

PROVIDER PERCEPTIONS OF ABLEISM AND SOCIAL SUPPORT  
NETWORKS IN THE HEALTHCARE SETTING

by

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B.S., University of West Georgia, 2011

A thesis submitted in partial fulfillment of the requirements  
for the degree of Master of Arts  
in the Nicholson School of Communication  
in the College of Sciences  
at the University of Central Florida  
Orlando, Florida

Spring Term  
2013

Major Professor: Jonathan Matusitz

## **ABSTRACT**

The objective of this study is to investigate ableism and social support networks in the healthcare setting. Social support networks play an important role in combating emotional distress in healthcare. They provide disabled patients a method for defending against the negative effects of ableism among other stressors. By definition, ableism refers to perceptions that disability is abnormal and undesirable. Ten healthcare providers in central Florida (i.e., in nursing homes, rehabilitation centers, and primary care offices) were interviewed, using in-depth face-to-face qualitative interviewing. Participants were asked questions relating to the effects of ableist language on patients with disabilities as well as the role of social support networks in combating related stress. Throughout the process of data analysis, five major themes arose as most relevant to the research questions proposed: (1) Traditional Social Support, (2) Online Networks as a Source of Informational Support, (3) Concerns about Ableist Language, (4) External Sources of Patient Social Support, and (5) Accommodation and Accessibility.

Results indicated a strong preference for traditional social support, as opposed to online support. Traditional social support is offered through accommodation of caregivers, availability of social workers, and creation of support groups. Benefits of online support networks are viewed mainly in terms of fulfilling the informational needs of patients with disabilities. Additionally, while some accommodations for patients with disabilities were described, these dealt primarily with alterations to the physical environment. Results showed a lack of attention paid to ableism in the healthcare field, particularly instances occurring in communication practices. Overall, there is room for improvement in the healthcare field concerning accommodations for patients with disabilities.

For my parents whose constant guidance and support brought me to where I am today

## ACKNOWLEDGMENTS

The completion of this thesis would not have been possible without contributions from several individuals with whom I have had the opportunity to work throughout this process. First, I must thank Dr. Jonathan Matusitz for his help and support in every step toward the completion of this thesis. His willingness to volunteer his time and effort to assist me is beyond thanks. Without his guidance, this thesis would not have been possible.

I would also like to express my gratitude to each of my committee members for all of their feedback. Dr. Jennifer Sandoval has been helpful in sharing her knowledge of qualitative research and the interviewing process to strengthen this thesis. Dr. Lindsay Neuberger has been valuable in offering detailed praise and criticism of this thesis in order to highlight areas of improvement. Their willingness to sit on my committee is greatly appreciated.

Next, I would like to thank my friends and family for providing the much needed emotional support. Drew, thank you for reading and rereading my thesis, for reassuring me that starting over was not necessary. Lindsey, thank you for sharing your own experiences and reminding me that it gets better. Valerie, thank you for sitting on the phone and providing a listening ear.

Lastly, I would like to offer my thanks to all the participants who took time from their days to meet with me. Their contributions were absolutely vital to the completion of this project.

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# CHAPTER ONE: INTRODUCTION

## Objectives of this Study

The objective of this study is to analyze the effects of social support networks on U.S. disabled patients who have been discriminated by ableist language. By definition, ableism refers to a type of discrimination based on the notion that being able-bodied is the standard human condition and is superior to a state of disability (i.e., being disabled) (Hehir, 2005). Ableism is maintained through language by using demeaning words or phrases in regards to disability (Cherney, 2011). Examples are “to turn a blind eye,” “to fall on deaf ears,” “mute,” “retarded,” etc. Social support networks are social structures made up of emotional (love, trust, understanding, and listening), informational (supplying information and knowledge to assist with struggles), and instrumental (relating to the provision of material assistance) assistance (Cohen & Wills, 1985; Kyngäs, 2004).

This study is framed from the healthcare practitioners’ perspective. To be more precise, the researcher asked what their opinions were on the impact of social support networks on U.S. disabled patients who have been discriminated by ableist language. This study used the method of in-depth, face-to-face interviewing. In order to study the effects of social support networks, ten healthcare practitioners from the Central Florida area (in nursing homes, rehabilitation centers, and primary care offices) were interviewed. This method was driven by the four research questions listed below:

**RQ1:** What is the association between ableism and U.S. disabled patients' experience of stress and negative well-being?

**RQ2:** How are U.S. disabled patients less likely to experience stress thanks to social support networks?

**RQ3:** How are U.S. disabled patients more likely to maintain a positive sense of well-being thanks to social support networks?

**RQ4:** In regards to the treatment of U.S. disabled patients, what is the difference between traditional support networks and online support networks?

This analysis used several theories to examine the communicative strategies employed by healthcare practitioners when helping U.S. disabled patients to access social support networks. First, communication accommodation theory (CAT) is used to explain the adjustments made to communication behaviors when engaging with individuals from differing social groups. Individuals may choose to accentuate their differences (diverge) or minimize differences (converge) between others (Buller & Aune, 1988; Buller & Aune, 1992; Giles, Coupland, & Coupland, 1991). Second, uses and gratifications theory (U&G) is used to highlight the agency of the audience in selecting particular forms of mass media. Individuals are understood to be active participants in the media they engage in, rather than an audience that has media imposed on them.

Finally, social cognitive theory (SCT) explores the way individuals simultaneously affect and are affected by their environment. It offers a framework for understanding the intersection of social, cognitive, and environmental factors (Bandura, 1986, 1997). Each theory helps create



a greater understanding of why individuals engage in the use of ableist language and strategies of limiting its negative effects on U.S. disabled patients (Wright et al., 2008). Each of these theories were useful when analyzing the interviewing data and in the conclusion of the study.

### Rationale for Conducting this Study

With approximately 20 percent of individuals living in the U.S. dealing with disability (Myers & Bersani, 2008), an examination of ableism generates much needed understanding of the perception of disability. The author of this study believes that reckless use of ableist language is akin to sense of privilege, or what Linton (1998) describes as “normate pathology.” Awareness is the first step in altering such behavior. As with other forms of discrimination, an examination of their effects and methods of addressing their impacts is essential to the elimination of such forms of discrimination. An analysis of ableism is particularly important in health communication, because it can have a significant impact on relationships in the healthcare setting. Ableist rhetoric can negatively impact provider-patient relationships, affecting the quality of care received when patients perceive interactions to be threatening. In response to these patient-provider interactions, individuals may be less willing to disclose particular information to a provider or may avoid care altogether in order to evade feelings of dehumanization.

Language is an important area of investigation. It serves as a reflection of societal norms. A focus on ableist language here generates greater insight into the prevalence of ableism in the U.S. and the rationale for its continued use. Concentrating on the use of ableist language allows

for increased consciousness of its use and a more complex investigation of language that is used (May & Ferri, 2005). A communication starting point diversifies ableism literature that has thus far been limited to disability studies. This limited inquiry decreases the scope of people exposed to the literature as well as the diversity of research conducted. This may aid in the expansion of disability research, a critical step in gaining a more complete understanding of ableism and perceptions of disability in the U.S. Beyond ableist language, understanding how individual interactions perpetuate ableism, and how these actions become acceptable within a population, makes a communication approach essential to the study of ableism (Young, 2001).

#### Preview of the Main Points

This study begins with a review of the literature exploring ableism in the U.S. Both disability and ableism have been described and understood in multiple ways. Thus, this study will begin with a description of key terms, and the ways that each of these terms has been defined in the past. Although ableism includes a broad set of behaviors, it is important to focus primarily on ableist language. Additionally, the extent of disability in the U.S. and the occurrence of ableism are explored.

As with other forms of discrimination, social support networks are often utilized to combat the negative effects of ableism. This study explores the use of these networks in relation to ableism. In response to the increased use of online support networks, there will be a comparison of traditional social support networks to these online sources in order to determine

the differences between the two. Comparisons are based on reasons for their use and the advantages or disadvantages of each.

Finally, the method of qualitative interviewing is described in detail. This section highlights reasons for conducting interviews as opposed to other possible research methods, including: the ability for individual viewpoints to be expressed, the opportunity for clarification as needed, and the structure focusing on the perspective of the participant (as interpreted by the researcher). Research participants are identified and how relevant they are to this research. Lastly, a rationale for the research questions identified above is explained in detail and an interview protocol designed to address these research questions is presented.

## **CHAPTER TWO: LITERATURE REVIEW**

This chapter examines language-based discrimination grounded in notions of mental and physical impairment. Known as ableism, this type of discrimination remains relatively ignored in comparison to other forms of discrimination. In this chapter, described in detail are ableism, its history, how it presents itself, and its impact on patients and their caregivers. Furthermore, the author of this study explores the importance of social support networks in combating stigmatization based on ableism. Online networks have become particularly important sources of support and are explored here. In order to better understand ableism and the use of social support to combat its effects, communication accommodation theory, uses and gratifications theory, and social cognitive theory are introduced.

### Ableism: A Description

By and large, ableism refers to a type of discrimination based on the notion that being able-bodied is the standard human condition and is superior to a state of disability (i.e., being disabled) (Hehir, 2005). The term evolved from the civil rights movements in the U.S. and the U.K. to question and draw attention to the discrimination experienced by individuals whose ability was labeled as impaired (Wolbring, 2008a, 2008b). There is little consensus as to what actions constitute ableism. However, it serves to shape perceptions of individuals with disabilities, maintaining biases and stereotypes about impairment or disability (Campbell, 2001, 2008; Myers & Bersani, 2008). The dynamic shaped between disability and the perceived norm

(i.e., being able-bodied) allows for judgment based on ability to become so embedded in society that its use for exclusionary purposes is rarely interrogated (Ferri & May, 2005; Wolbring, 2008a).

In the same train of thought, ableism is a series of beliefs, processes, and behaviors that yield a perception of self, one's body and relationships with others and one's environment (Wolbring, 2008b). Ableism frames perceptions of reality, reducing notions of disability to the normality of able-bodiedness and functional restrictions of persons with disabilities. It is the idea that disability is deviant and that society should strive to reform persons with disabilities into a desirable state (Brown, 2008; Gollledge, 1991, 1993).

The term ableism emphasizes the actions of the individual engaging in discriminatory behavior. Such behavior occurs as a discriminator that targets individuals on the basis of their degree of ability or disability, engaging in ableist actions or voicing ableist phrases (Harpur, 2009). Ableism, rather than emphasizing disabilities, focuses on these actions that create an assumption that each individual must meet the arbitrary standards set by the dominant group within society. Wolbring (2008) argues that, historically, ableist beliefs may have occurred alongside sexism and racism, using the perceived differences in physical and mental capabilities between the sexes and particular racial groups from the dominant group to maintain dominance. A greater understanding of ableism, therefore, has the ability to affect a broader segment of the population (Harpur, 2009).

Ableism has persisted through history and cultures. It has been used to outline ideas of social cohesion, social policies, as well as relationships between individuals and nations. Ableism is one of the most deeply embedded and widely tolerated forms of discrimination.

Historically, it has been utilized to justify the elevation of dominant social groups. For example, women were described as biologically more fragile, creating a rationale to exclude women from property ownership and suffrage (Wolbring, 2003; 2008b).

Individuals develop conceptions of disability at an early age; these understandings are gained from family, personal experience, and society's perception of the cause of disabilities (Link, Stuenkel, Neese-Todd, Asmussen, & Phelan, 2001). Early perceptions of disability were rooted in theology; individuals with a physical or mental impairment were believed to be heretics or the children of sinners (Covey, 1998).

The Enlightenment ushered in the notion of disability, replacing ideas about impairments being grounded in religion and moral deficiency. The shift to the medical approach removed the theological understanding of disability, but maintained the notion of defect. While an improvement to the often brutal treatment that characterized the early 19<sup>th</sup> century, the medical model of disability led to the establishment of asylums that continued the cruelty in new ways (Jimenez, 1987). In the years immediately following their establishment, these hospitals offered a degree of hope to the mentally ill. However, asylums eventually deteriorated into locations where the mentally ill could be removed from the broader population, rather than offered treatment. The medical model allowed for new forms of mistreatment, such as forced sterilization (Jimenez, 1987).

The social model of disability arose in the 1960s and was used to better understand disability by examining the role of health providers. It attempted to move beyond the medical model, arguing that disability is socially constructed and exacerbated by the labeling of individuals. Although many providers remain divided, an effort to resolve the differences

between the social and medical models proposes that negative labels of disability exacerbate the existing impairment for the individual (Corrigan & Kleinlein, 2005)

Although the compromise between the medical and social models has allowed society to move beyond some of the most explicit forms of oppression, stigmatization towards persons with disabilities is still pervasive. This stigmatization can affect individuals through direct discrimination (e.g., wage inequality), structural discrimination (e.g., the limitation of resources available for treatment), or self-stigma (e.g., the internalization of public stigma) (Brohan, Slade, Clement, & Thornicroft, 2010; Link et al., 2001).

Individuals with a disability are not exclusively affected by ableism. Family and friends can be affected by what is called “courtesy stigma.” Courtesy stigma is especially present in families where the individual with a disability is a child. Parents may feel the effects of the discrimination more than a young child who does not yet comprehend their situation (Birenbaum, 1992). This has shown to have increased in the past twenty years, suggesting solutions for reducing courtesy stigma must occur in conjunction with reducing primary stigma. Courtesy stigma negatively impacts friends and family members’ ability to provide social support. This can create a cycle in which the individual is further impacted by the disability and the courtesy stigma experience is increased (Corrigan & Kleinlein, 2005).

### Ableism: Language

A focus on language offers a way to assess the extent to which ableism is ingrained in our society. While the use of openly racist or sexist language is readily questioned, the use of ableist

language may go unrecognized by many (Gent, 2010). Ableist language constructs disability as undesirable. It does so by exploiting or manipulating the very concept of “disability” in order to describe negative behaviors, situations, or individuals. The use of metaphor perpetuates negative beliefs of disability, constructing an environment of exclusion (Ben-Moshe, 2005; McClintock, 2002).

Language is a critical area of investigation, as it is a reflection of the cultural stigma that surrounds disability. Ableism is maintained through language by carrying these beliefs on to the next generation (Cherney, 2011). An effort has been made in the U.S. to reform the language that is used to universally describe disability and those affected by it. A “people first” approach – as disabilities scholars have labeled it (e.g., Reiheld, 2010) – shifts the phrase “disabled person” to “person with a disability” in order to recognize that the individual’s humanity comes prior to impairment. Language is critical in helping people create new health-related identities. For instance, the term “cancer victim” has been largely replaced by designations such as “cancer survivor” (Wright, Sparks, & O’Hair, 2008). In contrast, disability activists in the U.K. use “disabled person.” Their position acknowledges that disability is socially constructed and such recognition is of greater consequence (Sayce, 2000).

Ableist language based on mental impairments is most salient; it includes references to “crazy,” “schizophrenic,” “loony,” “insane,” “retarded,” and “bipolar behavior” to describe individuals who behave undesirably or are perceived as less intelligent than the norm. Individuals claim that their spouse’s decision making is “bipolar.” Politicians are able to argue that their opponent is threatening to “cripple” the economy. And students can assert that a professor is “crazy” for assigning large amounts of schoolwork to complete (Rasinski,



Viechnicki, & O’Muircheartaigh, 2005). These instances of ableist language are rarely questioned, signifying the extent to which ableism has become embedded in U.S. culture. U.S. society has not placed the same concern on ableist language as sexist, racist, or heterosexist language, allowing a great deal to continue going unquestioned. Disability continues to be used to signify weakness, loss of control, or inadequacy (Rasinski et al., 2005).

### Stigmatization: Impact of Ableism on Patients

Stigmatization is an issue of disempowerment and social prejudice. It refers to an often unobserved denunciation based on some characteristic that creates a social dichotomy, allowing “insiders” to determine boundaries that maintain the exclusion of “outsiders.” This circumstance is analogous to Tajfel’s (1978) social identity theory (SIT), whereby an in-group intentionally creates a separation from an out-group. In-groups and out-groups tend to disagree on valued attributes or identity cues. In-groups are generally distinguished through similarities among members. Individuals share a sense of common destiny with members of the in-group.

Stigmatization is a creator of such “in-group vs. out-group” distinction. Naturally, this can lead to conflict and rejection (Tajfel, 1981). Boundaries allow the insiders to determine which individuals may be included or not. Additionally, they have the ability to strengthen the group’s solidarity through the exclusion of outsiders who disrupt the established norms of behavior within the group (Falk, 2001).

Erving Goffman (1963), a noted sociologist, described stigma as a practice where identity is blemished by the response from others. Stigma results in the condemnation of characteristics

determined to be oppositional to cultural norms. The word “stigma” stems from a Greek term used to describe a tattoo or branding found on criminals, slaves, or traitors. The intent of the marking was to physically label the individuals as undesirables. The term was sometimes used to denote the spots found on serpents. Eventually, stigma was used to indicate social discrediting, shame, or dishonor. Individuals who fell within the boundaries of the stigmatized group were actively avoided, particularly in community spaces where interactions with the group could be witnessed by the public (Jones, 1987).

Ableism can have a profound impact on individuals diagnosed with a disability, where ability is the defining characteristic forming the boundaries between the insiders and the outsiders. The three subsets of stigmatization (direct discrimination, structural discrimination, and self-stigma) each have a unique set of impacts on persons with disabilities (Brohan et al., 2010; Link et al., 2001). Direct discrimination is the most visible form of discrimination. It includes wage inequality and the absence of disability access in buildings. Structural discrimination is made up of societal norms that inhibit persons with disabilities. The common use of ableist metaphors and their acceptance within U.S. society is an example of such discrimination (Brohan et al., 2010; Link et al., 2001).

Self-stigma is the internalization of the former two, where individuals experience a sense of shame, hopelessness, guilt, and fear as a result of discrimination association with their disability. This can generally be described as a significant loss of self-esteem, where individuals accept public perceptions that they are inadequate because of their disability. This lack of self-esteem can have a widespread impact, affecting an individual’s ability to be a productive

member of society. This loss alone should be of significant concern to scholars (Brohan et al., 2010; Link et al., 2001; Van Brakel et al., 2006).

### Ableism: Sexist and Racist Issues

A factor in the prevalence of ableism, specifically ableist language, in the U.S. is the perception that it is not relevant. More often than not, individuals fail to see the very real impacts its use has. Additionally, some argue that criticism of ableist language that begins with “schizophrenic” or “retarded” has the potential to turn into a slippery slope where nuanced metaphors referencing sight or “standing tall” will no longer be politically correct terms. Refusal to critically reflect on the use of ableist language magnifies its impact on individuals with disabilities.

In 1999, David Howard, a staff member for the mayor of Washington D.C., commented on the budget in a meeting with two coworkers, describing the need to be frugal with the available funds as “niggardly.” Despite its merely coincidental resemblance to the racial slur, his comment caused Howard’s dismissal (McWhorter, 2001). Support for the end to sexism and racism has gained such momentum that remaining forms of the two are questioned and often confronted. The labels “sexism” and “racism” have the ability to reduce the prevalence of sexist and racist behaviors, facilitating cultural change through the power of the phrases. Ableism, however, has not established the same force to facilitate change (Harpur, 2009). Disability research and the disability movement are still in their fledgling stages, and remain decades behind other minority groups (Riley, 2005).

The most recent form of discrimination to gain momentum in spreading awareness has been heterosexism. For example, campaigns to end heterosexist language, such as the use of the phrase “that’s so gay” have been effective in beginning conversations about who was impacted by the choice of words and possible alternatives. Strategies have included: encouraging the public to comment when the phrase is used, listing alternatives that better illustrate what is being expressed, and using celebrities to explain the harmful impacts of the rhetoric (Byrne, 1997).

A major distinction between commonly discussed minority groups and persons with disabilities is the ease with which individuals’ disability status can change. In contrast to sex or race, membership in disability groups is transient. An accident can quickly lead to impairment, causing discussions of disability to be limited (Davis, 2002).

### Disability: A Description

Disability is used in many contexts, by both health providers and laypersons. The most recent interpretation offered by the World Health Organization (WHO) uses a comprehensive definition to describe mental and physical impairments that can limit involvement and restrict tasks or activities (World Health Organization, 2012). This definition views disability as a gradient, highlighting the various positions individuals may occupy due to personal and environmental factors (Census Bureau, 2012).

The Americans with Disabilities Act of 1990, established to ensure the civil rights protections of persons with disabilities, largely sets the definition for disability in the U.S., particularly in terms of legislation. The law was amended in 2008 to encompass a broader

understanding of the term disability; recognizing both physical and mental impairments, including mental retardation, visual and hearing impairments, learning disabilities, chronic illness, and multiple disabilities among others (Castañeda, Hopiks, & Peters, 2010; U.S. Department of Justice, 1999).

Not all forms of disability are observable. One subset of disability is described as “invisible disability” and includes impairments that are not readily seen without disclosure from the person with the disability. The stigmatization of persons the disabilities offers an incentive for individuals to keep disabilities hidden. These can be either physical or mental conditions such as heart disease or depression (Bryan, 1997; Shelton & Matthews, 2001).

Mental illness, in particular, offers individuals the opportunity to “pass” because there are rarely physical signs of mental illness (Flanagan & Davidson, 2009). However, these individuals may signal to the public that they are affected by mental illness in four ways: psychiatric symptoms, social skills deficits, physical appearance, and labels. Psychiatric symptoms are indicators of illness such as talking aloud to self and speech irregularities. Social skill deficits are characterized by awkward body language and impaired conversational skills. Regardless of disorder, individuals with a mental illness are thought to exhibit irregular social behaviors by the general population. Physical cues, such as an unkempt appearance, are also used as an indicator for mental illness. Labels can be placed by the individual, openly describing him- or herself as affected by a mental illness, or made through association, such as being observed leaving a psychologist’s office (Byrne, 1997; Corrigan & Kleinlein, 2005).

These four methods used to determine if an individual has a mental illness can be inaccurate if signals are misinterpreted, producing false positives and false negatives. For

example, social skills vary widely among the population and a social skills deficit might be a sign of introversion or shyness rather than mental illness. When false positive conclusions are made, these individuals may become the objects of discriminating acts targeted toward persons with mental illnesses (Corrigan & Kleinlein, 2005).

### Disability in the U.S.

Approximately 20 percent of individuals in the U.S. live with one or more forms of disability (Myers & Bersani, 2008). According to the U.S. Census Bureau (2012), roughly 56.7 million individuals (18.7 percent) claimed a disability in 2010, excluding individuals serving in the armed forces and those residing in assisted living facilities. Of this group, females made up the majority with a 2.4 percentage difference between males and females with disabilities. The 2010 census suggests the greater number of women 65 and older explain this disparity, as the risk of disability increases with age. When age is accounted for, the difference decreases to 0.7 percent (Davis 2002; U.S. Census Bureau, 2012).

Persons with disabilities are a significant social group domestically and abroad. With an estimated 600 million individuals with a disability, individuals with disabilities make up the biggest minority population globally and the group continues to grow as a result of aging, war, poverty, and contamination of the environment. Violence caused by war and terrorism creates disability directly and indirectly through the limitation of basic resources and increasing the spread of disease (Harpur, 2011; Harrison, 2004; Wendell, 2010).

Physical disabilities are the most common form identified in the U.S., with 41.5 million adults reporting a physical disability in 2010. Approximately 30.6 million individuals had limited functioning in their lower body and 19.9 million had difficulty with functioning of their upper body. The census also reported 14.9 million or 6.2 percent of adults experienced some degree of visual, hearing or speech impairment (U.S. Census Bureau, 2012).

Over 44 million Americans suffer from a diagnosable mental disorder. The most common include depression, bipolar disorder, schizophrenia, and obsessive-compulsive disorder. The WHO predicts that depression will rise to the second greatest cause of death in the developed world by 2020 (Rose, 2008; World Health Organization, 2005; Wright et al., 2008). The magnitude of individuals affected by the stigmatization of persons with disabilities makes the issue an area of concern for public health providers. Scholars, health providers, and caregivers must address the issue in order to minimize or eliminate such treatment of persons with disabilities. When discussing disability, individuals with mental or physical impairments are not the only group that requires attention. When caregivers, made up of family and friends, are added to the discussion, nearly half the U.S. population is managing disability (Davis, 2002).

### Social Support Networks: A Definition

Social support encompasses emotional (love, trust, understanding, and listening), informational (supplying information and knowledge to assist with struggles), and instrumental (relating to the provision of material assistance) forms of support (Cohen & Wills, 1985; Kyngäs, 2004). Social support networks have a significant effect on individual health; they have the

ability to produce shared positive experiences, influencing the well-being of individuals (Tardy & Hale, 2008).

Social support received from family, friends, and providers greatly affects physical and mental well-being. Studies have shown social support has the ability to foster coping of chronic illnesses and maintenance of treatment courses. Support is needed not only in response to health crises, but also to address and regulate everyday stressful events (Carson & Voorhees, 2001; Dunbar-Jacob et al., 2000; Kyngäs & Rissanen, 2001). Two models are used to explain the effects of social support: (1) the Stress Buffering Model and (2) the Main Effects Model. The Stress Buffering Model suggests that social support acts as a shield against the effects of stress. Conversely, the Main Effects Model argues that there is a direct relationship between social support and positive health outcomes. Each model concludes that social support networks have a positive impact on the individual. Nevertheless, the direct relationship proposed by the Main Effects Model suggests that the benefits can only be achieved through social support. The Stress Buffering Model allows for other stress-relieving methods to be used in order to obtain the same results. This implies that social support networks are not uniquely key to the physical and mental health of individuals (Cohen & Wills, 1985; Wright et al., 2008).

Defined as the appraisal of family and friends' ability to provide support during times of stress, perceived social support is as important as the support itself. Perceptions of social support are determined by the quality and accessibility of support in the past. Fear that members of one's social network might not aid in critical times is enough to result in emotional distress (Lakey & Cronin, 2008). Numerous studies have found a strong positive correlation between perceived social support and health, including low rates of depression (Haber, Cohen, Lucas, & Baltes,



2007; Lakey & Orehek, 2011). One such study listed traits for participants who acted as perceivers of social support. Participants selected desirable traits that suggested supportiveness. Openness and agreeableness were the most valued attributes in potential sources of social support. These perceptions are also formed by the characteristics of the environment and of the individuals being evaluated. Stable environments and similar personalities among group members were found to create positive perceptions of social support (Lutz & Lakey, 2001). Outside variables can influence the effectiveness of social support. Differences in coping styles may complicate the relationship and the perception of support being provided. For example, although a family member may be available to provide support, the strategies used may conflict with the individual's coping style and the perception of social support is decreased.

Healthcare providers play a role in the social support received by patients. Particularly in fields dealing with critically ill patients (i.e., oncology), the ability to determine when additional support is needed has proven to be a valuable skill. When oncologists learn that patients are distressed, they make sure that support be made available and what form of support should be offered. This knowledge positively affects patients' emotional well-being (Söllner et al., 2001). While providers are sometimes an integral part of patients' social support networks, the emotional toll and the absence of reciprocity in these provider-patient relationships limit the number of such possible relationships. By using support networks, providers have offered alternatives to patients in order to minimize their own emotional distress (Adler, 2002). For instance, some clinics have begun to develop entirely web-based components to their practice, offering self-care guides and support groups online to better assist patients (Ferguson, 2000). The gravitation towards health information available online is increasingly recognized by

providers, who have become more prepared to discuss potential sources of online health resources in order to aid patients in selecting superior sources and establishing online components to their practice (Diaz et al., 2002).

Effective social support networks require the potential for reciprocity. Individuals receiving social support require the opportunity to contribute to them in return (Giles et al., 2006). Without the potential for reciprocity, individuals feel as though they are overbenefitting from the network. Such a situation can overshadow the benefits of the social support network. The inability to reciprocate can lower self-esteem or encourage individuals not to accept the help of friends and family members (Wright et al., 2008).

Boundaries that exclude able-bodied individuals from participating in discussions of disability hinder progress, maintain the binary relationship of abled/disabled, and reinforce the hierarchy where persons with disabilities are seen as undesirable (Kitchin, 2000). In response to the stigmatization based on mental illness, a mental health movement has grown, often called “Mad Pride.” Members are already taking action to increase awareness of the dehumanizing effects of the stigma. However, as with other movements, it cannot survive without allies. Support from friends and family is vital to creating change successfully (Tomes, 2006).

### Online Support Networks

Social support has expanded to electronic media, where communication is facilitated through virtual communities. The expansion has been influenced by increased access to and comfort in using computer based communication (White & Dorman, 2001). In healthcare, online

support groups have grown as a means for individuals to better understand their health condition and establish communication with others having common experiences. Of Americans who utilize the internet, 28 percent take part in health based online support groups. Fifty-eight percent of cancer patients reported using the internet as a reference for cancer information and a source of social support (Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2002; Monnier, Laken, & Carter, 2002; Pew Internet & American Life Project, 2005). These communities function as electronic support groups for individuals with shared experiences (Eysenback et al., 2004).

Some of the forms online support networks take include discussion groups, online forums, newsgroups, email, list serves, and chat rooms (Coursaris & Liu, 2009; Wright, 2000). Online forums are sites where individuals are able to read and post messages, creating a “thread” where posts and responses are linked together to create a continuous strand of information (Vayreda & Antaki, 2009). In each of these methods, there is an expectation of reciprocity and shared responsibility for the members of the network. While there is no shared physical space, these networks begin with individuals having similar experiences and builds on the commitment developed through participation (White & Dorman, 2001).

For some individuals, online support is the most convenient and beneficial medium and for others it only serves as a supplement to traditional sources of support. For individuals who lack family or friends, online support groups can serve as sources of social support, giving these individuals the access to the health benefits of social support communication (Rains & Keating, 2011). Online support groups have the advantage of serving more individuals and more diverse populations because geographic restrictions are eliminated. This has the potential to broaden the perspectives shared in the group, by increasing the cultural diversity of the network. The

asynchronous nature of online media gives participants the capability to receive support at any time they need (Braithewaite et al., 1999; Finn, 1995, 1999; White & Dorman, 2001; Winzelberg, 1997).

However, online support groups are not without challenges. Unlike face-to-face communication, obstacles may increase due to absent visual cues (i.e., eye contact and facial expressions). This creates the potential for communication to be misinterpreted by the reader. Additionally, overreliance on electronic media has the potential to increase social isolation by pulling individuals from time with family and friends. While computer access has greatly increased, not everyone has access to computer or the internet, preventing some individuals from taking part in these online support communities (Sanders, Field, Diego, & Kaplan, 2000; White & Dorman, 2001).

### Online Support Networks and Ableism

Online support networks can be a solution for individuals seeking support, but lacking strong relationships. An evaluation of available social support may determine friends' and families' inability to fulfill support roles (Turner, Grube & Meyers, 2001). According to Shelton and Matthews (2001), family and friends who engage in ableism may be motivation for persons with disabilities to reach out to online support groups. Persons with disabilities who do not wish to disclose their condition to their immediate social network may choose to utilize online support groups for health information and emotional support in order to avoid stigmatization. Online support groups are welcoming places to explore sensitive topics with greater anonymity than

other social support mediums. Additionally, for individuals with mobility problems or speech and hearing complications, social support groups have the additional advantage of removing participation barriers. Individuals with mobility problems are able to participate in the support group without being burdened by transportation issues that can be a source of pain and frustration for some individuals (Ferguson, 1997; Galinsky, Schopler, & Abell, 1997; Madara, 1997; White & Dorman, 2001).

### A Look at Communication Theories

This section covers important communication theories within the context of ableism. First, communication accommodation theory (CAT) is utilized as an explanation of adjustments made in response to interactions with members of different social groups. Second, uses and gratifications theory (U&G) rests on the premise that audience members are active participants in the selection of particular media. While some participants prefer traditional media, others opt for new media (e.g., online channels of communication). Lastly, social cognitive theory (SCT) is used to explain how individuals are both affected by and affect their environment.

#### Communication Accommodation Theory (CAT)

While many theories used in the communication field borrow from other sciences, communication accommodation theory (CAT) has its roots in the field of communication (Giles, Coupland, & Coupland, 1991). It is an outgrowth of prior work conducted by Giles, speech

accommodation theory and the accent mobility model. CAT is an attempt by Giles and his colleagues to explain why individuals adjust their communication behaviors in response to others. CAT proposes that speakers adjust their communication in order to accommodate each other. Individuals constantly come into contact with members of divergent social groups based on education, age, race, sex, socioeconomic background, etc. These interactions require individuals to choose communication behaviors to engage in (Hummert, 2010). Speakers may either converge, attempt to align their communication behaviors with the other, or diverge, exaggerate their differences. Each form of accommodation can be expressed through adapting linguistic (e.g., accents, speed, vocabulary), paralinguistic (e.g., tone, pauses), and nonverbal features (e.g., nodding, smiling).

As an example of convergence, an individual may slow his or her rate of delivery in order to accommodate a non-native speaker. Individuals may be motivated to emphasize similarities, converge, in order to bond with the other person. Convergence creates a sense of closeness, identification, and bonding that can increase positive appraisal. Research has shown that listeners appreciate convergence to the listener's own speaking style. Increased understanding is another motivation for speakers to converge. In contrast, individuals may diverge in order to encourage a change in behavior or distance oneself from the other person. For example, primary school teachers sometimes intentionally diverge, speaking beyond their students' vocabulary, in order to challenge students to learn and expand their vocabulary. Students respond by accommodating to the challenge. Convergence is sometimes seen as a loss of personal identity, encouraging speakers to highlight differences in communication behaviors (Giles et al., 2006; Littlejohn & Foss, 2011; Zoffel, 2007).

Health communication primarily uses this model of accommodation to better understand provider-patient communication among intergenerational groups. Stereotypes of mature adults can cause providers to overaccommodate when attempting to converge during provider-patient interactions (Hummert, 2010). For example, the stereotype that the predominant amount of older adults suffer from age-related hearing loss, presbycusis, might cause providers to overaccommodate by speaking too loudly or too slowly. These actions can damage communication and lower the patients' self-esteem by creating the perception that the provider is patronizing them.

In contrast, by not allowing the 15 percent of individuals over 75 years suffering from presbycusis to adapt to speed and pitch, underaccommodating can also undermine communication. Patients would be less likely to understand everything being said, lowering quality of care and potentially patient self-esteem. The use of CAT in health communication can be expanded beyond the elderly to include division among all social groups. Its application to ableism has the potential to create a clearer understanding of the impacts of ableist language on perceived social support and access to health services. The application of CAT here can highlight ways for caregivers to reduce stigma, increase perceived social support, and increase self-esteem among individuals with a disability (Brohan et al., 2010; Wright et al., 2008).

Divergence and convergence have been used to alter the behavior and language of individuals. Intentionally diverging can influence the behavior of others as well. During conversation where undesirable language is used, these individuals can use different vocabulary to signal a desire for change. Diverging intentionally in order to influence communication behavior has the potential to be exceedingly affective because greater attention is drawn to

divergence than convergence. Individuals are more aware of diverging communication behaviors that highlight difference between the speaker and listener (Littlejohn & Foss, 2011). Such strategies have already been used by individuals in response to sexist, racist, and heterosexist language in instances where the individual wishes to avoid direct confrontation (Littlejohn & Foss, 2011; Zoffel, 2007).

Convergence creates a sense of closeness, identification, and bonding that can increase the positive appraisal of perceived social support (Littlejohn & Foss, 2011). Bonding and positive appraisal can each increase a patient's willingness to interact with caregivers. Additionally, positive appraisals of social support have the ability to benefit physical and mental health. Linguistic convergence has the potential to lead to psychological convergence. On this note, the Sapir-Whorf hypothesis postulates that the structure of a language impacts the manner in which its speakers view their world. In other words, language shapes the way we think (Sapir, 1929; Whorf, 1941). Language or language use influences or predetermines its speakers to particular modes of interpretation of their environment (Hoosain, 1986).

However, as Giles et al. (1991) explain, psychological convergence and divergence go beyond linguistic, whereby "individuals' beliefs that they are integrating with and differentiating from others respectively, while [objective] linguistic convergence and divergence can be defined as individuals' speech shifts towards and away from others respectively" (p. 32). Psychological convergence is more likely in interactions where there is greater power distance between the individuals involved. Additionally, because it is not always clear when an individual has a mental illness, the first strategy of convergence can be difficult to enact. Speakers may have a difficult time identifying when convergence is necessary.



## Uses & Gratifications Theory (U&G)

Uses and gratifications theory (U&G) emerged in the 1940s as researchers became concerned with why audiences preferred certain media and mass media content to others (Ruggiero, 2000; Wimmer & Dominick, 1994). U&G deviates from early theories relating to the power of mass media. Early theories suggest that mass media are exceedingly influential in altering behaviors, portraying the audience as passive members. Conversely, U&G is based on the idea that media cannot have influence over an individual unless he or she has a need for it (Rubin, 2002). The theory begins with the assumption that audience members are not merely compliant observers, rather they take active roles in interpreting and incorporating media into their lives based on their individual needs (Katz, 1959; 1987). Motivation for selecting certain media or media content is incredibly diverse; what the audience selects mediates the influence of mass media (Wright et al., 2008).

In this study, U&G is important because patients with disabilities have preferences as to what mass media they like to use. For instance, they have the ability to choose from media like WebMD.com, online forums (discussion groups), or online chatrooms. U&G has commonly been used to assess learning resources and student preference, particularly in regards to electronic learning. It frames the student as an active participant in choosing resources to satisfy their learning needs. The theory is used to assess preference for certain learning resources over more traditional academic tools. U&G argues that students actively choose the educational method that best satisfies their learning needs (Mondi, Woods, & Rafi, 2008).

Criticisms of the theory emphasize its reliance on self-reports, lack of clarification of the basis of audience needs, and neglect of the potential dysfunction in terms of audience needs. Early research based on U&G was principally descriptive, lacking an analysis of the shared relations between mass media functions (Katz, 1987; Ruggerio, 2000).

### Social Cognitive Theory

Social cognitive theory explores the way that social, cognitive, and environmental factors interact and influence one another. Individuals have the ability to affect their environment, manipulating their surroundings in the same way environment factors can modify behavior. Social cognitive theory offers a framework for understanding human actions, social relations, and psychological well-being (Bandura, 1986, 1997). The theory draws attention to the manner in which individual attitudes and behaviors are defined by persons in the social network, primarily significant others. These individuals often share a relationship where there is a significant level of emotional investment; they may include family and close friends. This method of gaining knowledge highlights the influence of social factors on behavior (Anderson & Chen, 2002). The theory identifies self-efficacy and expectations of results as factors that guide behavior. Self-efficacy influences the frequency of behaviors, the effort exerted in response to barriers, and the command of the behavior (Bandura, 1986).

A majority of other theories dealing with self-regulation concentrate primarily on the way individuals aim to minimize the disparities between their actions and the norm, or discrepancy reduction. However, this negative response process does not account for the complexity of

human behavior, where individuals take initiative to engage in self-development and work to transform their environment. Individuals may set goals for themselves that they strive to fulfill and, when met, replace with more challenging goals. The strength of self-efficacy influences the challenge and frequency of goals (Bandura, 2001). Self-regulation cannot be understood without the inclusion of both discrepancy production and reduction. Social cognitive theory draws on this notion of individual agency, recognizing people as agents capable of shaping their environment and engaging in self-development. Individuals employ their personal agency in conjunction with the social forces to manufacture changes to the social structure (Bandura, 1986; 2001).

#### The Four Research Questions: A Description for Each of Them

In order to gain a more complete understanding of ableism in the U.S., its effects on disabled patients, and the role of social support networks, this study was driven by four research questions. Each research question is essential to creating a new understanding of ableist language in the U.S. and the effects of social support networks on U.S. disabled patients targeted by ableism. A specific rationale for the formulation of each research question is outlined in this chapter.

Stigmatization is often a result of binary relationships where one social group is given a position above another. Although it may sometimes go unobserved, the impacts of stigmatization remain far-reaching and should be of significant concern (Falk, 2001). The three forms of stigmatization described by Brohan et al. (2010) each contribute to the potential stress

and negative well-being among U.S. disabled patients. Its effects can include economic disparity, decreased mental health, and decreased self-esteem (Brohan et al., 2010; Link et al., 2001). Given the fact that stigmatization based on mental and physical impairments negatively impacts U.S. disabled patients, the first research question is listed below:

**RQ1:** What is the association between ableism and U.S. disabled patients' experience of stress and negative well-being?

### The Stress Buffering Model

The Stress Buffering Model is used to explain the relationship between social support and mental health. According to the Stress Buffering Model, stress buffering occurs when an individual's social support network protects against the negative influences of stress (Lakey & Orehek, 2011). Stress arises from threatening situations in which the individual does not possess the required coping skills to respond independently, it results in feelings of hopelessness and loss of self-esteem. Stress can occur in response to life-threatening events, as well as in response to everyday stressors. The Stress Buffering Model is supported by the strength of the relationship between stress and reduced mental health among individuals with weak social support networks. Conversely, stress is less likely to result in reduced mental health among individuals with strong social support networks because these relationships have the ability to protect against external threats.

This relationship can be explained in two ways: (1) social support networks may intervene before stress occurs. Here, individuals include their networks' ability to assist with coping in the assessment of their own coping skills. (2) Following the stressful occurrence, social support networks may intervene between the event and the reduction of mental health. The social support network minimizes the impact of the stressful situation. When stress does not exist, there is no relationship between levels of social support and mental health (Cohen & Wills, 1985; Rook, 1987). The largest criticism of the model stems from its inconsistent usage. A second criticism is that the model makes generalizations about perceived and enacted social support, erasing the differences between the two (Lakey & Orehek, 2011).

In the context of ableism, the Stress Buffering Model can be used to explain the relationship between social support networks and mental health. As a result of the stress caused by ableism, individuals may rely on their social support networks in order to reduce the experienced stress. The Stress Buffering Model helps explain how strong social support networks are able to intervene and prevent the resulting stress from impacting the mental health of the individual. Given the fact that social support networks minimize the impact of stressful situations, patients in the U.S. are less likely to experience the potential stress that results from the use of ableist language. The second research question is listed below:

**RQ2:** How are U.S. disabled patients less likely to experience stress thanks to social support networks?

## The Main Effects Model

The Main Effects Model recognizes a link between social support and mental health, even in instances where stress levels are low. This is a key distinction between the Stress Buffering Model and the Main Effects Model (Lakey & Orehek, 2011). Additionally, the Main Effects Model argues that social support networks are not simply interventions. Rather, it contends that social support is intrinsically good, maintaining individual well-being by providing a sense of stability, positive affect, and acknowledgment of worth. This is reflected in people with high levels of social support having greater mental health than those without or with low levels of social support. Studies suggest that there may be a minimum threshold of social support that must exist before its benefits can be experienced. However, no conclusions have been made about where that threshold lies (Cohen & Wills, 1985).

A certain number of studies exploring the link between social support and mental health are in favor of the Main Effects Model as opposed to the Stress Buffering Model. Although both models offer different explanations of the link between social support and mental health, these models can be used in conjunction. Studies on the Main Effects Model have been repeated to find links between low perceived social support and depression, posttraumatic stress disorder, and other forms of psychological distress. A link also exists between high perceived support and happiness (Lakey & Cronin, 2008; Lakey & Orehek, 2011). Similar to the Stress Buffering Model, the Main Effects Model can be used to explain strong social networks' ability to offset the impact of ableism on the targeted individual. Even if stress is minimal, social support networks are able to negate the stress increasing the mental health and happiness of the individual. The perception of support increases the mental health and self-esteem of individuals,

so when confronted with ableism patients are better able to maintain positive mental health in relation to the stress resulting from ableism. Based on these facts, the third research question is listed below:

**RQ3:** How are U.S. disabled patients more likely to maintain a positive sense of well-being thanks to social support networks?

#### Traditional Support Networks vs. Online Support Networks

Social support networks have traditionally existed through face-to-face communication between individuals. These individuals typically have existing relationships that are not based on their disability status (e.g. friends and family). In recent years, in conjunction with increased access to and comfort in using computer-based communication, online support networks have become increasingly important (White & Dorman, 2001). In contrast to traditional support networks, these communities are often made up of individuals who previously had no contact. Connections are founded solely on shared experiences in regards to mental and physical impairments. Strangers are able to maintain their anonymity while participating in online social support networks. As a result of the fluid nature of the internet, online support networks are able to easily to adapt to the particular needs of the patient. For example, individuals with mobility or communication limitations are able to remove potential barriers to social support (Ferguson, 1997). Given this information, the fourth research question is listed below:

**RQ4:** In regards to the treatment of U.S. disabled patients, what is the difference between traditional support networks and online support networks?



## CHAPTER THREE: METHOD

The third chapter explains the methods that were used to analyze the effects of social support networks on U.S. disabled patients who have experienced discrimination based on ableist language. Ten healthcare practitioners were interviewed in Central Florida. Each interview contains a set of open questions (see interview protocol). The objective of each interview is to gather data on healthcare practitioners' perspectives about the use of ableist language *vis-à-vis* U.S. disabled patients. This section describes (1) qualitative interviewing and what it entails, (2) the objective as a qualitative interviewer, (3) the reasons that explain why the qualitative interviewing method was selected (as opposed to a quantitative survey), (4) the participants (who they are and how they were recruited), and (5) the interview protocol itself.

### Qualitative Interviewing

In-depth qualitative interviewing is a method that relies on an analysis of participant accounts (Lofland & Lofland, 1995). The analysis of qualitative data involves the examination of a phenomenon to research its essentials and inner workings. In doing so, the researcher creates a pattern for the whole by organizing categories or themes in one piece (Schwandt, 2001). From this vantage point, the information collected during the interviews allows meaning to be deduced. All ten interviews with healthcare practitioners were conversations – not between equal partners, but between a researcher and a participant. This means that the interviews were asymmetrical. The philosophy of qualitative interviewing infers that the researcher sets the

agenda of the interview – he or she controls or, at least, influences the situation. For example, the topics of ableism, ableist language, and social support networks are introduced to the participants by the researcher.

The participants' responses to the interview questions should be considered “stories” or “accounts.” A story is a narrative of a sequence of events (Atkinson, 1998). An account describes an event through some form of storytelling, with believability. It is a recounting of particular knowledge or past experience (Riessman, 1993). This is what makes interviewing a conversation; participants share their stories or accounts in a conversational manner. Ultimately, interviews were conducted at the pace of each healthcare practitioner and were each approximately 30 to 45 minutes. Participants were encouraged to share their experiences in their own way, in order to preserve the voice of the participants (Rubin & Rubin, 1995; Wengraf, 2001).

### The Objective as a Qualitative Interviewer

When conducting face-to-face qualitative interviews, the researcher occupies a unique part of the interview. While engaging in the conversation, the researcher has the simultaneous ability to regulate the flow of the conversation (King & Horrocks, 2010). The researcher must be informed, empathetic, reflexive, and understanding in order to produce successful interviews. The rationale of the researcher is reflected in the greater part of what occurs in the research, because of the significant role played by the researcher.

The goal of face-to-face qualitative interviewing is to consider the contributions made by each participant. Analysis of the accounts of interacting with U.S. patients who have been affected by the use of ableist language, made by participants guided the researcher in constructing an explanation. Analysis of the accounts guided the researcher in identifying unifying themes across the participants' responses. Themes are based on the reoccurrence of words, phrases, or topics all through and across interviews. While participating in the conversation, the researcher must also maintain reflexivity, paying particular attention throughout the interview process (Roulston, 2010).

Following the interviews, the information obtained was rigorously tested. Collection of data and analysis procedures was recorded. Vital stages of the analysis of accounts include the transcription of each interview (referring to the translation of verbal language to written language) and the interpretation stages (making sense of the rational and comprehensibility of the accounts) (Kvale, 1996). At this stage, the researcher moved from the accounts to the text of the research, making notes and expanding on the interpretation of the accounts. A thematic analysis was conducted in order to identify themes throughout the participants' accounts. These are preliminary attempts by the researcher to determine what knowledge is gained from the interview process; patterns were identified among each of the participants' responses. A completed text was the result of these preliminary stages (Denzin & Lincoln, 2003). The end objective was to create a final report that makes the information obtained through the interview process understandable to academics and laypersons.

## Why Qualitative Interviewing?

Three reasons for focusing on qualitative interviewing rather than quantitative have been identified. First, qualitative interviewing provides researchers with personalized accounts of lived experiences in the words of the participants (Brenner, Brown, & Canter, 1985). Quantitative methods limit the researcher's ability to do this, constraining the researcher to inferential methods that do not allow a complete understanding of the participant's viewpoint (Denzin & Lincoln, 1998). Second, interviewing permits the researcher to seek clarification of supplemental information provided in response to questions. For example, if a healthcare practitioner is unfamiliar with jargon included in the study, the researcher is able to begin with the interview by assessing the practitioner's knowledge of the topic. This can also help establish a mutual understanding of the terms used by the researcher and the participants, allowing for more complete data. For example, participants may be unfamiliar with terms such as *ableism* or *ableist language* and may instead be more familiar with the phrase "language used to discriminate a disabled person." Finally, interviewing allows for more structure than quantitative research. The qualitative researcher follows a process where interviews are recorded, interpreted, made into a text to be shared in order to contribute to the existing field of knowledge (Brenner et al., 1985; Denzin & Lincoln, 1998). This complete process allows the reader to learn from participant accounts through the perspective and interpretation of the data from the researcher (Silverman, 1993).

## Participants

The participants in this study consisted of healthcare professionals working in the Central Florida area. More specifically, the healthcare practitioners included nurses, nursing assistants, and healthcare coordinators. The majority of participants were female, with only three males. However, the group consisted of a broad age range and work experiences. The varied group of healthcare professionals participating produced responses that reflect their diverse interactions and relationships with U.S. disabled patients.

These participants were chosen in order to create a broad illustration of the experiences of U.S. disabled patients. Providers have unique vantage point in which they are exposed to both the emotional, physical, and informational needs of patients within the healthcare system. As each healthcare professional develops a different relationship with patients and is privy to varying information, a diverse set of participants created a more complete understanding of U.S. disabled patients in relation to ableism and social support networks.

First, to recruit participants, the researcher spoke directly with the head of a medical facility (or supervisor of a unit) and inquired if healthcare practitioners were willing to participate in the study. Second, the researcher asked the head of a medical facility (or supervisor of a unit) if they could provide names of healthcare practitioners allowed to participate in the study. Once a sufficient number of participants were acquired, the researcher notified each of them about the purpose of the study and scheduled appointments for conducting interviews. The interviews were conducted in the facilities themselves.

Prior to doing the interview, the researcher described, to each participant, the purpose of the informed consent form established by the Institutional Review Board (IRB) and requested

him or her to read it. Participants were also notified that the interviews would be recorded (on a tape recorder). In the event that a participant did not want his or her responses to be recorded, notes were simply taken by the researcher. To guarantee protection of the participants, the researcher assured them that their names would be kept confidential, that they could have a nickname, and that the recordings would be destroyed after all interviews were transcribed. Finally, the researcher gave participants her phone and email as well as the contact information for the faculty directing this study. The following statement was included: “You are encouraged to contact the researcher(s) if you have any questions.” If they had questions about their rights as a participant, they could contact the University of Central Florida Institutional Review Board. They were given a copy of this information for their records. In the event that they did not receive a copy of this consent form, they could request one.

### Interview Protocol

Interviews were semi-structured around the issues raised above. The interview protocol (Appendix B) is representative of the questions that were asked. However, additional questions proved to be relevant through the course of the interviews in order to follow up responses and gain information pertinent to particular providers.

The interview protocol was developed in order to answer each of the proposed research questions. In regards to RQ1, examining the relationship between ableism and patient well-being, providers were directly asked how they characterize the effects of ableism. In order to ensure an understanding of what was meant by “ablesim,” the term was explained or

rearticulated as “discrimination based on disability.” Two such questions were included in the interview protocol, one asking generally about ableism and the other specifically addressing ableist language.

RQ2, examining the relationship between stress experienced by patient with disabilities and support systems, was addressed using a series of open ended questions. For example, “In what ways are social support networks a good strategy for managing disabled patients’ stress resulting from discrimination?” RQ3, which sought to better understand the relationship between positive sense of well-being and social support networks, was addressed using a similar set of questions. As each participant responded, additional questions were asked based on the examples given.

Finally RQ4, identifying key differences between traditional support networks and online support networks, was addressed by first asking about the advantages of each and then asking for comparisons. The question, can you compare the main disadvantages of traditional support networks vis-à-vis online support networks? Was used to get at this point. To end the interview process participants were asked about their particular interactions with patients and if additional information needed to be added.

### Thematic Analysis

Following the interviews and their transcription, a thematic analysis was carried out to identify patterns in the way providers described the effects of ableism, patient stress, and the importance of social support networks. Data was analyzed for shared themes and patterns. This

researcher utilized Owen's (1984) criteria (Recurrence, repetition and forcefulness) for identifying themes present in the data. Recurrence suggests the theme was present throughout numerous messages made by individual contributors. Repetition concerns the regular use of particular words or phrases. Forcefulness, in terms of vocal emphasis, volume, and intonation, was also used to identify relevant themes (Hastings, 2009).



## **CHAPTER FOUR: DATA AND ANALYSIS**

This chapter provides a detailed analysis of the responses told by the participants. Once the interviews with the ten participants were recorded, listened to thoroughly, and individually transcribed on the computer, the accounts were color-coded based on themes that occurred during the interviews. All ten participants were from diverse backgrounds, made up of different ages, sexes, and ethnicities. Yet, each participant worked in medical facilities in the central Florida region. These facilities included nursing homes, rehabilitation centers, and primary care offices. Following transcription, the researcher compiled a Microsoft Word document of categories, each supporting the specific findings significant for the dominant themes that emerged during each of the interviews. Throughout the information analysis process, five key themes emerged as the most pertinent to the original research questions: (1) Traditional Social Support, (2) Online Networks as a Source of Informational Support, (3) Concerns about Ableist Language, (4) External Sources of Patient Social Support, and (5) Accommodation and Accessibility.

### Theme 1: Traditional Social Support

Traditional support systems, comprised of face-to-face interactions as a means of satisfying emotional, informational, and instrumental needs, play an important role in healthcare. Particularly in times of stress, individuals draw on traditional support networks to mitigate emotional distress. Simply, the presence of a member of an individual's support network can help manage or eliminate stress by providing emotional support. This theme highlights ways

participants described the role that friends, family, and caregivers played during patient-provider interactions.

*Frank*, a young male nurse described, ways in which traditional support networks are utilized by patients with disabilities when receiving treatment:

When we take someone back, the patient always goes by themselves. Only because it's easier for them to tell the other nurses what needs to be told without other people being around to jump in. But, like people in wheelchairs, a family member can go back to help them get out the chair and get dressed into the gowns.

This form of instrumental support helps medical visits proceed more efficiently for both the provider and patient. In facilities that fall into structural forms ableism, where resources for the treatment of patients of disabilities are lacking (i.e., narrow doorways), caregivers serve an even more instrumental role (Brohan et al., 2010; Link et al., 2001). More nuanced forms of ableism in these healthcare settings can increase the need for members of a social support network to be present. For example, analysis of the healthcare field has shown a lack of providers with disabilities. Preferences for able-bodied providers reinforce structural forms of ableism (Richardson, 1994).

*Frank* commented that patients with disabilities who have utilized this particular facility in the past have never visited without a companion. This supports the Stress Buffering Model, where an individual's social support network protects against threatening situations that can lead to stress. Members of an individual's support network are able to intervene before stress occurs (Lakey & Orehek, 2011). In the scenario described previously, the aid of a family member in leaving a wheelchair or changing into a gown prevents patients from needing to ask a stranger

for assistance or struggling with certain tasks on their own. While many patients with disabilities are capable of completing these tasks on their own, for individuals who cannot complete those tasks on their own, seeking assistance from a stranger may become a source of stress (Cohen & Wills, 1985).

At another facility, providers informed me that they were working to establish support groups to address the needs of patients and members of the community. *Debbie*, an older nurse employed at this facility described the progress being made towards establishing a support group:

As far as support groups, we don't actually... we're just discussing that one because that's something that we would want to say we could do. Kind of like invite the community to kind of like go... once a month kind of support group, but that's something that would be for our entire community and you know, family members. But that's something that is in the works now.

In part, a plan to increase exposure to their facility, the attempt to create support groups for patients and other members of the community was a plan to address the emotional and informational needs of individuals participating in the support groups. As a nursing home, the facility focused its support group on the needs and concerns associated with the elderly population. Examples are caring for individuals with dementia, adapting to decreased mobility, and staying active with age.

Although some facilities had formal processes for identifying a gap in social support, other providers were responsible for identifying that gap individually and determining a strategy for assisting those patients. The ability to determine when additional support is needed is a

valuable skill for healthcare providers. This skill ensures that patients are given quality medical care and that their emotional well-being is tended to (Söllner et al., 2001). For individuals dealing with a new disability, providers automatically referred patients to resources that would help patients adapt to the disability. *Lindsey*, a nurse working at an east Orlando rehabilitation center where many patients learned to negotiate new physical disabilities, explained actions taken for these patients to help them in learning to adapt to the disability:

If it's new than we're referring to the appropriate resources. Especially if it's a new disability, they're not going directly home; they're going to an alternative level of care. And we transition them to that alternative level of care. And from the alternative level of care, the social workers are usually setting up individualized services when they leave.

In addition to having a structured system to address the needs of patients, staff members in this facility were trained to address the specific needs of patients with disabilities. Individualized services included access to information about their condition and treatment, physical rehabilitation, and referrals to specialized services. The availability of these resources in caring for patients gives providers the ability to tailor care to the specific needs of patients, increasing the quality of provider-patient interactions and perceived quality of care (Lezzoni et al., 2004).

## Theme 2: Online Networks as a Source of Informational Support

In recent years, there has been an increase in web-based healthcare. Providers are able to supplement care given to patients, or patients are able to choose web-based healthcare as an alternative to visiting a provider. Websites offer information about ailments, symptoms, treatments, medications, recommended specialists, the emotional toll of diagnoses, and ways to

connect with others (Eysenback et al., 2004). The convenience of web-based healthcare is a primary cause of this increase (White & Dorman, 2001). Online resources are convenient both for patients (who require additional support) and providers (who are spread too thin or do not have a command of the specific needs of patients). Using online resources, providers and patients are able to access additional health information for more complete care.

The ability of online resources to fulfill emotional, instrumental, and informational support needs also works to alter the role that patients take in the fulfillment of their own healthcare needs. Uses and gratifications theory (U&G) suggests the selection of online resources is based on the individual needs of patients. The diverse needs of patients make online resources well suited to tailor information to the needs of specific patients (Rubin, 2002). Patients with disabilities can take a more active role in their healthcare by seeking out resources that increase their own understanding of diagnoses as well as the availability of treatments prior to or instead of visiting a healthcare provider (Rains & Keating, 2011).

Rather than settling for the information immediately available to providers, patients are able to expand their knowledge by seeking referrals to other sources of information or seeking out information on their own. Selection of online resources for informational support may be based on a variety of factors such as content (i.e., information relating to a specific diagnosis), medium (i.e., list serve vs. website), or delivery (narratives vs. facts). The process of acquiring information in addition to what healthcare providers have to offer, allows patients to become active participants in their medical care and sustain positive well-being (Rains & Keating, 2011).

The second theme reviews some of the methods that the participants have utilized (i.e., online resources) to aid in the care and treatment of patients. The majority of participants

mentioned using online sources as a means of providing informational support to patients. Some of these sources were websites set up by medical facilities and offered information specific to their locations and services. As *Jenny*, a female nurse working at an Orlando family practice explained: “We have a website, but it’s just a general website. It talks about the services that we provide, just contact information, it talks about our facility a little bit. That’s basically it. It’s pretty general.” These websites were designed solely as tools to assist patients in determining whether the respective facilities were appropriate for the treatment of their condition and as a means of guiding patients to the facilities by providing directions and contact information. The websites were used as a tool to better assist patients or potential patients. Any additional information required that the patient meet with staff directly or seek out another provider.

Other websites were general resources that offered information about the impairment, treatment, and resources online or in the patient’s community. These were not affiliated with the respective medical facilities. *Shannon*, young female nurse working in south Orlando described justifications for the use of one online network:

We do refer patients to 2-1-1 Network, because they are a computer based database that is sometimes a little more up to date than what we sometimes are able to keep up with because they’re more accurate and current and can connect patients with some of the resources they might need that we might not be aware of out there too. We do provide that as a resource.

Created in response to the SB 1276 mandate established in 2002 by the Florida State Legislature, the Florida 2-1-1 Network is an informational and referral service. Primarily a telephone-based service, the Florida 2-1-1 Network is an alliance of providers certified by the Agency for Health

Care Administration that works primarily to assist individuals during times of crisis by providing both health and support services (FLAIRS, 2013; United Way of Florida, 2010). This resource works to offer informational support as a supplement to care provided at Orlando facility. Patients are able to become active participants in identifying and selecting services that best fit their needs.

The ability to identify available resources without leaving their homes is a convenient tool for patients. For patients with disabilities, particularly those with mobility, speech, or hearing problems, the availability of online information may significantly improve their quality of care by removing barriers. For example, as examined by Ferguson (1997), individuals with mobility problems are able to narrow the field of healthcare providers that can best satisfy their health needs without the burden of transportation issues.

Although some healthcare providers discussed the availability of online networks created to provide emotional, instrumental, and informational support, these providers also cited unfamiliarity with and distrust of these networks. *Ruth*, an older female medical director employed at an Orlando primary care facility explained her decision not to utilize online networks in providing care to patients:

We just don't really refer people to online sources. We don't really know what is reputable and helpful for them, so that's not something we do. Unless it's for their personal knowledge, we don't do that. I don't know how they get paid, if they take insurance, so I don't know how they would help patients.

This facility chose not to utilize online networks primarily due to unfamiliarity with them. *Jenny* cited a disparity in access to online resources among patients:

I don't know how much online support our staff are recommending to patients, sometimes we're encountering patients who have limitations or are disabled, or are of lower... have a lower type of income and they don't have the computers and the ability to do online from home. A lot of our resources that we provide to them are actually phone resources that can call and speak to somebody. Those are a little more adapted and have those types of resources than we do refer them to services that they can access online, but most of our referral basis is phone calls to community services or agencies that can provide them with care.

The concerns raised *Ruth* and *Jenny* mirrored concerns discussed in past studies of online based healthcare information. The quality and accessibility of information are difficult factors for providers to control (Diaz et al., 2002). Although providers may offer suggestions for online health resources, it is impossible for these individuals to have complete knowledge of the resources available. No single site provides the comprehensive information needed, choosing instead to either focus exclusively on a diagnosis or treatment and offering in depth information; or offering a breadth of information about a diverse set of medical conditions (Bhavanani, 2003).

### Theme 3: Concerns about Ableist Language.

Ableism can have a substantial effect on individual wellbeing. Ableist language is particularly problematic because of the extent to which it has become embedded in our everyday language, actively reinforcing the dichotomy that exists between able-bodiedness and disability. Disability metaphors reinforce these dichotomies through everyday language practices, creating a social order where persons with disabilities are placed in a subordinate role (Grue, 2011).



Ableist language plays an important role in framing disability by reifying the dichotomies between disability and able-bodiedness, where they become equivalent to normal/abnormal and desirable/undesirable dichotomies.

The third theme analyzes responses to questions concerning stigmatization through language. Participants were asked to characterize the relationship between stigmatization and patient well-being as well patient stress. Each participant responded to these questions in either two ways: Whereas some providers asked the researcher to move on to another question, others acknowledged that ableism exists but explained how they try to avoid engaging in ableist practices.

In asking to move on to another question participants cited not having information relevant to the question and the question being irrelevant to the work they do as reasons to proceed. If rephrased to address their specific roles in healthcare, participants either declined to answer again, or gave a response that fit into the second group where answers were sensitive to allegations of discrimination. The second group of responses recognized problems associated with the uses of ableist language both inside and outside of their facilities. These responses also included answers that were intended to defend the participants and their respective facilities against accusations of discrimination. These participants each offered explanations similar to *Brenda*, a middle-aged female nurse employed at an Orlando nursing home:

We... we don't discriminate in any way towards any of our patients that come in. Our staff is excellent at taking care of everyone. And... and if someone has a concern, we follow through with an investigation.

Participants who provided the second type of response immediately distanced themselves from the notion of discrimination of patients and then highlighted positive aspects of their provider-patient interactions. *Kurt*, a middle aged male physician practicing in Orlando simply responded to the question with, “I treat them the same. I treat them with the same respect,” *Debbie* supplied a similar response, stating, “Everybody gets the same treatment, everybody.”

#### Theme 4: External Sources of Patient Social Support

Throughout the interview process, participants referred to sources of support that served as next-level care following identification of patient needs. The fourth theme examines how support did not come from the providers interviewed; rather, it came from external sources either through (1) a structured hierarchy within the facility or (2) referrals to facilities specializing in the specific needs of the patient. The latter was referenced most often during the interview process. In an interview recorded in late January 2013, *Kurt* described the process of identifying his limitations as well as the limitations of the facility in caring for patients with disabilities, “You have to be able to learn where you can’t help. So if you send someone to counseling, send someone to physical you need to. Otherwise, you’re not doing justice to that patient; you’re not giving good care.”

This statement supports research that has explored causes and prevention of burnout among healthcare professionals. Burnout can be understood as a form of fatigue where members experience uncertainty about their ability to care for patients and decrease the value assigned to their work (Maslach, Jackson, & Leiter, 1996; Van Beek, Hu, Schaufeli, Taris, & Schreurs,

2012). Provider-patient relationships where a single provider is responsible for both the physical and emotional needs of the patient can increase the emotional distress of the provider. Use of external sources to meet patient needs resolves this, simultaneously increasing the quality of care to ensure the particular needs of each patient are met (Alder, 2002). Although *Kurt* did not show signs of burnout, either in terms of exhaustion or negativity towards his work, his response indicated that burnout (as well as patient care) is a reason for seeking external care for patients with disabilities.

The ability of healthcare providers to determine when additional support is needed is a valuable skill in the care and treatment of patients. When providers are able to recognize the effect a specific impairment has on the emotional well-being of a patient, or vice versa, measures can be taken to eliminate or minimize the emotional distress (Söllner et al., 2001). *Kurt* continued:

Some have opened up things, you know about their marriage or how their parents treat them, and we just encourage more conversation. And if it's an issue that needs resolving beyond the medicine, than I encourage that they really need a social network either through counseling or through church group to be able to talk these through. Some have opted to go, and go for it. Sometimes you just need to hope that they do.

In this excerpt, it is evident that recognition of provider limitations, as well as the limitations of individuals in the patient's immediate support network, requires external sources of support to be utilized in the care of patients with disabilities.

In facilities with a structure in place designed to address both the mental and physical needs of the patient, several providers mentioned effective communication between departments

to facilitate the transition of the patient and a detailing of the patient's needs. For patients with disabilities whose care surpassed the ability of the provider, the next level of care was most often assignment of a case manager. *Lisa*, a young woman employed as a nurse and case manager in a Kissimmee-based long-term care and rehabilitation facility explained the process used by case managers following the assignment of a new patient:

So if they [patients] have a good support system and they need some additional help being connected to resources, the case manager or the social worker will evaluate what those particular, specific needs for that patient are and then try to connect them with the right resources that can help them enhance care at home or their safety or whatever it is that is challenging for them at the time”.

For patients learning to cope with a new physical disability, the rehabilitation center is a place of transition. At this location, one segment of the clinical staff was responsible for treating patients, as well as helping patients learn how to complete daily tasks in ways that cater to their new disability. Beyond the basic needs of the patient, the primary staff was not responsible for the care of patients in the process of the rehabilitation.

Other typically smaller facilities did not have a staff in place to address the specific needs of patients with disabilities. *Sue*, a female director of nursing, based in Orlando, stated the following: “If we can't help them, we send them to a doctor that can.” The decision to refer a patient elsewhere was primarily based on the inability to provide informational or instrumental support. This has already been demonstrated in previous studies (e.g., Cohen & Wills, 1985; Kyngäs, 2004). Providers at this facility had the capacity to provide a degree of emotional support, such as listening and being empathetic, but did not necessarily possess the knowledge or

resources to satisfy the unique needs of patients with disabilities. In these instances, referrals were made to outside facilities using existing partnerships and connections with hospitals, counseling centers, and specialty medical facilities.

### Theme 5: Accommodation and Accessibility

The final theme addresses accommodations made by participants when interacting with patients with disabilities. Accommodation has been shown to have positive impacts on the relationship between speakers. When speakers converge, there is a bonding that can increase positive appraisal (Littlejohn & Foss, 2011). Accommodating for patients with disabilities can similarly have a positive effect on provider-patient relationships. Accommodation reflects attention to individual patient needs and a desire to ensure these needs are met (Gowland, 2011). In the interviews conducted, the majority of accommodations made for patients with disabilities were to the physical environment, specifically for the needs of persons with ambulatory impairments.

Following social cognitive theory (SCT), persons in their social environment shaped providers' perceptions of accommodation for patients with disabilities. Exposure to patients with disabilities forms the perceptions of what accommodations are necessary. Interactions involving patients with disabilities during training and residency lay the foundation for accommodation practices. Formation of these perceptions become cyclical, where students are influenced by teachers, mentors, and peers and simultaneously have the ability to affect those around them in defining when and what accommodations should be exercised (Bandura, 1986,

1997). Healthcare providers without these interactions are not forced to critically investigate how their interactions with disabled patients might require accommodation. This is particularly important for healthcare providers during residency and training as a means of guiding provider-patient interactions through their careers.

Mentors help shape the practices of young doctors and propel medical students to actively question how to best care for patients. *Ted*, a doctor of osteopathic medicine in Orlando explained his medical school experience and introduction to patients with disabilities:

But it's during the third and fourth year of medical school and then during the residency that we're exposed to real patients. To answer your question, I think it would be determined by whether they're exposed more to disabled patients during their residency.

So a doctor, MD or DO, doing a physical medicine rehab residency will have more exposure to disabled patients. Or someone who does their residency in a VA with a lot of vets who are disabled will get more exposure. Where someone who goes to an ED residency where only people that are young and healthy go, they're not getting as much exposure. I think to answer your question; it's how they're exposed during the training.

*Ted*, having done his residency in a geriatrics unit, was frequently exposed to patients with disabilities. This exposure helped him understand the accommodations to be made during various provider-patient interactions.

When asked about interactions with patients and the types of accommodations made accordingly, all providers made references to the accessibility of the facility. *Ruth* explained, "We don't really accommodate. We have handicap access entrances and rooms, but other than that there isn't a lot that we can do. We also have handicap parking." Participants repeatedly

detailed the width of doorways, number of handicap spaces, and number rooms able to fit a wheelchair as their primary method of accommodating for disability. *Sue* stated:

What I would do is I guess have my rooms more accessible, big enough so that maybe a wheel chair can fit in and things like that. Those are things that I would have. But right now I think they're big enough that one would fit, we haven't had any issues where say a disabled person can't fit in the room to get treatment.

The second most common response was a reference to patients with hearing impairments. Given approximately nine to ten percent of Americans suffer from hearing loss, most healthcare providers will need to accommodate for hearing loss during their careers (Meador & Zazove, 2005). Communication barriers caused by hearing loss allow for quality of care to become compromised and should be a significant concern. For example, individuals with hearing impairments have referenced miscommunication about appointment scheduling, misdiagnoses, and incomplete information about treatment or medication (Lezzoni, O'Day, Killeen, & Harker, 2004). This goes along with communication accommodation theory (CAT), where providers make changes to their communication behaviors in order to accommodate the needs of patients with disabilities. *Debbie* explained her experience with these interactions:

I mean you have a lot of people who are hard of hearing so you have to speak loudly.

There are certain people we have to write stuff out for and want me to speak slow. So they can understand what you're saying, a lot of times you have to repeat yourself, but that's just the way it is, right?

In this facility, specializing both in long-term care and rehabilitation, hearing loss was a common characteristic among patients who were primarily elderly. Providers made accommodations

based on the resources available in their facility. Other locations had access to interpreters on staff who were able to sign for patients. These facilities either had an interpreter on site or on call, depending on the number of patients with hearing impairments. In long-term care facilities, rehabilitation centers, and primary care offices interpreters were utilized by participants to eliminate communication barriers with patients having hearing impairments. Although some miscommunication is inevitable, the use of trained interpreters helps minimize the number of these occurrences (Flores, 2005). For example, writing information out for patients can be ineffective for patients who must also negotiate vision impairments. Creating effective communication for patients with hearing impairments requires access to tools that help satisfy the individual preferences of these patients (Lezzoni et al., 2004).

Overaccommodation is also a threat to communication. Accommodating without being reflexive of the preferences of individuals' needs can cause miscommunications. It is possible for patients to become offended when providers unnecessarily accommodate for a disability (Hummert, 2010). This mistake can create a perception that the provider is not sensitive to the needs of the patient, disrupting communication and decreasing perceptions of quality of care.

Although "disability" is used to encompass a broad range of mental and physical impairments, including mental and physical, few participants talked about interactions accommodating for patients with mental impairments. Mental illness is often more difficult to identify, perhaps a reason physical disabilities are more readily discussed (Flanagan & Davidson, 2009). The presence of caregivers during physical exams and testing was one way that central Florida providers accommodated for patients with mental impairments. *Lindsey* commented, "I remember one that came in, in particular, the guardian was there because they were afraid they



would get to scared, but she got through it okay.” The assistance of a caregiver was made available to ensure treatment was completed effectively and efficiently.

For individuals whose impairments significantly alter their daily lives, the support and assistance from a caregiver can dramatically increase the quality of life for these individuals. Caregivers may include family, friends, significant others, and hired individuals. For some individuals, caregivers are an instrumental part of the social support network, by assisting with daily tasks, relaying information and providing emotional support for patients receiving treatment.

## CHAPTER FIVE: CONCLUSION

This study has gathered new data on ableist language in the healthcare setting and the use of social support networks in addressing emotional distress among patients with disabilities. In this conclusion the researcher discusses:

- (a) A summary of the findings (and, above all, addressing all four research questions of this analysis),
- (b) Limitations of this study, and
- (c) Recommendations for future research.

### Summary of Findings

Research Question 1 (RQ1), “What is the association between ableism and U.S. disabled patients’ experience of stress and negative well-being?” was addressed in the analysis of participant accommodation for patients with disabilities. Efforts made by providers to accommodate patient needs, through communication strategies and alterations to the physical environment, were done so in order to eliminate stress and increase patient well-being. Variations among participants were primarily based on the type of facility at which they were employed. Structural issues, such as employment of persons with disabilities and physical accommodation, were potential sources of ableism within medical facilities. Participants employed at long-term care facilities identified more strategies to adapt to the individual needs of patients with disabilities in order to increase their physical and emotional well-being. Stress

caused by impairments and their barriers to healthcare was deterred by accommodating individual disabilities. Nevertheless, despite effort made by providers to accommodate patient needs, limited inquiry into the effects of ableist language allows disability metaphors to continue to go unquestioned. Failure to consider word choice risks creating a perception that patients' emotional needs are not valued. Such a void can have a negative effect on the quality of provider-patient interactions and care received.

The ease with which providers can be drawn into lawsuits actively offers an explanation for some of the avoidant responses given. In particular, the proliferation of discrimination lawsuits in healthcare is a concern for healthcare professionals. These lawsuits are made in response to violation of the Americans with Disabilities Act (ADA) and the rehabilitation act. Although the system serves as a deterrent in order to protect patients against discrimination, it may have compromised the responses given here (Sturm, 2003). The nature of healthcare is intensive and filled with potentially life threatening situations. During medical school, avoidance of lawsuits is drilled into patients, receiving greater attention than communication skills to build provider-patient communication (Newton, Barber, Clardy, Cleveland, & O'Sullivan, 2008; Patenaude, Niyonsenga, & Fafard, 2003).

While incorporation of disability studies into medical education is perceived as a distraction from more pressing concerns, it has the potential to limit the number of lawsuits by better preparing healthcare providers to care for patients with disabilities. Teaching healthcare providers about the unique needs associated with various disabilities better ensures patients are receiving high quality of care and that providers do no harm (Ferguson & Candib, 2002; Wilson, 2000). Such an analysis should begin in medical school in order to guide patient interactions

involving patients with disabilities throughout their careers. Medical school is a “socialization process” where formal training and exposure to patients with disabilities direct future interactions (Ferguson & Candib, 2002; Wright et al., 2008). However, there is a scarcity of such training in medical schools and residencies where students receive inadequate preparation about cultural issues. Despite concerns from patients, communication and disability training is limited. This is in part a consequence of perceptions that these skills are common sense and less valuable than standard medical training (Flores, Gee, & Kastner, 2000; Rees, Sheard, & McPherson, 2002).

Limited inquiry into the effect of ableist language in order to distance themselves from accusations of discrimination allows disability metaphors to continue to go unquestioned. This is problematic and can significantly affect provider-patient interactions and the quality of care received. When providers are not actively taking into account word choice, they risk creating a perception for patients that they are unconcerned with their emotional needs. Among past studies, measuring patient satisfaction within healthcare, provider-patient communication was identified as a primary area of concern. Failed communication can create misunderstanding between patients and providers, allowing for misdiagnosis and treatment. In prior studies, patients with disabilities were more likely to be unhappy with provider-patient interactions (Ferguson & Candib, 2002; Patrick, Scrivens, & Charlton, 1983). In evaluations of provider communication, patients with disabilities reported greater feelings of anxiety stemming from disrespect and insensitivity from providers (Gowland, 2011).

In regards to Research Question 2 (RQ2), “How are U.S. disabled patients less likely to experience stress thanks to social support networks?,” participants identified ways in which

social support networks are able to minimize the stress by preventing its occurrence and increasing the threshold for stress to effect the well-being of patients. This analysis followed the Stress Buffering Model in explaining how social support networks were utilized to minimize stress. Social support networks were identified by participants as important tools in assisting patients with stress caused by disability and medical treatment. Types of social support identified included family, friends, support groups, and online networks.

For Research Question 3 (RQ3) “How are U.S. disabled patients more likely to maintain a positive sense of well-being thanks to social support networks?” it is clear, drawing on the principles of the Main Effects Model, that social support networks play a pivotal role in maintaining a positive sense of well-being. Members of social support networks contributed to the well-being by accompanying patients to appointments, communicating information to providers, and providing emotional support among other strategies. Providers placed a great deal of emphasis on identifying the need for additional social support among patients and providing resources for that support. The process of identification occurred at the individual level in some facilities, where providers were responsible for making a determination based on interactions with patients and their companions. Other facilities had formal structures in place to ensure patients received the necessary care. These structures consisted primarily of case managers whose sole job was to ensure the needs of patients were being met.

In answering Research Question 4 (RQ4) “In regards to the treatment of U.S. disabled patients, what is the difference between traditional support networks and online support networks?” participants described online support networks as sources to be used mainly for obtaining additional informational support. Online sources referred to by participants varied

from company websites to state databases. Participants expressed doubts about online resources in terms of accessibility to patients and the quality of the sources. A reason for these doubts about online support is likely to be related to the participants selected in this study. A majority of participants work in long-term care facilities that cater to elderly patients. Additionally, participants agreed on the value of traditional support networks and showed a preference for these in addressing the emotional and instrumental needs of patients. Patients' traditional support systems played a role in medical visits by assisting patients with disabilities in communicating with doctors and other tasks where necessary. For those lacking a support system, participants made efforts to connect patients with resources such as community counseling and support groups.

Although a great percentage of the populace has access to computers and the internet, accessibility remains a problem for large segments of the population. Individuals without access or with limited access to computers and the internet are disproportionately minority populations and individuals with a lower socioeconomic status. Income and professions that allow computer access can each contribute to the digital divide along socioeconomic lines. Income directly affects individuals' ability to access online information. Individuals employed in an office setting are likely able to access information regardless of internet access in their home. In contrast, individuals in blue-collar professions or those who are unemployed do not have the same access outside of their homes (Brodie et al., 2000; Norris, 2003). The digital divide may deter healthcare providers from referring patients to online resources and may contribute to its underutilization among provider interviewed.

Another dividing factor among internet use is age. While approximately one in three adults under sixty utilizes the internet to access health information, only one in ten adults over the age sixty uses the internet for the same purpose (Brodie et al., 2000; Hargittai, 2002). Given that the majority of participants were employed in long-term care facilities and whose patients were primarily elderly, it is likely that this affected responses given. For individuals less accustomed to internet use and with access to constant care, the ability to obtain healthcare information online may not have the same benefits as individuals living independently.

The primary consensus among participants was to provide patients with online networks as sources of informational support. This information served as a supplement to the information and care given by the healthcare providers interviewed. As reflected in the interviews conducted with the participants, simply providing informational support has a positive effect on provider-patient interactions and perceptions of the quality of care. Prior research has shown that information, such as how to identify symptoms, finances, and psychosocial issues tied to the patient's condition, influence patients with disabilities' perceptions of quality of life (Larson, Nelson Gustafson, & Batalden, 1996).

All in all, the findings of this study broaden our knowledge of both of ableism and social support networks in the healthcare setting. They suggest that incorporation of disability studies is a necessary part of clinical training in order to prepare healthcare providers for the diversity of provider-patient interactions and increase sensitivity toward ableism in the healthcare setting. These actions will serve to create more effective provider-patient communication and increase the quality of care made available to patients with disabilities by addressing both their physical and emotional needs.

### Limitations

Three limitations arose in the process of conducting this study. First, although the researcher was able to obtain ten valuable interviews, the use of healthcare providers only (as opposed to including disabled patients as well) may not be sufficient. Fear of violating the Health Information Portability and Accountability Act (HIPAA) deterred numerous individuals from taking part in this study and limited the accounts offered by those providers who agreed to participate. There is a possibility that this caused some participants to modify their accounts to better highlight their work as well as avert implications of discrimination at their facility. The quality of data obtained somewhat inhibited the researcher's ability to thoroughly answer some of the research questions proposed, specifically research questions one and two dealing with the effects on patient well-being and stress. However, the alternative of interviewing patients with disabilities would have been difficult to complete. Access to patients would be limited due to privacy concerns and the inclusion of a protected class would place this study under additional institutional review, requiring additional time for its completion. Despite this limitation, use of healthcare providers generated new research that has thus far been lacking.

The second limitation deals with time constraints both on the part of participants and the researcher. Each of the participants worked time-intensive positions that allowed for few interruptions to their daily responsibilities. The brief window of time allocated to data collection required that interviews be scheduled at the earliest convenience of the participant. Scheduling interviews that were convenient for participants and fit within the timeline of this study was a



challenging task. As a result of these constraints and at the request of participants, interviews were conducted at places where interruptions from colleagues and patients were allowed. These constraints had the potential to impact the quality of findings by shortening the participants' responses and creating distractions to the interview process. Given additional time to complete this study, participants with fewer time constraints could have been located in order to gather data without potential damage to the quality of the findings.

The final limitation concerns the use of face-to-face qualitative interviewing. As detailed above, with qualitative interviewing, there is opportunity for participants to alter responses in order to highlight more desirable aspects of their work. Not all interviews produced ample information relevant to the research questions proposed. In a similar vein, it is possible for the researcher to have misinterpreted the content of the interviews. Even following full audio recording, detailed transcribing, and repeated examination of transcripts, it is possible for human error to occur. Although every effort was made to minimize these concerns, it is impossible to completely eliminate the chance for error.

### Future Research

For future research, it may prove valuable to investigate cultural aspects of ableism, such as the extent to which ableism is found in various cultures. For example, a concern in this study is the use of disability metaphors in daily language practices (Gent, 2010). Future research exploring whether similar metaphors are present in other languages and the types of metaphors

used would be valuable. Such a study would help create an understanding of how ableism is allowed to persist in both the U.S. mainstream culture and other cultures.

It would also be interesting to study cultural aspects of social support networks. For example, among Latino populations, extended family bonds are often as strong as those to immediate family members. Prior research has shown that, among Latino families, it is viewed as the family responsibility to remain the primary caregivers and source of social support (Guarnaccia, Parra, Deschamps, Milstein, & Argiles, 1992). An exploration of how various cultural groups perceive responsibilities of social support with the growth in online support access could further aid healthcare professionals in detailing a specific plan of action for patients in their care.

Finally, a thorough investigation of communication and diversity training received in medical school and residencies may prove interesting. More information regarding patient-provider differences (as far as what is expected from interactions) is needed in order to increase patient satisfaction with care. Patient evaluation of quality of care is difficult to obtain. The insertion of patients with disabilities makes the process more difficult, particularly if there is an impairment that directly affects communication, such as hearing or speaking impairments (Gowland, 2011). Although similar studies have occurred in terms of general communication skills and ethnic minorities, little is known about training specific to the needs of patients with disabilities (Rees et al., 2002). Such an investigation would go hand-in-hand with the present study to highlight areas of growth for within the healthcare field.

It is the researcher's hope that this analysis of ableism and social support networks in the healthcare setting has informed both laypersons and academics. It is the researcher's anticipation

that accommodation and social support networks will continue to be valuable tools in patient-provider interactions regardless of disability status.

## **APPENDIX A: CONSENT PROCESS**



**PROJECT TITLE:** The Effects of Social Support Networks on U.S. Disabled Patients Discriminated by Ableist Language

**PRINCIPAL INVESTIGATOR:** Darcey McCampbell, Graduate Student, Nicholson School of Communication at the University of Central Florida, 651-270-1942, [dmccamp1@knights.ucf.edu](mailto:dmccamp1@knights.ucf.edu)

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## EXPLANATION OF RESEARCH

### Purpose of the Research Study

The objective of this study is to analyze the effects of social support networks on U.S. disabled patients who have been discriminated by ableist language. Ten to fifteen healthcare practitioners at nursing homes in the Central Florida area will be interviewed. They will be interviewed in a private room at their workplace or at any other place outside their work that is convenient to them (e.g., coffee shop or library). The method of in-depth, face-to-face qualitative interviewing will be used.

### Procedures

If you agree to be in this study, you will be asked to do the following things. I will use the method of qualitative interviewing. I will ask you to answer general questions about social support networks for U.S. disabled patients discriminated by ableist language. The interview will last 45-60 minutes. An audio-tape recorder will be used to record the interview because I need to transcribe the information that you will give me. Your name will NOT be mentioned. Your department and job title will NOT be mentioned either. Your participation is confidential. You can use a nickname or pseudonym.

### Confidentiality

The records of this study will be kept private. Participants will use pseudonyms. In published reports, there will be no information included that will make it possible to identify the research participant. Research records will be stored securely. I will store the transcriptions of the data and keep these transcriptions safe by locking them into a program file that can only be opened with a password. I will keep the audio-tapes in a private room that has a safe. I will destroy the audio-tapes as soon as I transcribe all the information recorded on those tapes. Only approved researchers (i.e., my thesis advisor) will have access to the records. When the tape recordings are made, only my advisor will have access to them. He will use them for educational purposes.

### Audio Taping of Study Activities

To assist with accurate recording of participant responses, interviews may be recorded on an audio recording device. Participants have the right to refuse to allow such taping without penalty.

### Contacts and Questions

The researcher(s) conducting this study can be contacted at 651-270-1942 or [dmccamp1@knights.ucf.edu](mailto:dmccamp1@knights.ucf.edu) (for Darcey McCampbell, the principal investigator) and (407) 708-2830 or [Jonathan.Matusitz@ucf.edu](mailto:Jonathan.Matusitz@ucf.edu) (for Dr. Jonathan Matusitz, the faculty sponsor). You are encouraged to contact the researcher(s) if you have any questions.

IRB contact about your rights in the study or to report a complaint: Research at the University of Central Florida involving human participants is carried out under the oversight of the Institutional Review Board (UCF IRB). This research has been reviewed and approved by the IRB. For information about the rights of people who take part in research, please contact: Institutional Review Board, University of Central Florida, Office of Research & Commercialization, 12201 Research Parkway, Suite 501, Orlando, FL 32826-3246 or by telephone at (407) 823-2901.

## **APPENDIX B: INTERVIEW PROTOCOL**

- (1) Please describe a typical interaction with disabled patients.
- (2) How do you characterize the relationship between stigmatization through language and disabled patients' experience of stress?
- (3) How do you describe the relationship between stigmatization through language and disabled patients' negative well-being?
- (4) In what ways are social support networks a good strategy for managing disabled patients' stress resulting from discrimination through language?
- (5) How important are traditional support networks for disabled patients?
- (6) How important are online support networks for disabled patients?
- (7) Can you compare the main (dis)advantages of traditional support networks vis-à-vis online support networks?
- (8) When interacting with disabled patients, in what ways do you need to accommodate your language or behavior?
- (9) In what ways do your interactions with disabled patients differ from other patients in general?
- (10) Do you have anything else to add?



## **APPENDIX C: IRB APPROVAL LETTER**



University of Central Florida Institutional Review Board  
Office of Research & Commercialization  
12201 Research Parkway, Suite 501  
Orlando, Florida 32826-3246  
Telephone: 407-823-2901 or 407-882-2276  
[www.research.ucf.edu/compliance/irb.html](http://www.research.ucf.edu/compliance/irb.html)

### Approval of Exempt Human Research

From: **UCF Institutional Review Board #1  
FWA00000351, IRB00001138**  
To: **Darcey K. McCampbell**  
Date: **February 22, 2013**

Dear Researcher:

On 2/22/2013, the IRB approved the following activity as human participant research that is exempt from regulation:

Type of Review: Exempt Determination  
Project Title: The Effects of Social Support Networks on U.S. Disabled  
Patients Discriminated by Ableist Language  
Investigator: Darcey K. McCampbell  
IRB Number: SBE-13-09115  
Funding Agency:  
Grant Title:  
Research ID: N/A

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request in iRIS so that IRB records will be accurate.

In the conduct of this research, you are responsible to follow the requirements of the Investigator Manual.

On behalf of Sophia Dziegielewski, Ph.D., L.C.S.W., UCF IRB Chair, this letter is signed by:

Signature applied by Joanne Muratori on 02/22/2013 10:47:54 AM EST

IRB Coordinator

## **APPENDIX D: SAMPLE DEFENSE ANNOUNCEMENT**

Announcing the Final Examination of Ms. Darcey K. McCampbell for the degree of Master of Arts in Communication.

Date: TBD

Time: TBD

Room: COM 161

Title: Provider Perceptions of Ableism and Social Support Networks in the Healthcare Setting

The objective of this study is to investigate ableism and social support networks in the healthcare setting. Social support networks play an important role in combating emotional distress in healthcare. They provide disabled patients a method for defending against the negative effects of ableism among other stressors. By definition, ableism refers to perceptions that disability is abnormal and undesirable. Ten healthcare providers in central Florida (i.e., in nursing homes, rehabilitation centers, and primary care offices) were interviewed, using in-depth face-to-face qualitative interviewing. Participants were asked questions relating to the effects of ableist language on patients with disabilities as well as the role of social support networks in combating related stress. Throughout the process of data analysis, five major themes arose as most relevant to the research questions proposed: (1) Traditional Social Support, (2) Online Networks as a Source of Informational Support, (3) Concerns about Ableist Language, (4) External Sources of Patient Social Support, and (5) Accommodation and Accessibility.

Results indicated a strong preference for traditional social support, as opposed to online support. Traditional social support is offered through accommodation of caregivers, availability of social workers, and creation of support groups. Benefits of online support networks are viewed mainly in terms of fulfilling the informational needs of patients with disabilities. Additionally, while some accommodations for patients with disabilities were described, these dealt primarily with alterations to the physical environment. Results showed a lack of attention paid to ableism in the healthcare field, particularly instances occurring in communication practices. Overall, there is room for improvement in the healthcare field concerning accommodations for patients with disabilities.

Committee Members:

Dr. Jonathan Matusitz (Chair)

Dr. Lindsay Neuberger

Dr. Jennifer Sandoval

The public is welcome to attend

## REFERENCES

- Adler, H. M. (2002). The sociophysiology of caring in the doctor-patient relationship. *Journal of General Internal Medicine, 17*(11), 883-890.
- Anderson, S. M., & Chen, S. (2002). The relational self: An interpersonal social-cognitive theory. *Psychological Review, 109*(4), 619-645.
- Atkinson, R. (1998). *The life story interview*. Thousand Oaks, CA: Sage.
- Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. Englewood Cliffs, NJ: Prentice-Hall.
- Bandura, A. (1997). *Self-efficacy: The exercise of control*. New York: W.H. Freeman.
- Bandura, A. (2001). Social cognitive theory of mass communication. *Media Psychology, 3*, 265-299
- Bandura, A. (2004). Health promotion by social cognitive means. *Health Education & Behavior, 31*(2), 143-164.
- Ben-Moshe, L. (2005). "Lame idea:" Disabling language in the classroom. In L. Ben-Moshe, R. C. Cory, M. Feldbaum, & K. Sagendorf (Eds.), *Building pedagogical curb cuts: Incorporating disability into the university classroom and curriculum* (pp. 107-116). Syracuse, NY: Syracuse University Press.
- Bhavnani, S. K. (2003). The distribution of online healthcare information: A case study on melanoma. *American Medical Informatics Association, 81-85*.
- Birenbaum, A. (1992). Courtesy stigma revisited. *Mental Retardation, 30*(5), 265-268.

- Braithwaite, D., Waldron, V., & Finn, J. (1999). Communication of social support in computer mediated groups for people with disabilities. *Health Communication, 11*, 123-151.
- Brenner, M., Brown, J., & Canter, D. (1985). *The research interview: Uses and approaches*. New York: Academic Press.
- Brodie, M., Flournoy, R. E., Altman, D. E., Blendon, R. J., Benson, J. M., & Rosenbaum, M. D. (2000). Health information, the internet, and the digital divide. *Health Affairs, 19*(6), 255-265.
- Brohan, E., Slade, M., Clement, S., & Thornicroft, G. (2010). Experiences of mental illness stigma, prejudice and discrimination: A review of resources. *BioMed central health services research, 10*, 1-11.
- Brown, L. S. (2008). Living with disabilities in the context of trauma. In the American Psychological Association (Ed.), *Cultural competence in trauma therapy: Beyond the flashback* (pp. 181-196). Washington, D.C.: American Psychological Association.
- Buller, D. B., & Aune, R. K. (1988). The effects of vocalics and nonverbal sensitivity on compliance: A speech accommodation theory explanation. *Human Communication Research, 14*, 301-332.
- Buller, D. B., & Aune, R. K. (1992). The effects of speech rate similarity on compliance: Application of communication accommodation theory. *Western Journal of Communication, 56*, 37-53.
- Byrne, P. (1997). Psychiatric stigma: Past, passing and to come. *Journal of the royal society of medicine, 90*, 618-621.

- Campbell, F. K. (2001). Inciting legal fictions: Disability's date with ontology and the ableist body of the law. *Griffith Law Review*, 10, 42-62.
- Campbell, F. K. (2008). Refusing able(ness): A preliminary conversation about ableism. *M/C Journal*, 11(3).
- Carson, A. R., & Voorhees, H. K. (2001). Adult pediatric patients. *American Journal of Nursing*, 101, 46-55.
- Castañeda, C.R., Hopkins, L.D. & Peters, M.L. (2010). Ableism: Introduction. In M. Adams, W.J. Blumenfeld, C.R. Castañeda, H.W. Hackman, M.L. Peters, & X. Zúñiga (Eds.), *Readings for diversity and social justice* (pp. 457-463). New York: Routledge Press.
- Census Bureau (2012). *Americans with disabilities: 2010*. Washington, D.C.: Census Bureau.
- Cherney, J. L. (2011). The rhetoric of ableism. *Disability Studies Quarterly*, 31(3).
- Cohen, S., & Wills, T. A. (1985). Stress, social support, and buffering hypothesis. *Psychology Bulletin*, 98(2), 310-357.
- Corrigan, P. & Kleinlein, P. (2005). The impact of mental illness stigma. In P. Corrigan (Ed.), *On the stigma of mental illness: Practical strategies for research and social change* (pp. 11-44). Washington, D.C.: American Psychological Association.
- Coursaris, C. K., & Liu, M. (2009). An analysis of social support exchanges in online HIV/AIDS self-help groups. *Computers in Human Behavior*, 25(4), 911-918.
- Covey, H. (1998). *Social perceptions of people with disabilities in history*. Springfield, IL: Charles Thomas.
- Davis, L. (2002). *Bending over backwards: Disability, dismodernism, and other difficult positions*. New York: New York University Press.

- Denzin, N. K., & Lincoln, Y. S. (1998). Introduction: Entering the field of qualitative research. In N. K. Denzin, & Y. S. Lincoln (Eds.), *The landscape of qualitative research: Theories and issues* (pp. 1-34). Thousand Oaks, CA: Sage.
- Denzin, N. K., & Lincoln, Y. S. (2003). Introduction: The discipline and practice of qualitative research. In N. K. Denzin, & Y. S. Lincoln (Eds.), *The landscape of qualitative research* (pp. 1-45). Thousand Oaks, CA: Sage.
- Diaz, J. A., Griffith, R. A., Ng, J. J., Reinert, S. E., Friedmann, P. D., & Moulton, A. W. (2002). Patients' use of the internet for medical information. *Journal of Internal Medicine*, *17*(3), 180-185.
- Dunbar-Jacob, J., Erlen, J. A., Schlenk, E. A., Ryan, C. M., Sereika, S. M., & Doswell, W. M. (2000). Adherence in chronic disease. *Annual Review of Nursing Research*, *18*, 48-90.
- Eysenbach, G., Powell, J., Englesakis, M., Rizo, C., & Stern, A. (2004). Health-related virtual communities and electronic support groups: Systematic review of the effects of online peer-to-peer interactions. *British Medical Journal*, *328*, 1166-1170.
- Falk, G. (2001). *Stigma: How we treat outsiders*. New York: Prometheus Books.
- Ferguson, T. (1997). Health care in cyberspace: Patients lead a revolution. *Futurist*, *31*(5), 29-34.
- Ferguson, T. (2000). Online patient-helpers and physicians working together: A new partnership for high quality health care. *BioMedical Journal*, *321*(7269), 1129-1132.
- Ferguson, W. J. & Candib, L. M. (2002). Culture, language, and the doctor-patient relationship. *Family Medicine and Community Health*, *34*(5), 353-362.
- Ferri, B., & May, V. (2005). Fixated on ability: Ableist metaphors in feminist theories of resistance. *Prose Studies*, *27*(2), 120-140.



- Finn, J. (1995). Computer-based self-help groups: A new resource to supplement support groups. *Social Work with Groups, 18*, 109-117.
- Flanagan, E. H., & Davidson, L. (2009). Passing for “normal:” Features that affect the community inclusion of people with mental illness. *Psychiatric Rehabilitation Journal, 33*(1), 18-25.
- Flores, G. (2005). The impact of medical interpreter services on the quality of health care: A systematic review. *Medical Care Research and Review, 62*(3), 255-299.
- Flores, G., Gee, D., Kastner, B. (2000). The teaching of cultural issues in U.S. and Canadian medical schools. *Academic Medicine, 75*(5), 451-455.
- Florida Alliance of Information and Referral Service (2013). *Florida 2-1-1 Network*. Fort Meyers, FL.
- Fogel, J., Albert, S. M., Schnabel, F., Ditkoff, B. A., & Neugut, A. I. (2002). Internet use and social support in women with breast cancer. *Health Psychology, 21*, 398-404.
- Galinsky, M. J., Schopler, J. H., & Abell, M. D. (1997) Connecting group members through telephone and computer groups. *Health and Social Work, 22*, 181-188.
- Gent, P. (2010). Service-learning and the culture of ableism. In T. Stewart & N. Webster (Eds.), *Problematizing service-learning: Critical reflections for development and action* (pp. 223-244). Charlotte: Information Age Publishing
- Giles, H., Fortman, J., Dailey, R. M., Barker, V., Hajek, C., Anderson, M. C., & Rule, N. O. (2006). Communication accommodation: Law enforcement and the public. In R. Dailey & B. A. Le Poire (Eds.), *Applied interpersonal communication matters: Family, health & community relations* (pp. 241-269). New York: Peter Lang Publishing.

- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New York: Prentice-Hall.
- Golledge, R. (1991). Special populations in contemporary urban areas. In J. Hart (Ed.), *Our changing cities* (pp. 146-169). Baltimore: Johns Hopkins University Press.
- Golledge, R. (1993). Geography and the disabled: A survey with special reference to vision impaired and blind populations. *Transactions of the Institute of British Geographers*, 18(1), 63-85.
- Gowland, S. (2011). Enabling people to give feedback about their healthcare. *Learning Disability Practice*, 14(8), 32-36.
- Grue, J. (2011). Discourse analysis and disability: Some topics and issues. *Discourse & Society*, 22(5), 532-546.
- Guarnaccia, P. J., Parra, P., Deschamps, A., Milstein, G., & Argiles, N. (1992). Si Dios quiere: Hispanic families' experiences of caring for seriously mental ill family member. *Cultural, Medicine, and Psychiatry*, 16, 187-215.
- Haber, M. G, Cohen, J. L, Lucas, T., & Baltes, B. B. (2007). The relationship between self-reported received and perceived social support: A meta-analytical review. *American Journal of Community Psychology*, 39, 133-144.
- Hargittai, E. (2002). Second-level digital divide: Differences in people's online skills. *First Monday*, 7(4).
- Harpur, P. (2009). Sexism and racism, why not ableism? Calling for a cultural shift in the approach to disability discrimination. *Alternative Law Journal*, 34(3), 163-167.

- Harpur, P. (2011). Time to be heard: How advocates can use the convention on the rights of persons with disabilities to drive change. *Valparaiso University Law Review*, 45(3) 1271-1296
- Harrison, O. (2004). As disability is emerging globally, so is advocacy for full participation for people with disabilities. *Access New England*, 9(1), p. 1.
- Hastings, S. O. (2009). Embarrassing E-mails in organizations exploring online embarrassment and identity management. *Journal of Creative Communication*, 4(1), 33-43.
- Hehir, T. (2005). *New directions in special education: Eliminating ableism in policy and practice*. Cambridge: Harvard Education Press.
- Hoosain, R. (1986). Language, orthography and cognitive processes: Chinese perspectives for the Sapir-Whorf hypothesis. *International Journal of Behavioral Development*, 9(4), 507-525.
- Hummert, M. L. (2010). Age group identity, age stereotypes, and communication in a life span context. In H. Giles, S. Reid, & J. Harwood (Eds.), *The dynamics of intergroup communication* (pp. 41-52). New York: Peter Lang Publishing.
- Jimenez, M. (1987). *Changing faces of madness: Early American attitudes and treatment of the insane*. London: Brandeis University Press.
- Jones, C. P. (1987). Stigma: Tattooing and branding in Graeco-Roman Antiquity. *The Journal of Roman Studies*, 77, 139-155.
- Katz, E. (1959). Mass communication research and the study of culture. *Studies in Public Communication*, 2, 1-6.

- Katz, E. (1987). Communication research since Lazarsfeld. *Public Opinion Quarterly*, 51, 525-545.
- King, N., & Horrocks, C. (2010). *Interviews in qualitative research*. Thousand Oaks, CA: Sage.
- Kitchin, R. (2000). The researched opinions on research: Disabled people and disability research, *Disability & Geography*, 15(1), 25-47.
- Kuzel, A. J., & Like, R. C. (1991). Standards of trustworthiness for qualitative studies in primary care. In P. G. Norton, M. Stewart, F. Tudiver, M. J. Bass, & E. V. Dunn (Eds.), *Primary care research: Traditional and innovative approaches* (pp. 138-158). Newbury Park, CA: Sage.
- Kyngäs, H. (2004). Support network of adolescents with chronic disease: Adolescents' perspective. *Nursing and Health Sciences*, 6, 287-293.
- Kyngäs, H., & Rissanen, M. (2001). Support a crucial predictor of good compliance of adolescents with a chronic disease. *Journal of Clinical Nursing*, 10, 767-773.
- Labov, W., & Waletzky, J. (1967). Narrative analysis: Oral versions of personal experience. In J. Helm (Ed.), *Essays on the verbal and visual arts* (pp. 12-34). Seattle: University of Washington Press.
- Lakey, B. & Cronin, A. (2008). Low social support and major depression: Research, theory and methodological issues. In K. S. Dobson & D. Dozois (Eds.), *Risk factors for depression* (pp. 385-408). San Diego: Academic Press.
- Lakey, B. & Orehek, E. (2011). Relation regulation theory: A new approach to explain the link between perceived social support and mental health. *Psychological Review*, 118(3), 482-495.

- Larson, C. O., Nelson, E. C., Gustafson, D., & Batalden, P. B. (1996). The relationship between meeting patients' information needs and their satisfaction with hospital care and general health status outcomes. *International Journal for Quality in Health Care*, 8(5), 447-456.
- Lezzoni, L. I., O'Day, B. L., Killeen, M., & Harker, H. (2004). Communicating about health care: Observations from persons are deaf or hard of hearing. *Annual Internal Medicine*, 140(5), 356-362.
- Link, B. G., Stuenkel, E. L., Neese-Todd, S., Asmussen, S., & Phelan, J. C. (2001, December). Stigma as a barrier to recovery: The consequences of stigma for the self-esteem of people with mental illnesses. *Psychiatric services*, 52(12), 1621-1626.
- Linton, S. (1998). *Claiming disability: Knowledge and identity*. New York: New York University Press.
- Littlejohn, S. W., & Foss, K. A. (2011). The conversation. In S. W. Littlejohn & K. A. Foss (Eds.), *Theories of human communication* (pp. 179-228). Long Grove, IL: Waveland Press.
- Lofland, J., & Lofland, L. H. (1995). *Analyzing social settings: A guide to qualitative observation and analysis*. Belmont, CA: Wadsworth Publishing.
- Lutz, C. J., & Lakey, B. (2001). How people make support judgments: Individual differences in the traits used to infer supportiveness in others. *Journal of Personality and Social Psychology*, 81(6), 1070-1079.
- Madara, E. J. (1997). The mutual-aid self-help online revolution. *Social Policy*, 27, 20-26.
- Maslach, C., Jackson, S. E., & Leiter, M. P. (1996). *MBI: The Maslach Burnout Inventory: Manual*. Palo Alto, CA: Consulting Psychologists Press.

- May, V. M., & Ferri, B. A. (2005). Fixated on ability. *Prose Studies: History, Theory, Criticism*, 27(1), 120-140.
- McClintock, M. (2002). How to interrupt oppressive behavior. In M. Adams (Ed.), *Readings for diversity and social justice* (pp. 483-485). New York: Routledge.
- McWhorter, J. (2001). *Losing the race: Self-sabotage in black America*. New York: Harper Perennial.
- Meador, H. E. & Zazove, P. (2005). Health care interactions with deaf culture. *Journal of the American Board of Family Medicine*, 18(3), 218-222.
- Mears, C. L. (2009). *Interviewing for education and social science research: The gateway approach*. New York: Palgrave Macmillan.
- Monnier, J., Laken, M., & Carter, C. L. (2002). Patient and caregiver interest in internet-based cancer services. *Cancer Practice*, 10, 305-310.
- Myers, C., & Bersani, Jr., H. (2008). Ten quick ways to analyze children's books for ableism. *Rethinking Schools*, 23(2).
- Newton, B. W, Barber, L, Clardy, J., Cleveland, E., & O'Sullivan, P. (2008). Is there hardening of the heart during medical school? *Academic Medicine*, 83(3), 244-249.
- Norris, P. (2003). *Digital divide: Civic engagement, information poverty, and the Internet worldwide*. Cambridge: Cambridge University Press.
- Owen, W. F. (1984). Interpretive themes in relational communication. *Quarterly Journal of Speech*, 70, 274-287.

- Patenaude, J., Niyonsenga, T., & Fafard, D. (2003). Changes in students moral development during medical school: A cohort study. *Journal of the Canadian Medical Association, 168*(7), 840-844.
- Patrick, D. L., Scrivens, E., & Charlton, J. R. H. (1983). Disability and patient satisfaction with medical care. *Medical Care, 21*(11), 1062-1075.
- Pew Internet & American Life Project (2005). *Trends*. Washington, D.C.: Pew Internet & American Life Project.
- Rains, S.A. & Keating, D.M. (2011). The social dimension of blogging about health: Health blogging, social support and wellbeing. *Communication Monographs, 78*(4) 511-534.
- Rasinski, K. A., Viechnicki, P., & O’Muircheartaigh, C. (2005). Methods for studying stigma and mental illness. In P. W. Corrigan (Ed.), *On the stigma of mental illness: Practical strategies for research and social change* (pp. 45-66). Washington, D.C.: American Psychological Association.
- Rees, C., Sheard, C., & McPherson, A. C. (2002). A qualitative study to explore undergraduate medical students’ attitudes towards communication skills learning. *Medical Teacher, 24*, 289-293.
- Reiheld, A. (2010). Patient complains of... How medicalization mediates power and justice. *International Journal of Feminist Approaches to Bioethics, 3*(1), 72-98.
- Richardson, M. (1994). The impact of the Americans with Disabilities Act on employment opportunity for people with disabilities. *Annual Review of Public Health, 15*(1), 91-105.
- Riessman, C. K. (1993). *Narrative analysis*. Thousand Oaks, CA: Sage.

- Riley, C.A. (2005). *Disability & the media: Prescriptions for change*. Lebanon, NH: University Press of New England.
- Rook, K.S. (1987). Social support versus companionship: Effects on life stress, loneliness, and evaluations by others. *The Journal of Personality and Social Psychology*, 52(6), 1132-1147.
- Rose, D. (2008). Madness strikes back. *Journal of Community & Applied Social Psychology*, 18, 638-644.
- Roulston, K. J. (2010). *Reflective interviewing: A guide to theory and practice*. Thousand Oaks, CA: Sage.
- Rubin, A. M. (2002). Media uses and effects: A uses and gratifications perspective. In J. Bryant & D. Zillmann (Eds.), *Media effects: Advances in theory and research* (pp. 525-544). Hillsdale, NJ: Lawrence Erlbaum.
- Rubin, H., & Rubin, I. (1995). *Qualitative interviewing: The art of hearing data*. Thousand Oaks, CA: Sage.
- Ruggiero, T.E. (2000). Uses and gratifications theory in the 21<sup>st</sup> century. *Mass Communication & Society*, 3(1), 3-37.
- Sanders, C. E., Field, T. M., Diego, M., & Kaplan, M. (2000). The relationship of internet use to depression and social isolation among adolescents. *Adolescence*, 35, 237-242.
- Sapir, E. (1929). The status of linguistics as a science. *Language*, 5.
- Sayce, L. (2000). *From psychiatric patient to citizen: Overcoming discrimination and social exclusion*. New York: Macmillan.
- Schwandt, T. A. (2001). *Dictionary of qualitative inquiry*. Thousand Oaks, CA: Sage.



- Shelton, M. & Matthews, C. (2001). Extending the diversity agenda in forensics: Invisible disabilities and beyond. *Argumentation & Advocacy*, 38(2), 121-130.
- Silverman, D. (1993). *Interpreting qualitative data: Methods for analyzing talk, text, and interaction*. Thousand Oaks, CA: Sage.
- Söllner, W., Devries, A., Steixner, E., Lukas, P., Sprinzl, G., Rumpold, G., & Maislinger, S. (2001). How successful are oncologists in identifying patient distress, perceived social support, and need or psychosocial counseling? *British Journal of Cancer*, 84(2), 179-185.
- Sturm, R. (2003). Increases in clinically severe obesity in the United States, 1986-2000. *Archive of Internal Medicine*, 163(18), 2146-2148.
- Tajfel, H. (1978). *Differentiation between social groups*. London: Academic Press.
- Tajfel, H. (1981). *Human groups and social categories: Studies in social psychology*. New York: Cambridge University Press.
- Tardy, R.W., & Hale, C.L (2008). Bonding and cracking: The role of informal interpersonal networks in health care decision making. In L. Lederman (Ed.) *Beyond these walls: Readings in health communication* (pp. 219-234). New York: Oxford University Press.
- Tomes, N. (2006). The patient as a policy factor: A historical case study of the consumer/survivor movements in mental health. *Health affairs*, 25(3), 720-729.
- Turner, J. W., Grube, A., & Meyers, J. (2001). Developing an optimal match within online communities: An exploration of CMC support communities and traditional support. *Journal of Communication*, 51, 231-251.
- United Way of Florida. (2010). *Florida 2-1-1 Network*. Tallahassee, FL.

- U.S. Department of Justice. (1999). *ADA Legal Documents: Public Law 101-336*. Washington, D.C.: U.S. Department of Justice.
- Van Beek, I., Hu, Q., Schaufeli, W. B., Taris, T. W., & Schreurs, B. H. J. (2012). For fun, love, or money: What drives workaholic, engaged, and burned-out employees at work? *Applied Psychology, 61*(1), 30-55.
- Van Brakel, W.H., Anderson, A.M, Mutatkar, Bakirtzief, Z., Nicholls, P.G., Raju, M.S., Das-Pattanayak, R.K. (2006). The participation scale: Measuring a key concept in public health. *Disability and Rehabilitation, 28*, 193-203.
- Vayreda, A., & Antaki, C. (2009). Social support and unsolicited advice in a bipolar disorder online forum. *Qualitative Health Research, 19*(7), 931-942.
- Wendell, S. (2010). The social construction of disability. In M. Adams, W. J. Blumenfeld, C. R. Castañeda, H. W. Hackman, M. L. Peters, & X. Zúñiga (Eds.), *Readings for diversity and social justice* (pp. 477-481). New York: Routledge Press.
- Wengraf, T. (2001). *Qualitative research interviewing: Semi-structured, biographical and narrative methods*. Thousand Oaks, CA: Sage.
- White, M. & Dorman, S.M. (2001). Receiving social support online: implications for health education. *Health Education Research, 16*(6) 693-707.
- Whorf, B. L. (1942). Language mind and reality. *The Theosophist, 63*(1), 281-291.
- Wilson, J. C. (2000). Making disability visible: How disability studies might transform the medical and science writing classroom. *Technical Communication Quarterly, 9*(2), 149-161.

- Wimmer, R. D., & Dominick, J. R. (1994). *Mass media research: An introduction*. Belmont, CA: Wadsworth.
- Winzelberg, A. (1997). The analysis of an electronic support group for individuals with eating disorder. *Computer in Human Behavior*, 13, 393-407.
- Wolbring, G. (2003). Science and technology and the triple D (disease, disability, defect). In M. C. Roco & W. S. Bainbridge (Eds.), *Converging technologies for improving human performance: Nanotechnology, biotechnology, information technology and cognitive science* (pp. 232-243). Dordrecht, The Netherlands: Kluwer Academic Publishers.
- Wolbring, G. (2008a). Human enhancement through the ableism lens. *International Journal of Applied Ethics*, 3.
- Wolbring, G. (2008b). The politics of ableism. *Development*, 51, 252-258.
- World Health Organization. (2005). *Mental health declaration for Europe*. Copenhagen: World Health Organization.
- World Health Organization (2012). *Disabilities*. Geneva, Switzerland: World Health Organization.
- Wright, K. (2000). Computer-mediated social support, older adults and coping. *Journal of Communication*, 50, 100-119.
- Wright, K. B., Sparks, L., & O'Hair, H. D. (2008). *Health communication in the 21<sup>st</sup> century*. Malden, MA: Blackwell.
- Young, I. M. (2001). Foreword. In M. Corker & T. Shakespeare (Eds.), *Disability/postmodernity: Embodying disability theory* (pp. xii-xiv). New York: Continuum.

Zoffel, N. A. (2007). *Accounting for student voice within critical communication pedagogy: An ethnomethodological exploration of student perceptions and expectations* (Unpublished doctoral dissertation). Bowling Green State University.