INVISIBLE DIS/ABILITIES: TO DISCLOSE OR NOT DISCLOSE?

by

Julia Roma Broderick

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Julia Roma Broderick

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Kelly Rossetto, Ph.D.	Chair, Supervisory Committee
April S. Masarik, Ph.D.	Member, Supervisory Committee
Heidi M. Reeder, Ph.D.	Member, Supervisory Committee

The final reading approval of the thesis was granted by Kelly Rossetto, Ph.D., Chair of the Supervisory Committee. The thesis was approved by the Graduate College.

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ABSTRACT

Approximately 56.7 million people currently live with a disability in the United

States (United States Census Bureau, 2012). Many of these disabilities are invisible to

others, which make disclosure necessary to gain support. Through the analysis of open-

ended questionnaires, I investigated disclosure decision-making factors and outcomes for

individuals living with invisible disabilities. Factors considered for disclosure included:

(a) support; (b) fear of negative response; (c) perceived appropriateness; and (d) no

choice or perceived obligation. Disclosure outcomes included: (a) relief; (b) closeness in

relationship; (c) loss of relationship; (d) differential treatment; and (e) no change or

negative outcome. Theoretically, the findings help extend our understanding of the

Revelation Risk Model (Afifi & Steuber, 2009) in terms of the disclosure process for

people living with IDs. Additionally, I explore practical implications for better supporting

those with IDs through the disclosure process.

Keywords: dis/ability, invisible disabilities, stigma, secrets, putative secrets, risk,

revelation, disclosure

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CHAPTER 1: INTRODUCTION

Social Significance

One in five individuals in the United States have a disability, which equates to 56.7 million people (United States Census Bureau, 2012). Living with a disability can influence every aspect of one's life, including relationships (Galvin, 2005), self-identity (Newheiser & Barreto, 2014), and employment (Dalgin & Bellini, 2008). Failing to recognize and understand these difficulties can marginalize those with disabilities.

Just like "sexism" and "racism" refer to assumptions about the superiority of a group, ableism is the lens that assumes what a body 'should be' (Hehir, 2002). This lens can include perceptions of dis/abilities both seen and unseen. Ableism can make those with disabilities feel isolated or mistreated (Hergenrather & Rhodes, 2007). To avoid using ableistic vocabulary, I will use the word "dis/ability" to highlight that within the word itself, there is ability. One may have a dis/ability that limits them in some regards (e.g., hearing) but not limit them in other aspects of their life.

When society stereotypes those with dis/abilities, human rights can be jeopardized (Duncan, 2001). Individuals with dis/abilities, both physical (e.g., lupus) and non-physical (e.g., dyslexia), may be at risk when held to ableistic expectations (Duncan, 2001). An example of an ableist structure is a building that is not wheelchair accessible. Ableism does not often consider accommodations or inclusivity that would allow all to partake in society (Duncan, 2001). For this reason, those with dis/abilities should be studied to understand how they can be better supported in society.

The overall goal of this study is to understand how individuals with disabilities choose to disclose or not disclose their diagnoses. My curiosity for this topic stems from personal experience living with a dis/ability since birth and a concern for others who experience mistreatment due to their abilities. To ground the terms for this study, I first define dis/ability, invisible dis/ability, disclosure, and stigma.

Dis/ability and Invisible Dis/ability

Acknowledging that no single definition of dis/ability can fully encompass every experience, Iezzoni and Freedman (2008) call for both medical and societal definitions to be made on a case-by-case basis. I adhere to this framework and attempt to create inclusive language surrounding dis/ability. As such, dis/ability is defined as a diagnosis or syndrome that creates any kind of barrier in an individual's life (Iezzoni & Freedman, 2008). One's perception and experience of their dis/ability can be unique; one may see their diagnosis as a curse and another as a blessing. For example, deafness is not exactly the same for all that experience hearing impairment.

Invisible dis/abilities (hereafter, IDs) are dis/abilities not immediately apparent to others (Canary, 2008). The invisibility of a dis/ability may influence one's perceived ability (Canary, 2008). Although not apparent to others, due to their unrecognizable traits, IDs are constantly present for the impacted individuals. Examples of IDs include infertility, epilepsy, chronic pain, hearing impairment, cerebral palsy, and diabetes. This is a small list of diagnoses that impact many individual's lives. These examples have a variety of symptoms, severities, and stories that are worthy of study because having an invisible dis/ability obligates an individual to weigh the risks of sharing or concealing their diagnosis. However, with the invisibility element of IDs and the need for sharing a

diagnosis for others to know, disclosure is a key to understanding individuals' personal and relational experiences. However, stigma can be a barrier to this self-disclosure (Smith, Rossetto, & Peterson, 2008).

<p style="text-align:center"><u>Perceived Stigma and Over-generalization</u></p>

Stigma is a communicated occurrence built on stereotypes about a group and its members (Smith, 2007). Stigma messages provide cues to distinguish and categorize people as a separate social entity and evoke disgust, fear, and anger (Smith, 2007). Related to stigma and dis/ability, Brewster (2004) studied adjectives linked to those with dis/abilities and found terms such as shame and helplessness attached. Although stigma is often communicated, it can also be anticipated or perceived, based on one's fear, even if it is not overtly present (Shi et al., 2017). This perceived stigma can stem from a lack of support, both informational and emotional, from others (e.g., medical support groups; Shi et al., 2017).

People often make assumptions or over-generalizations about people living with dis/abilities, which can be isolating (Fitch, 2002) and negatively impact relationships (Brewster, 2004; Galvin, 2005). Participants in Wong and Wong's (2006) study reported mistreatment (e.g., hurtful questioning) and stigmatization from medical professionals, hospital visitors, and loved ones when they disclosed their HIV status. In Gonzalez and Jacobsen's (2012) study on patients with lung cancer, patients who perceived stigma had increased depressive symptoms and overall negative emotions (Gonzalez & Jacobsen, 2012). Stigma from one's social network can be more traumatizing than outside the network (Wong & Wong, 2006). For example, being laughed at for having a dis/ability

can result in feeling shame (Gray, Parkinson, & Dunbar, 2015). Over-generalized and clichéd questions about one's abilities are also perceived as unsupportive (Galvin, 2005).

Perceived stigmatization surrounding one's dis/ability can affect communication with the self and others (Guo et al., 2012; McMillan, Hill, & Mossey, 2011). For example, individuals with IDs may attempt to avoid taunting from others (Gray et al., 2015). Avoidance, and lack of disclosure, is a way to shield one's self from future perceived stigma (Newheiser & Barreto, 2014). Once individuals perceive they have been stigmatized (e.g., after disclosing a previous mental illness battle), they are likely to conceal in the future (Newheiser & Barreto, 2014; Smith et al., 2008).

The preceding sections reviewed dis/ability and stigma, and framed invisible dis/abilities as secrets to be disclosed. For one's ID to be known to others, the diagnosis must be disclosed. However, disclosure can be difficult due to potential stigmatization. Indeed, the more stigma one faces, the less likely they are to disclose (Smith et al., 2008). Based on these reasons, secrets and disclosure must be explored and applied to IDs in the proceeding review of literature. With the exploration of the Revelation Risk Model (Afifi & Steuber, 2009), reasons to disclose or not disclose secrets will be established and applied to IDs.

CHAPTER 2: REVIEW OF LITERATURE

Secrets

Secrets are the act of deliberately keeping information private from others (Bok, 1983). Secrets contain information that at least one individual consciously withholds from at least one other person because they do not want to or cannot reveal to others (Frijns, Finkenauer, Vermulst, & Engels, 2005). They can range from an indiscretion to the knowledge that one has a serious diagnosis. The invisibility of a dis/ability makes it something that could be held as a secret. There are different types of secrets, including individual secrets, family secrets (Vangelisti, 1994), putative secrets, and third party secrets (Caughlin, Scott, Miller, & Hefner, 2009). The proceeding section will explore different types of secrets as they relate to disclosure and secrecy behaviors.

People can know secrets when a secret keeper is unaware it has been leaked. These types of secrets are called putative secrets and involve ongoing attempts to conceal a secret that is actually known (Caughlin et al., 2009). Common examples of putative secret topics include dating or sexual history, partying, or physical health (Caughlin et al., 2009), but IDs could also be putative secrets. A secret keeper of a diagnosis (e.g., diabetes) may think that others do not know about their diagnosis, but in reality, someone does. Putative secrets highlight how more than just the secret keeper can become involved in a secret. For example, Greenberg and Smith (2016) analyzed how secrets about genetic testing affect a family as a whole. In the context of family health

information, different family members attach ownership or personal concern to the secret or disclosure (Greenberg & Smith, 2016).

Interestingly, both the secret keeper and the putative secret holder are concealing information. Putative secrets are kept for a variety of reasons. For example, one might keep a putative secret for personal gain, to avoid negative evaluation, to protect privacy, and to protect the relationship (Caughlin et al., 2009). For some, putative secrets are kept to avoid negative outcomes for the person the secret is about or to protect a loved one from being judged or stigmatized by a potential revelation (Caughlin et al., 2009). An example of this may be keeping another's positive HIV status secret. If a person feels they would keep a secret private if the information was their own, they are more likely to conceal the putative secret about someone else (Caughlin et al., 2009). On the other hand, third parties who know about a secret may reveal it, even if they were advised to conceal it (Caughlin et al., 2009). They may also pressure the secret concealer to reveal the information to other family members in events such as a medical crisis (Afifi & Steuber, 2009).

Although the different parties involved can complicate keeping secrets, secret revelation is often an act associated with the secret keepers themselves. Keeping secrets occurs through different behaviors, such as not bringing them up, attempting to act normal, avoiding the subject, and overt denial (Caughlin et al., 2009). This act of secrecy can be instinctual at all ages, including children (Anagnostaki, Wright, & Papathanasiou, 2013). According to Frijns et al. (2005), secrecy requires secret keepers to actively engage in protecting the secret and preventing others from finding out about it through various behaviors (e.g., omission, deception, lying, distraction, inhibition, thought

suppression). Therefore, "secrecy is not merely the opposite of self-disclosure (i.e., sharing personal information with others)" (p. 138), though clearly the two partner with one another.

Disclosure

To share a secret with another is to self disclose (Kowalski et al., 2015). Disclosure involves sharing information with another person (Anagnostaki et al., 2013). More specifically, disclosures are admissions of fears, beliefs, values, and experiences (Gray et al., 2015). Disclosing is a strategic act in the pursuit of social approval, relationship and identity development (Omarzu, 2000). Studies of disclosures pertaining to dis/abilities demonstrated the complexities of sharing a diagnosis or experience pertaining to ability issues (Rocco, 2004; Valle et al., 2010). The act of disclosing a learning disability, for example, is not a singular event, but a personal process with ongoing factors without finalization (Valle et al., 2010). Furthermore, people with visible dis/abilities have different experiences disclosing a diagnosis than those with IDs who could pass as a non-disabled person if they chose (Rocco, 2004). Valle et al. (2010) refer to this as "coming out" with an ID to others.

Individuals with dis/abilities (physical and non-physical) may be reluctant to disclose their diagnosis in a professional setting (e.g., to a prospective employer) and in educational settings (Pennington, 2010; Valle et al., 2010). One's disclosure pertaining to a diagnosis can depend on their experience with previous questions, education, and how their diagnosis was discussed in their familial setting (Duggan, Bradshaw, & Altman, 2010; Valle et al., 2010). The role that a diagnosis has in one's life may determine if their diagnosis is framed as a secret, and therefore, something to be disclosed. For example,

Valle et al., (2010) studied teachers with learning dis/abilities. Some participants were raised in environments that acknowledged the dis/ability as a part of one's identity rather than labeling the individual as disabled (Valle et al., 2010). Also, some of the participants grew up going to schools that integrated them in 'regular' classes, despite having learning dis/abilities; other participants were consistently placed in special education. Perceptions surrounding disclosing their diagnoses (e.g., to students) were dependent on the background and experiences of these individuals.

Similarly, Greenberg and Smith (2016) found in their work that young people have a tendency to see more value in disclosure than those who are older. This tendency is in part based on upbringing and the perceived acceptability of disclosing personal information, such as genetic testing (Greenberg & Smith, 2016). Individuals weigh interpersonal outcomes (Kim, Harris, & Warneken, 2014) or risks (Afifi & Steuber, 2009) when considering disclosure of a secret. Disclosure can be perceived socially acceptable for younger generations who may have been raised in a more open environment (Greenberg & Smith, 2016). While weighing outcomes and risks, people find reasons to disclose or not disclose secrets to others.

Reasons to Disclose

There must be a significant reason to disclose a personal secret to another person (Vangelisti, Caughlin, & Timmerman, 2001). Disclosing a diagnosis can be a cathartic act (Afifi & Steuber, 2009). Incentives for disclosing include seeking support and closeness in a relationship (Afifi & Steuber, 2009; Anagnostaki et al., 2013). Additional incentives to disclose include the desire to support others, the perception of the inevitability of the secret's revelation, and family obligation (Vangelisti et al., 2001). As

such, determining the 'right people' to disclose to is important to consider for the secret

revealer (Emmerick, 2006). These reasons for disclosure are useful in understanding

secret revealing and are likely to be applicable to IDs.

A reason for disclosure can be for the development of one's self-identity

(Omarzu, 2000). An individual may wish to disclose a secret (e.g., sexual orientation) to

avoid 'passing' (Croteau, Anderson, & VanderWal, 2008; Herek, 1996). In other words,

if one does not disclose their sexual orientation in the workplace, this may lead to

feelings of fabrication of one's self identity (Croteau et al., 2008). This experience can

span to other secrets, including dis/abilities (Valle et al., 2010). To disclose one's

learning dis/ability is to be honest and not falsely pass as a person without this ID (Valle

et al., 2010). Secrecy may perpetuate internal stigmatization and shame because one has

left unchallenged the misperceptions that may equate to faulty assumptions such as low

intelligence (Valle et al., 2010). For some, disclosing a secret feels more truthful and can

lead to self-acceptance.

Some individuals reveal secrets to seek support from others, including one's

social network, friends, spouses, and family members (Greenberg & Smith, 2016). With

IDs and illnesses, such as HIV, individuals who disclose their diagnosis to others receive

more support than those who conceal (Smith et al., 2008). A primary motive of disclosing

a secret, such as genetic testing results or a diagnosis, may be to seek resources and help

with that experience (Greenberg & Smith, 2016). This support can range from medical

attention to venting about the diagnosis. Venting to others in the event of disclosing can

be cathartic and a way to receive support (Afifi & Steuber, 2009; Greenberg & Smith,

2016).

Individuals may also disclose a secret to provide support (Afifi & Steuber, 2009) or modeling for others (Valle et al., 2010). Some individuals find purpose in disclosing a secret, such as a learning dis/ability, to connect with others and lend their experience of sharing a similar difficulty (Valle et al., 2010). Importantly, disclosing to support others can potentially influence others to have better self-acceptance and esteem going forward in their own lives (Valle et al., 2010). Valle et al., (2010) found that teachers with learning disabilities sometimes felt that being open and honest about their dis/ability may inspire others to see people with their diagnosis thriving in the world.

Finally, intimacy with another individual can oblige a person to disclose a secret or diagnosis (Afifi & Steuber, 2009; Greenberg & Smith, 2016). A disclosure may seem like an ethical choice based on one's relationships with whom they desire to disclose (Afifi & Steuber, 2009). This obligation can exist in a family situation, such as a wife disclosing her infertility diagnosis to her spouse. Obligatory disclosure may be motivated based on the perception that the loved one is entitled to the secret, and not necessarily the revealer's need for a cathartic experience exclusively. Greenberg and Smith's (2016) study demonstrated that individuals who underwent genetic testing believed their families could be affected by their results; therefore they felt it necessary to disclose.

Reasons Not to Disclose

Although some individuals find reasons to disclose, others do not. Individuals may find reasons to conceal a secret from past experiences or the perception that a negative experience might occur. Reasons not to disclose a secret may be based on the fact that they wish to keep it a secret (Vangelisti et al., 2001), or perceived negative relational outcomes and negative reactions from others (Vangelisti, 1994). Even if one

has the desire to disclose, they may perceive there to be a lack of opportunity (Vangelisti et al., 2001). Some individuals keep secrets with the hopes that others may ask a question to promote a disclosure (Herek, 1996). For those living with IDs, the invisibility component of the experience may hinder another to consider probing a question about dis/ability. While sharing secrets can have the outcome of growing closer to others, there is also the risk of negative relational outcomes and reactions, including relational distancing (Vangelisti, 1994). Upon receiving a disclosure, a recipient of a secret has influence of the revealer's future disclosures based on follow-up questions they may pose (Vangelisti et al., 2001). Intrusive or insensitive follow-up questions after a disclosure can be harmful to one's tendency toward future disclosures (Vangelisti et al., 2001). Negative reactions to disclosures can influence the revealer's efficacy and may therefore discourage future revelations (Afifi & Steuber, 2009).

Receiving a negative reaction to one's ID disclosure can make the revealer feel unsupported (Afifi & Steuber, 2009; Afifi & Caughlin, 2006). Revealers may need time to distance themselves from the secret they have disclosed to another (Afifi & Caughlin, 2006). Time to reflect after the disclosure can benefit the revealer by allowing them to select positive attributes of the communicative exchange (Afifi & Caughlin, 2006). However, for those with IDs, it may not be possible to disassociate from one's own secret if they revealed their diagnosis. Valle et al. (2010) described some of their participants' experiences with concealing their learning disabilities in the workplace. For some, the act of disclosing created a sense of fear that they would be labeled in the future at work as a 'disabled' person (Valle et al., 2010). Being labeled as well as bias shown toward others with similar dis/abilities are possible negative reactions that may instigate non-disclosure

in the future (Valle et al., 2010). Indeed, serious ramifications can occur from being labeled as a negative reaction from a dis/ability disclosure, such as losing an opportunity for employment (Pennington, 2010). The fear of negative responses, including the fear of dismissal, ridicule, or concerns about losing credibility, may also influence decisions to disclose (Valle et al., 2010).

Disclosures for those with dis/abilities have been studied in academic settings (Valle et al., 2010) and in employment (for a review, see Pennington, 2010). The current study aims to broaden the scope of knowledge about disclosing one's dis/ability and to understand how these decisions are made for those with IDs. As indicated in the preceding review, there are many reasons people may choose to reveal or conceal secrets, particularly those related to dis/abilities. The Revelation Risk Model (Afifi & Steuber, 2009) provides a useful framework for further understanding this choice.

Revelation Risk Model

Disclosure is a decision that requires weighing perceived outcomes and benefits with unknown results (Afifi & Steuber, 2009). Disclosure is expected to have a transformative power changing the relationship and the relationship should then influence the disclosure itself (Rocco, 2004). The RRM examines the risk and likelihood of individuals disclosing secrets to others and how individuals reveal secrets (Afifi & Steuber, 2009). Revealing to another person can be a risky decision (Afifi & Steuber, 2009). Afifi and Steuber (2009) provide reasons for secret disclosure and concealment that are based on risk assessment and efficacy.

Risk assessment involves the evaluation of severity of sharing a secret with another person (Afifi & Steuber, 2009). This risk assessment may also be based on

perceived negative or positive outcomes (e.g., disclosing a HIV positive status) and is

tied to one's protection motives (Afifi & Steuber, 2009). In other words, revealers

consider the risk to self, others, and relationships when choosing whether or not to

disclose. In addition to the severity of the secret, the valence of a secret affects the degree

of risk individuals feel for other people, themselves, and their relationships (Afifi &

Steuber, 2009, p. 150). Secret valence involves whether one perceives the secret to be

positive, negative, or neutral (Afifi & Caughlin, 2006; Afifi & Steuber, 2009). Finally,

closeness with the target can also influence perceptions of risk and the willingness to

reveal (Afifi & Steuber, 2009).

The RRM also acknowledges that when individuals disclose to others, they

believe themselves to be prepared, which is influenced by perceived levels of risk (Afifi

& Steuber, 2009). Thus, communication efficacy plays an important role in revealing or

concealing a secret (Afifi & Steuber, 2009). Individuals are willing to reveal a secret

when they believe that they have the ability to discuss the secret (Afifi & Steuber, 2009).

The more efficacy a person believes they have, the more direct the disclosure technique

(Afifi & Steuber, 2009). Those who believe they have the ability to disclose a secret will

do so in person, without third party disclosures, and they may be more likely to entrap

their recipient (Afifi & Steuber, 2009). The less efficacy a person has the more likely

they may conceal their secret or use a third party disclosure (Afifi & Steuber, 2009).

Individuals with lower efficacy may be insecure of how to approach the disclosure with

another based on the perceived negative reaction that the recipient may have (Afifi &

Steuber, 2009).

Figure 1 provides a visual representation of secret valence, risk assessment, and communication efficacy as they relate to willingness to reveal and subsequent revealing or concealing. This figure demonstrates the relationship these factors have in weighing the risk of disclosure, as well as hallmark conditions of disclosures (e.g., catharsis, need to know, pressure).
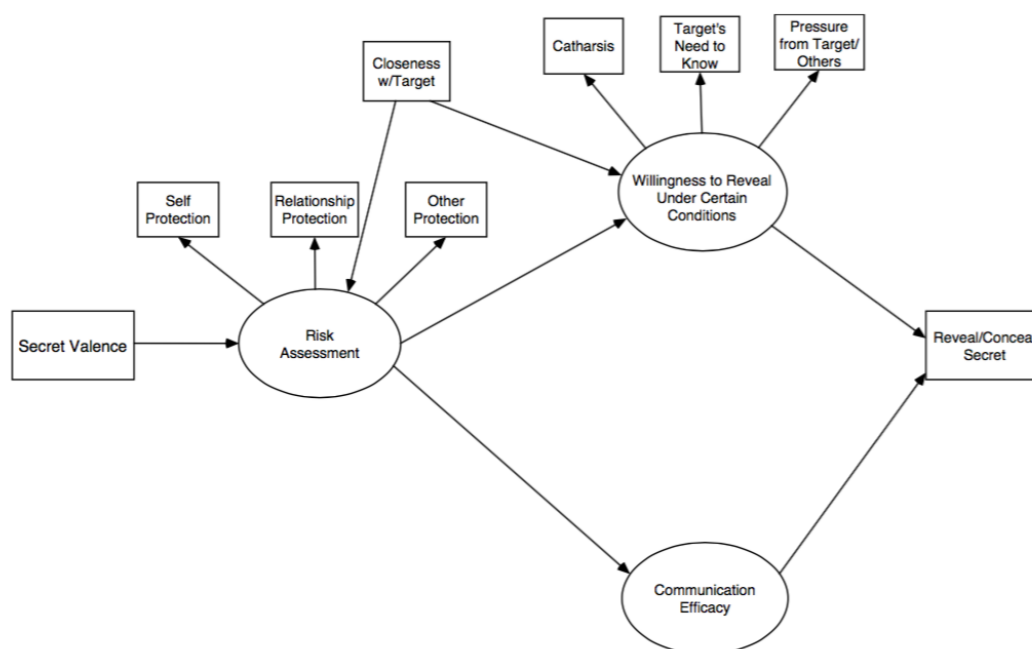
Figure 1.   **The Revelation Risk Model (Afifi & Steuber, 2009)**.

The RRM has been used in a variety of contexts to study disclosure, such as the planning process of disclosing HIV (Choi et al., 2016) and sexual orientation in medical disclosure situations from patients' perspectives (Venetis et al., 2017). These studies both concluded that one's ability to reveal secrets depended on the level of risk that was perceived by the individual who was in the process of disclosing (Choi et al., 2016; Venetis et al., 2017). In sum, these studies align with Afifi and Steuber's (2009) predictions outlined in the RRM.

The review of literature established clear definitions of dis/ability, secrets, and disclosure, and provided reasons for disclosure and concealment, using the RRM as a framework (Afifi & Steuber, 2009). Previous research has discussed disclosure and dis/ability pertaining to employment (e.g., Pennington, 2010) and educational settings (e.g., Valle et al., 2010), but less information is available on the relational aspects of dis/ability disclosure. Exceptions include Choi et al.'s (2016) study conducted with people living with HIV and Greenberg et al.'s study about genetic testing. With knowledge gained from these findings, the current research seeks to deepen our understanding of invisible dis/ability experiences and the decision making process of disclosure. Without the confinements of a particular setting (e.g., workplace) or diagnosis (e.g., HIV, learning dis/abilities), I aimed to understand the disclosure decision-making process for those with any identified invisible dis/ability. Furthermore, the current study seeks to inquire about how individuals with IDs perceive their experiences with others as they make their decision to disclose or not disclose their diagnoses. With these goals in mind, the current study poses three **research questions:**

RQ1: What factors do individuals with IDs consider when choosing to disclose or not disclose their dis/ability to another person?

RQ 2: What perceived outcomes occur when individuals disclose an ID?

RQ 3: How do individuals living with IDs perceive the ways their relationships are affected by disclosure of their dis/ability?

CHAPTER 3: METHOD

To explore the reasons that individuals with IDs choose to disclose or not to disclose, I used a qualitative open-ended questionnaire to find emerging themes. Qualitative research can be a way of knowing the world by understanding stories and dialogue (Manning & Kunkel, 2014). Qualitative methods allowed me to understand the relationships and interactions of individuals living with IDs through the analysis of their own words and accounts (Lindlof & Taylor, 2011). I was able to use the participants' stories to explore themes across their responses and present the findings in a way that is authentic to experiences of disclosing or not disclosing an ID.

Procedures

Individuals with disabilities are considered a vulnerable population (Lindlof & Taylor, 2011). For this reason, I chose to implement in-depth online questionnaires with the intention of protecting the identities of the participants. Distributing the questionnaires online was important because it allowed those who preferred not to discuss their experiences face-to-face the opportunity to participate anonymously. Participants were also able to decline any question, go into depth where appropriate, and take their time with each question. As explored in the literature review, individuals with IDs may have faced stigma and/or may be hesitant or resistant to disclose. Anonymity helped encourage open and honest responses to answer the research questions while also being respectful of the potential difficulty of disclosing an ID. As approved by the Institutional Review Board (IRB), the open-ended questions were designed to gain

personal accounts about ID disclosure and perceived outcomes (see Appendix for the full list of interview questions). Example prompts included: Please write about a time that you chose to disclose (reveal) your dis/ability to another person? Please write about a time that you chose NOT to disclose (reveal) your dis/ability to another person? When (and how) do you choose to talk (or not talk) about your dis/ability to another person?

Sample and Recruitment

I utilized network sampling to gain initial participants. I posted a link to the questionnaire on Facebook and emailed those who expressed interest in participating. Through sharing the link on Facebook, my own network members could also share the study information with their Facebook associates. After the process of network sampling, I implemented snowball sampling to recruit more participants (Lindlof & Taylor, 2011). Snowball sampling was accomplished through inviting participants to share the questionnaire link with others who met the criteria and wanted to participate. It was transparent in the recruitment email and on Facebook that the goal of the study was to gain insight of real-life experiences from the participants without compromising their anonymity.

Participants needed to be 18 years of age or older and able to consent to the study. This study aimed to be inclusive and was open to participants of all IDs, gender expressions, and ethnicities. To qualify for participation, one must have identified as having an ID. In the study recruitment letter, I included a definition of ID in order to allow participants to identify as living with an ID.

Based on the U.S. Census Bureau data (2012), I included a list of possible IDs, such as epilepsy, infertility, diabetes, sight/hearing impairment, cerebral palsy, chronic

pain, and lupus, with a clear acknowledgement that many more diagnoses could be applicable to the study. The study was open to participant interpretation of the definition given for IDs in the spirit of inclusivity. It was made clear to those interested in the study that if their ID was not listed in the examples, they could still qualify to take the questionnaire. I asked for demographics in the questionnaire, including age, ethnicity, sexual orientation, relationship status, income, and ID (see Appendix A for demographic information).

Forty individuals completed the online questionnaire. One of the participants responded with "NA" for all 10 interview questions and therefore was not included in the analysis. This left a sample of 39 individuals living with an ID. The sample included 33 individuals who identified as female, and six who identified as male. Ages ranged from 22-70 years of age with an average age of 43. Approximately 97% of the participants identified as white or Caucasian ($n = 38$). Approximately three percent of the sample identified as Native American ($n = 1$). Thirty-five percent ($n = 25$) of the participants identified as being heterosexual. Ten percent ($n = 4$) of the participants identified as bisexual, five percent ($n = 2$) as pansexual, approximately three percent ($n = 1$) identified as polyamorous, and approximately three percent ($n = 1$) as asexual. Fifty-five percent ($n = 22$) of the participants identified as being married, approximately 18% ($n = 7$) were single, 15% ($n = 6$) were in a long-term relationship, eight percent ($n = 3$) were dating, and five percent ($n = 2$) were divorced. Twenty-four percent ($n = 9$) earned between $0-20,000 in the course of a year, 15% ($n = 6$) earned $21-$35,000 per year, 19% ($n = 7$) earned $36,000-$50,000, 5% ($n = 2$) earned $51-$70,000, and 27% ($n = 10$) earned $101,000+ per year.

Participants reported a diverse set of IDs. Several ID diagnoses included Type 1 diabetes ($n = 11$), lupus ($n = 1$), irritable bowel syndrome ($n = 1$), polycystic ovarian disease ($n = 2$), and blood cancer ($n = 1$). In this study, 28% of the participants shared the diagnosis of interstitial cystitis ($n = 11$), 10% ($n = 4$) had a form of diabetes, and eight percent ($n = 3$) used the term "chronic" to describe a painful diagnosis (see Appendix B, Table 1 for all diagnoses).

Analysis

To analyze the data, I conducted a qualitative thematic analysis. More specifically, first I used open coding to make sense of the collected responses to the open-ended questionnaire. As Lindlof and Taylor (2011) suggested, I created categories to sort the data as a way to find meaning in the collected data in order to develop initial themes.

I printed out each of the anonymous responses for the ten questions, totaling 37 pages, and used a color-coding method to categorize the responses I collected. Green (RQ1), maroon (RQ2), and pink (RQ3) were used to color code when participants' answers were addressing the research questions in this study. Color-coding the responses was a way to become familiar with the data and organize potential themes that were emerging. It was productive to take notes in the margins of the documents to associate the responses with the RQs. An example of how I implemented this practice is with RQ3. Anytime a participant mentioned a relationship, I marked it in pink to come back to on another round. On the second time around, I wrote notes in the margins with terms such as "stigma" and "stared at" to develop context of the response and begin organizing into categories. During the first process of open coding, 17 initial categories emerged across the three RQs. A useful step in the coding process was making a distinction in each

participant's third question response with "D" for disclosed or "ND" for not disclosed. This allowed me to count how many participants chose to disclose, and how many did not if there was enough context to make the determination. 23 participants discussed or implied that they generally choose to disclose their IDs. Thirteen implied or stated that they do not disclose their ID or have had negative experiences that have made them refrain from future disclosures.

Next, I began the process of axial coding to condense the themes. Axial coding involved taking themes that were similar and making them one theme, if it was appropriate. I also developed theoretical connections between themes. First, I looked for patterns in the master list of 17 themes to see which could be synthesized. It was important to make sure that the themes were concise, non-repetitive, and named appropriately to represent the data. An example of this was combining "receive support" and "give support" to become sub themes of the overall theme "support."

During the axial coding process, I realized that the majority of the participants discussed themes of RQ1 and RQ2 together. That is, when determining factors to disclose or not disclose their IDs (RQ1), participants considered the perceived outcome (RQ2). However, they also discussed outcomes following the disclosure (RQ2), which could be combined with relational outcomes (RQ3). After discovering this, I combined participant responses related to RQ1/RQ2 (i.e., pre-disclosure decision making factors) and responses to RQ2/RQ3 (i.e., post-disclosure outcomes). Lastly, I went back to the data and checked that they fit within the finalized themes. At the end of this open and axial process of coding, nine themes emerged; four for pre-disclosure and five for post-disclosure. The themes for "pre-disclosure decisions" explain factors and emotions that

occurred pre-disclosure (if a disclosure occurred) and perceptions of outcomes participants considered before they chose to disclose or not disclose their ID. "Post-disclosure outcomes" showcase the perceived outcome of disclosure.

CHAPTER 4: RESULTS

Pre-disclosure: Decisions and Perceived Outcomes

The 39 participants provided insightful and, at times, vulnerable answers for the

ten open-ended questions. When participants discussed factors they considered when

choosing whether or not to disclose, they tended to also describe the potential outcomes

based on past experiences. Themes that emerged regarding the pre-disclosure decisions

and perceived outcomes included the following: (a) receiving and providing support; (b)

fear of negative emotional response; (c) perceived appropriateness; (d) and no

choice/perceived obligation. The proceeding sections define each theme as well as give

examples from the personal accounts provided by the participants.

Receiving and Providing Support

Support was a desired outcome when choosing to disclose an ID. Support in this

context includes instrumental support (e.g., babysitting) and emotional support (e.g.,

discussing infertility with another that has experienced it). The emergent theme of

support is organized in two ways: receiving support and giving support.

Receiving Support

Participants weighed the goal of gaining support as a reason to disclose an ID.

The context of receiving support varied from participant to participant, however this was

overwhelmingly shown to be a positive experience for those with IDs in this study. An

example of receiving support was participant #17 when they shared, "telling my very best

friends and close family was easy because I know I have their support. I know many

don't have the family or friend support that I do." This participant shared insight to the pre-disclosure process and seemed to anticipate that their existing relationships with their loved ones would likely result in receiving support.

Instrumental support (e.g., childcare, help with tasks) and emotional support are examples of support that participants considered as reasons to disclose. An example came from participant #15, who shared, "I had to disclose my disability to my folks as soon after diagnosis as I needed help with my children when my husband was at work." Another example that was specific to the ID diagnosis itself was participant #35 when they said, "I disclosed that my visual impairment limits my ability to drive at night so that someone else would drive." Both of these participants shared their diagnosis to others to gain support and assistance for activities they had barriers to accomplishing because of their IDs.

Giving Support

Participants also disclosed to help others and provide support. Several participants found the desire to share their experience and diagnosis as a way to bond with others. This happened particularly when the individual participants considered disclosing to someone who had a similar ID. A powerful example of this was participant #31 when they shared, "I would describe it as a 'need to know.' I have also shared about my PCOS (polycystic ovarian disease) with girlfriends and others suffering with infertility." Participant #38 contributed the sentiment, "I always discuss my Graves Disease when I know that another person is struggling dealing with the diagnosis, treatment, etc." Like other participants, participant #38 shared that they choose to disclose when another

person has the same ID. When they noticed individuals struggling with the disease, they were supportive and shared their knowledge and experience about Graves Disease.

Giving support also included informational support. When asked about the outcomes of disclosure, participant #3 was positive about helping others understand their experience. Participant #3 stated, "I enjoy sharing info about my issues, since maybe then that person will take into account that not all young people are healthy and not all sick people look [sick]." Support in the context of helping others was a positive tone in the responses from participants. Educating and supporting someone with a similar diagnosis were reasons for many participants to disclose to others.

Fear of Negative Response

While some participants had positive relational experiences with disclosure, others did not. Past negative experiences were shown in the data to be reasons to conceal IDs in the present or future. The fear of negative responses, including disbelief, fear, disgust, and stigma/judgment, encompassed the unpleasant experiences the participants expressed as reasons to consider when weighing to disclose or not disclose their ID. The proceeding subthemes go into depth of specific fears established in the responses of the participants as they weighed reasons to disclose or not disclose.

Fear of Disbelief

Disclosing an ID left some participants feeling doubted by others, which led to future non-disclosure. An example of this is participant #21's response to the reaction they received when disclosing an ID, "Negative- no one believes it's as serious as I describe. Can't say I've really had a positive experience." Participant #21 was not alone

in the fear of disbelief when it came to sharing an ID. Participant #24 shared their story as well of feeling a fear of disbelief,

> I had to tell a lady that I couldn't volunteer for something that she usually phones (or catches me in person) to do a few times every year. It was awful because the day I saw her, I was actually not doing too badly and I'm sure she thought I looked fine. I gave her a vague answer about my health being unpredictable and felt awful about it. When I try to find the words to tell someone about my condition I usually either feel like people won't believe me or will feel like I'm exaggerating, with nothing in between.

Participant #24 shared in this response that they fear disbelief of their ID by another. This example showcases the shame and complexity that one may feel when others cannot apparently see their diagnosis, and may make judgments on their perceived choices. This fear of disbelief is accompanied by other fears, such as judgment and stigma.

Fear of Judgment and Stigma

A prevalent fear of negative emotional response to disclosure was related to stigma and judgment. Participant #6 stated, "I have a strong fear of people thinking less of me due to my disability." This statement was echoed by Participant #4 who had fear about their ID in the workplace and the impressions others may have about their work ethic. They reported, "I experience a lot of fear and uncertainty when disclosing my disability because I do not want anyone to think I am less capable or lazy due to my disability." The perception of what others may think of an individual with an ID creates fear of negative responses for the participants in this study.

Participants, particularly with IDs that involved bowel difficulties, felt that people were disgusted with their IDs, creating a challenge to disclose. Participant #4 revealed, "Some people think it's gross and don't want to know anything about it. I've had looks of

disgust and wrinkled noses, with conversations cut very short." Participants who expressed stories such as this appeared to feel stigmatized by others in past disclosures. For some, past experience of mistreatment contributed to the choice of not disclosing in the future. Participant #11 provided an example of this when they stated, "I chose not to disclose my medical issues on a regular basis. There is so much stigma about these issues and people are quite vocal about their ignorance." The fear of negative reactions from others was a powerful pre-disclosure decision for some participants.

Perceived Appropriateness

Participants reported reasons to disclose or not to disclose based on the appropriateness of the setting and confidante. Participants revealed that they considered the setting and if the person they considered revealing their ID to needed to know. This was the theme that emerged in both capacities of disclosing and not disclosing an ID; it depended on the circumstance. When it came to the setting, some participants considered disclosing their ID to another because it was relevant to a specific conversation or situation. Participant #32 expressed, "I disclosed it recently to my class when we were discussing difficult experiences and discrimination within the healthcare system." In this instance, participant #32 incorporated their ID to the discussion in their classroom that was relevant. In terms of the potential disclosure recipient, participant #4 stated,

> First is deciding if they REALLY need to know. Then second, I test the waters before I really divulge all the details, ask a few questions to help determine their level of empathy. Then, I start explaining in brief terms, and only elaborate if they have questions. If they react poorly, I try to downplay it.

This example encompasses the decision-making process that is relatable to other accounts shared in the study. The perceived appropriateness of the setting and the confidante's reactions were constantly negotiated as a reason to disclose or not to disclose.

No Choice and Perceived Obligation

Sometimes related to the perceived appropriateness, participants shared instances in their stories about having no choice or feeling obligated to disclose their ID. The overall tone of this theme varied from feeling trapped and shamed into telling another about an ID to sharing with a boss because of a work hindrance. For example, participant #39 stated, "I had to tell a significant other about my pain because it was the reason why I didn't feel like going to a social event." The perception of the severity of this theme ranged from a negative reaction to feeling apathetic from the discloser's perspective. An example of a participant who did not seem severely affected by disclosure was participant #1, "I usually just lay it out there right away. It makes the fact that I might interrupt them and say, 'hold that thought, I have to run to the bathroom,' while they are in the middle of a sentence understandable." No choice/perceived obligations were reasons for participants to disclose, even if disclosure was not their preference.

Post-disclosure: Perceived Outcomes of ID Disclosure

The perception of general outcomes of disclosure tied with the relationship outcomes from the perspective of the participants in this study. Upon analysis, the following themes emerged: (a) relief; (b) closeness in relationship; (c) relational loss; (d) differential treatment; and (e) no change or negative outcome. The proceeding section explains and defines each theme grounded in the participants' words.

Relief

Participants shared that relief, and the positive feelings associated with relief, was an outcome of their ID disclosure. Nine of the participants specifically used the term "relief," "relieved," and "peace" in the response to the question, "How do you feel after

you have told someone new about your ability, and what makes you feel this way?" This is present in participant #7's description, "relief...I feel like I am being honest about myself. I put myself out there and usually receive compassion and not judgment." Sometimes relief was difficult for participants to describe but involved a feeling of peace. For example, participant #11 stated, "Relieved. I can't give a specific example, but I often obscure the truth to hide my medical problems. It's freeing not to have to do this anymore around someone." These quotations eloquently encompass the overall tone of several participants' responses as they expressed relief; it seemed that telling another about their ID relieved the burden of hiding their diagnosis.

Relief was uncomplicated in the analysis because of the overwhelmingly positive way that the participants discussed it when describing perceived outcomes of disclosure. However, relief was often dependent on the reaction from the recipient. An example is in participant #4's account when they claimed, "Sometimes it's relief that I don't have to suffer in secret, if the person is supportive." Participants related the positive outcome of relief with the positive response from the recipient of the ID disclosure.

Closeness in Relationship

Closeness in relationship referred to feelings of growing closer or strengthened relationships with loved ones after disclosing. This theme was portrayed in participant #9's account of being diagnosed with their ID and disclosing to their best friend,

> My best friend has been a godsend. We're both single and were roommates for many years, including the time I was diagnosed and learning to live with it. I don't think [the relationship has] changed in its fundamental nature, but I've had to learn to give up my independence a bit and rely on someone else for support. That's hard for me, and I only allow my closest friends to actually see me struggle. So maybe it's been strengthened because of it.

The potential difficulty of disclosure and vulnerability was apparent for participant #9, but the outcome was positive: a stronger relationship. Participant #26 also shared, "In many instances I have grown closer to those that I disclosed to. It may often lead to the other person disclosing something about their life, usually an invisible illness or disability, and us developing a deeper connection." The connection with others was an outcome for some participants whom disclosed an ID.

Disclosing an ID created closeness in participants' relationships as well as a new understanding between themselves and others when bonding over difficulties. Participant #22 reported taking opportunities to bond with others who had struggles with ability of some kind, "I felt like we bonded over diabetes." Likewise, participant #17 said, "Mostly, it's best/easiest talking to others with disabilities, especially those who understand chronic pain." Disclosure can bring closeness in a relationship and a stronger bond, particularly when the recipient of a disclosure also had an ID.

<u>Loss of Relationship</u>

Although closeness occurred after disclosures for some participants in this study, others had more negative relational outcomes. Participants shared stories of losing relationships after a disclosure. Some participants lost relationships with significant others, parents, and friends. This theme was stated outwardly in participants' accounts, such as #16, "I've lost friends who didn't understand." Similarly, participant #18 stated,

> I lost most of my family after my diagnosis. They couldn't handle my limitations or maybe they just thought I was making it up. I never cared enough to ask them why, because it's best NOT [to] have them in my life, if they can't love or support me, no matter what.

Regardless of the interpretation of the loss of relationships that participants had, it was evident that the outcome of an ID disclosure can be as severe as losing the relationship.

Differential Treatment

A theme that was apparent for multiple participants was being treated differently as an outcome of a disclosure. Participants reported general feelings of differential treatment. Participant #5 shared,

> My relationship with my parents has been significantly affected by my diagnosis as my mother now doubts whether I can take care of myself with my disability. She often focuses on my disability rather than other, more positive aspects of my life, which is difficult for me.

Participants #5's statement was not unique in regards to the frustration of others focusing on a diagnosis rather than the participant as a whole person. Specifically, overprotection was a feeling expressed by some of the study's participants. Participant #21 stated, "My husband often doesn't let me do things I'd like to do because he's overprotective and he has no way of seeing how I feel inside." For some, such as participant #21, the disclosed diagnosis appeared to be the direct reason for being treated differently by another.

Being treated differently created a sense for the participants in this study that other people's perceptions of them were altered after the disclosure. For example, participant #11 stated, "I've felt like people treat me differently. Once I disclose, people often treat me a little more fragile or act weird around me like I'm a different person." These personal accounts provide powerful insight to the adjustment of treatment that individuals who choose to disclose IDs risk.

No Change or Negative Outcome

For some individuals in this study, disclosure left no change or negative outcome in their opinion. No change or negative outcome was a theme that spanned across the responses that disclosing an ID had not changed or impacted a participant's relationship or self-esteem. For example, participant #29 shared, "I don't really feel any different than

I did before." Participant #27 said, "I feel no difference." When discussing how disclosure influenced their relationships, participant #21 stated, "Nothing special...it is just a fact of life." It is notable, however, that participants with IDs such as Irritable Bowel Syndrome, were not represented in this emergent theme. IDs related to bathroom needs left many participants to report feeling ashamed and negative.

The nine themes of the current study have represented the personal accounts provided by the participants in both pre-disclosure and post-disclosure contexts. The accounts of the participants were powerful and create an opportunity to further understand disclosure, secret revealing, and relational communication. The discussion will suggest practical implications for supporting individuals with IDs.

CHAPTER 5: DISCUSSION

The current study highlighted the ongoing process of disclosure, including both

factors and outcomes involved in the disclosure decision-making process, adding to the

body of knowledge on invisible dis/ability disclosure in interpersonal relationships. The

investigation uncovered *pre-disclosure* factors and perceived outcomes involved in

choosing to disclose or not disclose one's ID (e.g., support, fear of negative emotional

response, perceived appropriateness, no choice/perceived obligation). Many of these

themes connected to previous studies on reasons to disclose or not to disclose and can be

better understood through the Revelation Risk Model (Afifi & Steuber, 2009). Moreover,

this study provided *post-disclosure* outcomes (e.g., relief, closeness in relationship, loss

of relationship, differential treatment, and no change or negative outcome) through the

personal accounts of those with IDs, which add to the RRM. The outcomes of disclosure

show that secret revealing can be seen in a cyclical way; outcomes of past disclosure may

be factors for disclosing or the reason to conceal in the future. With knowledge gained

through participants' reports, I will next further explain the theoretical contributions of

the study based in the Revelation Risk Model (Afifi & Steuber, 2009).

Connecting the RRM with the Current Study

The RRM (Afifi & Steuber, 2009) helps further illuminate the current study's

findings, particularly through the application of three key elements of the model: valence,

risk assessment, and efficacy. Whether participants disclosed or concealed their

diagnosis, risk assessment and valence were portrayed in their responses as they chose

whether or not to disclose based on the perceived risks or benefits. These risks were assessed prior to disclosure. Importantly, however, outcomes of past disclosures became future factors involved in risk assessments for potential disclosures.

Participants assessed how their ID disclosure would positive or negatively influence others, themselves, and their overall relationships (Afifi & Steuber, 2009). This protection was present as factors and outcomes the participants shared in their responses, including those with high risk or low benefit (e.g., loss of relationship, fear of negative response, differential treatment, perceived appropriateness) and those with low risk or high benefit (e.g., closeness in relationship, relief, to give or receive support, perceived appropriateness). Participants who shared they chose not to disclose demonstrated high-risk assessment when concealing a secret from others. Protecting oneself occurred in situations such as concealing a secret in a new friendship, a professional relationship, and a romantic partner. The assessment of this protection appeared in the responses as debating the timing of a disclosure and how well the participant knew the potential recipient (e.g., perceived appropriateness). Individuals who disclosed in the past and reported to have felt negatively about the outcome, such as differential treatment, of their disclosures shared instances of concealment. It is possible this was to protect themselves from future hurt. As participants shared accounts surrounding the loss of relationships, they seemed hesitant about the future, likely to protect relationships. On the other hand, feeling supported and relieved appeared enjoyable and positive for those with IDs who disclosed to others, perhaps decreasing the perception of risk and necessity for protection. These themes from the current study relate to Choi et al.'s (2016) study, which found intimacy, closeness, and anticipated responses to be necessary for disclosures to occur.

The current study demonstrated that positive experiences with disclosure (e.g., receiving support, relief, closeness in relationship, no change or consequence) could occur. If a participant had good experiences in the past with disclosing an ID (e.g., feeling relieved or supported), they seemed to perceive more ability to disclose. In other words, positive experiences may positively influence disability disclosure efficacy. Planning ahead may also improve efficacy. Choi et al (2016) found that individuals living with HIV may need to schedule a disclosure in order to increase what appeared to be feelings of self efficacy. This planning appeared in the current study's analysis because participants who disclosed often implied that it was a decision made prior to a conversation, perhaps reducing perceptions of risk and improving their ability to disclose. On the other hand, some participants disclosed when a relevant topic came up in a classroom or upon a friend's disclosure of a similar diagnosis (i.e., there was no chance for planning). It is possible, then, that conversations that naturally lead to disclosure (e.g., perceived appropriateness) may also limit the sense of risk and increase feelings of efficacy.

On the contrary, perceived negative experiences (e.g., fear of negative response, loss of relationships) and inappropriateness can negatively affect those with IDs and their sense of disclosure ability. In terms of negative experiences, for participants with perceived stigmatized IDs (e.g., irritable bowel syndrome), the efficacy seemed to be perceived as low in their accounts. In terms of inappropriateness, participants sometimes felt forced to disclose their IDs for another person(s) (e.g., obligation), even if the time/place felt inappropriate and their efficacy was low. Situations included not being able to eat something or to complete a task at work or having to leave a meeting to go to

the bathroom. Interestingly, in these situations, efficacy could be interpreted as low, but disclosure-by-necessity still occurred. Overall, the current study aligned well with previous research; however, these nuanced finding emerged in the context of ID disclosure.

Peer Support and Vulnerability

In addition to utilizing the RRM to better understand dis/ability disclosure and echoing previous studies on disclosure, the current study also illuminated more reasons to disclose or not disclose secrets specific to IDs (e.g., to share related IDs with another who has the same diagnosis). Most importantly, this study offered outcomes of the risk assessment and disclosure that can be added to the RRM, as it relates to IDs. Connections to peer support and vulnerability help to clarify the current study's contributions and suggestions.

<u>Peer Support</u>

In the current study, some participants indicated that talking with others in a safe space, and even in support groups (e.g., for participants with interstitial cystitis), was a factor they considered for disclosure (i.e., getting support). They shared their diagnosis to seek support from individuals with the same diagnosis. In addition to gaining support, they also often noted feeling relief upon such disclosures. Previous research has shown that peer support can help a person feel supported, understood, and have the space to discuss their secrets (Steginga, Pinnock, Gardner, & Dunn, 2005). This seemed to be the case for the current participants. Another factor of disclosing an ID was to provide support to another person going through a similar difficulty (i.e., a peer). The process of disclosing to help another can be cathartic and benefit both the recipient of the disclosure

and the revealer (Afifi & Steuber, 2009; Vangelisti et al., 2001). It did appear that disclosure created a sense of relief for many participants, particularly those with interstitial cystitis who disclosed to others with the same diagnosis. Participants perceived some IDs to be stigmatized (e.g., irritable bowel syndrome) by non-peers, which could make peer support even more beneficial. Future studies should investigate whether the sense of the relief and other positive outcomes are more prominent when disclosing IDs to peers.

An important attribute of peer support is not only the setting to discuss one's own difficulty with their ID, but to be able to listen and support others who share their experience (Dunn, Steginga, Rosoman, & Millichap, 2003). The act of sharing and listening to others with similar diagnoses was present in the findings of this study and can relate to the importance of implementing more peer support opportunities for those with IDs. Participants shared their diagnosis with others when they learned that someone else had the same illness or circumstance, such as with infertility, Graves disease, or polycystic ovarian disease. Support, relief, and closeness in relationship were associated with positive experiences of disclosure. These were significant reasons for participants to disclose their ID diagnoses to others with with the same ID. As the results showcased previously, participant #17 shared, "Mostly, it's best/easiest talking to others with disabilities, especially those who understand chronic pain." The evaluation of the disclosure (i.e., "it's best") suggests disclosure to peers could produce the most positive outcomes (e.g., support, relief, connection). The disclosure efficacy (i.e., "it's easiest") involved with peer support may also lead to more disclosure, which could in turn lead to more support (Smith et al., 2008). Thus, the current study suggests that individuals with

IDs may benefit from encouragement of sharing their stories with peers. Perhaps if peer support were more prioritized on a societal level for those with IDs and apparent dis/abilities, more disclosure, and thus support, may occur.

<u>Vulnerability</u>

Whether participants in the current study reported disclosing or not disclosing their ID diagnosis to others, a sense of vulnerability was present in their accounts (even if the word was not used explicitly). Taking the step to disclose an ID to another with unknown results opens up the possibility of becoming vulnerable. Vulnerability can be considered/understood as openness to being wounded. It can be the beginning of acceptance, healing, and support, yet also bring the possibility for shame and discouragement (Brown, 2006). This vulnerability was present in participants' accounts of fear while also seeking support and connection when disclosing IDs. For example, the desire to seek or provide support from others was present in the explanations of ID disclosures, which made for positive experiences with disclosure when connections were created and relationships strengthened. These positive disclosure experiences may create motivation for future disclosures. On the other hand, disclosure opened individuals up for devastation when it resulted in the loss of a relationship. As discussed, disclosure presented risks, as was clear for participants who experienced the loss of relationships, differential treatment, and stigma. Previous or anticipated experiences of stigma may leave individuals with IDs in a vulnerable position when assessing the risk of disclosure. Even if participants would like others to know the truth about their diagnoses, in some cases to gain relief, the fear of stigma or misunderstanding may hinder the disclosure.

Overall, disclosure can be a vulnerable experience, making it necessary to assess the various risks involved. With the understanding of the RRM (i.e., efficacy, risk assessment, and valence) and the vulnerable nature of disclosing an ID, it becomes clear that disclosure is a continuous process for those weighing its risks. Participant #27 shared the many questions that must be considered: "Do I trust this person? How will they potentially use this information? Is my job or relationship in jeopardy if I disclose? Will they judge me? Will they be sympathetic?" The answers to these questions, in terms of positive or negative outcomes, provide reasons to disclose or conceal IDs in the present and potentially in the future.

<u>The Role of the Recipient</u>

An individual's risk assessment, consideration of valence, and belief of efficacy can help determine disclosure or concealment. The current study offers insight into how the role of the recipient is crucial for others when assessing their disclosure efficacy and the risks or benefits of sharing their diagnoses. Looking at the data holistically, it was clear that the reaction to a disclosure of an ID was impactful for those revealing secrets. The themes of fear of negative emotional response, loss of relationships, and differential treatment help illustrate that receivers of disclosures do not always react with positive communication. Referring back to participant #4, the current findings highlight the potential for hurtful messages to appear during disclosures:

> I test the waters before I really divulge all the details, ask a few questions to help determine their level of empathy. Then, I start explaining in brief terms, and only elaborate if they have questions. If they react poorly, I try to downplay it.

Consequently, from the perception of the revealer, responses from others help determine if they will reveal their secret. These responses connect to the way participants perceived

their recipients responded to a disclosure, or, how they would if one happened. Feared

negative reactions ranged from having a person crinkle their nose when a participant

revealed their diagnosis to the potential of stigma and disbelief. Differential treatment

involved being treated as a more fragile and unstable individual as a whole. Both could

be considered hurtful messages, which could have lasting impacts on the recipient and the

overall relationship (Young, 2010). Also, for participants who experienced loss of

relationships upon disclosing an ID, a change ensued when making future disclosure

decisions. In other words, they thought twice before disclosing again (i.e., weighed the

risks). The potential negative reactions from others, whether they were intentional or not,

had relationship consequences for the participants. Navigating these potential relationship

changes or mistreatments called for participants to make thoughtful decisions about

disclosure or concealment going forward.

Future research should further investigate the influences of disclosure responses

to extend theory, such as the RRM, and make sense of the ongoing pattern of weighing

pre-disclosure factors and post-disclosure outcomes, including responses from others.

Acknowledging the depth of hurtful messages and the relationship with disclosure

outcomes is crucial. Disclosing can involve risk and reward, leaving the revealer in a

vulnerable position, so better understanding how recipients can best respond to others

who disclose is worthy of future investigation.

This study showcased experiences of disclosing IDs and the decision-making

factors and outcomes of this act. Furthermore, it represented a marginalized community,

aiming to capture what it may be like to disclose a diagnosis with uncertain results (i.e.,

vulnerability). This difficulty can be based on perceived and experienced negative

reactions or the overall fear of being treated differently and even losing relationships. Understanding the complexity of weighing the risks of ID disclosure should be prioritized. If as a society these challenges are understood, the reaction to vulnerable disclosures could better be managed. The current study suggests, by way of disclosers' experiences, that responding with supportive communication and trust, while avoiding judgment (e.g., stigma) and hurtful communication, is a good starting point. Future research can assist with bringing education to others, making the risk of disclosing IDs more visible, and perhaps inciting the empathy and support that people living with dis/abilities (visible and invisible) deserve.

Limitations

Although the current study brought to light important issues pertaining to ID disclosures, it was not without limitations. To begin, the sample was homogenous. Approximately 97% of the participants identified as white or Caucasian ($n = 38$) and 82% ($n = 32$) of the participants identified as female. Future research should seek stories from people of color and men who are living with IDs. Although the sample was homogenous in terms of ethnicity and gender, it was broad in terms of ID diagnoses. The definition of IDs for recruitment was broad and attempted to be inclusive. However, to understand IDs (e.g., diabetes, irritable bowel syndrome, cerebral palsy), those with visible dis/abilities were excluded in the recruitment materials. Future researchers should seek a breadth of stories of those with different abilities and their disclosure processes. One may still have to assess risks of disclosure if their dis/ability is apparent to others.

Anonymity was important in the study for the protection of the participants, but it did have drawbacks. Because the participants were anonymous, this eliminated a chance

to create a follow-up interview or survey. The online questionnaire was pre-set and approved by the IRB and therefore could not be altered in the study. Questions I would have asked in the follow-up interview would have been about how the participants felt after disclosing and what their perception was of the outcome. The online questionnaire also made it impossible for participants to ask follow-up questions or seek clarification. The inability to ask follow-up questions could have limited the depth of the response. Although the participants were quite forthcoming with their responses, more depth may have been accessed with a different method of collecting responses, such as in-person interviews. Future studies should consider in-person interviews with those with IDs.

Finally, the current study focused on factors and outcomes of disclosure. Reasons not to disclose were uncovered, but outcomes of this lack of disclosure were not. Future studies should investigate the outcomes of concealment, and how coping occurs when one desires to reveal a secret but does not (for the many reasons outlined in this study and in previous research). Based on the current findings, support and feelings of relief are contingent upon disclosure; yet disclosure also brings potential negative responses and outcomes. The same is possible for nondisclosure.

Conclusion

This study focused on the perspective of individuals living with IDs and how they chose to disclose or not disclose, presenting voices that have been limited in previous disclosure scholarship. Adding to the ongoing conversation about disclosure, dis/ability, stigma, and support, the current study revealed reasons to disclose or not disclose (i.e., support, fear of negative response, appropriateness, and perceived no choice/obligation). Uniquely, the study provided insight to disclosure outcomes for those with IDs (i.e.,

relief, closeness in relationship, loss of relationships, differential treatment, and no change/no outcome). Participants who weigh the risk of disclosing their diagnosis to others often consider the reception (and reaction) of their secret as a factor for disclosures. Thus, this study concluded that the reception of disclosure may influence future disclosures for those living with IDs.

People living with IDs are in a vulnerable position as they choose whether or not to disclose their diagnoses. If recipients of ID disclosures are supportive, this could create a more positive experience for the individuals disclosing. Future researchers should now move forward to investigate how receivers of disclosures can be supportive during the interaction to promote positive outcomes and future disclosures. The role of a disclosure recipient is powerful and further education is necessary in order to support and empower marginalized communities, such as those living with invisible dis/abilities.

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APPENDIX A

Full List of Interview Questions and Follow Up Questions

1. Please write about a time that you chose to disclose (reveal) your dis/ability to another person.
2. Please write about a time that you chose NOT to disclose (reveal) your dis/ability to another person.
3. When (and how) do you choose to talk (or not talk) about your dis/ability to another person?
4. What are the steps leading up to telling another person about your dis/ability? Think about specific things you consider when making the choice.
5. What have been outcomes you've experienced when disclosing your dis/ability?
6. How do you feel after you have told someone new about your dis/ability, and what makes you feel this way? Please give examples.
7. Do you feel like you usually have a choice when you tell people about your dis/ability? Why or why not?
8. Can you write about how a relationship in your life that has been affected by your disclosure of your dis/ability or diagnosis?
9. How do you explain or describe your ability/ dis/ability to another person?

Demographic Survey

1. Sex:

Male_____ Female_____ Other: _____

2. Age _____ (fill in)
3. Current residence (city, state): _____ (fill in)
4. Invisible physical disability diagnosis name _____ (fill in)
5. Sexuality (choose all that apply):
   a. Homosexual
   b. Lesbian
   c. Bisexual
   d. Bicurious
   e. Heterosexual
   f. Asexual

    g. Pansexual

    h. Demisexual

    i. Polyamorous

    j. Queer

    k. Other: _____

6. Yearly income:

    a. $0-20,000 per year

    b. 21,000-35,000 per year

    c. 36,000-50,000 per year

    d. 51,000-70,000 per year

    e. 70,000 – 100,000 per year

    f. 101,000 - + per year

7. Race/Ethnicity (choose all that apply):

    a. Black/African American

    b. Native American

    c. Asian

    d. Middle Eastern

    e. Pacific Islander

    f. Hawaiian

    g. Hispanic/Latina/Latino

    h. White (Caucasian)

    i. Other: _____

8. Relational Status

    a. Single

    b. Married

    c. Long term relationship

    d. Dating

    e. Divorced

    f. Widowed

    g. Polyamorous

    h. Civil union

i. Legally separated

j. Other: _____

APPENDIX B

Table 1.   Full List of Invisible Disabilities

<u>**Invisible Disabilities**</u>	<u>**Frequency**</u>
Acute amuse hepatitis	1
Adjustment disorder	1
Anxiety	3
Bipolar	3
Bladder cancer	1
Blood cancer	1
Chronic back and shoulder pain	1
Chronic migraine with aura	1
Chronic pain syndrome	1
Cyclic vomiting	1
Cysts	1
Depression	2
Diabetes & type 1 diabetes	5
EDS (Ehlers-Danlos Syndrome)	1
Endometriosis	5
Familial Mediterranean fever	1
Fibromyalgia	2
Graves disease	1
Hashimoto	1
Hypothyroidism	1
IBS (Irritable Bowel Syndrome)	2
Interstitial cystitis	13
Intractable chronic migraines	1
Low blood pressure	1
Lupus	4
Lyme disease	2
Mini seizures	1
Myasthenia gravis	1

Osteoarthritis	1
PCOS (Polycystic Ovarian Disease)	2
Pelvic floor disorder	1
Poor digestion	1
Presbyopia/Cataracts	1
PTSD (Post Traumatic Stress Disorder)	2
Rectocele	1
Rheumatoid arthritis	2
Severe fatigue	1
Sinus bradecardia	1
Sjogrens	1
Spasmodic dysphonia	1
Spinal stenosis	1
Terets	1
Ulcerative colitis	2
Visual impairment	2
Vulvodynia	1
Total	79

Note. The full list of diagnoses is larger than thirty-nine. Several participants listed

multiple diagnoses in their questionnaire. Some of the listed diagnoses have been

corrected in spelling or capitalization.