

MANAGEMENT OF PRIVACY BOUNDARIES FOR PEOPLE WITH VISIBLE
DISABILITIES

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Introduction

If a stranger asked someone who used a wheelchair why they had to use a wheelchair, the person could answer in several ways. What they would have a difficult time doing, however, is denying that they use a wheelchair. Something that many Americans consider private, such as a health condition (Petronio, 2002), is visibly obvious. The tension between private and public information is compromised and privacy becomes an issue because people may feel a sense of ownership over their information. Private information such as the condition becomes public and the question becomes *how much* to reveal or conceal. For those living with a disability, maintaining privacy can be difficult (Braithwaite, 1991). If the disability is visibly obvious, the capability to maintain privacy is challenged further.

The U.S. Census Bureau reported that there were 57 million Americans living with a disability in 2010. Of that 57 million, 3 million Americans use a wheelchair and 12 million people use a mobility device, such as crutches. Thirty one million people over the age of 15 have trouble walking or climbing the stairs, (“Anniversary for Americans,” 2012). These statistics represent the possible number of people with a disability who have little choice in whether or not to reveal that they have a disability because it is visually apparent. Not having the choice to reveal something such as a disability can have an impact on the way that people with disabilities view themselves (Galvin, 2005). The purpose of this study is to explore the way that individuals with visible disabilities manage and make decisions regarding their privacy boundaries. The contribution of studying individuals with visible disabilities will be to expand knowledge in the intersection of privacy and disability. Also, the results of the study could lead to

improvements in communication with people who have a visible disability by informing those who do not have a disability of what could be avoided in communicative situations. Examining the literature covering topics such as visible disabilities, privacy, communication and identity allows the reader to gain essential knowledge that will form the backbone of my study.

Literature Review

People with visible disabilities commonly face complications related to identity (Olney & Brockelman, 2005; Galvin, 2005), which then can influence decisions about privacy and communication (Braithwaite, 1991). The following pages will explore some of the issues faced in communication for people with visible disabilities, such as self-perception and the attitudes of those without disabilities, while also looking at communication in various interpersonal contexts (Shippen, Crites, Houchins, Ramsey & Simon, 2005; Duggan, Bradshaw & Altman, 2010).

One of the author's goals in a study exploring self-perception in people with disabilities by comparing hidden versus visible disabilities was to explore how the visibility of a disability ties into one's self-concept (Olney & Brockelman, 2005). The results of the study indicated that people with visible disabilities have a more stable identification than people with hidden disabilities. People with obvious disabilities claim disability as part of their identity because of the visibility of it. According to Olney and Brockelman (2005) "those who had obvious disabilities seemed to have worked through many of their concerns about the judgments of others" (p. 84). Thus explaining that people who have a visible disability see their disability as part of who they are. However, individuals who had visible disabilities also felt that there was a need to control information about the disability (Olney & Brockelman, 2005). For example, one of the women in the study described that her goal at her new job was to not let her coworkers know what she had to go through just to get to the office. This showed that although a disability may be obvious, there are ways to regulate the information that is disclosed. At the same time the study highlighted the impact of disability on identity (Olney &

Brockelman, 2005). The relationship between disability and identity sets the stage for examining the ways in which visible disabilities interact with other concepts.

Disability, Identity and Communication

Individuals with visible disabilities experience challenges that people who do not have disabilities do not experience (Braithwaite, 1991). The challenges faced are not only because of the obvious physical differences, but also because disability is a stigmatized identity. “Stigma means negative characteristics imputed to an individual because of membership in a social group or category held to be inferior. The imputation is frequently based on a physical sign” (Frank, 1988). Thus, living with a visible disability is stigmatized. A person who has what Goffman (1963) referred to as a spoiled identity is seen as incompatible with what is socially acceptable.

In his work Goffman explores situations where individuals cannot conform to what is considered normal. People with visible disabilities do not conform to what is considered normal according to society’s terms of physical able-ness and may therefore be considered a member of the out-group. Being a member of the out-group means that people do not have full social acceptance and are working to adjust their social identities (Goffman, 1963). Similarly, Frank (1988) found that individuals with congenital limb deficiencies strive towards making adjustments to appear normal. The desire to appear normal stems from the fact that disability is seen as undesirable. In the Frank (1988) study, interviewees admitted not feeling the stigmatization of their disability until other people reacted negatively, which is what Goffman (1963) called enacted stigma.

Enacted stigma is the reaction of a person in a situation to a visible or obvious stigmatizing condition. For example, if a person who does not have a disability hesitates

saying hello to someone with a facial deformity, that would be enacted stigma (Stuenkel & Wong, 2009). For someone who lives with a visible disability enacted stigma can have a bearing on their perception. The results of the Frank study showed that disability, especially through the lifespan, has a substantial impact on a person's entire being (Frank, 1988).

Cardillo (2010) argued that the experiences of individuals who have experienced life-long disability or chronic illness are needed "to gain a deep and essential understanding of the whole-life meanings and impacts of illness [or disability] in their lives" (p. 527). People who have lived with a visible disability and stigmatized identity provide a unique perspective into the challenges of privacy management. A study that looked at the shifts in self-perception of people who became disabled found that a person's identity is greatly affected by the attitudes of those without physical disabilities (Galvin, 2005). According to Galvin (2005) "All those whose impairments were visible spoke about the markedly different and disturbing reactions they received from other people and how this affected the way they felt about themselves (p. 397)." Although Galvin's study was not specifically looking at communication, it was looking at self-perception of people with disabilities and many of the findings of the study involve communication. Reactions and responses that people who are visibly disabled receive from people who do not have a disability play an instrumental role in shaping perception.

Adults with visible disabilities tend to think that non-disabled people perceive them as unintelligent (Olney & Brockelman, 2005). The Olney and Brockelman study looked at the visibility of a disability and the self-perceptions of people with visible disabilities. The results of their study indicated that people with visible disabilities are

more likely to be aware of other people's perceived attitude and as a result try to prove their intelligence. According to Olney and Brockelman (2005), proving competence facilitates the movement of a person with a stigmatized identity (e.g. with a disability) to a person with a less stigmatized identity. Although the stigma of disability never completely goes away, people with visible disabilities feel that proving competence can reduce the stigmatizing effects. The ways in which having a stigmatized identity because of a disability influences interpersonal communication are complex. The complexity of these phenomena can have various effects on privacy.

Interactions

A similarity that is consistent across patient-provider, educator-pupil and other interpersonal relationships is that communicative interactions between individuals with disabilities and people without disabilities are initially uncomfortable and discomfort becomes unease and in extreme cases avoidance (Braithwaite 1991; Shippen, Crites, Houchins, Ramsey, & Simon, 2005; Duggan, Bradshaw & Altman, 2010; Hart & Williams, 1995). Likewise, interactions between people with physical disabilities and people without physical disabilities can be filled with negative and positive emotions, such as fear, compassion and sympathy (Hirschberger, Florian and Mikulincer, 2005). People with physical disabilities might remind people without disabilities of their own physical vulnerability and at times arouses fears of death.

The link between fear and physical disability was tested in a study that indicated emotions relating to death do hamper interactions with people with disabilities, although females tended to respond with more compassion and men with avoidance (Hirschberger et al., 2005). Regardless of the response that the person who has a physical disability

receives, the interacting individual's attitude and the way that the person responds can affect the person with a disability (Galvin, 2005). For instance, a person may react with a nonverbal response showing sympathy, fear or disgust. In turn, this has an impact on a person who has a disability and their sense of self. Although the Hirschberger et al., (2005) and Galvin (2005) studies were not solely focused on communication, both of the studies indicate that the mixed emotional responses to people with disabilities can have an impact on communication.

Future medical practitioners react to the visibility of disability in distinctive ways (Duggan, Bradshaw & Altman, 2010). Previous research had stressed the need to study interpersonal medical encounters between a doctor and patient because people with disabilities are less likely to be satisfied with the interaction. A study looking at the communication between medical students and people who have a visible disability showed that disability can be a complex topic that not everyone is comfortable inquiring about in the same way. There were some students who requested information using the word disability, there were students who indirectly inquired, and there were students who avoided the topic altogether. Not inquiring about a visible disability indicated the medical student experienced discomfort and held prior assumptions about disability. The findings of this study indicated that interactions might be complicated by the uncertainty of disability while the practitioner might also be wrought with assumptions.

For instance the medical student may assume that the patient does not want to talk about their disability and therefore not inquire. Although the context is different from everyday interactions, the interpersonal nature of these encounters may help to inform the way in which disability is inquired about in everyday conversations. Prior assumptions,

for instance, can influence medical students and may just as well influence interactions in everyday situations. Also, if medical students are uncomfortable inquiring about a visible disability and they are trained in health, the implications in interpersonal situations could be substantial. The implications of this study indicated that integration of disability disclosure into the doctor-patient relationship is a necessity (Duggan, Bradshaw & Altman, 2010). This study reinforced the idea that uneasiness can accompany these interactions.

The apprehension that accompanies interactions between people with disabilities and people without disabilities can also be present in education. A study that looked at teachers-to-be and attitudes towards serving children with disabilities found that soon-to-be teachers feel unprepared to teach children with disabilities (Hart & Williams, 1995). As a remedy, knowledge of disabilities can reduce anxiousness. Although this study was in the education field this study, just like the previous study, demonstrates that even as a professional the attitudes and the way we interact with others can still depend on personal feelings and attitudes (Galvin, 2005). Thus, the interactions that occur between a teacher and a student shed light on how interpersonal interactions may be approached. The study focusing on medical interactions and the study looking at education were also similar in sampling because they both looked at communication between one person with a disability and one person without a disability.

However, in a study examining communication apprehension it was found that uncertainty and apprehension were decreased when the person with a disability initiates the conversation with a person with no disability (Ayres and Sonandre, 1999). Participants were put in communicative interactions in which a person who uses a

wheelchair may or may not initiate the conversation. The students then completed an apprehension inventory and wrote an essay about what their thoughts were during the interaction. When the person who used a wheelchair initiated the conversation, apprehension was decreased and the person without a disability was more satisfied (Ayres & Sonandre, 1999). Although the Ayres and Sonandre (1999) study did not focus on a particular type of interaction, the results are revealing in terms of anxiety reduction. Implications indicate that discomfort in communication between a person with a disability and a person who is not disabled can be reduced and by reducing discomfort the interaction results in more satisfying communication.

Maintaining Privacy

Similarly to the literature that has been reviewed, disability and maintaining privacy has also only been looked at between individuals with a disability and individuals without a disability. Research on disability with regards to privacy has shown the important role disclosure plays in fostering satisfying relationships. According to Olney and Brockelman (2005) “regardless of how obvious the disability was to others, deciding what to reveal, when, and to who was problematic (p. 86).” Although Olney and Brockelman were not specifically looking for findings about privacy issues, disclosure came up when they were looking at the results of their study. The finding about disclosure stresses the important role privacy plays in everyday conversations. Furthermore, a study looking at people with disabilities and whether or not they are comfortable talking about their disability revealed that people with disabilities were frequently open to disclosure, but did not feel more at ease themselves after disclosure (Rosye & Edwards, 1989). Although disclosure may help the person who is not disabled

feel more at ease, it does not necessarily calm the person with a disability's nerves. This study also shows that the concept of disclosure and privacy oftentimes surfaces in communicative interactions. However, what this study also does is demonstrate that by putting the other at ease, a person who has a disability may have to forgo some level of privacy.

Likewise, individuals with disabilities are often expected to answer questions about their disability in the early stages of a new relationship (Braithwaite, 1991). There are also interactions in which complete strangers approach people with disabilities and ask questions regarding their disability. In either case the person who has a disability is being asked to sacrifice their own privacy to meet the demands of the other person. It is assumed that people with visible disabilities will make a private disclosure since their disability is already visible. According to Braithwaite (1991), "it is clear from these results that making choices about revealing private information does play a significant role in the communication between ablebodied and disabled persons" (p. 267). Therefore, whether or not a person who has a disability reveals information about their disability to other's can play a large role in the communication early on in a new relationship.

According to Petronio (2002), each person has a way of deciding whether or not something should be revealed or if the information should remain private. Petronio called this a "mental calculus" (p. 3). Although everyone has a different mental calculus and the decision about what to reveal is not the same for everyone, there are still similarities and common trends that occur amongst people. How an individual reaches the decision of how to answer a request for private information can be theorized using Communication Privacy Management (CPM). CPM gives us a way to discern how people make decisions

related to revealing and concealing (Petronio, 2002). The theory has been applied in different settings and in different types of communication situations (Bute & Vik, 2010; Petronio, Helft, & Child, 2013; Petronio, Sargent, Reganis & Cichocki, 2004; Hosek & Thompson, 2009; Polk & Hullman, 2011; Donovan-Kicken, Tollison & Goins, 2011). Although the research provides valuable insights into the types of situations studied, what the research does not yet provide is the way that CPM theory is applied to individuals with visible disabilities.

What is missing from the research is how privacy boundaries are managed when the communication occurs between two people who both have a visibly obvious disability. The communication between two people with disabilities may be different than communication with someone who does not have a disability (Goodwin, Johnston, Gustafson, Elliott, Thurmeier & Kuttai, 2009). In a study looking at wheelchair rugby player's sense of community, the research revealed that there was a difference in what could be talked about when the players were with each other versus with their friends that have no visible disabilities. According to one of the players interviewed, "My able bodied friends ... I'm a minority around them. They don't really understand what I'm going through. I can't really get into it with them. I think that's why we talk about it here. You're allowed to share" (p. 111). In other words, the sport gives players an opportunity to discuss experiences with another person who is quadriplegic and who understands what they are going through. Another one of the rugby players reflected on how self-care activities were part of the everyday discussion amongst wheelchair rugby teams and how personal care was a taboo issue with able-bodied friends (Goodwin et al., 2009).

Likewise, the sense of community that exists among people who both have a visible disability has also been looked at in online communication, which indicated that a sense of commonality was established through disability-specific websites (Obst & Stafurik 2010). The sense of community, shared understanding and the ability to communicate more freely amongst a group of people sharing a similar identity paves the way for conceptualizing disability as a culture (Brown, 2002). The notion of disability as a culture necessitates the need to look at the communication between two people who have a disability. The knowledge gained could facilitate needed improvements in communication with people who have disabilities, such as in healthcare contexts. The results may also aide in ways to engage those with disabilities in conversations without crossing a boundary. Looking at interactions with people who do not have a disability and people who do have a disability will provide a more complete picture of everyday privacy management practices of people with a visible disability. Therefore, the purpose of the study is to explore the management of privacy boundaries for people who have visible disabilities across of variety of interpersonal contexts. Using CPM as the theoretical framework to look at the ways that individuals manage boundaries around private information, I will provide background on CPM, share the results of my study and discuss the implications of my findings.

Communication Privacy Management

Virtually everyone has faced the decision of what to disclose, what to conceal and to whom. Disclosure, privacy and deciding to reveal or conceal can be a challenging process that involves the consideration of many different factors. CPM is a practical theory that provides a way to understand how people make decisions about what to disclose or not disclose. According to Petronio (2002) “CPM uses the metaphor of boundaries to illustrate that although there may be a flow of private information to others, borders mark ownership lines so issues of control are clearly defined” (p. 3). In other words, individuals regulate and control access to information because they feel that the information is theirs to own. To make decisions about disclosure, CPM asserts that everyone has a rule management system they rely on to decide whether or not to provide personal information.

Supporting this system are five basic suppositions, which form the backbone of the theory. The suppositions are that the information is private information, a boundary exists between private and public information, control is an issue when making decisions, a rule-management system is used to help in making decisions and privacy and disclosure are dialectical. (Petronio, 2002). Although all five suppositions are important to privacy management, there are a few that are particularly significant when looking at individuals with visible disabilities. The suppositions that are of interest to the current study are assumptions relating to control and ownership and privacy boundaries as determined through a rule-based management system (Petronio, 2002).

One of the suppositions of the theory is that feelings of ownership over private information can lead to individuals wishing to control whether or not to disclose, what to

disclose and under what conditions to disclose. One strategy of using the ability to control private information is through incremental revelations (Petronio, 2002). In a study using CPM to explore the disclosure patterns of children who experience sexual abuse showed that the kids often made small revelations over time. Victims of sexual abuse would tell small amounts because they wanted to see how revealing a little bit of information was taken by the person they were talking with (Petronio, 2002). Other strategies of control have also been used.

A study looking at the disclosure patterns of individuals with cancer found that the sense of control created by making decisions as to reveal or conceal gave people a feeling of stability. A common theme in the study was that cancer may be uncontrollable but what is controllable is how much one chooses to reveal (Donovan-Kicken, Tollison & Goins, 2011). The information control that was demonstrated by cancer patients in the Donovan-Kicken et al. study is also present in disability as well. Olney and Brockelman (2005) found in their self-perception study that no matter how obvious the disability, the participant felt a sense of control by deciding what to reveal. With a disability that is seen, a person may still control access to information beyond what is obvious such as how they became disabled. Although disability and chronic conditions are not always looked at together, there is a link between the two.

Although disability and chronic illnesses such as cancer are separate conditions, there are similarities between the two. Disability and chronic illness are sometimes looked at together because of the fact that chronic illnesses and disability can both have physical, psychological and social implications (Cardillo, 2010). A literature review looking at HIV disclosure revealed that the disease has “immense difficulties, the life

changing social implications, and the psychological and psychosocial effects of HIV” (Moskowitz & Roloff, 2007). Likewise, a visible disability can also affect multiple facets of life. Moreover, there are certain chronic conditions and illnesses that can have both visible and hidden symptoms (Docherty & McColl, 2003). For example, a narrative of a man who has Multiple Sclerosis first experienced the disease when his leg became numb and he was unable to walk (Docherty & McColl, 2005). This study showed that disability is intertwined with chronic illnesses and conditions. Thus, while the following study focuses on individuals with visible disabilities, looking at chronic illnesses can reveal useful information about disclosure patterns.

When making decisions about disclosure, risks and benefits are considered in what Petronio refers to as privacy-rule foundations (Petronio, 2002.) When choosing whether or not to disclose HIV or another illness, many people report weighing the risks and the benefits of disclosure (Petronio, 2002). People who have disabilities may be wary of whether or not to disclose based on what they see as the potential gain-loss. The reason according to Petronio (2002), that privacy boundaries are controlled is because of the fact that people measure gains and loss. Therefore even though a person may have a visible disability, the extent of specific information disclosed depends, in part, on the potential rewards in disclosing. The risk-benefit assessment is one of several criterion considered when developing privacy rules.

Culture is a contextual criterion used to reach a decision about disclosure. Thus, culture also plays an important role in the development of privacy rules. According to Petronio (2002), “each culture values privacy differently and the values we place on privacy influence the rules we have for managing our privacy boundaries” (p. 41). In

other words, different cultures place an emphasis on which aspects of privacy management are more important. Research shows that disability has been looked at as a culture within the context of wheelchair rugby (Goodwin et al., 2009), online disability communities (Obst & Stafurik, 2010) and the deaf community (Hamill & Stein, 2011) while there has also been a push to view disability and deafness by taking a cultural perspective (Johnson & McIntosh, 2009).

Using a cultural perspective allows for those with a disability and the person they are communicating with to be seen as members in the same culture and sharing a common experience if they are both visibly disabled. Moreover, Petronio (2002) used the concept of identity linkages to describe the collective identification that is felt through shared experience. According to Petronio (2002) “ identity linkages evolve when two or more individuals disclose similar amounts and kinds of private information because they are both going through comparable experiences” (p. 132). Identity linkages are important to the study of disability because it implies that two people that have shared experiences or common understanding disclose similarly. Although CPM stops short of asserting whether the identity linkage has a positive or negative influence on communication, the theory does recognize that there is an impact on disclosure when there is an identity linkage. By looking at the identity linkages visible disabilities create we can begin to see that two people with similar experiences and identities, such as disability, may impact the decision to reveal or conceal. Likewise, in situations where one person has a disability and one person does not, there may be a cultural difference and that too may influence the way that privacy boundaries are negotiated.

Individuals who share a common culture such as disability may also place emphasis on certain aspects of CPM. Steven E. Brown (2002), Co-Founder of the Institute on Disability Culture in the US, describes disability as a culture because of the similarities in experiences and the history of oppression that is shared. Thus, recognizing disability as a culture also acknowledges the identity linkage inherent within the culture of disability. The idea that having a sense of shared meaning was also examined through research on adaptive sports. In a descriptive study intended to interpret wheelchair rugby player's sense of community, Goodwin et al. (2009) found that one common theme was that being around other wheelchair rugby athletes gave rise to a feeling of connection and allowed for virtually "anything" to be talked about. Therefore, if disability is considered a culture, the level of information revealed and the privacy rules that are developed may be influenced by the culture of disability. Privacy rules, however, take into consideration other factors besides culture (Petronio, 2002).

In a study examining transracial and international adoption the decision-making criteria in deciding whether or not to reveal private information changed over time. With experience the parent of the child was able to reach the decision about what to disclose and what to conceal with privacy boundaries already in place (Suter & Ballard, 2009). Although this study was not looking at health-related information, similar results have also been found in health contexts. In a study looking at women who have experienced infertility, it was found that boundaries evolve and change over time. Although in some cases the boundaries become more open, in other cases the women were less open over time. In either instance however, it was found that privacy boundaries might shift (Bute & Vik, 2010). Both studies were conducted in different contexts but had similar results in

the shifting boundaries. Thus, when looking at individuals with life-long disabilities it may be important to recognize that boundaries shift and change over time.

In most of the studies reviewed about disability and privacy boundaries the study largely focused on one person who is apart from the rest in some way and one person who is not. For instance in the Bute and Vik (2010) conversations were explored between someone experiencing infertility and family members or other people who may not be attuned to the challenges of infertility. The Bute and Vik study shows the valuable insight that can be gained through studying one person who is and one person who is not.

However, CPM literature, to the best of my knowledge, does not examine conversations between two people who are both apart from what is commonly expected in society.

Looking at both the privacy management between one person who has a visible disability and another person who may or may not also have a visible disability and their privacy decisions sheds light on a view that has only been addressed in part. Awareness into the management of privacy when both parties may or may not have a visibly obvious disability provides a unique perspective. Therefore my research question is:

RQ1: How are the boundaries around disability-related information managed by people with visible disabilities in communicative interactions?

In the following sections I will describe my study, discuss the results, share researcher insights and acknowledge pitfalls and implications of my study.

Method

I conducted interviews with seven individuals who have visible disabilities and volunteered to talk about their own experiences of managing privacy boundaries in communication. The interviews explored interpersonal communication between two people, one person who has a visible disability and another person, regardless of whether or not they also have a disability. I used in-depth interviews, which is a technique from grounded theory (Creswell, 2012), to address the experiences of managing privacy boundaries for people with disabilities. Although my study does not employ a full use of grounded theory, interviews are relatively common in American society and can be used in conjunction with techniques from other methods, such as grounded theory (Donovan-Kicken, Miller & Goldsmith, in-press). Therefore I chose to conduct interviews.

Study Participants

I made initial contact with individuals who have a visible disability through the sport of power soccer. According to the United States Power Soccer Association, power soccer is one of the only sports for people in power wheelchairs (United States Power Soccer Association). I began my recruitment of participants by focusing on power soccer players and others involved in adaptive sports, which was a form of convenience sampling. Convenience sampling is sometimes used because of the ease in getting participants (Tracy, 2013). For instance it may be convenient to gain participants that one sees on a daily basis. However, using this technique is not always the best choice. Kreps (2012) cautioned against using convenience sampling because health research is typically applied and should examine the most relevant population and not the most convenient. However, looking to the most relevant population intersects with a convenient sample in

the case of my research. I play power soccer and have easy access to the population. Power soccer players are also good participants for my study because playing the sport assures they have had experiences communicating with others who have a visible disability on their team as well as at school or in the community where their interactions are with people who do not always have a disability. I found that there were pros and cons to using convenience sampling.

My initial recruitment strategy was not aggressive enough because the strategy only included contact through email. I contacted the founder of Power Soccer of Indy, who oversees all of the teams in Indiana, and my message to her included what my study was about, what the interview entailed and who I was looking to interview. She sent out the information to coaches. However, the initial requirements for participants only included people whose disability was visibly apparent by age 6. I decided my initial strategy was too limiting and opened up my study to those who became disabled later in life. Although people who did not experience childhood with a physical disability would have a significantly shorter timeline of disability, their perspective was still important to capture. I also decided to change my strategy to be more aggressive. I wrote an advertisement aiming to gain people's attention and posted information on my wall on Facebook describing my study and who could participate. I also posted a flyer at the Lawrence Branch library and posted 6 flyers throughout the IUPUI campus. The new recruitment strategies resulted in four participants. Initially to limit undue coercion my study was limited to outside teams and not my own team in Henry County. However, on my power soccer team a couple of teammates had heard about the study and inquired about participating. Therefore, since my teammates freely chose to inquire, as I had never

mentioned the study to my team, I included my teammates as well and gained one more participant.

Seven people with visible disabilities participated in the study, four men and three women. Six participants used a wheelchair, and one person used crutches. Three participants had a form of muscular dystrophy, two participants had cerebral palsy, one participant was a double amputee and the other participant had had a brain tumor that had left him immobile. Five of the participants had been visibly disabled by age 6; one had become disabled at age 46 and the other at age 20. The average age was 31 years old and ranged from 20 to 64; although the average is skewed because one participant was in her 60's but 5 of the remaining 6 were in his or her 20's. All seven participants identified their hometown and current location as being located in the Central Indiana region. All of the participants were white, and six of the seven participants had schooling beyond high school. Two participants were college students, one participant was an attorney and another a web designer, one was a beautician, and two participants were not employed. Of the two who were unemployed one was searching for a job.

Data Collection

I conducted in-depth interviews to gain an understanding of how participants manage private information about their disability. The less structured nature of in-depth interviews has been described as a conversation, allowing for rich insight into the interviewee's experiences and the meaning attached to them (Donovan-Kicken, Miller & Goldsmith, in-press). Interviewing was also a helpful way to look at the management of private information (Bute & Vik, 2010). Because I was looking to find out how individuals with visible disabilities manage privacy boundaries and many encounters are

random and with strangers (Braithwaite, 1991) participant observation would not be feasible because my inquires were about specific interactions. According to Bute & Vik (2010) “Interviews also allow scholars to ask questions about conversations in which people avoid talking about certain topics, a phenomenon not easily observed” (p. 7). Again, this statement is reinforcing the need for interviewing and not another form of research such as observation. As a requirement of the study the interviews were audio recorded. The consent form was distributed and collected before the interview. After each interview I wrote field notes so that there is documentation of my initial thoughts and feelings and methodological and theoretical notes. The interview protocol was semi-structured so that there was room for changes during the study (Appendix A). To begin the interview, the participant was first asked to describe their disability and the onset so I could get an idea of the age their disability became visible and the diagnosis.

After participants described their disability, the participant was asked about conversations growing up, what types of questions they were asked and their comfort in answering. I followed those questions by asking if there were any aspects of their disability they did not like to discuss and how they dealt with the issues they did not like to discuss when the topics were brought up. The questions gave me a general idea of the participant’s experiences in childhood. If this was not applicable to their unique situation, I skipped over the childhood questions and started at the next set of questions. The same series of questions that were asked about childhood were repeated for adult life and the questions about adulthood were asked about both acquaintances and others who also have a visible disability. In the first interview and then throughout all of the following interviews, it became obvious that most participants had a difficult time remembering

specific conversations from childhood. Therefore, the questions in the interview protocol had to be adjusted to accommodate what the participants could remember by omitting questions about specific conversations in childhood and adding more general questions about their comfort level and topics they talked about.

The interviewee was then asked to describe any differences in having conversations about his or her disability with others who also have a visible disability versus no visible disability and then I followed up with questions pertaining to the (non)differences. I was interested in finding out whether or not there are certain issues discussed with those who do not have a visible disability but not with those who have a visible disability or vice versa. After inquiring about discussion topics, I asked about past experiences that might inform the way private information is now handled. The reasoning for the question about the handling of private information was to see how privacy boundaries have changed over time and to get an idea of how the boundaries are currently managed.

The Role of the Researcher

According to Tracy (2013) “Self-reflexivity refers to the careful consideration of the ways in which researchers’ past experiences, points of view, and roles impact these same researchers’ interactions with, and interpretations of, the research scene” (para 1). Self-reflexivity is about recognizing how past and present experiences shape research interests, opinions, beliefs and attitudes. Before starting the current study I already knew that my research focus of disability would require me to be self-reflexive because I was researching a part of my own identity. Through being honest and authentic with oneself as the researcher, self-reflexivity is made possible (Tracy, 2010). Being self-reflexive is

defining in qualitative research because of the fact that it allows the researcher's voice to be heard, which is not always an option in other types research. Another difference important in qualitative research is that the researcher should be open about motivations and biases in conducting the research, if relevant (Tracy, 2013). In addition to being honest with yourself, being self-reflexive means being honest with participants. To be honest with participants I answered inquiries that the individuals had and let them know why I am interested in conducting this research if they asked. Finally, I recorded personal feelings and reactions to others in field notes.

I conducted this study from the position of a person with a visible disability. My role was that of a researcher who has a visible disability and has a genuine interest in understanding and studying other people's perceptions and experience of disability. I recognized my own personal feelings but I also know that my views on disability are my views, not everyone else's. Each person has a unique way of thinking, and I am interested in looking at other people's experiences. I did not know whether what I experienced is what other people experience. I became disabled when I was nearly 14 years old. Therefore, I have no experience of growing up and being in elementary school and having a disability. The majority of my research participants experienced disability in childhood and therefore may have a different perspective. I think that one of the reasons I chose this research project had to do with my desire to learn about other people's experiences. No two people have the same story and no two people manage privacy boundaries in the exact same way, but there are commonalities and patterns amongst groups of people. That sparked my interest because I wondered how other people experience the disclosure dilemmas faced.

The work of communication scholar Ellingson (2003) informed my research regarding the role of the researcher. Ellingson conducted research into communication in an oncology clinic and she also had cancer, which was in remission when she conducted her study. Thus, Ellingson was researching a part of her identity. However, she exemplified being self-reflexive by being honest and genuine, which is what I strived towards in my work on people with visible disabilities. For instance, Ellingson had a limp that was the result of her cancer. If a participant inquired about the limp, she was honest and explained her limp. I also strived to be self-reflexive by being honest.

While interviewing participants it was visibly obvious that I too, have a disability. If at any time a participant inquired about anything, I answered openly and then guided the participant back towards the interview. When I felt that one of the participants did not understand a question the way I asked it, I reframed the question by using my own experiences in managing privacy boundaries as an example to explain it. By allowing the participant to know that I, too, have had the experiences in boundary management, I felt it put them more at ease. I also find that using examples made understanding easier, and I feel like it helped develop rapport. After the interview, I reflected on the process and recorded theoretical and methodological notes.

Data Analysis

I uploaded the transcripts into NVIVO software after completing transcription. I read through each of the transcripts at the beginning to get a feel of the larger picture of the interviews. As I read through the first time, I also began to mentally note some themes or patterns across transcripts about how privacy boundaries were negotiated when talking to someone about disability-related information. Whenever I noticed a point

reoccurring in another transcript, I would note it on paper. According to Tracy (2012) “coding is the active process of identifying data as belonging to, or representing, some type of phenomenon. This phenomenon may be a concept, belief, action, theme, cultural practice, or relationship” (para 2). In the current study the primary focus was on themes that were repeated by participants about managing privacy boundaries. I was particularly interested in seeing whether or not there were described differences between conversations with others who had a visible disability and people who do not have a disability. There were indeed differences and so while I was reading through the transcripts I began noting what the participants had to say about these experiences. Based on previous research, there were certain issues within privacy management that I was attuned to look for. For instance, because disability is a stigmatized identity (Galvin, 2005), I was cognizant of statements about managing information for purposes of trying to appear “normal.” Also, the management of private information may be different when the interaction is with someone else who has a disability (Goodwin et al, 2010) and so I looked for described differences. Thus, I also looked for participants describing changes in how they approached questions and shifts in how they managed private information. The coding process was made much more efficient by the NVIVO software because everything was in one place and could be easily managed.

I focused first on primary codes. I lumped together statements that had similarities in broad categories that were noted across transcripts. I used a general term or phrase to classify statements. Any phrase or statement that fell under that theme was coded. The initial code chart is in Appendix B. After I read through and noted themes that re-occurred, I went back re-read and noted more of the common themes I saw. Then I re-

read the transcripts and put statements under the code it belonged with. With the initial codes I used “umbrella” terms. I lumped things together in a more general or overarching theme. Tracy (2013) pointed out that lumping things together has advantages and disadvantages. Because the current project is my first research study, I chose to lump things together because I felt more comfortable and capable using the method of general themes. One alternative would have been fracturing (Tracy, 2013). Fracturing is coding smaller pieces instead of the entire excerpt. Fracturing is more detailed and allows for deeper insight, however I decided to go with lumping because I felt more comfortable with the method of lumping (Tracy, 2013).

Initially I had 6 categories: managing assumptions, initiating conversations, identity linkages, mood as motivation, not wanting to appear helpless and giving general information. “Managing assumptions” was the category I named for when an interviewee described disclosing private information so that the inquirer would not assume something else. At times the statements were explicit where the participant would clearly state her or his decision was so the other person did not assume. There were also instances when the interviewee would allude to managing assumptions through story telling in which they responded in a way to quell assumptions. “Initiating conversations” was the category for statements made about having to initiate a conversation about their disability-related private information because the individual with a disability wanted to share information. “Identity linkage” was the code for comments about how it was easier to talk to another person with a visible disability because of the common experiences and similarities. “Mood as motivation” included statements about how the disclosure of private information was dependent on the interviewee’s mood at the time. “Not wanting to

appear helpless” was reserved for when the interviewee managed the information to not appear helpless, needy or something similar. Some interviewees stated that they only give general information and so I used the code “generality.” I also set aside statements that did not necessarily fit anywhere but seemed to be insightful. For instance, a statement I chose to set aside was one of my participants explaining why she felt more confident around other people with visible disabilities.

In-vivo coding makes use of the actual language used in the interviews as the coding name (Tracy, 2013). This was how some of my coding categories were created. The reason that I used in-vivo themes was two-fold. Using codes such as “not wanting to appear helpless” reminded me of what that category defined without needing to go back and check what I meant. Also, in-vivo coding allowed me to constantly be reminded that I need to immerse myself in the data and think of more specific codes while I coded the transcripts. As I was doing the primary coding I was also thinking of ways in which the codes could be more specific, such as with the initial category “managing assumptions.” Within a category I looked for how the data coded was similar and different than other data in the theme and what accounted for that difference. The constant comparative method is the name for the method of comparing the data in each set and makes decisions as to whether the data fits in the current category or if a new category needs to be created (Tracy, 2013). The initial codes however, were only primary, as the name denotes. Next, came the classification of the codes into themes.

After going through the data and coding and recoding into general categories, I was able to create themes. I used the primary codes as the foundation to create themes. Using the primary codes I built themes that are comprised mainly of primary code(s) but

also include additional findings. I then chose to create a codebook. Although I am the only person coding the current project, having the codebook helped me feel more organized. The codebook provided a quick way to check the definition of a theme without having to look through my notes. Also, I felt that I got a better grip on the analysis of the data if I laid out my exact thinking. I explain each theme and have an example. The codebook is shown in Appendix C.

Initially, there was a lot of lumping together of similar statements. However, some of the initial codes were too general which was why in the codebook I tried to be more specific. To do this, I looked over my list of the initial codes and read through the transcripts. I read through the statements I had coded in a category and looked for sub-patterns within a broader pattern. For example, managing assumptions was a broad pattern. However some of the statements were not only about quashing assumptions but they made explicit reference to wanting to educate others. Therefore, within “managing assumptions,” I created the sub-code “through educating.” This process was repeated until I had gotten through all of the codes. However, a few of the initial codes do not appear in the codebook and vice-versa. Instead, a few of the umbrella terms used initially are now either within another category or are under a different code name.

For example the initial category of “giving general information” was changed to “no specifics.” Using the code “no specifics” was more self-explanatory. There were a few changes to code names to make them a little more explanatory. After finishing the secondary coding I looked for ways in which the categories relate to each other and then created broader themes that defined the categories. The reason I chose to categorize and then create themes is so after coding I could look at the relationship between categories

and create a theme to reflect back to how the categories answered the research question.

After completing the classification of excerpts into themes, the time came to analyze my findings and write up my results.

Results

The results of my study indicated that individuals with visible disabilities have complex and vibrant ways of deciding whether to reveal or conceal private information. The decision of what to reveal and why the private information was managed in a certain way may have been somewhat different for each person, but also bore similarities to other people with visible disabilities. There is no one-size-fits all way of deciding what to reveal. Instead, the decision involves many different considerations. Overall, the results of the analysis fall under several themes that illustrate the ways that the privacy boundaries are managed with both people who have disabilities and people who do not have disabilities. Some individuals described a willingness to answer questions, while some people put limits on how much they are willing to share. And yet some people's privacy boundaries depended on motivational criteria (Petronio, 2002) or even external characteristics of the person that they were conversing with. In all of the situations the decision to disclose is not simple. In the next sections I will explore the information that I gathered as I attempt to make sense of the way that people's privacy boundaries are managed. The themes that I have identified look at the overall permeability but at the same time also look at the specific motivators that encourage people to make decisions about what they are willing to reveal and what they choose to conceal. The following results section reflects on people's experiences in managing boundaries.

Permeability varies by inquiry

The first theme is "permeability varies by inquiry," and it was derived from statements describing openness. I decided to use the term permeable instead of open because permeable is a term Petronio (2002) discusses in CPM and I think it is a more

accurate term. This is because by calling boundaries permeable it acknowledges that boundaries still exist, while openness is more of a direct term that does not acknowledge that there are variations. Since Petronio (2002) discusses that there are varying degrees of the way in which boundaries fluctuate I decided that using permeability was a better word choice.

Boundary permeability (Petronio, 2002) speaks to people's willingness to disclose. The more permeable, the more open people tend to be with private information. Some of the participants quickly responded that when faced with an inquiry by someone who does not have a visible disability, their privacy boundaries tend to be flexible. The individuals who described themselves as open might have privacy boundaries that are more permeable than others, but privacy boundaries still guard certain information. Participants such as Rachel who has a form of muscular dystrophy and has never walked, has no problem answering inquiries about her disability. "I've never really gotten a question that I felt really uncomfortable with...Some rude questions by some drunk people a couple times, but other than that, no. I've never really felt uncomfortable answering questions." However, at the same time Rachel describes that she might feel uncomfortable if a person who does not have a disability asked about something personal, such as going to the bathroom. However, Rachel could not recall getting those types of inquiries. Thus, Rachel's boundaries according to her are open to an extent but she is not going to share everything. However, Rachel prefers that people ask questions such as in the grocery store when other people talk to her loudly as if she has a hearing impairment. If someone took the time to ask Rachel she would tell them she is in a wheelchair but can hear fine. Still other participants choose to share information because of the visibility of

their disability. Consider Doug, who has grown up with a visible disability that is blatantly obvious:

I didn't hide anything because once you have a physical disability, to a certain extent, people already know enough that you can't really hide that much; it's not like you can...it's not like it's not obvious...I am very outspoken and my general thought is yea, I don't want to make people uncomfortable; but at the same time, if they ask, I'm going to answer.

It is not necessarily that Doug has *no* privacy boundaries. When the inquiry however, is why he is disabled, Doug is going to answer the question. Doug is consciously aware of the fact that he is already sharing a big piece of information because of the visibility of the disability and so he may as well share the rest. Doug described being bullied in high school and even though he is comfortable with providing information about his disability he is skeptical of inquiries that go beyond what his disability is and how it affects him.

If they ask me a question about, let's say...getting out of bed in the morning and not falling out of bed in the morning, then that's something that I'll give them a cursory answer. They don't really need to know everything because they don't live with me...If they just asked out of curiosity, then I'd answer, if they asked because they were going to turn around and make fun of me with it, I'd shut up.

Although Doug has permeable boundaries and he does not mind answering questions regarding the “why” aspects of his disability, Nancy describes her privacy boundaries as being extremely permeable. “I'd rather people ask than sit and stare...It doesn't matter because of the way I look, I'm asked and stared at every day of my life, for no matter where I go, I'm stared at.” A double amputee that includes her hips and legs, Nancy explains that even sensitive questions that go beyond “why” such as sex and going to the bathroom, she will answer. “Oh yea...I just tell them it's easier because, just picture yourself going to the bathroom and you don't have no legs in the way. I could go forward, backward, sideways; I can go any way, it doesn't really matter...just slide on, slide off.”

Like Nancy, Maria claims to be an open book, too, but she acknowledges that she was not always that way. Maria was never able to walk and today needs help from the time she gets out of bed to the time she goes to sleep at night. Although she has experienced lifelong disability she describes being uncomfortable talking about her disability as a child.

I would pretty much give nasty answer [to an inquiry] because I was so offended by their stupidity, yea, it's not the reaction that I would give now, but as a child I was very frustrated...I think when I was younger; I did not like to be associated with disability at all.

However, now Maria prefers to answer questions because she likes things to be in the open. “Not until adulthood was I willing to give people the benefit of the doubt asking questions.” Maria’s privacy boundaries went through a transformation where they became much more permeable than they were when she was a child. She now says that she cannot think of any topic that she would be uncomfortable with, even the personal aspects of living with a disability.

Rachel, Doug, Nancy and Maria all demonstrate that privacy boundaries are complex and just as much as there are differences there are also similarities. In essence, all four participants describe being open to inquiries about their disabilities. Thus, they are all similar in being open to the “why are you disabled” aspects of living with a disability. Where they begin to differ however, is how much information they are comfortable giving and how far beyond general terms they are willing to go with the information that they give. The difference in openness and closed-ness can at times be attributed to motivating factors.

Motivation to Disclose

Just as in virtually every aspect of life, motivation plays a substantial role in the permeability of privacy boundaries. Participants were motivated to open their privacy boundaries when communicating with someone who does not have a visible disability for several reasons. According to Petronio (2002), many people make decisions about openness and closed-ness that hinge on motivational criteria. Likewise, many times the person revealing the information also considers the risks and benefits to disclosing. As the participants in my study revealed, before making the decision of whether or not to reveal information there are several surrounding issues such as their own mood, the gender of the other person and getting the support that is needed.

“Motivation to disclose” to someone without a disability contains three categories that are motivating factors and that regulated whether or not private information is disclosed. The research question asks, “how are privacy boundaries managed by people with visible disabilities?” and I chose this heading because it explains that privacy boundaries fluctuate depending on the motivating factors involved. The categories within the theme are mood, gender and getting the support needed. Within “mood as motivation” I included statements where the interviewee described that their answer to an inquiry was based on their mood at the time someone asked. “Gender as motivation” was next and talked about privacy boundaries being affected by gender. At times privacy boundaries fluctuated for the sole purpose of romantic interests. I chose to include statements such as these because the statements are still important and still relate to motivators for revealing. “Getting the support needed” was the last sub-theme of

“motivation to reveal” and is comprised of statements in which the decision to reveal is because the interviewee needed support.

Mood as motivation

For several of the participants, privacy boundaries were impacted by their mood at the time. Although some of the participants discussed that there were personal characteristics about the inquirer that changed their mood and encouraged the person to loosen their boundaries, for others nothing could change how they felt about the day. For Kenneth, the decision of whether or not he answered an inquiry was heavily influenced by the way he felt at the time. Kenneth explained, “It's more like my attitude. It's more like well, I don't really feel like talking about anything today.” Thus, Kenneth’s way of deciding was that if he were not in a good mood, he would not answer the question in full and he might give an answer that reflected his mood. Kenneth who became visibly disabled at age 20 recalls:

It really depends on my mood at the time...like I used to volunteer at the children’s museum and a little kid asked me what happened to you and I wasn’t really thinking at the time of what he meant, but I kind of knew, but I looked at him and said, what do you mean?

For Kenneth, mood is the one of the most important factors in deciding whether his privacy boundaries are going to become more permeable. Although he acknowledged that the decision does rest on his mood, he also mentioned that he is not in a bad mood often. For his boundary to be closed off he is usually under a lot of stress, which in turn makes him irritable. Likewise, Doug admits that his mood plays a big role in whether or not he reveals disability-related information. For Doug, however, his mood can change if he realizes that there is a personal connection for the inquirer with disability.

Well, a lot of it depends on how I'm feeling that day, but there's one example where I was sitting on the bus in high school, and a kid came up to me and sat down next to me and just started randomly asking questions about my disability. He asked 3 or 4 different things; and at that point, it had been a long day. And about after the 3rd or 4th question, I turned to him and said look I just don't want to talk about this right now, because I was dead tired and he was starting to annoy me. And then he turned around and said, well my step dad is in an electric wheelchair; and I was just asking because this, this, and this. And I went ok, and we sat and talked for another half hour.

From the example it becomes apparent that although Doug's own mood can influence what he is willing to share, he also is open to allowing his boundaries to become more flexible. Doug shared that when he knows that the person asking has a personal stake in the information, Doug is much more likely to share, even if he is in a bad mood. On the other hand, when Maria was younger she admits that she was always frustrated when people asked questions and was never willing to give an answer. When people asked questions, Maria viewed them as ignorant and thus put her in a bad mood and she was unwilling to answer. Maria expressed that until adulthood she was not prepared to give other people the benefit of the doubt. During adulthood, however, she realized that people really do not know unless you tell them, bad mood or not. For Maria, mood was a motivator but is no longer an issue. For Kenneth and Doug however, mood does play a role in deciding how to answer an inquiry. Likewise there are other motivators.

Gender as motivation

Many times the inquirer's gender was the basis for why a person who has a disability chose to reveal information. Although the reasons that people gave were diverse, the participants who chose to talk about gender agreed that they are more likely to talk to females about their own disability. For Nancy, however, she did not stop at disability-related information. She admitted that in general she prefers to talk to females

because they are easier than men to talk to. Adam on the other hand also prefers to talk to women over men but about disability-related information for a completely different reason:

I'd say if a girl asks I'm more likely to tell her things about my disability, than I am a guy. I think it's because I want to see what kind of chemistry we can develop, like as friend to friend, for a possible relationship.

Adam went on to say that if a woman has certain physical traits he is much more likely to be open. Thus he admits that attractiveness serves as a motivator for his privacy boundaries to become more open. For Adam, the benefit of possibly building a relationship outweighs the risk. Rachel's reasoning for talking to women over men about disability-related information is Adam's reasoning flipped, and instead leads her to hide information. Rachel drives, but she has to ask a co-worker to help her put on her chest strap. When it comes time for her to leave work, she prefers to ask women to help her because she does not want a man to know she needs help. Rachel also tries to make sure that no man is around when she has to put her chest strap on. "Especially with men or guys they are very um...they hone in on physical appearance and so I try and hide things that aren't so attractive, whatever." Nancy, Adam and Rachel may have different reasoning to consider gender when they are making a decision about revealing disability-related information, but all three participants show that gender does play a major decision-making role.

Getting the support needed

A couple of the participants talked about the motivation to open up their privacy boundaries to elicit what is needed and accept support from others. The participants both talked about how it was tough at first, but they had to get over it because they needed

something and therefore had to ask for help. For Sam, in college there were occasions when his nursing staff was not there because he only got a certain amount of help per day. None of his friends were available to help him out and he needed some personal help. “You know the first time asking them like could you...like could you help me use the restroom or...it was like...I need to go, but I don’t really want to ask, but there’s not really any other option at the moment.” The fact that Sam had to use the bathroom and had to disclose to an acquaintance that he needed help, affected the management of his privacy boundaries and the benefit of getting the needed help triggered them to open. However, Sam was not the only participant motivated to reveal to get the support needed.

Although Maria was not always comfortable revealing information about her disability, over time she learned that in order to get what she needed, she had to.

When I was ashamed of the disability and all that, I had trouble speaking up for myself, advocating for myself, requesting anything. So as I've grown older, I've learned that I have to say what I want or need, and I shouldn't be tentative about it. I get what I want more if I'm direct and sound very much like I expect a person to do whatever I'm asking them to do.

Being motivated to disclose information to someone was not something that came naturally to Maria. Over time however, Maria realized that the only way to get what was needed was to accept the support other people offered. Similarly to Sam however, was the idea that there are times when you have to get over asking for help. Also, there are times in which Maria had to disclose to a stranger.

...You have to fake it to make it. And so, when I got to work, I know I was afraid (inaudible word) of how things were going to get done, but I thought well I just have to, even though it makes me horribly uncomfortable...just talk to people and tell them what I need; ask random people to help me.

Although with both Sam and Maria it is not about people inquiring or being direct about disability by saying something like “my disability affects my arms, could you help me?” The idea that Sam and Maria know that they need something and are willing to ask for help reveals information about their disability. Thus, when they know they need assistance both Sam and Maria open their boundaries and admit that they need help because the benefit of getting what is needed is greater than the risk of admitting they need help.

The need to manage assumptions

There are times in interacting and conversing where people have beliefs about the other person based on their identity that are assumed to be true (Olney & Brockelman, 2005). “Managing assumptions with a person who does not have a disability” was the theme used for findings in which the person with a visible disability revealed disability-related information to get rid of assumptions. I chose to divide them up into two groups, to educate and to correct. The reason I separated the two categories is because I felt that it is important to distinguish the different reasons that individuals choose to diminish assumptions. The reason I chose not to include managing assumptions with motivators to reveal was because participants talked at length about the desire to lessen assumptions and I felt that based on the importance it should be its own theme. Many times people with visible disabilities experience this phenomenon and may reveal private information to correct the assumptions. A similarity consistent among several of the participants was the need to manage assumptions made by someone without a visible disability about the other person’s disability. Managing assumptions is a theme separate from motivation. Managing assumptions is described as a two-step process; first the participants were

annoyed or frustrated by and then they were compelled to manage the assumption.

Motivation on the other hand is a one step process; participants were compelled to act by the motivator.

Nancy mentioned that she would rather get questions than just sitting and staring, a feeling that that was expressed by a few of the participants. The need is what Petronio (2001) refers to as an expressive need. Revealing information fulfills a personal need or desire (Petronio, 2001), which is essential to a person's identity. The need to reveal disability-related information to quash assumptions was a factor that was considered when deciding whether or not to reveal. Although some of the people in the study corrected assumptions to educate, others chose to reveal information to simply correct. Either way, however, the similarity showed that privacy boundaries tend to become more unprotected when the person without a visible disability makes assumptions about the nature of the other person's disability.

Educate and inform

Although Maria went through a transformation in which her boundaries became more permeable, she reached that point in adulthood.

I would say not until adulthood was I willing to give people the benefit of the doubt asking questions. Um, it wasn't until that point where I could understand, look, these people really don't have any idea what's going on, and the only way that they will is if you answer and educate them.

Maria recognized as an adult that in order to quell assumptions, she had to educate the people who asked questions and made the assumptions. As she mentioned, "people really don't have any idea what's going on" and over time she recognized that by not revealing her private disability-related information when asked, she was doing a disservice to the person who inquired about her disability. Now Maria views questions as an opportunity

to educate people who may not otherwise learn. Although Rachel has never minded answering questions, she too likes to use the opportunity when a person does ask to educate them. Rachel explained that people assume she cannot drive, and so she loves when she has the chance to let them know that their assumptions are wrong and show them how she does drive.

I got out of the car and this old man, he's like probably 65, 70 years old, and he's just standing there, like with this look on his face...He's like (surprised voice) "did you drive that thing?" I was like "I sure did!!!" He's like "Wow! Well good for you!" (laughs) I was like "well...thank you." It was funny but I do get people say that and I've had a couple times where they're like "well how do drive it? Like what do you...how do you, you know." And I'll say...well I love showing off my car and I'll say well, come here and I'll go show them my joystick and um...Everything, so I, there are quite a few people at work...it blows their mind for a second...they're like "what's that??"

Rachel's privacy boundaries around educating others on how she can drive are extremely permeable. Rachel even admits that she has waited until someone is walking by to open the door. This way they are surprised and hopefully ask Rachel questions, which gives her the opportunity to teach. She demonstrates her abilities in an effort to change perceptions and assumptions. Her permeable boundaries to help others be educated came from her parents. Rachel explained that her parents taught her to speak up and educate because people who ask questions are just curious. So she chooses to help others learn.

Correcting

Educating someone who makes an assumption involves helping someone learn about disability and to become more aware. Correcting on the other hand, does not always involve helping the other person learn. Correcting a misconception is another motivator to allow privacy boundaries to be permeable that some of the participants talked about. Adam does not like when people make assumptions. Thus, he chooses to

correct people by revealing his private information even when it means feeling uncomfortable and revealing personal information. “Well this is another misconception...some people just assume...If you're in a wheelchair, you need help going to the bathroom. And that happened one time...and I hate it when people assume that because it's...it's weird.” Adam went on to say,

well one time um...when I...one time when I was down in the nurses office, and I asked her if...if I could use her restroom. And she said...ok what do I need to do? Do I need to cath. you...and I thought...What? What did you just say? But yea, that was awkward.

Thus, in this instance Adam was uncomfortable with the assumption. However his annoyance at the nurse’s assumption facilitated the need to correct the misconception. For Adam, assumptions are the foundation for certain privacy rules related to correcting misconceptions. Likewise, Doug often faces misconceptions about his disability. However, there are times that he chooses not to correct the assumptions outright.

And what I found out from dealing with a lot of people who've asked me questions is...they assume that because, you hear the word cerebral palsy and you think brain, and you think mental...you don't necessarily think physical. Obviously, it didn't affect my mental capacity at all...so people assume until they start talking to me and realize...he's actually probably smarter than me.

Therefore, the strategy that Doug uses in instances where he shares that he has cerebral palsy is to manage his identity by simply talking to the person further and allowing them to see that he is smart. However there are times for Doug where he has to be more blunt and outright. As previously mentioned, Doug was bullied when he was an adolescent.

Rumors were started and spread about him and Doug had to correct them.

Well...there were rumors going around about what did and didn't work...uh...body wise, and I would just flat out answer them because people are mean and they start rumors, but those rumors, obviously, aren't true. So, you just have to clarify yourself occasionally.

High school and adolescent years were pretty tough for Doug because he got bullied. Although he was skeptical in the instance that someone inquired about his disability, when it came to people assuming things because of his disability he had no problem bluntly correcting them. Bluntness is something that Nancy relies on when other people make assumptions. Like the others, Nancy also dislikes assumptions but is used to them. Nancy explained that before inquiring about her disability, people make a statement assuming why she has no hips or legs. The assumption that she has diabetes or was in a car wreck bothers her because the reason she lost both of her legs was a blood clot, and instead of asking people to assume. However Nancy's boundaries are quite permeable and she has no problem correcting people's misconceptions.

As shown through Maria, Rachel, Adam, Doug and Nancy a common reason for them to share disability-related information is to clear up assumptions that are made about their disability and the impact it has. As Brockelman and Olney (2005) found, people with visible disabilities tend to have a solid identification with disability and therefore want to clear up assumptions that other people have about their disability. Also, the participants managed the way in which their identity was perceived by quashing of how their disability affected them. Although the reasons span from wanting to educate to attempting to correct incorrect information, the desire or the need to reveal information is present. With the five participants that discussed assumptions what can be seen is that through both educating and correcting, an attempt is being made to help people who are not disabled understand, even when it means having to sacrifice privacy.

Regulating and controlling information

Disability is visibly obvious in the people that I interviewed. However, the interviewees still found the opportunity to control their information beyond what could be seen. The theme “regulating and controlling information” contained the sub-headings managing the extent of information given and managing the type of information revealed. For the sub-theme pertaining to extent the participant specifically spoke about regulating the range of disability-related information given, for the subtheme about type participants described managing the kind of information revealed. At the same time the interviewees were consciously aware of the decision they were making. Some of the individuals with visible disabilities had diverse ways of managing and regulating their privacy boundaries and the information revealed to someone who does not have a visible disability. Information management could be another way to describe the various ways of regulating the stream of information. What makes this theme distinct from others is that participants describe making deliberate decisions about the flow of information. Although interviewees do not describe being dishonest in the information revealed, they do describe purposely managing the way that the information is revealed. This is different from the other themes because this theme focuses on the way the information is managed. Whether participants were managing information to make sure the inquirer did not feel sorry for them or feel overwhelmed or controlling the type of information they let others know, the participants reported that they were aware and particular about the information that they were revealing.

Managing the extent of information given

There are times that people who do have disabilities report that in revealing information the other person has sympathy or pities them for having a disability. A couple of the participants talked about being uncomfortable if their disability-related information is met with pity. Thus the decisions made about the flow of information include controlling the extent to which something is revealed. For Rachel, although she uses a wheelchair 100% of the time and has never walked, one of the last things she wants is for others to pity her.

People don't really know what to say in other situations. Like "uhhhh I'm sorry!" And they, they feel bad, and I'm like don't feel BAD I'm just, ya know saying...I'm joking. Usually I was just making fun of myself, it's if it's with somebody without a disability because they'll feel uncomfortable and then guilty...Err not guilty, but um...feel bad for me and that's um bad is just...I'm just so that's why I guess why a lot of times I don't bring it up with people I don't know very well. Because the people that know me know that, ya know my personality. They know that I'm not looking for pity and so with people that don't know me as well I guess I generally don't bring it up as much because I don't know how they'll take it, and how they'll perceive me for it, so...

Rachel is aware that in many instances people will feel pity and that is why she controls the extent of her disability-related information. If she does not know the person well and they inquire about something, Rachel will be careful about what she reveals because she does not want pity. For Rachel, the notion of being pitied is a risk she does not want to take. For Doug however, the idea that he does not want pity is especially prevalent when it comes from women. "Obviously...I mean...as a man, you don't want to feel like...you don't want to feel like you're less of a man because you can't do something." Doug admits that he does not want women to know certain things about his disability because he is afraid that they will then look down on him. At the same time Doug also hides things that

may make it seem like he needs more help, although he thinks that he hides it without even realizing it. His privacy rule is to not let women pity him and he has learned that in order to do so, he must manage the information that he reveals. Sam on the other hand, does not necessarily hide information because if he needs help there is no way around that. What Sam does however, is manage the flow and the amount of information given.

That's always the (inaudible word) thing, to ask for help, cause I know I need it you know you don't want to be over with like people you just meet and all that stuff, you don't want to bombard them with stuff that you need, so just I'm just very nice and careful about how much you start out saying, like give them not all the information at one time.

Sam's strategy is not to overwhelm the other person, especially when asking for help. What is a little different for Sam than Doug is that he does eventually reveal all of the information. Sam just makes sure it is not all released at once. In this instance, Sam's privacy boundaries start out just opened a little and then expand, making sure that the information he wants to reveal is out there but in increments (Petronio, 2001).

Therefore, what Rachel, Doug and Sam showed is that there are reasons that cause them to manage the extent of what that they reveal and most times the outcome is to get the reaction they prefer. The reasoning for managing is shown to be different, however the idea that one can and does control the flow of information is not. Controlling the extent of information is more about managing the flow and making decisions about how much information is revealed when. Another strategy however, is to control the type of information revealed, which is more about making decisions as to how something is expressed.

Managing the type of information revealed

Two participants managed information in a similar way, but had different reasons for doing so. Although there are only two participants that comprise the subtheme “managing the type of information received,” I still chose to include the subtheme because both participants discussed managing the type of information several times during their interview. Sam controlled the type of information by not giving specific details of his disability-related information to people who inquired. “I just shared basically, they don’t really talk exactly about the disability itself, just like basic stuff, like muscles weak and stuff like that.” Sam manages his own privacy boundaries by only giving the generalities of his disability. Sam mentioned that he typically answers questions in a general way because he does not want to overwhelm the person. As Sam has gotten older he has become much more interested in learning more about his disability but he does not share the information such as his prognosis.

Likewise, Doug does not always reveal a lot of specific information either but for a much different reason. Since he was bullied Doug mentioned that he was a little leery when revealing private information about how the information was going to be used. For instance, Doug gave the example of being questioned about how he gets out of bed in the morning. His answer would have “scratched the surface” because he sees no reason to go into detail. At the same time, if he did not know the person well there was a fear of how that information would be used. Thus, for Doug he manages the specifics of his disability related information partly out of fear. Sam and Doug show that even if privacy boundaries are managed in similar ways people have differing reasons for doing so. The fact that they had different reasons for managing the type of information continues to add

to the idea that privacy boundaries can have similarities but those similarities only go so far. So far the themes have revolved around a person with a disability communicating with someone who does not have a disability. We will now move into looking at two people who both have visible disabilities and the way their privacy boundaries are managed in these instances.

Relating through identity linkages

Having similarities in identity and having the ability to relate plays a large role in the management of private information (Petronio, 2001). Several participants talked about how it was easier to talk to someone else who has a disability about their own disability. I chose not to separate statements about being able to relate to individuals who also have a visible disability into more than one category because as I was going through the transcripts I noticed that although there were variations of statements, it all boiled down to the ability to relate because of similarities in identity. Experience comes only from *being*. To connect through experience however, you must live the physical-ness of a visible disability. Thus statements that made reference to understanding because of physical awareness were categorized as well as statements referring to relating and understanding. Although the reasons that the participants gave were multifaceted and different from one another, there was one common element that wove through all of the explanations. That was the identity linkage they felt with the other person who also has a visible disability. As Petronio (2002) explained, identity linkages come from the shared experiences. However, more so than just shared experience participants felt a common identity, the ability to relate and had similarities in their privacy rules. From participant's descriptions, they describe less of an identity threat when talking with someone with a

visible disability. The interviewees do not need to explain their disability as much or manage assumptions in the same way. There was an understanding inherent in living with a disability, which was also exhibited through embodiment. Thus, there appeared to be a culture of disability that existed and was distinctly characterized by its own rules about privacy.

Rachel's own views of why she feels more comfortable talking to other individuals who have a disability shows that her privacy boundaries are more permeable because of the common experience. "I think when I'm with other people with disabilities I feel like...there's like a common ground just because they've experienced it." Although no two people are exactly the same, Rachel feels that there is a commonality that those who have not lived with a disability cannot relate to. However, for Rachel there is a heightened awareness that extends to others with a disability. "I feel like it's easier to talk about it with those people because they know better what I'm trying to say or better what I'm talking about because they usually have had similar experiences. When she talks about her own disability, there is an understanding inherent in the experience, such as when she tries to explain that she has difficulty swallowing. It takes her a moment sometimes and at work her co-workers think she is choking. She explains that she has trouble swallowing but sometimes has trouble explaining it. With someone else who has a visible disability the understanding of her disability's impact on her swallowing and what she is trying to explain is met with understanding. Another aspect of why Rachel's boundaries are more permeable with others who are visibly disabled is her disability itself and how her own disability can affect her talking. However, people without a disability

are less likely to have the awareness that a physical disability can affect breathing and volume.

Like sometimes I'm hard to hear, and so they don't know that I'm talking to them or whatever and then it gets really awkward like oh did she just say something to me, "yes I'm talking to you" (laughs) or they'll, they'll like just nod and smile because they don't wanna hurt my feelings or something like that, like I get that a lot at work where people don't really talk to me because...

Thus, Rachel understands that experience extends beyond understanding and can have an impact on the realization of how disability can affect the body. Similarly, Sam who has lived with a lifelong disability also recognizes that his own privacy boundaries become more permeable around a person with a disability because of the experience of disability. For Sam, having a disability means that one has more of an in-depth knowledge of disability.

Yea, like you can say more specific about the disability because a lot of people go through the same, not the exact same thing, but similar experiences with dealing with living with the disability and all that kind of stuff...I mean, you can be a little more open talking about another person with a physical disability than you can...you don't have to use as many generalities when talking to someone who has another physical disability, cause similar life, similar experiences they may share. And if you just say...if you talk more in the scientific terms and stuff of your disability to a person who doesn't, they might not exactly understand exactly what you're saying or going through.

While Sam recognizes that there are similarities and differences he also recognizes that there is also knowledge of disability that comes from experience. For instance Sam has Duchene's muscular dystrophy. He spoke of how he will tell people who do not have a disability he has muscular dystrophy. However, when he is talking to a peer who has a visible disability he will say he has Duchene's. This is because there is an understanding that comes from experience that muscular dystrophy could mean a host of different

diagnoses and more often than not, if he tells a person with a visible disability he has MD, the next inquiry is what kind? That is not to say that no one without a disability would know what Duchene's is, however unless it was a known that the person is substantially connected to disability, Sam would not start off a conversation that way. Therefore, for Rachel and Sam the knowledge of the bodily experience of living with a disability serves as facilitator for privacy boundaries to dissipate around someone else who has a visible disability. Experience included more than just understanding, which only requires empathy and can be achieved by virtually anyone. Shared experience came in a more physical state because to Rachel and Sam, living with a disability results in a greater awareness of disability and the ability to relate to others who have a disability.

Some of the participants described ways in which the similarities between the things that people with visible disabilities go through help to loosen up the concealment of private information and allows for revelations. Through the stories shared and from the understanding expressed, the individuals demonstrate that conversations are more open because of the commonalities already present between the individuals. At the same time it also becomes obvious that the understanding of what each other goes through allows for a less guarded dialogue. For Sam, when he is around others with visible disabilities he can compare stories with others.

I mean the topics that we talk about with other people that have their own helpers and aids and basically the help and stuff. You just bring up small little topics and stuff about cause' they have like sort of similar stories about the aids and nurses coming to help you get up and all that stuff.

Sam spoke of comparing stories about topics that people who are not disabled may not be able to relate to, such as having helpers and aides. He does not have to be as cautious about disability-related topics around people with disabilities because they are often used

to having help like him. Sam also talked about discussions about services that those who are disabled can talk about.

But yea and you mostly talk about the nurses and just like sometimes voc. rehab and stuff like that, like services that people like me use or the soccer team use and stuff that per say people that don't, might not really understand what exactly you have to go through to get everything that you need.

An interesting point he brought up is that people who do not have a disability may not realize what people who have disabilities have to go through to get what is needed.

Likewise, Maria drew from her own experiences on some of the topics that people without a disability may not be aware of or do not have the ability to relate to.

I guess it's easier to talk about certain disability matters in those kind of circumstances. And there are some things able bodied people just don't understand, like how hard it is adjusting to a new wheelchair...um...so those times it's great to have friends with disabilities...to talk about that kind of thing.

Maria likes having some friends who are also disabled because she then has people who can recount their own stories about the topic. This is known in CPM as reciprocity (Petronio, 2002) and in the instance with Maria it is because of the symmetry in personal characteristics and the social support that can be gained. She felt like talking about topics such, as a new wheelchair with people who are also wheelchair-users was easier because they could relate to how she felt. Her comfort also extended to more personal topics, such as dating.

When I was younger, there was definitely relationships that I didn't want to talk to able bodied people about...I had a lot of...I mean in high school, I genuinely felt that because I was disabled, no one, no able bodied person would love me in a romantic way. And so you know, I would never talk to any of them, about that kind of thing; whereas my friend Gina, who is in a wheelchair, I thought that she would understand cause she was having a lousy dating life too. So that was the kind of thing that she and I would talk about. We would commiserate together.

Thus Maria described that because she and Gina both shared in the ability to relate and had a common identity, it was a reciprocal relationship. Thus her privacy boundaries along with her friend felt comfortable enough to share things with each other and had similar stories about the hardship because they shared an identity linkage (Petronio, 2002). Maria talked about completely avoiding the topic of dating relationships with her able bodied peers in high school because they would not understand. The similarities were not there. And there was a fear that her peers would confirm that she may never have a relationship. With Gina however, the threat was not there because of the similarities in experience. Nevertheless, Doug brought up that he often would still talk to non-disabled peers about his dating troubles however, only with other people with disabilities could he elaborate. Doug acknowledged that although there are those times in which people without disabilities try to relate, for example if they break their arm and need physical therapy, they often do not realize the impact of having a lifelong disability.

Well obviously, when you have a disability, and you've been through a different...basically a different type of life than a normal person would have been through, then you sort of have a bond...I can say that I'm much more comfortable talking to a person who has a disability, and has been through...uh, a really a boat load of physical therapy or anything else...something that's just not...not a normal person wouldn't have had to go through. We've...uh...I went through physical therapy for years, and yea...if you break your arm, you might...if you normal and you break your arm, you might have that for like 6 weeks, and then you deal with it, but...all the different doctors visit and stuff like that. Uh...I'm definitely more comfortable talking about that with somebody who's already been part of it at least, than a normal person.

However, what was different with Doug was the realization that although he may be able to relate more to a person who has a disability his boundaries do not have to be completely impermeable with people who cannot relate. "I would say something to everybody, and realize that because people have different...people have been through

different things, people...disability wise...able bodied wise...they're going to have different reactions to the same answer to a question.” Although a non-disabled person could not exactly relate their insight was important still something that Doug was interested in hearing.

Although there was marked variability amongst the participants when it came to understanding and relating when talking to other people who have a disability, the feelings associated boiled down to the identity linkage present in these interactions. Although not all of the participants articulated why this was, Rachel had an “ah-ha” moment in which she reflected on why she feels more comfortable.

My friend told me this a couple weeks ago that she notices about me is that when I'm, whenever...I'm much more outgoing when I'm talking to people in wheelchairs or with disabilities than I am with other people, or with ya know...Pedestrians. Um, and I thought about it and was kind of annoyed at first, then I was like that's kind of true (laughs). Um, and I think it's because, I think it's because I feel more confident with like, people with disabilities because I've accomplished a lot in terms of...that kind of community. In terms of um, people like without disabilities I feel intimidated a lot of times because they don't understand. Probably with any group like whatever group you belong to you probably.

Thus, through self-reflection Rachel came to the conclusion that she is more confident around other people with a disability. Her privacy boundaries are more relaxed and she does not feel nervous. Although Rachel does not speak for all of the participants, her insight into the reason she is more outgoing further stresses the idea that disability is its own culture.

Discussion

Privacy decisions play a substantial role in the lives of most people (Petronio, 2002), and for individuals with visible disabilities research has confirmed an additional challenge of maintaining privacy (Braithwaite, 1991; Galvin, 2005). The additional challenge unique to people with visible disabilities is that their disability is obvious. The results of my study confirmed that there are difficulties in maintaining privacy but participants showed they have various ways of making decisions on how to disclose private disability-related information. While there are similarities and patterns among the decisions of people with visible disabilities, there are also variations in the specific ways people deal with their decision. While some participants disclosed private information in order to avoid the other person's assumptions, other participants managed the flow of information or even managed their privacy by revealing it in increments. Overall however, the participants exhibited that there is no one-size-fits-all process for revelations.

Discussion on Results

Although Galvin (2005) did not specifically discuss privacy boundaries, her research confirmed that people with visible disabilities are influenced by the attitudes and perceptions of other's without a disability. This point was then demonstrated in my study by the permeability of participant's privacy boundaries. Although it was not always explicit in the interviews and the interviewee did not share direct statements of being influenced by other's perceptions, their answers reflected that they were affected by other's attitudes. Such notions were identified by the need of many participants to clear up prior assumptions. For instance, Maria knows that people who do not have a disability

assume she cannot drive. She then puts herself in situations to show others that she can drive. Thus, my study showed a desire on the part of a person who is visibly disabled to prove the assumption wrong.

Likewise, Brockelman and Olney's (2005) study they found that people with visible disabilities think that others see them as unintelligent, which as Doug said is an assumption that he often faces. Doug uses the strategy of proving his competence to quash the assumption (Brockelman & Olney 2005.) Several participants mentioned various ways of dealing with assumptions because they often hamper interpersonal interactions (Braithwaite 1991; Shippen, Crites, Houchins, Ramsey, & Simon, 2005; Duggan, Bradshaw & Altman, 2010). Some participants see a person who has a preconceived notion as an opportunity and they use the chance to educate the person who has assumptions about disability, whereas other participants were annoyed and simply corrected the mistake. The differences in seeing an assumption as an opportunity and seeing an assumption as an annoyance shows that although there is a common pattern of managing assumptions there are also personal differences in approaches. The reality of assumptions, along with other factors influences a person with a disability to make decisions about their privacy boundaries.

People who have visible disabilities tend to spend a great deal of the decision-making process on deciding the specifics about who to disclose to, what sort and how much information to reveal. Adam for example, preferred revealing to women and likewise, several participants spoke about how they find it easier to disclose to women than men. Although my interviewees had varied reasons for disclosing to women, the finding of my study may be attributed an earlier study that found women have more

compassion towards people with visible disabilities (Hirschberger et al., 2005). The ability to control information however, extends beyond gender decisions. Regulating information is commonly exhibited in the context of chronic conditions (Olney & Brockelman, 2005; Donovan-Kicken, Tollison & Goins, 2011). The participants in my study exhibited numerous ways of controlling information. The interviewees not only managed the flow of information, but also managed the way in which they chose to reveal. Similarly to the findings in the Donovan-Kicken, Tollison & Goins (2011) study, while condition may not be controllable, controlling the flow of information means that participants still have some ability to regulate it.

Maria demonstrated regulating information in an interesting way. Throughout her interview, Maria describes a transformation going from regulating and controlling the information to the point of saying nothing about her disability to being open in adulthood. As shown through Maria there were changes in the way she regulated information over time, which was exemplified in the literature (Suter & Ballard, 2009; Bute & Vik, 2010). Maria also described that some of her transformation had to do with accepting her disability, because as a child she wanted nothing to do with disability or others who had disabilities. Although as a child Maria had trouble associating with people who also have disabilities, most of the participants in my study felt more at ease with people who also have a disability.

Participants were for the most part more comfortable talking to someone else who has a visible disability than to someone without a visible disability. The notion that the interviewees were able to be more at ease allowed their private information to freely flow. The participant Kenneth described being able to let his guard down, and other

participants had similar ways of explaining the difference they felt communicating with someone else who has a visible disability. Disability is sometimes described as a culture, and more specifically the sub-culture or community of people with a visible disability was confirmed by the results of my study (Goodwin, Johnston, Gustafson, Elliott, Thurmeier & Kuttai, 2009; Obst & Stafurik, 2010). Participants described being more open because of shared experience and understanding. Petronio uses the term identity linkage to describe ease conversing with someone who has similar experiences. Participants had numerous ways to describe this phenomenon but the thread weaving through all of the reasons are that was that having an identity linkage was an important part of interpersonal relationships. The identity linkages that people who share a common bond experience and the difference that is experienced in interpersonal communication with people who do not have a disability furthers the notion of disability as a culture or at least a community (Goodwin et al., 2005).

Although the findings cannot be generalized in a qualitative research study, consistently the results revealed that the identity linkage (Petronio, 2001) present with two people who both have a disability makes boundaries more permeable. The results of the interviews showed that participants are also aware that they are more comfortable in situations where another person with a disability is present. Participants often reported that because there is a greater awareness and knowledge about disability, it is easier to reveal the information. It was interesting to see a difference when participants talked about the experience from knowledge.

Overall what I captured from the interviews is that people who also have a visible disability are more aware of the day-to-day challenges of living with a disability. Having

the understanding and knowledge of having a disability means that several participants felt like they could reveal more because someone with a disability is going to understand what they mean. For instance, Rachel talked about her swallowing. Someone else with a disability is more likely to understand that disability affects more than the external being (Docherty & McColl, 2005). My study contributes knowledge in the area of disability and communication. This is because my interviews and results looked at communicative interactions beyond what has been previously looked at by examining privacy management in a situation where an identity linkage exists.

Discussion on Methods

Looking at my methods, I found that there were pros and cons to using convenience sampling. The pros were that I was able to get to the founder of Indy Power Soccer easily and was able to get the word out there quickly because I already know her. However, there were downfalls. Even if I only know of the players on a very impersonal level, the fact that the people may see me again after the interview may have deterred some participants. Also, the founder of power soccer told me that several of the Power Soccer of Indy players had participated in a long drawn-out survey and may not want to do any type of research. Although she informed me of this, I went ahead and attempted to recruit. Overall, I should have started the study with a more aggressive recruitment strategy. I feel like I wasted some time by starting out too timid and trying to connect through power soccer when I could have tried other means.

During the interviews I noticed that there were times when the wording of the question I asked was not clear to the participant. I chose to employ a unique method to approach this. I reframed the question by using my own answer as an example. I did not

disclose private disability-related information, however. For instance, one question that seemed to give a lot of the participant's trouble was when I asked them if an earlier conversation informed the way that they now handled private information. The way I explained it was "from early conversations I learned that I should avoid divulging too much information at once because it makes the person without a disability uncomfortable." Thus I was able to explain what the question meant without giving too much information. Overall I felt it was a good tactic. However, it had its pros and cons. Besides the fact that my tactic helped the interviewee understand the question better, it also served as a way of connecting with the participant. The con was that by providing an example I felt that sometimes the interviewee took the example and said the same was true for them. The results however, proved to be multi-faceted while also having distinct similarities.

The researcher's voice

I conducted this study on the management of privacy boundaries by people who are visibly disabled from the perspective of a person who is visibly disabled. Some of my motivation can be attributed to curiosity and some a personal interest. After collecting and writing up the results, I had time to reflect on the various themes that were identified. In this section titled "the researcher's voice" I have decided to include my own personal feelings and reactions to the themes I identified. The reason I have chosen to do this is because being part of the population I am studying allows me to relate to the participants in a personal way but at the same time still allows me to maintain the role of researcher (Tracy, 2013; Ellingson, 2003).

What was surprising was that several of the participants reported not ever having gotten a question that makes them uncomfortable. I thought I was the only one who never got asked anything inappropriate because I have heard numerous stories about the rude inquiries people get. Rarely, however, do people mention the opposite and that is why I wondered why I have never been asked something awkward. It is not that I want to be asked something that makes me uncomfortable; it just seemed odd that I had not. So I was somewhat glad to know that I am not the odd one out and there are people like me. Although I was not surprised that people with visible disabilities have substantially permeable boundaries when it comes to general disability information, something that really struck me was that a person's mood interfered with how they responded to an inquiry. I had never really considered the interference of one's mood because I do not like to let my mood show in how I interact with people. Thus I try to just "grin and bear it" even if I am annoyed or stressed. The first time that someone mentioned mood, however, I remember being surprised and after that I made sure to ask further questions if an interviewee mentioned their mood playing a role. However, there was one finding that did not surprise me at all.

Managing assumptions is something that I often engage in. I can relate to a lot of the participant's strong dislike for assumptions about the disability and the need to qualify them. I was not surprised at the desire to manage assumptions once I heard my first participant say it, but I did not go into the project thinking I would find that people do not like assumptions. Although I have often wondered why I dislike assumptions so much, at least now I realize that disliking assumptions goes across the board. With identity linkage and the culture of disability, I hoped that I would find that conversations are more

comfortable with someone else who has a disability because that was how I felt. Yet I went into my study with an open mind because I knew my interviews might prove me wrong. I did find that most of my participants were more comfortable, confident and outgoing with someone else who has a disability however. I think that part of the reason for this ease of comfort with others who have disabilities is because of the ability to relate.

Overall, there were a few surprising revelations participants made but there were also things I knew to be true of myself that I found were similar to others. What this demonstrates is my own personal connection to disability shares some common patterns with others who have a visible disability. From a scholarly standpoint I was interested in finding that there were similarities and patterns amongst the participants and I was most interested in the identity linkage finding. I have read literature that supports the notion of disability as a culture and I have seen other literature dismissing the idea. However, I had never conducted a study for myself. Although my study looked at privacy management and not solely disability culture, there were findings that supported the idea of disability culture or at best a sub-culture.

Limitations

There were three main limitations to my study. Although there seemed to be a difference between people who were disabled early in life and participants who faced a disability later in life, I did not have the participant number I hoped and was unable to study just one group. I had begun the study planning to only study those who had a visible disability by age 6. The reason for this had to do with Cardillo (2010) who spoke of the unique insight from people who have a lifelong disability. However, because I was unable to do this I opened my study up to those who became disabled later in life. Thus,

my results are not always looking at privacy boundaries over the course of the lifespan, which I think would have given the study a more complete picture of the way that disability affects the way private information is managed. Another limitation of my study is that my sample was all from the Indianapolis area and no participants from rural areas were included. Rural communities are less populated and interactions are typically with the same people throughout life. In a metropolitan area there is more of a chance that people interact with different people. The sampling may have been more diverse if there were geographic variations. There may have been differences in the management of privacy boundaries between people living in a metropolitan area versus living in a small rural area. Also, my sampling could have been more racially diverse, which I feel is a limitation. All of my participants are white. Being more diverse in race may have given a different perspective on the way privacy boundaries are managed because across races there can be cultural differences.

Lastly another limitation in my study was that I was the only person to code the data and write up the results. The reason that I chose not to ask an outside party or one of the participants is because I double-checked my decisions. I created both primary codes and secondary codes, so first the data went through primary coding where I categorized broadly. Then the secondary coding was more specific. Having both primary and secondary codes meant that I was familiar with the data even more and I had even more of a chance to catch any errors. Thus, I did not feel that at this time I would have someone else check. Overall, although my study did have limitations I am confident that my results are revealing about the management of privacy boundaries by people with visible disabilities.

Future directions

The results are revealing but the current study facilitated the need for further research. The results have implications for further studying healthcare. The results of my study revealed that there are differences in the way that disability-related information is shared with people who do not have a disability versus people that do. At the same time a difference in comfort levels and a willingness to address inquiries seems to exist because of the similarities in identity and experiences. Thus, strategies that may foster better health outcomes are needed and the knowledge from this study may help inform future research. For instance my study found that all of my participants are okay sharing general disability information. This finding can inform medical personnel who is hesitant about inquiring. Also, the findings on identity linkages and the culture of disability have implications for further study. Research could be done examining the people who have had a life-long disability, people that came to have a disability later in life and whether or not the living with a visible disability throughout life impacts the strength felt of the identity linkage.

Conclusion

Privacy boundaries mark the limits of how much private information someone is willing to reveal. In my study I looked at the ways privacy boundaries are managed for people who have visibly obvious disabilities. However, what was apparent was that privacy boundaries could be made more or less permeable depending on motivation and assumptions. Although participants in my study expressed that they do not always have control over whether or not they are going to reveal disability-information because it can be seen, what participants did have control over was the specifics of the private

information that goes beyond the visible. The boundaries however seem to be more open when a person who has a visible disability is talking to someone else who has a visible disability. The reason for participants to allow information to flow freely is because they feel more at ease and share a common identity with someone who has a visible disability.

APPENDIX 1

Privacy Management in People with Disabilities Interview Protocol

Thank you for your participation. I'm conducting research on how people with visible disabilities manage the boundaries around private information with others who also have a visible disability versus when talking with someone who does not have a disability. If there are questions in the interview that you'd rather not answer, just let me know. If you have any questions for me, please feel free to ask them at any time.

1. To begin, please describe your disability and the onset.
2. What did the conversations about your disability with your peers growing up look like?
 - What were the types of questions you were asked?
 - Tell me about your comfort in responding.
 - What were the aspects of your having a disability you did not like to discuss?
 - How did you deal with the issues you did not like to discuss when the topics were brought up?
3. Tell me about your discussions nowadays with acquaintances or strangers who do not have a disability about your own disability.
 - Tell me about the conversations you have.
 - Tell me about issues you do not like to discuss with regards to your disability.
 - What is your response when these issues are brought up?
4. What are some of your experiences with others who also have a visible disability?
 - What do your conversations with them about private information look like?
 - Tell me about your (non) comfort in responding.
 - What are the aspects of your life you do not like to discuss?
 - How do you deal with it when these issues are brought up?
 - What aspects are you more/less comfortable in talking about?
5. Describe any differences in having conversations regarding your disability with others who also have a disability versus no visible disability.
 - *What are some memorable conversations you can recall that illustrate the difference?*
 - Describe any differences in what issues related to your disability you discuss.
 - If there is a difference, what do you feel the reason is?
6. How do you feel that your privacy boundaries change when you are talking with someone who has a visible disability also?
 - What do you feel accounts for this (non) difference?

7. Please account for whether or not there are certain issues that you discuss with those who do not have a disability but not with those who have a visible disability or vice versa?
 - For instance, please explain if there are certain topics you only talk about with those who do not have a disability.
 - What are your feelings about this difference?
8. Please explain any conversations or topics of conversation regarding your disability that changed the way you handle private information about your disability.
 - Please describe the conversation(s).
 - What did this conversation do in terms to your privacy boundaries?
9. When you talk to others about your disability, what factors or characteristics do you look for before disclosing disability related information?
 - Vice versa, what factors or characteristics make you decide not to disclose disability related information?
10. Please explain whether your privacy boundaries have changed over your life in communication with those who have a visible disability?
 - (To clarify) What have you learned from past conversations that inform future conversations?
11. Before we end the interview, is there anything else you would like to add?

APPENDIX 2

Code:	Definition:	Example:
Managing assumptions	Divulging private information because they fear the other person making an incorrect assumption.	I try to make sure that people don't just assume things; and if they assume things, I correct them if they're wrong.
Initiating conversations	Initiating talk about private disability information.	I do bring it up at work... I'm always the one who brings it up and then they'll chime in a little bit.
Identity linkage (Petronio, 2001)	Comments on feeling more at ease when talking to someone else who has a visible disability.	We knew what each other had been through and how each other were thinking about things, usually
Mood as motivation	Interviewee's mood regulates the information they give.	It really depends on my mood at the time.
Not wanting to appear helpless	Managing private information to not appear helpless, not wanting pity.	I'm not looking for pity.
Giving general Information	Not giving specifics about disability. Instead only providing general information.	I guess generally I don't like to talk about specific things,

APPENDIX 3

Privacy Management Codebook

	Explanation	Example	Primary codes
Permeability varies by inquiry	In general, the interviewee’s boundaries are permeable to a certain extent but permeability varies by inquiry.	“I’m an open book now and I prefer that things be out in the open, so that they can be addressed.”	Openness
Motivation to reveal or not reveal to a person without a disability			
Mood as motivation	A statement that the decision to reveal hinged on the interviewee’s mood	“It really depends on my mood at the time”	Mood
Gender as motivation	The decision to reveal information depends on gender of the other person	“I’m more open with pretty much a female than a male. I feel more comfortable speaking with them about something that has to do with the disability.”	Gender
Getting the support needed	A statement by the interviewee that refers to revealing or not revealing disability-related information to get the support needed	“You know the first time asking them like could you...like could you help me use the restroom or ...it was like...I need to go, but I don’t really want to ask,”	Helpless
Managing assumptions with a person who does not have a disability			
By correcting	Revealing private	“I would just flat out answer	

	information to correct a false notion	them because people are mean and they start rumors, but those rumors, obviously, aren't true. “	
By educating	The interviewee responds to a disability-related assumption by revealing information to educate others	“ My parents always got me to speak up for myself and ya know, help other people learn.... They're just curious.”	
Managing and controlling information			
Managing the extent of information given	A statement referring to controlling or regulating the amount or extent of information shared with a person without a disability.	“You don't want to bombard them with stuff that you need, so just I'm just very nice and careful about how much you start out saying, like give them not all the information at one time.”	
Managing the type of information revealed	A statement referring to controlling or regulating the type of the information shared with a person without a disability.	“ I just shared basically, they don't really talk exactly about the disability itself, just like basic stuff, like muscles weak and stuff like that.”	
Relating through identity linkages			

Examples:	A statement explicitly referring to being aware of the physical experience of disability and thus being able to share information with someone else who has a disability	“Yea, like you can say more specific about the disability because a lot of people go through the same, not the exact same thing, but similar experiences with dealing with living with the disability”	Experience
Examples:	A statement in which the interviewee discusses being more at ease because of connectedness talking to someone who also has a disability	“ I guess it's easier to talk about certain disability matters in those kind of circumstances. And there are some things able bodied people just don't understand”	Understanding Comfort

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CURRICULUM VITAE

Erin McAloon

Education

Master of Arts in Applied Communication
Indiana University, IUPUI
July 2014

Bachelor of Social Work
Indiana University, IU
May 2010

Current Memberships

National Communication Association
Disability Caucus, Secretary

Awards

Volunteer of the Year, Bosma Enterprises, 2011

Research Experience

Qualitative Research Assistant
IU School of Medicine
Supervisor: Tucker Brownsyne Edmonds, MD
Winter 2013

- Project looked at how resuscitation options are presented by neonatologists to pregnant women who experienced rupture of their membranes at the pre viable gestation age
- Utilized NVIVO software to code transcripts

Community Based Research Project
Department of Communication, IUPUI
Faculty Supervisor: Elizabeth Goering, PhD
Summer 2012

- Research team completed a content analysis on a nonprofit organization's communication with the larger Indianapolis community regarding a community program
- Applied critical evaluation to the numerous messages communicated by the organization.

Days Analysis Team
Department of Communication, IUPUI
Professor: Nancy Rhodes, PhD
Spring 2012

- In-class research project looking at undergraduate's knowledge of communication theory
- Analyzed the results of focus groups and interviews using SPSS software
- Presented findings to faculty of the Communication Department.

Applied Rhetorical Project
Professor: Kristy Horn Sheeler, PhD
Fall 2011

- In-class project involved critical examination of the department's website
- Utilized knowledge from rhetorical persuasive methods to suggest and present changes

Experience

Autism Society of Indiana
Indiana Youth Leadership Forum Coordinator
Executive Director: Dana Renay
May 2013-Current

- Developing the Indiana Youth Leadership Forum, a youth leadership-training program for 11th and 12th graders with disabilities.
- Responsibilities include the recruitment of students and volunteers, develop curriculum and handle logistics
- Utilize effective communication to develop relationships with organizations throughout the community, to facilitate discussion and hold meetings.

MDwise
Indianapolis IN
Customer Service Representative
May 2012- May 2013

- Assisted members in understanding their health coverage and educated them on what their coverage entailed
- Applied interpersonal and relational skills as the first point of contact for members
- Responsible for representing the company and holding up the integrity of the department and had to utilize conflict management when working with members

Community Service

Bosma Enterprises, Indianapolis IN

Volunteer legislative researcher and outreach dispatcher

Volunteer Supervisor: Lise Pace

2010-2012

- Conducted research into the interests of various legislators and helped to create a legislative communication plan
- Coordinated outreach events by organizing and preparing materials, staffing the attendance of events with volunteers, assisted with trainings and represented the organization at events
- Administrative duties as needed