however, parents expressed that they like the flexibility of leaving

online communities when there are certain viewpoints that dominate discussions or when they find strong views to be ‘tiring.’

Conclusion

The prevalence of cochlear implants is dramatically growing, and it affects multiple industries and fields such as medicine, education, policy enforcement, and communication. The findings from this study will extend to real-life applications to expand and broaden knowledge on the effectiveness of specific websites. This study broadens our understanding of the complex sorting through of websites, interpretation of the credibility of these websites, and benefits parents perceive from using online social support communities. It provides us with new information that can be utilized to improve web sites. It also provides insight to professionals for them to recommend certain online sites to parents of their patients. Lastly, it advances our understanding of values and perspectives surrounding websites associated with cochlear implants which ultimately can facilitate the education of parents, surgeons, academics, the d/Deaf community, and policy makers about parents experiences online.

Practical implications

This study generated new insights into the experiences of parents of d/Deaf children who undergo the decision-making process to get the cochlear implant or not for their child and their experiences online. The findings have several important practical implications for support teams consisting of health professionals (i.e. audiologists, psychologists, otolaryngologists, social support groups) that guide parents to make this decision. Hearing parents especially are likely to need additional time, support, and information to be able to make the most informed decision. It is

recommended that these teams be aware of nuances of parents online experiences as well as be sensitive and mindful of parents' diversified and varied knowledge and preferences regarding the cochlear implant. Parents would benefit from these health professional teams contextualizing the aspects of the websites that they could recommend. Parents would also benefit from the provision of comprehensive and holistic information about certain websites and online social support communities. Through the application of a more thorough information provision process, delineation of addressing and tailoring to parents specific concerns, and encompassing all aspects of the decision (i.e. medical, social, cultural, etc.), health professional and support teams may be able to reduce the uncertainty and anxiety for parents in this decision-making process for cochlear implantation, especially as they navigate through various sites online. Another practical recommendation stemming from the current study is that web sites should be developed to help parents build an online social support community and to promote communication among parents, professionals, and researchers that is separate from any specific agenda.

CHAPTER 5

GENERAL DISCUSSION

Stigma is a complex and multidimensional phenomenon. It affects social interactions, particularly ‘mixed’ interactions between ‘perceivers’, which refers to individuals who stigmatize others, and ‘targets’, which refers to individuals who are stigmatized, in a stigma communication context (Heatherton et al., 2000; Major & O’Brien, 2005; Smith, 2011), which leads to feelings of anxiety, discomfort, tension, and other negative emotions (Hebl, 1997; Miller & Kaiser, 2001). These negative outcomes of stigma interactions can affect both perceivers and targets. To manage stigma and the outcomes of stigma interactions, many individuals seek, engage in, provide, and receive social support via social interactions. This dissertation addresses social support interactions as a mechanism for managing stigma, by investigating different invisible disability contexts – chronic pain, the d/Deaf community, and individuals who express distress on social networking sites - that further illuminate various stigma management strategies.

Stigma management communication and the application of the construct are unique to each of these contexts, and each of them challenges or illuminates different components of stigma and has implications for different stigma management strategies. Because of stigma’s highly contextual nature, most literature on stigma communication research has focused on specific contexts (e.g., Hanisch et al., 2016; Lee & An, 2016; Livingston & Boyd, 2010; Livingston, Milne, Fang, & Amari, 2012;

Sengupta et al., 2011). My dissertation specifically investigates social support interactions as a means of stigma management in three different contexts from three different perspectives and stakeholders. I summarize the findings from each study before synthesizing the results from this dissertation with stigma management communication strategies.

The first study (Chapter 2) explored how older adults with chronic pain communicate about their pain-related experiences and emotions to social partners both face-to-face and through mobile devices, and the effects of such interactions on their affect and psychological adjustment to pain. The context of chronic pain allows exploration of how ‘targets’ communicate about their invisible disability to others, and how these interactions affect them. Integration of the quantitative and qualitative analyses showed that pain-related discourse that older adults with chronic pain have with close relations is associated with feelings of being cared for and understood by their communicative partner. The findings also showed that older adults with chronic pain prefer not to communicate about their pain, and instead actively self-isolate when experiencing pain and pain-related emotions. However, when they did talk to others about their pain-related experiences and emotions, they sought out other individuals who also have chronic pain. Furthermore, we found that older adults primarily had pain discourse face-to-face, with email, mobile phones, the Internet (e.g., online communities and information-searching) following in popularity. Older adults who are categorized as pain catastrophizers discussed pain-related emotions, but not practical pain-related content, with close relations. Finally, the results showed that older adults who are more comfortable and confident using ICTs have more pain-related discourse

on mobile devices, and in doing so feel more cared for, understood, and socially supported. Findings also indicated that when older adults with chronic pain have pain discourse on their mobile phones, they have more positive affect and better psychological adjustment to their pain.

The second study (Chapter 3) investigated how college students undergo the decision-making process of choosing whether to provide or not provide social support in response to distressed posts they observe on Facebook. This study examined the perspective of an observer of ‘mixed interactions’ in the context of a social networking site and distressed individuals. The results emphasized the complexity of young adults’ decision-making experiences on social networking sites like Facebook. The study elucidated factors salient for viewers when they decide how to respond to distressed posts. It also led to the development of a parsimonious framework that explains the relationships between the factors that govern decisions about responding to a distressed SNS post. As represented in Figure 3, young adults are primarily driven by relational closeness when deciding whether or not to respond to a distressed post, and are more likely to respond to someone they are close to. However, if the responder is not close to the poster, there were several intervening conditions that affected the response process. First, when viewers interpret the content of the distressed post as serious and acute, they will respond. Secondly, participants reported that they are more likely to respond when the distressed poster is silent and then posts an extremely distressed post. Third, the viewer’s self-efficacy in providing instrumental support to the distressed poster affects the response decision, such that if the viewer thinks they can provide concrete support, they will respond. Finally, our study found an effect of

commiseration and empathy, such that the viewer will respond when he or she thinks the distressed poster is looking for someone to genuinely empathize. The study also shows that there are more prevalent and pressing factors that influence viewers to not respond. These conditions include perceived attribute of poster, such as posting frequency and perceived sensitivity, and attention-seeking behavior, as well as viewer displacement of responsibility and fear of judgment from others.

The third study (Chapter 4) delineates the online social support activity of parents with d/Deaf children, specifically parents who undergo the decision-making process of whether or not to give their child(ren) cochlear. This study takes place from the perspective of someone who holds a courtesy stigma and in the context of various online platforms. Three main findings emerged from this data: the types of websites parents actively sought to get information from, how parents interpreted certain websites, and finally, the benefits and advantages of online support communities. Parents primarily sought out objective information-based websites hosted by medical associations and online social support groups. They would interpret the credibility of these websites by looking at various web links associated with the site, the host of the website, and language clues (i.e., if the site used little ‘d’ or capitalized ‘D’ when spelling out d/Deaf). Finally, online support communities were especially beneficial for parents living in rural areas, parents who confront hostile face to face situations, and parents who could communicate with other parents about similar lifestyles.

The findings from these studies are reflected in the conceptualization of stigma, particularly how certain components converge and interact. Link and Phelan’s (2001) conceptualization of stigma emphasizes cognitive separating, in which

individuals in a mixed interaction create a separation of ‘us’ versus ‘them’ (Morone, 1997). As discussed in the introduction, cognitive separation leads members of the ‘us’ group and ‘them’ group to accept societal stereotypes and increase the distance of separation. It is important to emphasize that both the target group and the perceiver group can drive cognitive separation. The findings from Study 1 and Study 3 exemplify and extend the concept of cognitive separation to chronic pain and parents of d/Deaf children, respectively. In Study 1, older adults actively tried to avoid communicating about their pain and pain-related experiences with others, but when they did, they sought out other individuals with chronic pain. Participants explained that they did so because those others shared similar experiences, and they perceived “solidarity with others who also have pain.” This suggests that cognitive separation occurs between targets, or ‘us,’ others who also have chronic pain, and ‘them,’ others who do not have chronic pain. This specific cognitive separation affects the interpersonal resources and support networks older adults with chronic pain use to communicate about their pain-related experiences.

The findings from Study 4 also demonstrate cognitive separating from those who experience secondary stigma. Specifically, the results showed that individuals use online communities as a tool to enhance cognitive separation. Parents of d/Deaf children who actively seek out social support groups online expressed that they felt camaraderie with other parents who had similar lifestyles as a result of having a d/Deaf child who might have received cochlear implantation. The data shows that one of the main benefits of these websites, from the perspective of the parent, is facilitating connection with similar others with whom they can communicate about

non-child-related topics, especially those related to secondary stigma (i.e., being a single mother). Again, we see cognitive separation driven by those who have courtesy stigma, and how they use online platforms to execute this cognitive separation.

Another component of stigma reflected in the findings from all three studies is emotional reactions (Link et al., 2004). Emotional reactions that accompany stigma can help us better understand the behaviors of both the perceiver and the target, as both may experience anger, irritation, anxiety, pity, and fear. As can be seen in the findings in Chapter 3, young adults experience various emotions in their decision-making process, and their emotional reactions influence the likelihood of providing support to distressed messages that they see on Facebook. For example, young adults reported experiencing fear of negative evaluations from their peers. This fear decreased their likelihood of interacting with the distressed poster. They also experienced irritation at observing large numbers of distressed posts, which also decreased their likelihood of responding to the distressed poster. The non-response and lack of attention to the distressed post may in turn impact the target by negatively affecting their psychological and social well-being. The findings from Chapter 3 demonstrate how negative emotional reactions affect young adults' social networking site behaviors, particularly the likelihood of engaging with and providing support to distressed posters on Facebook.

Emotional reactions can also fluctuate depending on the stigma communication context. For example, emotional responses to stigma interactions, especially mixed interactions, include feelings of embarrassment, isolation, and anger (Smith, 2011). We see examples of how emotional responses can fluctuate in the chronic pain

interactions described in Chapter 2. Specifically, when in pain, older adults with chronic pain often experience anxiety and anger that promotes self-isolation and communication avoidance. However, when they allow themselves to discuss pain with close others, they felt more cared for, better understood, better supported, and had higher levels of positive affect. In disclosing their pain, they were looking for opportunities to vent and receive validation, and experienced frustration and anger when they did not obtain it from their communication partners. As demonstrated through these findings, emotional reactions that stem from stigma-related communication depend on the interpersonal communication dynamics that individuals experience in a social interaction. For example, the type of relationship they have with a person they communicate with and how that social interaction manifests can lead to positive effects for the target like feeling supported and understood. Study 2 highlights this manifestation in older adult's pain discourse with close relations leading to older adults feeling cared for and understood by their close relational communication partner.

In addition to components of stigma illustrated above, there are also constructs specific to mixed interactions that apply to the findings in all three studies. Disruptive stigma (Jones et al., 1984; McGuire, 1998), which refers to the noticeable stigma in mixed interaction, can create discomfort for both perceivers and targets. McGuire (1998) found that those who possess disruptive stigmas have more aversive reactions in social interactions compared to those who possess less disruptive stigmas. Disruptive stigmas can still be applied to invisible disabilities, as they cannot always be hidden (i.e., when an individual with chronic pain grimaces from the pain they

experience). As illustrated by the findings in the chronic pain context (Chapter 2), the communication that occurs between individuals with chronic pain and their communicative partner(s) is complex. The disruptive effects of chronic pain could occur on a level of communication avoidance and isolation, as older adults with chronic pain preferred not to interact with others about their pain experience and instead managed their pain alone. It is possible that perceivers who are embarrassed by their inability to understand the target's condition would also avoid future interactions. Furthermore, targets who have chronic pain could consequently avoid and ultimately socially withdraw from mixed interactions, which could be detrimental to their interpersonal relationships (Roberts et al., 2015).

Anxiety and avoidance are additional themes that emerge as a result of mixed interactions, and are demonstrated again from the findings from Chapter 2. Individuals with chronic pain may experience anxiety leading to avoidance of mixed interactions. Findings showed that individuals could strategically arrange their interactions to minimize or altogether avoid mixed interactions. Specifically, older adults with chronic pain prefer to communicate about their pain-related experiences and emotions with others who also have chronic pain. This interaction among older adults with chronic pain would be considered target-only interaction. Moreover, participants expressed that they actively self-isolate to avoid interacting with others who do not understand their circumstances. These findings illustrate how targets execute strategies such as avoidance to avoid mixed interactions.

Courtesy stigma, also known as secondary stigma, refers to stigmatization by affiliation (Goffman, 1963). Courtesy stigma occurs in a variety of different relational

ties, but I focus on secondary stigma based on parental and children relationships in this dissertation. Chapter 4 examines how parents of d/Deaf children who are considered secondary stigma holders manage stigma. We find that these parents use online communities to connect with similar others. Unique to secondary stigma holders, courtesy stigma serves as a catalyst for group solidarity with other courtesy stigma holders (Falk, 2001). The camaraderie that secondary stigma holders share can consequently enact cognitive separation through a clear distinction of insiders and outsiders, illustrated through different online social support communities for parents.

Other stigma management communication strategies, such as passive acceptance (e.g., Meisenbach, 2010), can be applied to the findings of these three studies. Passive acceptance is when individuals in a mixed interaction actively acknowledge the interaction, but discontinue further communication (Meisenbach, 2010; Camp, Finlay, & Lyons, 2002). This is also known as the ‘no comment’ route, and is common in crisis communication. The findings from Chapter 3 show this strategy being implemented by young adults when they decide not to provide support to distressed posters on Facebook. Many observers of stigma engage in passive acceptance because they do not want to stand out, especially if other individuals do not engage as well (Miller & Major, 2000; Roschelle & Kaufman, 2004).

Another strategy of stigma management communication is blaming the stigmatized condition for the negative outcomes of mixed interactions (Major & O’Brien, 2005). Individuals with chronic pain often consider their pain to be a barrier to enhancing social relationships (Roberts et al., 2015). Blaming the condition that causes stigma helps targets protect their self-esteem (Smith, 2007a). Another strategy

that individuals activate is isolation and avoidance of mixed interactions. However, there are situations in which targets can cope by avoiding mixed interactions because it can lead to targets bonding or socializing with other targets of similar stigma (Roschelle and Kaufman, 2004), as demonstrated from the findings in Chapter 2 and Chapter 4.

This dissertation clearly demonstrates strategies or techniques for stigma communication management in mixed interactions (e.g. Meisenbach, 2010; Smith, 2007). Because stigma is highly contextual (Kreiner et al., 2006), there has been momentum for scholars to build a unifying framework to explain different stigma management communication strategies (e.g., Meisenbach's Model of Stigma Management Communication; Figure 1), and illuminate generalizable strategy components across contexts (e.g., Green and Banerjee, 2006). However, these strategies are focused primarily on the target. Themes of social support-based communication strategies, which emerged across all three studies of this dissertation, can potentially advance the theoretical work on stigma communication management strategies. The contexts that I have studied illuminate interpersonal strategies of participants in mixed interactions, which add to Meisenbach's (2010) model of stigma management communication (refer to Figure 3).

This dissertation finds consistent stigma management and social support communication strategies reflected across studies. First, the importance of interpersonal dynamics and actively seeking different types of relationships for stigma communication and interactions is highlighted. Another theme across studies is the active seeking of similar others to interact with, as to avoid mixed interactions. For

example, Study 3 demonstrates that individuals who have courtesy stigma use online support groups to actively seek relationships with people who have similar lifestyles and experiences. Experiencing stigma with similar others can be an enriching and affirming experience (King, 2006). A third theme is seeking and receiving validation. Study 1 shows that older adults with chronic pain seek validation of their pain-related experiences and emotions after disclosing about their pain to their communication partner(s). A fourth theme is anxiety or fear of evaluation and judgment. For example, Study 2 highlights the fear of evaluation and anxiety felt by the observer of a distressed post on Facebook. This combination of negative emotions influences the decision-making process of engaging in a social support interaction or not. Most communication research focuses primarily on health and disability stigmas (e.g., Agne, Thompson, & Cusella, 2000; Smith, 2007; Thompson, 2000). I build on this line of research and the stigma management communication theory (Meisenbach, 2010; Smith, 2007) to include interpersonal and social strategies of 1) purposefully communicating with different types of relations about stigma-related content, 2) actively seeking similar others to engage in stigma communication, 3) seeking and receiving validation, 4) negative emotions of fear influencing behaviors in stigma interactions.

The findings from these three studies can be understood through the lens of existing components of stigma conceptualizations and stigma management strategies. However, they also offer propositions of stigma communication management strategies to advance stigma management theories. Next, I turn to future research

directions, which could further advance the understanding of stigma management and communication.

Future Research

This dissertation advances several exciting avenues for future research. Further research in stigma management, particularly for people with invisible disabilities in mixed interactions, can advance comprehensive theoretical frames for stigma communication and management strategies as well as practical implications.

As this dissertation shows, there are interpersonal dynamics and social support-based stigma strategies that various stakeholders in mixed interactions implement. Based on the degrees of stigma and different types of outcomes, future research should parse out specific strategy choices for targets and perceivers to help them cope and manage stigma communication, especially because individuals could execute different strategies based on the context. Future studies could create frameworks of specific stigma management strategies for specific contexts. For example, specific strategies could be recommended to individuals with chronic pain or individuals who experience familial secondary stigma, rather than general suggestions that target all individuals with invisible disabilities. Outcomes of these studies could help us better understand the effects of strategies on health outcomes and social well-being for each context.

Another prospective research topic to advance is the development of stigma management and stigma mixed interaction scales. It is often difficult for researchers to conduct purely quantitative stigma-based studies. One of the main reasons for this difficulty is the lack of generalizable stigma measures. Survey measures for outcomes, processes, and perceptions for specific contexts, as well as more generalizable stigma

scales that could apply to several contexts simultaneously could help advance the field of stigma communication.

The relationship between stigma communication and interpersonal relationships, especially in social support interactions, is extremely complex and multidimensional. In order to continue to unpack these constructs, researchers need to examine different aspects of relationships. As demonstrated in all three studies of this dissertation, individuals involved in stigma interactions actively seek out, avoid, and engage with different types of people, which further validates the importance of interpersonal communication in stigma communication. For example, stigma can affect social networks within family interactions and dynamics (i.e., Study 1 and 4). Stigma that affects not only the target, but also his or her family, can result in stress for the social unit (Poindexter, 2005). Therefore, future research could investigate how families manage a target's stigma and their own secondary stigma. Researchers could explore how management strategies affect family relationships, both positively and negatively, as well as how those who enjoy family support manage and cope with stigma compared to those without the advantage of family support.

Scholars have yet to fully explore similarities and differences across stigma contexts and stigma communication interactions. One way to approach investigating these similarities and differences of stigma communication is to create a more unified understanding of stigma through longitudinal studies of mixed interactions and the effects of such mixed interactions. Findings from longitudinal studies on mixed interactions could set up foundational understandings of how strategies of stigma fluctuate in different contexts and why.

These proposed future directions of research could help us better understand specific mechanisms and effective stigma management strategies in various situations. I hope that my research will encourage scholars to pursue these areas of study, especially to promote stigma management communication. I am very excited to continue to explore the management of stigma in my research program.

Table 1

Summary of Hypothesis Testing Results

Hypothesis	<i>F</i> value	Df	p-value	<i>B(S.E.)</i>	Significance
<i>H1a.</i> Pain-related discourse that older adults with chronic pain have with close relations is positively associated with older adults with chronic pain feeling cared for	21.980	488.657	.000	.03(.01)	Supported
<i>H1b.</i> Pain-related discourse that older adults with chronic pain have with close relations is positively associated with older adults with chronic pain feeling understood	26.867	486.854	.000	.03(.01)	Supported
<i>H2.</i> Pain catastrophizing in older adults with chronic pain is positively associated with pain-related discourse with close relations	10.591	484.458	.001	.03(.02)	Supported
<i>H3a.</i> Pain-related discourse that older adults with pain, who are categorized as high pain catastrophizers, have with close relations is positively associated with content of pain-related emotions	5.140	51.993	.028	.07(.03)	Supported
<i>H3b.</i> Pain-related discourse that older adults with pain, who are categorized as	3.323	38.189	.076	.05(.03)	Not Supported

high pain catastrophizers, have with close relations is negatively associated with pain-related practical content					
<i>H4.</i> The self-efficacy and comfort level of using ICTs for older adults with chronic pain are positively associated pain-related discourse on mobile devices	4.871	22.473	.038	.31(.14)	Supported
<i>H5a.</i> Communicating practical pain-related content on mobile devices is associated with feelings of being cared for older adults with chronic pain	42.757	491.929	.000	.26(.04)	Supported
<i>H5b.</i> Communicating practical pain-related content on mobile devices is associated with feelings of being understood for older adults with chronic pain	29.254	489.763	.000	.20(.04)	Supported
<i>H5c.</i> Communicating practical pain-related content on mobile devices is associated with perceiving social support for older adults with chronic pain	29.819	487.950	.000	.14(.03)	Supported
<i>H6a.</i> Communicating about pain on mobile devices is associated with positive affect for older adults with chronic pain	11.057	492.686	.001	.14(.04)	Supported

<i>H6b.</i> Communicating about pain on mobile devices is associated with psychological adjustment to pain for older adults with chronic pain.	44.029	488.850	.000	.18(.03)	Supported
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Note: *p<.05, **p<.01, ***p<.001

Figure 1.

Percentages with Information and Communication Technology Use by Older Adults with Chronic Pain

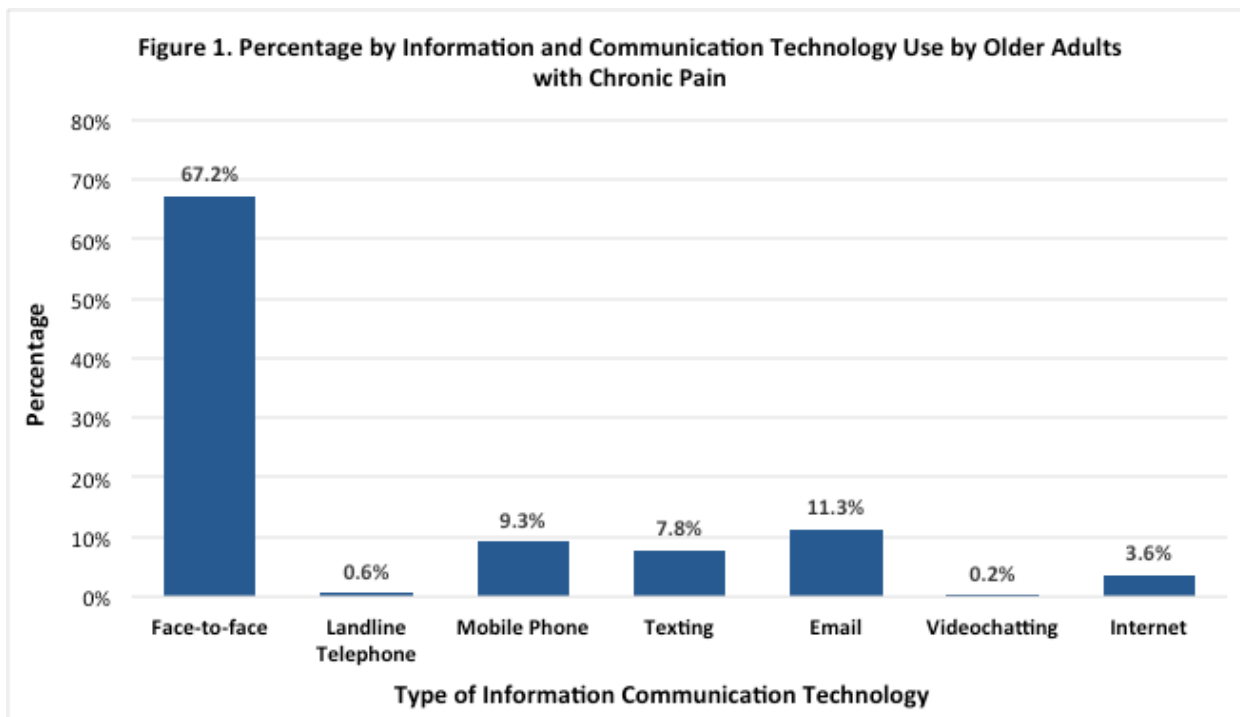


Table 2.

Decision-making process for responding to distressed posts on Facebook in non-close relationships: Comment categories, sub-themes, and examples

Category / subtheme For overall sample; N=25	Example
<u>High acuity and seriousness of content leads to likelihood of viewer responding to poster</u>	<p>Q1. "It wouldn't matter if I wasn't close with the person because if it was super serious like if someone was like I'm going to kill myself and nobody responds to this post then I would respond to the post. I think it's hard because on Facebook your name is on everything and everyone sees what you write but when it's serious like this, you have to respond"</p> <p>Q2. "It definitely depends on the severity and the situation, but in a situation where it's like rape, I don't think my non close relationship would matter about responding because that's the most serious. They definitely would need help...or if it's something that's even more severe like they're posting something about suicide, contemplating suicide on Facebook then of course I would say something. You never want to be regretful it's scary to think about so when it's super serious content like rape or suicide you respond no matter what"</p>
<u>Posting patterns</u>	
<i>Frequent posts indicate non-serious content and desensitizes the viewer leading the viewer to not respond</i>	<p>Q3. "I always knew she was very weak and sensitive and she was definitely like a feeling-centered person than like logic or reason but then the posts she makes me think is she serious? Like if something is a problem all the time it is no longer a problem...so if you post negative distressed posts all the time people take it less seriously...it almost becomes like boy who cried wolf"</p> <p>Q4. "I think that sometimes we can all kind of get caught up, if we have one friend who posts on Facebook <i>all</i> the time. You can get a little bit um diluted almost where you've seen it so many times you wonder how true it is, or...and it could just be them looking for someone to reach out again and again and again but at some point I do think it can change your perception of someone, through social media, just from pure frequency, it just being so much...so I usually don't respond because I think it just kind of feeds the fire."</p>
<i>Frequent posts indicate poster to be generally 'sensitive' and 'emotional' leading the viewer to not respond to the poster</i>	<p>Q5. "If they post all the time and they post and post and post it gets kind of old and people stop wanting to comfort you or respond to you because it's like do you have to say every negative thing in your life? Some people are just sensitive and emo; those are the people I don't respond to because who knows what post of theirs is more distressed or not?"</p>
<i>Frequent posts followed by silence followed by an extreme post lead viewers to respond to the poster</i>	<p>Q6. "I think it's really common because I see a lot of people even like students who are busy or who have a family crisis and they deactivate their Facebook. That's total silence and that is a sign that something is not going so well so when they come back and post all of a sudden I definitely respond. I would feel so guilty if I didn't and then later found out something really bad happened."</p> <p>Q7. "So I remember when I did have depression I didn't like going on Facebook, I was really silent so that's why for me I would take silence or absence from social media as a huge indicator or like a distressed factor so if I see this on Facebook or any social media then I'll understand and at least like it and most likely respond with some type of</p>

content. Silence for a while and then a *really* distressed post is a bad sign. So you respond then.”

Feasibility and self-efficacy of providing support increases likelihood that viewer will respond to poster

Q8. “Well even if I’m not that close with the person but I feel like I can actually help them I would respond, like actually do something for them that will support them and make them feel less distressed. Like if I went through something similar and it worked for me then I feel like I could give them concrete advice or concrete support that would affect them. So yea, if it was actual help and support that they could receive not emotional support I would respond.”

History of reciprocity across SNSs increases likelihood to respond to posters

Q9. “I don’t respond when they are dramatic. Some posts are a cry for attention because I think people are just dramatic, so I was like okay, these people are exaggerating, I won’t respond...but sometimes I’ll respond anyway because there is expected reciprocation down the road for if I’m distressed...you like for likes and comment for comments...kind of like an unwritten contract independent of the content on social media. So I guess it’s like ugh okay even if you are attention-seeking, maybe I’ll respond just because of our unwritten contract.”

Higher levels of commiseration and empathy increase the likelihood for viewers to respond to posters

Q10. “I think that they’re kind of looking for sympathy, I think that the point of posting to people in their social networks is that people in their social networks are like them, they’re probably going through similar things, so I think they’re kind of just looking for a little bit of like pity or sympathy. Um, when they post things like that they are looking for other people who are just like them, like commiserating buddies.”

Perceived attention-seeking behavior of poster decreases likelihood of viewer to respond

Q11. “Some people just need and want attention because it’s their personality. So if the content is so outrageous like ‘oh my god I should contact the police I don’t know what to do’ and they are a drama queen and say that at every party then I know they are just calling for attention. I would definitely not buy into that and would feel less inclined to take part and respond. That stuff is so annoying”

Q12. “they want attention I think. Um attention in my personal opinion when people post about their heart being broken. I think when people post that stuff on facebook to make it public to all their facebook friends, the majority of which are people who they don’t even know that well, I think that makes it less serious, and they’re not actually that hurt, because if they were I don’t think they would want everyone to know.”

Others’ responses and its influence on the viewer

Displacement of responsibility increases the likelihood that the viewer will respond to the poster

Q13. “Well when I usually see a lot of comments, I won’t read through them, because there are too many of them which leads me to not answer – other people already covered it”

Q14. “I think the perception I have is that because I’m sure that there are people who do this all the time and other people do respond so I don’t have to...like a ton of people respond to statuses and you’re like oh I feel like I don’t need to do it because other people already got there first and there are so many responses already.”

Fear of judgment and negative evaluation from others decreases likelihood that the viewer will respond to the poster

Q15. “I’m less likely to post when other people can see my response especially if the distressed post is so intense I don’t want other people to judge my response...”

16. “I think of what everyone will think of my response, it has to be like really well-worded otherwise you just look dumb and you’re not adding value to the conversation. Stuff like that, like repercussions, the future so that’s why most of the time I don’t respond.”

Figure 2.

Behavioral Explanation of the Likelihood of Responding to Distressed Posts on Facebook from the Viewer's Perspective.

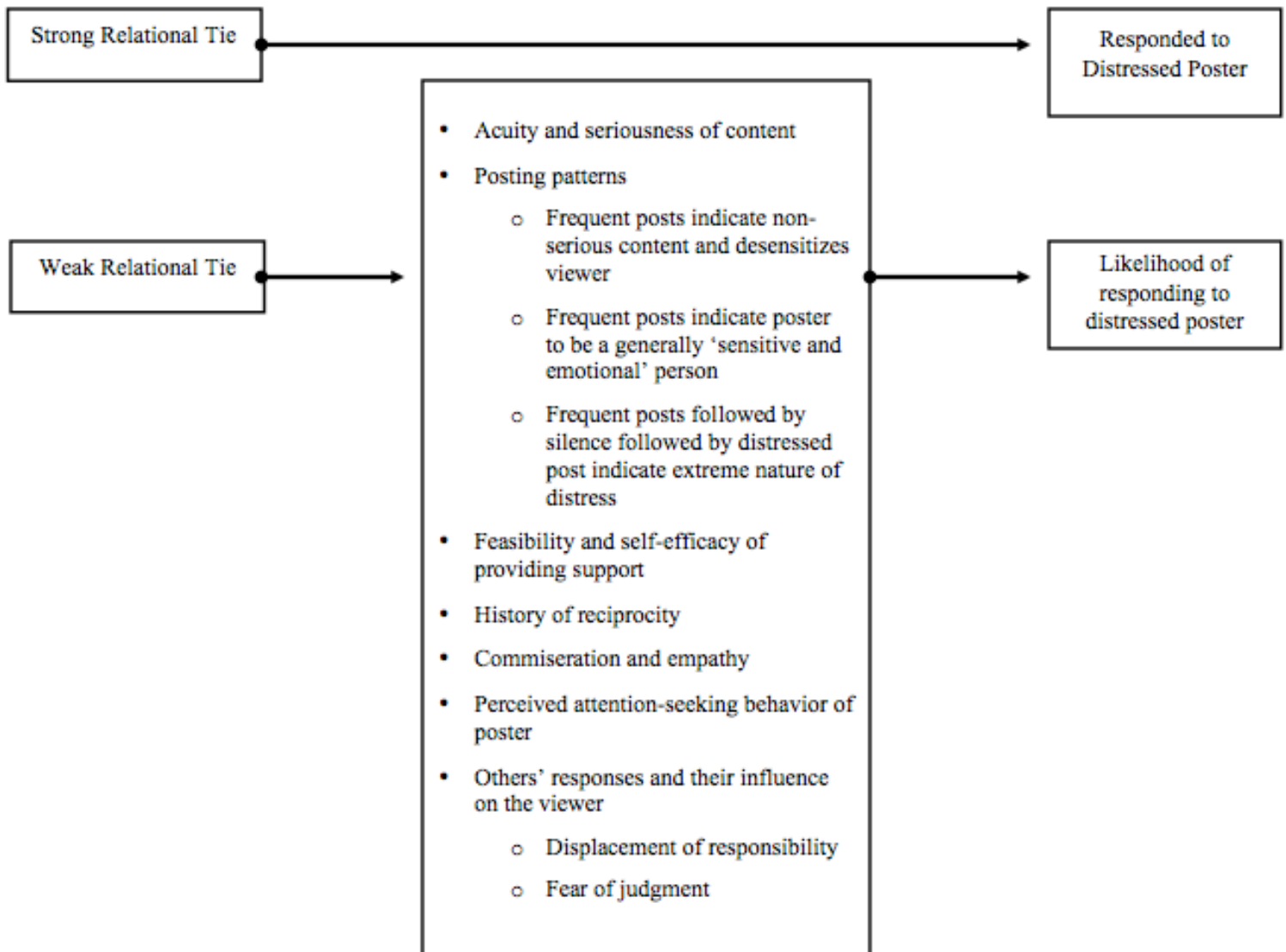
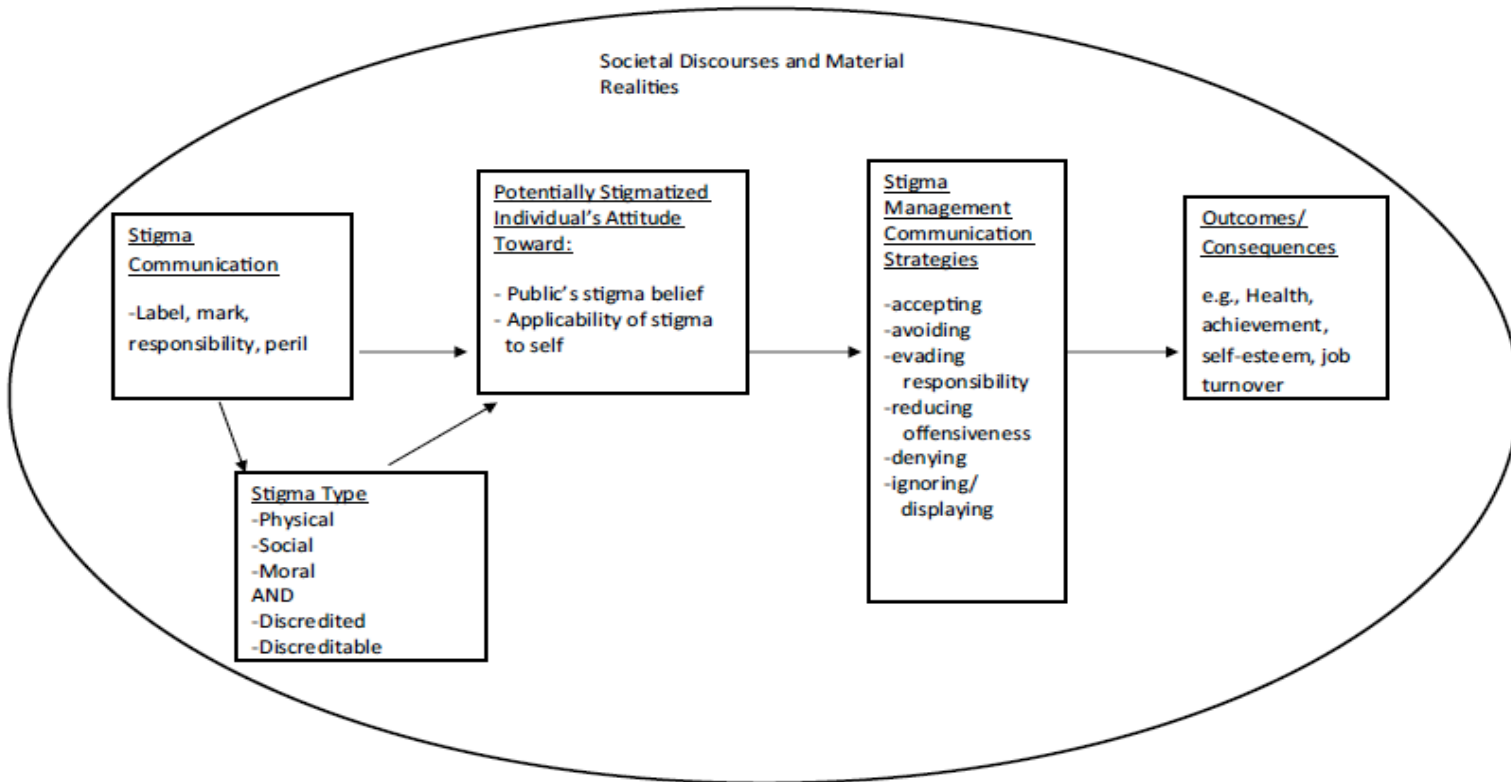


Figure 3.

Model of Stigma Management Communication (Meisenbach, 2010)



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