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# How Individuals Disclose Health Information: a Study Examining the Choices Made When Sharing Health Information

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HOW INDIVIDUALS DISCLOSE HEALTH INFORMATION: A STUDY EXAMINING THE  
CHOICES MADE WHEN SHARING HEALTH INFORMATION

by

Jessica Marie Samens

A Dissertation Submitted in  
Partial Fulfillment of the  
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## ABSTRACT

### HOW INDIVIDUALS DISCLOSE HEALTH INFORMATION: A STUDY EXAMINING THE CHOICES MADE WHEN SHARING HEALTH INFORMATION

by

Jessica Samens

The University of Wisconsin-Milwaukee, 2017  
Under the Supervision of Professor Mike Allen

This dissertation examines the decision making process and the reasoning an individual uses when deciding how, what, and when to disclose. Results should offer a better understanding of the process an individual goes through in the when sharing information, including the motivations and reasons of what is hoped to be gained from each interaction. Results found people incorporate a variety of reasons for deciding on disclosure. Close relationships and duty to inform were the two most common reasons. Health literacy impacted disclosure as people were unable to disclose information before they had the necessary knowledge about the illness.

Methodology of the study included quantitative and qualitative analysis asking about time frame of disclosure and reasons for the timing of the disclosure. Three themes emerged from the research: people will notice, stigma surrounding Type II diabetes, and obligation to disclose/desire to educate. Timing of disclosure was dependent on perceived outcome and risk of the disclosure and its impact on the social and working relationship of the receiver. The results offer a better understanding of the process and the importance of health literacy and the ability to create a narrative about the illness.

*Keywords:* health disclosure, stigma, disclosure process, cancer, diabetes

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To all of the people who have helped make this goal a reality. I am not sure there is a way to express the gratitude I feel to each and every one of you. The patience, love, support and encouragement you have shown over the last four years have all contributed to this accomplishment.

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To my family, who always reminded me I could do it. I guess you were right! To uncle Joe who asked me at the age of 10 if I was a Dr. yet. Well Joe, I am now. To my parents, who always support any dream I have – I could not have done it without your support. All of my friends, family, and all of the people in my life. Thank you.

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## How Individuals Disclose Health Information

The diagnosis of an illness places the body into a spin of change. Physical and mental changes take place, as well as disruptions to everyday routines and expectations. Decisions regarding health care and choices exist, often made immediately and without significant processing time. The critical decision of when, how, and to whom to disclose information regarding the illness exists. Greene, Magsamen-Conrad, Venetis, Checton, Bagdasarov, and Banjaree (2012) explain the process of disclosing information as integral to social support as well as physical and mental well-being. A variety of strategies may become employed deciding to whom and what to disclose, as the decisions come with consequences.

Strategically, the choice of whom to share information and when to disclose is only partially up to the person disclosing. Understanding other factors that come in to play, such as relationship, risk level, and obligation impact the strategy. Westerman, Miller, Reno and Spates (2015) found that after disclosure in the workplace, boundaries need re-coordination in terms of privacy and information sharing. Derlega, Winstead, Greene, Serovich, and Elwood (2002) discuss differences in disclosure in interpersonal relationships, highlighting concerns of stigma and what happens to the relationship after disclosure. Strategically, an individual might choose not to disclose based on the anticipated impact to the relationship.

The challenge of disclosure is rooted in multiple concerns over what happens after sharing the information. Disclosure creates vulnerability for an individual. In some instances, disclosure of an illness becomes necessary, such as an individual reporting unable to work due to illness more frequently

facing death for a potentially terminal illness, or the relational implications for an illness transferable to sexual partners (Agnes, Thompson, & Cusella, 2000). Persons receiving disclosure can rely on stigmas or outside information about the illness for understanding, which influences understanding the disclosed information. For example, stigmas can be developed from the receiver possessing preconceived notions about breast cancer because of a mother diagnosed, or from television or movie depictions. Misconceptions about an illness can influence future interactions with the individual disclosing information. While much of the risk surrounding disclosure relates to stigmatized illness, all health disclosures are met with some risk rooted in misunderstanding, such as not understanding transmission or long term health effects (or lack of).

Individuals disclosing health status not only consider the challenges of disclosure, but make decisions regarding the process involved. Decisions regarding the level of disclosure, whom to tell first, and whom to withhold information from can vary based on the impact on the other individual or if it will be impossible to keep the information private.

The following research examines the reason and timing of decisions for disclosure. The following literature review covers significant areas related to health disclosure and decisions, including stigma, social support, health disclosure, reciprocity, and privacy management. Discussion examines the methodology for data collection and finally, study results examining the implications, limitations, and potential future research are offered.



## Literature Review

Disclosure of health status becomes necessary to receive social support. However, health status revelation leads to loss of privacy and generates a need to negotiate boundaries regarding the information. When making the decision to disclose, a tension exists between the need to keep information private and the need to disclose to receive social support. Greene and Faulker (2002) found “expected reaction of others affected disclosure decisions” (p. 311). Because awareness of an illness can change or even end relationships, understanding how individuals communicate an illness to others becomes vital. The negotiation between who to tell (and potentially receive support) and who not to tell (to maintain privacy) becomes complex, as reasons for disclosure to each individual rely on professional and interpersonal factors.

The need to disclose information about health changes as health status or relationships change. Information may need to become disclosed when the illness begins to impact work, relationships, activities, or to receive social support. Greene, Magsamen-Conrad, Venetis, Checton, Bagdasarov, and Banerjee (2012) argued that a person assesses five factors before disclosure: (a) stigma, (b) prognosis, (c) symptoms, (d) preparation, and (e) relevance.

Stigma, the most widely studied factor of the five, can create the perception of an us versus them relationship and promotes incorrect information about the disease, often including labels related to the disease (Smith, 2007; Vangelisti, 1994). Limandri (1998) argues stigma provides the critical determining factor when deciding to self-disclose. Goffman (1963) explained stigma was discrediting and reduced a person’s identity. Prognosis relates outcomes of a disease for self and others involved and can change during

the course of diagnosis or treatment (Checton & Greene, 2012). Checton and Greene found that symptoms effect disclosure, such as if the symptoms of the disease are visible and force disclosure or if they impact the relational partner or family. Preparation considers if the diagnosis is anticipated (such as family history) and impacts disclosure uniquely and encourages other family members to get tested if genetic (Greene, 2009). Finally, relevance examines if others will be impacted by the diagnosis. Greene et al., (2009) explains individuals become more likely to disclose when and if the illness can be transmitted or relevant to others.

Overlapping, all five factors create a complex environment to determine disclosure. Factors about the sender and receiver must be observed. Green (2009) explained that in addition to these observations, relationship quality impacts potential outcomes of the disclosure. Early in a health diagnosis, prognosis might not be understood(e.g., not knowing outcome, treatment plan), making it more difficult to disclose. Green (2009) explains “people are constantly in a process where decisions have to be made about sharing updates, not simply the initial diagnosis” (p. 232). Therefore, timing of the disclosure depends on the interpersonal relationship or disease prognosis. Updates about the illness require multiple disclosures over time, forcing the decision making process to occur frequently.

Bute and Vik (2010) frame privacy as unfinished business because of the continual change in health status. Health status represents a dynamic rather than a static element, which may prevent disclosure until the diagnosis is understood. Hogan and Brashers (2009) explain disclosure in terms of uncertainty during diagnosis (as the process can be time intensive) or if chronic, a lifetime of evolving health changes. However, the need to

disclose is key. Wright and Rains (2013) found individuals with an illness received social support and experienced improved health outcomes.

As medical advancements progress and a diagnosis no longer means loss of quality of life or that a disease is fatal, individuals must consider how to make sense of identity and share the diagnosis information with others. Venetis (2014) articulates multiple conversations must happen because the outlook on health changes – future conversations might be taboo after diagnosis but changes as treatment goes well. On the other hand, conversation might become required if the opposite is true and treatment does not go well. The changing dialogue creates a tension on the narrative regarding how much information to disclose and what to avoid to decrease the positive and negative disclosures.

Rains (2014) explained reasons for revealing information surrounding an illness are complex, with each reason for disclosure unique. For individuals with stigmatized illnesses, self-disclosure comes with a high level of risk of how the information will be handled. Fear of a change in the relationship may prevent full disclosure or about the seriousness of the disease. Rains found there exists a fear of becoming viewed as different, fragile or incapable after diagnosis, which may result in partial disclosure for social support but involves risk if information is kept private.

Sloan (2010) posited many disclose information for therapeutic reasons, finding a sense of relief, creating an understanding about why they have not felt well, or to explain a change in behavior. Individuals disclosing face potential social-rejection or misunderstanding of the illness by the recipient of the information. Any illness comes with a risk that others will change the way they behave around the sick individual socially, such as not getting invited for drinks from a diagnosis of diabetes, or assuming somebody is

tired from hypothyroidism. For those disclosing any health-related information, some level of risk and associated stigma exists. A shift in identity from healthy to sick may influence social, work, romantic, or family interactions (Kim, 2009; Phua, 2013; Smith, 2007).

The following literature review highlights the risks and outcomes of disclosure of health status, as well as the negotiation of boundaries. A theoretical examination of Goffman's Facework and Petronio's Communication Privacy Management Theory sets the frame for this examination. Self-disclosure, identity, privacy versus social support, stigma and the health belief model highlight the key concepts about this topic.

### **Facework**

Goffman's research about face provides important grounding for understanding why and how of information disclosure. Goffman's (1967) concept of face explains how individuals present an image of self to others, a socially acceptable identity influenced by cultural norms, "an image self delineated in terms of approved social attributes" (p. 5). What an individual willingly reveals draws on socially accepted attributes directed from cultural and societal expectations. Social expectations work to create boundaries concerning identity and information disclosure. Cho and Sillars (2015) explain that facework uses "messages to protect, maintain, or repair face" (p. 537). Thus, facework becomes a tool for controlling information dissemination and boundary creation.

Goffman's (1967) theory highlights how losing face is more devastating than gaining face. Losing face creates feelings of inadequacy, which is even more negative when considering changing lifestyles and abilities related to health come into play. While face serves as a basis for cultural research, Ting-Toomey and Kurogi (1998) argued concern for face is universal. A face threat generates the need to repair or protect face and self-image.

Cho and Sillars (2015) argued in terms of health, conditions are often face-threatening conditions across all cultures. Because of the fear of threat, individuals may use strategies including postponing, mitigating, suppressing, or ending the conversation if face is threatened during disclosure.

Considering facework in the context of disclosure of health status is intriguing, as it is often impossible to maintain face in terms of the illness. Presentation of self is often operationalized to fit in a specific context. After a health diagnosis or reveal, change can occur in presentation of self. For example, visible physical changes such as scars, a rash or loss of hair would reveal perceived health status before sharing the message. Level of disclosure becomes even more complex when emotional, physical, and mental aspects of health are considered as they can have as great an impact on self as physical changes. Thus, the decision of what to share in order to save face may require different levels of control over the conversation.

The interaction which occurs within facework draws on previous interactions with the individual and takes into consideration “person-centered attributes like social identity, public self-image, or social wants” (Arundale, 2010, p. 2078). Because a health diagnosis requires an identity shift, facework occurs during the presentation of the new identity. For men, a more significant identity shift can occur as lack of health (such as pain, weakness, inability to care for self and others) contradicts traditional masculinity (Haig, 2006; Helme, Cohen, & Parrish, 2012).

The level of facework needed in a health disclosure connects to the severity of the diagnosis. Cho and Sillars (2015) report cultural differences existed in health disclosure between Koreans and Americans, the differences were smaller compared to other facework

research, with the main difference being Koreans employed more direct approaches with disclosure. Thus, both groups used some level of facework depending on the severity of the illness.

**Face in work organizations.** Fawkes (2015) explains that in organizations, face involves impression management and symbolic interaction within the organization. Revealing an identity which includes an illness can reduce professionalism and change the way others see an individual. Edwards (2010) cited changes in appearance as a shift in professional identity or changes in behavior (such as work attendance) to alter how professionally an employee is viewed. Watts (2003) argues that politeness in relation to face means that facework is socially-situated and driven by socially acceptable practices. Talking and asking questions about an illness may be perceived as impolite, whether in a social or organizational context. Conversation about body changes and behaviors can involve very personal information making people uncomfortable or feeling as if too much information was revealed.

Work settings include legal issues about asking about an illness. Protections are in place to prevent people from revealing information that is too risky or would create an uncomfortable or inappropriate work environment. However, disclosure functions by encouraging reciprocity to compel people to respond and participate in conversation about the illness. Even in a legally protected situation, interaction during the narrative is likely to take place.

Bulger, Matthews, and Hoffman (2007) argue that work/personal life balance becomes a continuum to be negotiated during the illness disclosure process. While Human Resources works through the legal aspects of the job, disclosing an illness to a manager or

colleagues may require a negotiation between the professional and interpersonal relationship. Work and personal boundaries present before the diagnosis often need to be renegotiated and office relationships altered. While the researchers found there were typically positive outcomes when balancing multiple roles and identity changes, the individual disclosing the information may feel vulnerable or hesitant to disclose the information. Finkelstein (2007) argued the time surrounding disclosure to have great anxiety, as group and teams often feel high levels of confusion and disruption over potential changes to work flow. Coworkers could feel resentment if they are required to pick up extra hours, increase their own workload to support the individual during their illness.

Research on facework provides further understanding into managing boundaries and how an individual uses face when disclosing health status. Decisions about what to disclose could be made based on what needs to be shared, or what needs to remain unrevealed to maintain privacy and not show weakness or feel social rejection.

**Politeness.** A final aspect of facework to examine involves politeness. Holtgraves (1997) explained that politeness remains critical to facework and extends the original theory by focusing on verbal communication. Three strategies used in politeness include: (a) seeking agreement, (b) avoiding disagreement, and (c) asserting common ground. Applicable to health disclosure, finding common ground remains difficult if not impossible to discover unless both members connect to the illness. Even if both connect, illnesses are not all similar and common ground could end at the diagnosis.

Offering of support during a disclosure can be seen as face threatening (Goldsmith, 1992). While offering support is typically seen as a positive outcome of a health disclosure,

the response threatens when it is incompatible with potential outcomes, for example, telling somebody they will be “alright” after a diagnosis with uncertain outcomes.

Additionally, offering assistance in response to the disclosure can be seen as threatening to the newly constructed identity, making person feel incapable of continuing on as they have been. If the risk is high, a person will work to minimize the threat. Brown and Levinson (1987) discuss potential techniques to mitigate including avoiding the face threatening activity, positive, and negative face. If risk is too high, the face threatening act will be avoided as long as possible or information will be provided in an ambiguous way with multiple interpretations. Individuals seeking positive face want acceptance and approval of the status while negative face desires autonomy and behaviors to be uninfluenced by others. Strategies need to change as the illness progresses or changes.

### **Communication Privacy Management Theory**

Based on the risk of disclosure surrounding health conditions, Petronio’s Communication privacy management theory (CPM) will be useful to help frame the study. While many areas of disclosure are important in a relationship, health status is unique because of the far-reaching implications (infertility, loss of limb, impairment or fatality) and status of the disease may shift during the relationship (such as no longer being in remission or an infection no longer being dormant). If the disease is transferrable, the partner may need to decide if they are willing to risk transmission. Key to this theory is the constant negotiation of boundaries regarding private information between the sender and receiver.

Petronio’s (2004) theory supports a gap in previous research on self-disclosure at the most fundamental level, examining the actual process of self-disclosure. Self-disclosure



provides the basis of any theory for relationship development, but proposed as a natural progression rather than examining the process of deciding how to disclose the information. Petronio (2002) emphasized the importance of understanding self as the crux of self-disclosure. However, decision for disclosure considers how the recipient of the information will react. Previous negative reactions may change the when and how information is shared, or even avoiding the disclosure of the information.

For individuals with health issues, boundaries and disclosure are particularly unique as the illness may have an effect on how they view self in a relationship. Core thoughts of self can change, health status permeates far reaching into the depths of how one views self. Even the status of being healthy or unhealthy constructs part of an identity (Rain, 2014). While identity is relatively static, a health condition that permeates into a lifestyle or forces a lifestyle change (attending treatments, checking blood work multiple times a day) may alter sense of self.

CPM provides a powerful framework because by breaking disclosure into two critical areas – what is disclosed and the process of disclosure (Petronio, 2002). By acknowledging the process, researchers understand in more depth the decisions of disclosure and face saving mechanisms used. In 2013, Petronio argued that research using CPM in health privacy issues is growing, framing everything from patient care, confidentiality, stigma, and e-health.

Bute (2010) argues that risk of disclosing any information may require the need to disclose further information, such as private ways the disease acts in the body or future impact of the disease. While these functions of disclosure are part of a standard discussion in health care, during a personal conversation may feel uncomfortable and overly

disclosive to people who do not have an established interpersonal relationship. Greene et al., (2013) found that after weighing the risks and benefits of disclosure the decision becomes easier to not share the information with a relational partner. Fear of rejection or a negative reaction could outweigh the need to share information.

**Guiding themes of CPM.** Three themes guide CPM. The first addresses the public-private dialectical tension. To understand how individuals navigate privacy decisions, the theory posits there exists a tension between maintaining privacy and disclosing information (Petronio, 2002). Second is privacy management assumptions. Individuals believe they own their personal information, even after disclosure occurs. However, rules regarding ownership of this information are flexible and may change as relationships change. The management of information breaks down after the actual sharing (and potentially resharing), resulting in privacy changes. Multiple owners of the same information means each assumes different rules regarding privacy even when rules have been established. The final theme considers the use of boundary as a metaphor. When the walls of the boundary are “thick” less information is likely to be shared. When the walls are thin, individuals may be more likely to reveal information. Boundaries can change and evolve, such as becoming thick again if the person disclosing the information feels threatened, decreasing the desire to disclose (Petronio, 2002).

Petronio (2007) presents five principles regarding how people regulate disclosure. First, “individuals or collectives believe their private information” (Petronio, 2007, p. 219). The second principle explains the owner has control over the flow of information. Third, “people use privacy rules to decide whether to open a privacy boundary so they can disclose or keep the boundary closed to conceal information” (p. 219). Fourth, negotiations

are necessary with the others who now share the boundary and fifth, managing boundaries can become turbulent. While the first four principles address the rule making process, it is important to note there is no guarantee what will happen to the information once it has been shared with others.

Bute (2010) explained “CPM is an applied theory that views the management of private information as an ongoing process” (p. 4). CPM uses a boundary metaphor, which explains how people create boundaries for information and decide when and how much to disclose. Petronio (2002) explains that individuals create rules for how they decide to disclose information based on previous experiences with the information or the individual they are disclosing to. As information is shared, the recipient becomes a co-owner of the information, shifting the boundaries. Therefore, future disclosures reflect what has occurred during previous experiences, such as having less disclosure if information was not well received or shared in ways that violated the rules. Or, clear boundaries of what can and cannot be shared are discussed at each disclosure.

Additional criterion can factor in during disclosure (Bute, 2010; Petronio, 2002). Factors include aspects of risk-benefit management, culture, or motivation. For example, culture rules may dictate that certain aspects of life are more difficult to disclose due to stigma or if a topic is taboo based on cultural dictates. Relating back to Goffman’s work, certain cultures are more likely to work towards saving face to control the disclosure process. For somebody who has been taught that sex before marriage is not acceptable, revealing an STD diagnosis is devastating, as it reveals they were sexually active and contracted a disease from their behaviors. Because the disclosure grants access to the illness and stigmatized behavior, risk and loss of control increases.

CPM's focus on control over disclosure provides an important criterion to consider when thinking about the process of disclosure. An individual considers the role of stigma into the process, involving social acceptance of the illness as well as past experiences with disclosure. Once the disclosure occurs and the boundaries have been thinned, the information takes on a public presence and represents an interpretation based on the experiences of the recipient. In the case of a cancer revelation, the disclosure may be interpreted differently if the receiver had lost a family member or friend to cancer, even if the individual disclosing is no longer at risk or going through treatment. CPM allows for understanding the process of making such a risky decision.

For individuals able to conceal the illness, there is an element of control in deciding how and when to reveal the information. For individuals who have a visible mark, such as a scar or rash, less power is present on how to disclose status.

### **Self-Disclosure**

Self-disclosure constitutes the core of relationship building and development. Self-disclosure creates relational intimacy, closeness, and trust between people. Cline and Musolf (1985) explain decisions are typically based on the duration of the relationship, intimacy level, value of the receiver, and cost reward analysis. Health disclosure challenges traditional disclosure rules. Disclosure to a coworker or manager is based on need over the relationship and can have a higher cost than reward.

Key to disclosure becomes the relational function the information serves after disclosure, more specifically how the recipient reacts. Greene (2009) argued health disclosure requires an extra level of understanding because "disclosure decision-making unfolds in a situation of health uncertainty" (p. 277). Disclosure may need to occur on

multiple occasions as the diagnosis or treatment changes. What is needed from each of these disclosures can change based on differing relationships, such as support, acceptance, or inclusion.

After disclosure occurs, the relationship may become stronger and flourish or become constrained and even terminate. In typical disclosure, the receiver of the message reciprocates sharing similar information in an attempt to build empathy. In the case of a health disclosure, there may be no equivalent disclosure to reciprocate, changing the trajectory of the relationship. If the romantic partner is unable to deal with the information, the relationship could end. While the disclosure may not affect the relationship in any way, the recipient may have pre-conceived notions (such as cancer patients being infertile due to radiation treatments or an illness being contagious or transmittable) or stigmas associated with the illness. Greene, Carpenter, Catona, and Magsamen-Conrad (2013) found nondisclosure more common in areas of high poverty and health disparities, due to high levels of social isolation and lack of education about the illness. Lack of disclosure heightens isolation and reduces social support systems often necessary for recovery.

Walker and Dickson (2004) found couples use distinct scripts related to illness based on relationship typology. The script focuses on needs based on the illness and relational dynamics. A critical part of the script was acknowledgment of the illness and having the partner recognize needs associated with the illness. When needs were not meant, strain was present in the relationship and on communication.

**Risk of disclosure.** Caughlin, Bute, Donovan-Kicken, Kosenko, Ramey, and Brashers (2009) explained that while disclosure is necessary, individuals with an illness understand the risks of sharing information about self with others. In their study focusing on HIV-

positive individuals, disclosure routinely occurs to medical professionals, but not always to other persons. Lack of disclosure to other persons was supported by Allen, Timmerman, Ksobiech, Valde, Gallagher, Hookhalm, Bradford, and Emmers-Sommers (2008) who found 40% of HIV positive individuals did not disclose their health status to sexual partners. Reasons for non-disclosure include high relational risk and loss of positive face.

Talking about illness is part of the treatment process and disclosing information is required when working with a medical professional for appropriate treatment to occur. Disclosure is necessary when looking for social support. An illness can be very isolating, as others in their familiar social support network are unlikely to have the illness. If the illness was contracted from unsafe or unhealthy behaviors, feelings of isolation could be even higher. The secrecy of not disclosing often created a felt stressor on the family, creating a feeling of stress without understanding what was causing the feeling (Tenziak, Herrman, May, Feiner, & Allen, 2013).

Derlega, Winstead, and Folk-Barron (2000) found the reason people are unlikely to disclose information about health status to an intimate partner is from fear of rejection. Once the information has been shared, privacy is lost and negotiations regarding boundaries of how the new information can be used must be discussed, placing a strain on the relationship.

The basis of rejection varies depending on the disease. Considering STI's or HIV/AIDS, Emmers-Sommer, Passalaqua, Warber, and Luciano (2007) found disclosure of STI status was considered inappropriate at the start of a relationship but should be disclosed before sex. Participants in the study indicated high perceived risk of disclosure if the STD was contracted through risky behaviors and the most important reason for not

disclosing was fear of rejection. Smith, Hernandez, and Catona (2014) explain misunderstanding is high for disclosers and informants. Lack of knowledge about the disease from both parties contributes to understanding the disease and increasing disclosure risk.

In comparison, risk of rejection when disclosing non-transmittable illness differs. Smith, Hernandez and Catona (2014) found that less rejection among peers was found for non-transmittable illnesses and ones that were unpreventable. Greene (2009) stresses the importance of understanding the quality of the relationship between the discloser and confidant, as it could be more important than the stigma of the disease and negate any negative perceptions. Finally, Goldsmith and Miller (2015) found when couples talked about feelings associated with the disease, higher levels of distress and relational dissatisfaction were reported. In contrast, talking about treatments related to the individual with the illness (not treatments received by friends or family with cancer) increased communication satisfaction in the relationship.

Thus, further understanding the process of disclosure as well as how the decision for disclosure is made becomes a critical area to study. Romantic partners receiving a diagnosis find difficulty disclosing information about the illness, as individuals entering a relationship strive to show positive qualities of themselves to their potential romantic partner. The risk associated with revealing a “flaw” could end the relationship or prompt further discussion depending on the illness and how it impacts the other individual.

**Labels and disclosure.** Disclosure of health status requires a labeling of the illness which can increase stigmatization and risk. Smith and Hipp (2010) discuss once an illness is labeled, consequences are associated with the illness and vulnerability is increased. Link,

Cullen, Strening, Shrout, and Dohrenwent (1989) suggest that individuals often use label management, especially in highly stigmatized and discriminated illnesses as a coping technique. Label management allows control over boundaries and over perceptions of the illness.

### **Privacy versus Social Support**

Tension exists in the decision to disclose information about health status. While a desire for privacy often exists, in opposition is the need for social support. Kennedy-Lightsey, Martin, Thompson, Himes and Clingerman (2012) explain that individuals may practice on others before revealing information to the intended target. Revealing to third parties decreases the need to worry about boundary management, since the disclosures are outside of an individual's social circle and a maintained relationship unlikely. Anker and Feeley (2011) explain that message development changes as the need for privacy changes between disclosures and social support is needed. Disclosers consider different ways to frame the message to achieve a desired outcome, such as receiving social support (including requests) or which details of the message to include.

Donovan's (2011) research focusing on cancer communication found that one of the key changes in an individual's life after diagnosis is loss of control. Loss of control can be over treatment, body, and lifestyle; therefore, disclosure of status can by proxy mean loss of control of personal status. While an individual is in remission they might consider themselves "cured", others may still see the "sick" identity. Once ownership of the information is shared, those with the information can now share the story, decreasing privacy.



Levels of privacy are handled differently depending on context. Westerman, Miller, Reno and Spates (2015) found conflict when disclosing to employers and colleagues because of negative perceptions such as others picking up slack or stigmatizing the individual. For friendships, Koenig Kellas, Horstman, Willer and Carr (2015) found that discussing health situations increased relational satisfaction and benefitted the entire group's health through connection and education.

Petronio (2002) explains that risk is the key factor when making disclosure decisions. However, this research extends previous research to examine the need to understand the role of privacy and the need for social support. While disclosure does contain risk, needing support (emotional, physical) can trump the need to evaluate risk.

Derlega, et al., (2008) explains that seeking help and duty to inform are two of the most frequent reasons for disclosure to significant others. In comparison, reasons for nondisclosure include privacy and the disclosure not being important to the relationship. Nichols (2012) talks about the dangers of concealing information and placing others at risk if privacy is valued over everything else. If an individual sees concealment of information as a right in the relationship, it may set the standards for non-health related disclosures.

**Social support.** Satisfaction with using a social support network has many patient benefits. Lepore, Allen, and Evans (1993) stress that support networks serve to can provide positive health outcomes, such as reduced stress and better adjustment to living with a disease. Adjustment to living with the disease is important, as Jones and Reznikoff (1989) explain that longer survival times correlate with how an individual adjusts to a cancer diagnosis. Greene, et al., (2009) support this notion because a response to a better prognosis will solicit a more positive response to the disclosure, positively impacting

future disclosure. Spiegel and Bloom (1983) further support the importance of social support by saying that patients who had social support were better able to cope with the experience of pain associated with cancer treatment.

Shim, Capella, and Ham (2011) found disclosure to gain social support not only happens in face to face communication but written. Written communication includes blogs, letters, or social media posts. The social support received resulted in both physical and mental health benefits.

The Health Belief Model explains benefits of seeking social support. Jones, Jensen, Scherr, Brown, Christy and Weaver (2015) cite “people will take action to prevent illness if they regard themselves as susceptible to a condition (perceived susceptibility) if they believe it would have potentially serious consequences” (p. 567). Social support from others are at risk for illness (sexually active individuals for HPV) could not only gain support but creates proactive behaviors for similar peers.

**Health and relationships.** For social support in relationships to occur, disclosure must occur first. As seen in the previous research, disclosure comes with the risk of placing a strain on or even ending a relationship, making the decision of how, when and what to disclose very complex. Petronio (2002) argues the balance of risk and reward, the tension between potential outcomes. Because of the dialectical outcomes, the decision to disclose is highly contentious. Anticipating the reaction to disclosure can be attempted but never certain; it is not possible to pre-determine if reactions will be positive or negative.

Goodall (2004) explained how persons create and shape narratives has an impact on the relationship. The way narrative is structured can leave out, further develop, and even control the message received. Smith and Brunner (2016) talk about the importance of

using narratives in order to create and explain the personal experience. Yaskowich and Stam (2003) explore narrative creation as “biographical work”. Their research found that narratives were different for in-group (others with cancer) and outgroup (those without).

**Disclosure as a form of information seeking.** Information seeking for an individual newly diagnosed with an illness is likely to begin soon after the diagnosis is received. As the individual goes through an identity shift from healthy to unhealthy, information about the disease, outcomes, and treatments will be sought from a variety of sources. Initially, Pennebaker’s (1997) theoretical paradigm suggested that emotional inhibition prevents an individual from translating an event into language, which prevents that person from understanding and assimilating to the event. The ability to translate an event into words is fundamental to be able to communicate about the experience. Hearing others talk about the event can provide the necessary language, as patients may seek out how others have talked about the disease and experience in order to become familiar with the medical terminology. In order to be able to communicate about the disease, seeking out information becomes necessary. Information seeking includes questions about the disease and relational aspects. Will he still love me after I tell him I have an STI? Can my coworkers still see me as competent as my role at work changes?

### **Stigma**

Even as the stigma surrounding an illness changes, old beliefs and mentalities about an illness are hard to change. Stigma exists not only between social relationships but often starts within medical communities (Agne, Thompson & Cusella, 2000). Parker and Aggleton (2003) report stigma is highly political and replicated across a variety of institutions, social norms, service providers and results in loss of necessary services.

Goffman (1959) referred to individual with stigma as having a “spoiled identity”. The label of stigma allows for the individual to be seen as “unusual, bad, morally suspect or inferior” (Pointdexter, 2005, p. 64). An individual with stigma is likely to manage the stigma through disclosure decisions about what information to highlight. If the diagnosis is unexpected to atypical for the individual to acquire, they may feel even more stigmatized and be less likely to disclose information (such as men getting a disease primarily in women or being young and getting a disease more common in the elderly).

Fear and stigmatization may prevent an individual from self disclosing information about their diagnosis to others. Bloom and Spiegel (1984) argue that stigmatization can lead to an identity crisis. While many of the social stigmas of cancer may have changed as more is learned about the disease, the social implications of managing a changing identity can lead an individual to feel stigmatized about their condition. Stigmatization could lead to less self disclosure about the illness, forcing the patient to feel alone and isolated. In addition, Cohen and Wills (1985) explain that the lack of communication can actually create more health problems, such as higher levels of stress, which have a negative impact on healing.

Illnesses that come with the consequence of being terminal or involve mental health are often highly stigmatized, heightening risk when disclosing information. Greene, et al., (2012) explained “perceptions of stigma likely decrease intentions to disclose, although these effects may be mediated by anticipated reactions and efficacy” (p. 96). Stigma and viewpoints on the illness can be outdated or not true (based on where knowledge came from).

Wright and Rains (2013) explain that not disclosing information has the capacity to decrease social support for the individual. However, the risk of a negative reaction may override the desire to seek support and understanding. Quinn and Chaudoir (2015) add to the complexity when an illness is not concealable. They explain those who have other stigmatized identities (race, religion, sexuality) may have more hesitation and feel stigmatization from multiple identities impacting reasons for, against, and when disclosure occurs in various relationships.

A final consideration is whether the individual assumes the illness carries stigma. An illness with a stigma impacts disclosure by the person. For example, revealing lung cancer when not a smoker could include not only disclosure of health status but justification that the illness wasn't caused by a lifestyle choice.

Stigma has the ability to discredit and cause discrimination against the individual disclosing. Nayar, Stangl, DeZealduondo and Brady (2014) found in families where a highly stigmatized illness existed, both the unhealthy individual and the family were often discriminated against. Discrimination can lead to being discredited and socially isolated, both of which negatively impact health outcomes.

**Pre-existing conditions.** The term pre-existing condition is typically used by insurance carriers to determine if they will cover a medical condition (American Medical Association, 2015). While the Affordable Care Act prevents insurance carriers from denying coverage, stigma and misunderstanding of the disease still exist ([www.healthcare.gov](http://www.healthcare.gov)). Conditions are costly and chronic, diagnosed before receiving benefits and require treatment over a lifetime. Conditions include diabetes, heart problems, epilepsy, and multiple sclerosis, to name a few. Disclosure of pre-existing conditions is

important to study because an individual may choose to delay sharing information to different groups.

For a chronic condition, disclosure can happen each time a new relationship is established, impacting the way information is discussed as the illness changes or an individual chooses what information to disclose.

### **Research Questions**

While previous research has focused on disclosure to specific groups of individuals such as family or employers, this dissertation hopes to highlight a comparison in the decision making process. As Holt, et al., (1998) explains, the stressors due to stigmatization and potential role and identity changes can manifest in different ways. Important to discover is the consideration of timing of disclosure of health related information. Because the choice to verbally disclose information is deliberate, the current study will examine the decision making process and relationships of those disclosed to.

Therefore, the first research question will ask about the relationship between timing of disclosure and relationship to the other individual:

*RQ1: What is the relationship between the time frame of disclosure and the recipient of disclosure?*

Larson and Chastain (1990) posit individuals are likely to conceal information from others if the news could be seen in a negative way. Van Der Molen (2004) found that disclosure was dependent on information and support needs. An understanding of timing of disclosure could help explain why and how information is disclosed. Understanding the relationship between the sender and receiver can allow understanding of the types of relationships critical to the disclosure.

The second research question asks which factors motivate disclosure in relationships. Even for immediate receivers of the health information exist different reasons for motivation and understanding the who and why.

*RQ2: What factors (fear, stigma, need) motivate disclosure?*

Greene (2013) found that building social networks represents a positive result of the disclosure creating a connection. However, social networks are not the only reason for motivation. Obligation, inability to complete tasks, or fear can motivate without the intention of expanding social networks for an individual. This understanding leads to the third research question.

*RQ3: Do motivations for disclosure of health status differ between family, friends, coworkers, romantic relational partners or other interpersonal relationship?*

A final question and hypothesis examines the influence of risk on disclosure. Kosenko, Hurley, and Harvey (2012) explain that when there is uncertainty surrounding the disclosure, risk levels are increased. Risk is calculated in terms of disclosure efficacy, “the confidence and ability to disclose a specific piece of health information to a specific receiver” (Smith, Hernandez, and Catona, 2014, p. 429).

Venetis, Magsamen-Conrad, Checton, & Greene (2014) discussed elements of risk related to partner burden as in influence on the narrative of the disclosure. Bunston (2001) explained the impact of disclosure on work and working relationships. While all disclosure comes with the element of risk, important to timing is the intersection of immediate or delayed disclosure based on risk levels of the interaction.

*RQ 4: How does the perception of risks associated with disclosure influence timing of disclosure?*

*H1: Delay of Disclosures increases with the risk associated with the outcome of the disclosure.*



## **Methodology**

Decisions on how to disclose health status occur for several reasons. Visible illness, obligation to disclose, and need for support can impact the process of deciding who and when to share information with. Tracy (1991) found primary and secondary goals determined how and what information would be disclosed. Primary goals could include obligation to disclose while secondary could be education or catharsis. Smith, Hernandez and Catona (2014) contend the health condition, the intended receiver, and disclosure efficacy will be driving factors determining disclosure. To accurately examine reasons for disclosure, research design must allow for participants to address all possible reasons for disclosure. The survey allows participants to include choices of when the decision to disclose took place and an explanation why the disclosure occurred. Information about the timing and reasons for disclosure provide in-depth understanding of the breadth and depth of the process.

The following section describes the methods employed by the study. Quantitative and qualitative methods combined to provide a full spectrum of information about disclosure and to allow for method triangulation (Patton, 1999). After answering quantitative questions, participants provided further information about decision making and demographics. Participants needed to fit the stipulation of being a cancer survivor or having Type I or II diabetes to allow for comparison of data. The following section examines recruitment, participants, procedures, method design, instrument, and data analysis.

### **Recruitment and Participants**

**Recruitment.** To participate, a person must indicate status as a cancer survivor or a diagnosis of diabetes and be at least 18 years old. Participants were asked to identify the type of cancer they survived or whether a diagnosis existed for Type I or Type II diabetes. Participants could define “survivor” in anyway they chose with the intended definition indicating post-treatment status for cancer (realizing other health complications were possible). After Institutional Review Board (IRB) approval, the survey was distributed via multiple social networks and email.

Participants were recruited using multiple points of contact, initially, emails and posts to social media (*Twitter, Facebook, Instagram*). Participants frequently asked to share the survey with others, which created an opportunity to use snowball sampling. Hopmann (2012) explained snowball sampling increases potential participants (17-21% of initial participants share the survey) and creates a perceived second layer of protection between the researcher and participants. Participants requested the ability to share with support groups for cancer and diabetes. The participants were thanked with no follow-up (asking if they posted) so no harassment or obligation existed for peers to participate. Social media posts were to the researcher’s personal contacts along with online support groups.

**Participants.** Seventy-six usable surveys were collected. Participants were cancer survivors ( $n=36$ ) and twenty-nine ( $n=29$ ) identified as diabetic. Twenty-eight participants ( $n=28$ ) identified as female, fifteen ( $n=15$ ) identified as male and twenty-eight ( $n=28$ ) opted not to disclose. Twenty participants were high-school graduate ( $n=20$ ), fifteen college graduates ( $n=15$ ), and two held post-graduates degrees ( $n=2$ ). Lack of demographic information reported will be discussed in the results section.

A recruitment message, consent form, and Qualtrics link were shared with possible participants and researcher contacts via email and social media posts, which appear in Appendix A. The link to Qualtrics led to a survey which first asked if they agreed to participate followed by if they were diabetic (by type) or a cancer survivor with a space to fill in the type of cancer. No incentive was offered to participants. Participants received assurances that not finishing the survey would impact the relationship with the University of Wisconsin-Milwaukee or the researcher as all participants remained anonymous and no identifying characteristics were requested. Participants could terminate the study at any point.

### **Instrument**

The instrument was created using the outcomes of the Derlega, Winstead, Matthews and Braitman (2008) study on attributions for self-disclosure in close relationships. Results of the initial 12 attributes included (1) close relationship, (2) trust, (3) seeking help, (4) duty to inform, (5) similarity, (6) availability, (7) other asked, (8) other involved, (9) catharsis, (10) to educate, (11) increase intimacy/closeness, and (12) self-clarification (Derlega et al., 2008). For consistency, the definitions used in the previous study were maintained in the current study. Table 1 (Appendix B) provides a list of definitions for reasons attributions for disclosure and reasons for nondisclosure. Reasons for nondisclosure included (1) protecting the other, (2) concern about losing other's respect, (3) privacy, (4) superficial relationship, (5) self-blame/low self-esteem, (6) Dissimilarity, (7) would put relationship at risk, and (8) other can't help. Definitions can be found in Table 2 under Appendix B.

The present study aimed to learn more about the list of attributes by including multiple relationships and timing of disclosure. While Derlega et al's (2008) study examined five close relationships, the current study expands to utilize a participant created list of receivers to include disclosures which may be higher risk. Smith, Hernandez and Catona (2014) explained the disclosure process is often emotional and strife with insecurities regarding outcome of the information. If the outcome is considered high risk (a negative outcome is expected), will the disclosure be delayed? Or non-existent? Thus, understanding the timing decision of disclosure made by the discloser and allowing them to dialogue about why or the outcomes from the disclosure provides more depth to understanding the interaction. The methodology used in the current study used the pre-established attribution categories and extended the research by examining multiple time frames and creating open ended responses for relationships types.

Descriptives collected from the current study allow for comparison between the illnesses. Participants were asked to describe their illness in their own words and offer an explanation of who and when they decided to disclose. Participants talked about the medical aspects (describing their illness) followed by emotional based on research by Goldsmith and Miller (2015). Goldsmith and Miller found in qualitative interviews participants first wanted to talk about the specifics of the illness and then transition into the emotional aspects of the disease. A final question asked for any final remarks they wanted to make about the disclosure process not addressed by the provided questions.

Timing of the disclosure was essential to the research in the current study. Participants were asked to explain whom they disclosed to immediately, delayed, and did

not disclose. Understanding of disclosure timing allows analysis of the decision making process over an extended period of time.

**Procedure.** After receiving the link, participants viewed the consent form asking for participation, but only if they were over 18. The second page asked if they were a cancer survivor (along with type) Type I diabetic, Type II, or none of the above. If none of the above was selected, participants were directed to the end of the survey and thanked for their participation. Those eligible described the illness in detail and then selected relationships for each disclosure. The first two screens examined immediate and delayed disclosure with boxes to enter who and why they disclosed to during these two time frames. After each time frame, an open ended question prompted each participant to provide more information about the decision making process. The same experience was used for nondisclosure using new categories along with a question about why the participant chose not to disclose information. The survey ended with questions regarding the illness and a few demographics for analysis.

### **Variables and Coding**

After data collection was complete, data was exported to SPSS. Data was cleaned by removing participants who were not qualified for the study. Partial studies containing usable data were kept if considered usable. For example, a survey might look incomplete but a category simply didn't apply or case specific categories did not apply, such as the information was shared with nobody immediately, thus left blank. Data was coded to examine relationships and timing of disclosure. Data was coded only from the three specific questions about disclosure timing, not the initial question asking participants to be thinking about the data. Relationships were coded to help clarify data. Data was grouped

based on different terms for each (mother, mom, and momma were coded together) for ease of analysis based on discretion of the researcher. Any data that did not fit in an easily understandable category was not included in the study. Tables 3-8 represent the outcomes for each category and illness (immediate, delayed, and nondisclosure) and the relationships in each, found in Appendix C.

Qualitative data was analyzed by coding the open-ended comments and finding general themes (Corbin & Strauss, 2008). Patton (1999) argues of utmost importance is making sure the data has quality, validity, and credibility. Patton further explains the process should involve a competent analyst who finds patterns, linkages, and explanations. Based from Patton's research on enhancing quality in qualitative research, Hay, Shuk, Zapolska, Ostroff, Lischeweski, Brady, and Berwick (2009) suggest a multi step process to ensure credibility.

Hay et al., (2009) suggest an initial read through of the data to begin discovery of the content and to get a feel for the data. For each of the time frames of disclosure, responses were pulled from SPSS and separated into time and illness. For each illness, the data was separated into five categories before examining. Categories included information about the disease, immediate disclosure, delayed, non-disclosure, and any other information provided.

In Phase two of the analysis, preliminary themes were created based on additional read throughs of the data. Patterns, links, and explanations were noted in each of the categories. Additionally, results from the categorical data proved helpful. Using the reoccurring relationships and attributes allowed for further understanding of the explanations for each category. Triangulation, or use of multiple methods to (such as

interviews and observations) can enhance the research in several ways. Patton (1999) argues triangulation assists in improving consistency in the findings (methods triangulation) and consistency of the sources (triangulation of sources).

Barbour (2011) explained the importance of a systematic approach to qualitative analysis. The use of a systematic process and mixed-methods provides a checks and balance system in the thematic and coding process. The following section will highlight the results of the survey and address the research questions and hypothesis.

## Results

The following section provides the results from the coded data and considers the research questions and hypothesis. As Blockman (2015) contends, anybody with an illness or differing ability can display a prominent or uncommon visual cue that allows others to notice a difference. While some illnesses allow for maintaining privacy, the results shed perspective on choices regarding the disclosure process. Visibility of the illness motivates the disclosure process compared to illnesses that are able to be hidden. Disclosure may be delayed until the visual cues appear that can longer be kept hidden. No longer hidden, decisions about how to disclose the health condition become required.

As Matthews, Derlega, and Morrow (2008) explain, people tend to create patterns for whom they self-disclose with based on close relationships. In the context of communicating health status, disclosure follows previous patterns and the need to share information about health status. Different narratives exist for different relationships based on need for information and level of information shared. While close relationships were prominent in immediate disclosure, obligation provides a very common reason. Reasons for disclosure are varied, from necessity to being unavoidable. Unique needs and requirements for each individual influence disclosure decisions.

### Emergent Themes

**Shifting control in diabetes disclosure.** Participants with diabetes, specifically Type I, communicated a shift in control of boundaries from diagnosis to later disclosures. Many were diagnosed as children with the parent(s) present, resulting in immediate disclosure to the attending parent(s). Participants discussed the transfer of control of boundary creation from parents to the child when they were responsible for the illness. A



parent often became the person first recognizing signs of the illness (*I lived at home and fainted. Dad took me to the hospital; was tired and kept fainting to my parents to me to the dr, ran tests and this was the outcome*). Ownership of the information started with the parents because of the young age (ten persons reported under the age of 13 at initial diagnosis) and parents deciding whom to inform, mainly people around the child the most frequently, including other family members, teachers, and camp counselors/coaches. Creation of the illness narrative was a dual effort, with parents/guardians creating the initial illness narrative for the child or helping in the construction of the narrative.

The finding aligns with research by Vishwanath (2014) which found that because Type I is considered a juvenile disease, individuals with diabetes often feel as if they should communicate about the illness as a child but begin to conceal the information as they get older because of the associated stigma. Diabetics feel the stigma of having a chronic illness which should be kept quiet. As one participant explained it is similar to wearing glasses – you don't even think about it any more. Participants commented as they got older and took charge of daily treatments, control shifted from the parents back to the child. Participants did not offer explanation on how the narrative shifted/changed with the control shift. It is important to note participants used the phrase “my parents” when talking about the initial disclosures, showing shared or lack of control during childhood disclosures. The participation in social activities, such as being away from parents attending camp, generated the need for the child needing to take charge of the information and education for interactions with other people.

Research about shifting control exists in the medical field but with little research outside of a clinical setting reported. Research by Hummelinck and Pollock (2006) explain

the parent becomes a third-party to the illness, making decisions and setting goals, which may not reflect the preference of the patient. Patients lack the ability to make the decision, including being too young or unable due to medical condition. The decision making process of parents shifted the role of boundary management from the patient to the parent, altering the narrative. As one participant explained:

*“My mom said she told anyone close to me with the most important of those being my teachers and family. They were told because of “need” and education”. Essentially, anybody I’d need to be left alone with had to know right away and that is how they made the choice”.*

In this instance, risk of not disclosing and experiencing a disease related event outweighed the risk of telling and receiving a negative reaction to the disclosure. Boundaries were negotiated based on safety over privacy, supporting duty to inform being a reason for disclosure.

Theoretical implications of facework and boundary setting must be addressed. When parents create and share the narrative, need for knowledge can outweigh need for saving face. Facework is transferred to parents who can see different needs for disclosure. As one participant explained, he didn’t want his illness (diabetes) to be seen as an illness by friends, yet his parents shared because they wanted him to be safe and others to know how to act if something happened to him. Present is a conflict in face: the child didn’t want to be seen as ill in front of his friends while his parents did so the friends could help in case of a medical emergency. Parents who initially create the narrative could set the trajectory for how and when to disclose about the illness. The narrative created by the parents can differ from the child’s, creating a conflict if the child is trying to save face. One participant shared

the story of being told by his parents to not tell friends so they wouldn't treat him differently. He struggled because his mother didn't want him to be treated differently, but he felt the need to explain why he left class frequently for insulin injections. While the parent wanted to help him save face by not telling others, the child felt the best way to save face was to tell people and offer explanation.

Shifting control of facework has far reaching implications after a health diagnosis. As Folwer, Fisher, and Pitts (2014) explain, during facework the goal is to protect or enhance another's face during the interaction. A health disclosure finds protection and enhancement in possible conflict. Sharing health status protects an individual in several ways. It creates understanding of health related behaviors (missing work, struggling with physical activity, loss of energy) which do not enhance personal identity. Not disclosing saves face by not creating a sick identity but does not allow protection for behaviors that demonstrate a sick identity. Fowler, Fisher, and Pitts suggest using negative politeness strategies for disclosing status that belongs to somebody else, such as starting conversations with statements such as "I don't know if you have noticed my child having problems". Hearing parents talk about their health they can feel as if their face and competence is being threatened. Teaching others how to give injections makes the child feel less competent in their ability to take care of themselves, threatening face and effecting boundary management.

A shift in ownership potentially appeared when the child began to take control of the illness or no longer received daily injections. While many reported still identifying the same people, participants cited continued disclosure often related to safety – people needing to know in case something happened requiring medical assistance and knowledge

of the illness. While the people included in the more frequent disclosures stayed similar, control over the boundaries shifted. The children/emerging adults were now responsible for communication about the illness.

**People will notice.** A second theme in diabetes disclosure defined the inability to keep illness private, resulting in disclosure surrounding physical actions, such as administering insulin before meal times. 34% of diabetic participants included “Inability to keep private” as a reason for disclosure. As one participant wrote when sharing a meal with friends, *“I would often give myself a shot before eating so I would tell them if they saw mostly because they would make it awkward for me. I never wanted them to feel bad and felt like I would tell people to protect them. They look at me like I am a drug dealer otherwise!”*. The public nature of the action and immediate response can be seen as a face saving gesture. The immediate disclosure of diabetes and need for insulin provides an immediate explanation for the behavior.

Mayberry, Rothman and Osborn (2014) explain a hesitation to share health status often comes from lack of health literacy. They explain both the person disclosing and the receiver lack the ability to comprehend the illness or the knowledge to provide answers about the illness. Visibly showing an insulin injection creates an opportunity for the observer to ask questions the individual is not equipped to answer (how much, how does it work, what happens if...). Increased literacy could offer explanation on why the response on noticing the illness occurred in the delayed or non-disclosure category. The farther away from diagnosis, the potential for increased literacy surrounding the disease (Leung, Cullen, Struening, Shrout, & Dohrenwent, 1989). An increase in knowledge decreases stigma felt by the individual. Literacy about the illness helps an individual understand and

provide explanation to de-stigmatize, such as ability to explain the illness was not caused by poor habits or unhealthy activities.

Young adult cancer survivors ( $n=7$ ) discussed the importance of educating others about the diagnosis. Open-ended responses frequently discussed the importance of telling others that cancer occurs at a young age. Young adults must be proactive in the process when failing to fit the expected demographic, e.g., diagnosed with breast cancer in your 20's and become the spokespeople from lack of material discussing the young demographic. Mayberry et al., (2014) found adults with limited literacy more vulnerable and often harmed when disclosing and taking advice from family members during the early stages of the disease. Early disclosure also prevents against unhelpful advice, as one participant described, "*telling me about your grandma who dies from cancer does not help my situation*". Delaying disclosure could provide insulation while educating one's self about the disease and acquiring the ability to talk about the illness.

A second issue to address with "people noticing" is the role of stigma. Participants with Type II diabetes commented not wanting judged as unhealthy or at fault for diabetes because it is a result of being overweight or living an unhealthy lifestyle (*I don't tell people. They think it is my fault. It is. Very embarrassing and I don't want them to think less of me which I know they already do. People always comment on my weight*). As McMullen and Sigurdson (2014) found that using diabetes as an analogy for depression, participants (with depression) viewed the comparison to Type II diabetes more stigmatized, causing participants to challenge the comparison when Type I diabetes wasn't the analogy. Within diabetes the stigma exists, as one participant explained for a reason to delay disclosure,

*“Being misinformed about types 1 and 2. They aren’t the same but I don’t think people know that. Means they don’t ask the right questions”.*

Butler and Modaff (2016) explained that stigmatized illnesses (or other stigmatized characteristics) are often kept private in the workplace so the characteristic isn’t preferred against all others, such as using health status as a decision making point over work abilities. Keeping health status private makes it irrelevant to others, maintaining an outward healthy identity and allows the person to manage face. Participants required to tell managers or co-workers used words like “judged” or “embarrassed” to symbolize the process of sharing the stigmatized illness. Obligation to disclose does not allow for saving face and can lead to feelings of judgment over lifestyle choices. Non-disclosure removes stigma from the equation for an illness that can be hidden, creating a catalyst for maintaining privacy.

**Type II stigma.** A third theme emerging from the responses involved the stigma associated with Type II diabetes. While stigma was also discussed in the previous theme, the stigmatization of Type II diabetes warrants further analysis. As Weiner, Perry, and Magnusson (1985) advocate, if the perceptions of the disease are negative, patients feel more stigmatized about the disease. Delayed and non-disclosure of Type II diabetes frequently mentioned reasons related to stigma (*it’s my business; i don’t tell people. I know they think it is my fault. It is; people don’t know the difference*). Varma (2009) found stigma related to other labels associated with a disease. Varma examined connection between HPV vaccinations and a promiscuity label. Participants connected diabetes with unhealthiness, increasing stigmatization of the illness.

While delayed and non-disclosure appeared most connected to strangers (those not involved in a relationship with the discloser), less stigma was felt in disclosing to family members. Prevention and education for family members emerged as reason to disclose to encourage lifestyles changes to prevent other family members from developing diabetes (*I told mom overweight girlfriend because she is also at risk*). Disclosing to family members provides needed social support which leads to better physical and mental health outcomes regarding the disease (Baek, Tanenbaum, & Gonzalez, 2014). Bannon and Shaw (2015) found that even friends and family could make the individual feel stigmatized through lack of connection and social support/empathy (*I don't want them to judge and see me like a smoker who willingly put tobacco in their body and then acts like they had no idea*). Lack of connection was represented in the category that appeared only once from all participants, the attribute of similarity, as a reason for disclosure. Being the only person to have a disease leads to isolation and stigma from fault of getting the disease. Overcoming the stigma allows for education, a driving factor in disclosure. Decreased stigma and increased education (health literacy) are associated with more positive health outcomes, which increases quality of life. Knowledge of the disease allows for saving face during a disclosure by the ability to explain stigmatized aspects of the illness, dispelling myths and explaining truths about the illness. One participant explained, "*I told my family and then tell other people with my health condition to make sure they get tested*". Increased health literacy and facework are connected, demonstrating knowledge of the disease has power over the illness.

**Cannot hide the cancer but want to educate/obligation.** Non-disclosure yielded key results in terms of deciding to disclose cancer status related to timing of disease and

ability to educate. Because participants were required to be cancer survivors (as defined by them), participants were in remission from 5-50 years from the original diagnosis. The cancer was potentially no longer affecting their lives (*this was ten years ago. Not part of my life*). Education frequently described the reason for disclosure under each category – if the conversation allowed, the cancer was brought up as a way to educate the other (*it sucks having to educate but it is ok; 26 with colon cancer it is nice to educate people*). Schmidt, Kowalski, Pfaff, Wassermann, Wirtz, and Ernstmann (2015) found education at the forefront of needs for women newly diagnosed with breast cancer. While the pace of gaining information differed for each woman – gaining knowledge was a high priority from medical professionals. Gaining knowledge is necessary in creating a narrative about the illness. Not having the knowledge prevents creation of the narrative and ability to communicate the illness to others. As they found, an increase in literacy was helpful for the women and their employers whom they needed to explain their health needs to. For young adults who are less likely to be diagnosed with cancer, the desire to educate others is a high priority. National organization *Stupid Cancer: The Voice of Young Adults with Cancer* discuss on the website the importance of education, social support, and understanding the unique lived experience of being young with cancer ([stupidcancer.org](http://stupidcancer.org)). Top discussion posts include the topics of feeling abandoned, just looking for people who understand, when strangers find out you have cancer, and should I tell my friends. Education (seeking information about the cancer) constitutes a frequent goal of the discussion boards and reflected the content on the social media sites used by the survey. Education could be used as a form of social support as “the brochures are nice, but they don’t feature people like me” referring to young adults with cancer ([stupidcancer.org](http://stupidcancer.org)). Support in facework is often sought in the



discussion boards and many individuals ask how to share information about the cancer and appear to be looking for support in narrative creation and boundary management.

Disclosing cancer treatment at a young age requires a different narrative than an older diagnosis. For example, the narrative might include fertility questions (will you still be able to have children after chemotherapy, what if your spouse wants children) that would not be present later in life.

McQueen, Arnold and Baltes (2015) found the use of narratives to be useful when educating others on procedures related to the medical experience. Narratives allow for a transfer of knowledge (facts and experience) and a chance to educate individuals receiving the disclosures. Narratives provided in the open-ended questions provided humor (*cancer sux, jokes on me, at least it's not cancer*) in describing the illness. Harzold and Sparks (2006) explained the importance of humor and how it predicts a relationship between sense of humor and morale of the illness. The ability to joke can symbolize acceptance and understanding of the illness.

Participants reported telling other people out of obligation (needing to turn down a vacation, work travel, inability to play sports). In delayed disclosure, duty to inform was the most reported reason. For some this was based on treatment or obligation to tell family members currently living with them, the need to ask for help, needing support from friends, or telling boss of a need to adjust work conditions. Matthews, Derlega and Morrow (2006) found that people feel an obligation to disclose personal information in close relationships but make the decision based on the prospective response. Petronio (2002) explains social rules often dictate disclosure, increasing the obligation to disclose. Hiding an illness could be seen as morally or ethically wrong if it puts the other person at risk or

nondisclosure changes the trajectory of the relationship (e.g., talking about having kids when the illness prevents, knowing illness is terminal, impending loss of ability),

### **Time Frame and Receiving Disclosure**

RQ1 asked, “*What is the relationship between the time frame of disclosure and the individuals being disclosed to*”? Differences existed between immediate and delayed disclosure in cancer and diabetes. In both situations, parents were found in the category of immediate disclosure. Because many Type I diabetics were children at diagnosis, parents were present when they found out. Boss/manager appeared under immediate disclosure for cancer ( $n=9$ ) but less frequently for diabetes ( $n=2$ ).

In response to immediate disclosure and cancer, of the 13 relationships reported, 11 included close relationships as a reason for immediate disclosure. The only two relationships not included were security (participant, age 23, was treated at a children’s hospital and had to explain why she was at the hospital so frequently) and doctors. For those who delayed disclosure, the most frequent was duty to inform with 9 of 12 of the relationships falling in this category. Children, friends, and coworkers were the top three relationships reported during delayed disclosure. The highest frequency of disclosure was duty to inform (friends  $n=4$ , co-workers  $n=5$  and children  $n=3$ ), which promotes the desire to have an open and honest relationship while having important information the other needs to know (Derlega et al., 2008). The findings are supported by previous research by Butler and Modaff (2016) who found that disclosure was used to offer explanation about the condition. Because these three relationships represent people the individual might have frequent interactions with, disclosure could relate to facework if the individual is no longer able to hide the illness. Explaining the illness explains why a person behaves

differently or struggles to maintain current abilities, both mental and physical. An explanation saves face, preventing the person from receiving the disclosure to speculate on changing behaviors. Saving face can protect boundaries, preventing the recipient from talking about the situation with other people rather than the person who is ill.

Diabetes (Type I and Type II) reported mother, father, and significant others as the highest frequency of disclosure followed by teachers and friends. Immediate disclosure had the most incidents of disclosure under close relationship (7 of 14 indicated close relationship) and duty to inform (11 of 14). 10 of 14 participants indicated duty to inform as the most significant reason under delayed disclosure. 10 participants also indicated education as a reason for delayed disclosure. Increased time after diagnosis allows for an increase in health literacy and the ability to educate others. An increase in education during delayed disclosure could correlate to an increase in ability to talk about the disease and ability to answer questions during the disclosure.

Previous research by McGrew and Kline (2009) supported the current finding. The study found fear of disclosure as a reason for unwillingness to talk about diabetes even though disclosing was equated with better health outcomes. Disclosure is necessary for social support leading to positive health outcomes yet there is no guarantee positive social support will follow disclosure making the risk seem bigger than the reward. Checton and Greene (2012) found increased disclosure about health status in relationships relates to talking about a wider breadth of topics, increasing intimacy and trust in the relationship. A positive outcome of disclosure becomes the increased social support and focus on relational needs associated with an illness. A negative outcome is termination of the relationship and an increase in isolation.

However, one present duty to inform increased as diabetes involves a chronic illness needing treatment for a lifetime. The ambiguity of healthy and sick identities changing and complications arising through the duration of the illness can compel an individual to disclose, as a complication likely rises at some point in time. Chronic illnesses create complex situations in a person's life. The ability to hide a chronic illness could impact when disclosure occurs. Feelings of betrayal and lack of trust for not disclosing earlier become possible. Disclosure could be based on the inability to keep the illness hidden forcing disclosure. Forced disclosure removes the ability to control the disclosure and takes away the ability to control timing of the disclosure.

Close relationships provide a driving force of disclosure supported by research done by Water and Ackerman (2011) reporting that the most common reason for early disclosure was relational intimacy. Sharing a significant life event such as an illness does have the ability to enhance relationships. Relational closeness is increased by sharing personal information and creating interdependency between people. Both sets of participants listed family as one of the first types of relationship disclosed to (mom, dad, siblings, significant others), which are likely to be relationships spanning the lifetime and stable relationships, potentially decreasing the level of risk of disclosure. Hay, Shuk, Zapolska, Ostroff, Lischewski, Brady, and Bernwick (2009) found family members were disclosed to because of intimacy, emotional closeness, gender, family communication style, convenience and proximity, and perceived negative effects. Open ended responses in the current study indicated proximity, intimacy, and perceived negative effects as reasons for disclosure. Relationship where people were likely to live together (spouses or significant others) were told immediately. Parents were told most frequently and supported in the

open-ended responses as people who were supportive during the diagnosis. Family members not told represented high risk from the open-ended questions with lack of closeness and not wanting to increase stress as reasons to avoid disclosure.

Revealing health status in romantic relationship was discussed frequently in the open-ended responses. Participants reported disclosing to romantic partners in all three time frames. Feelings of relief and regret became reported with each disclosure. Disclosure was viewed as high risk

Participants with cancer reported immediate disclosure under each category except similarity and education. The two most frequent reasons for reporting were for close relationship ( $n=6$ ) and duty to inform ( $n=4$ ). Contrary to these results, the open-ended questions showed hesitation in disclosure (won't tell somebody I am dating until I think they can handle it; I chose not to tell my boyfriend which is likely why we broke up). To understand disclosure in romantic relationships, a more complex set of facework may be happening to married/committed couples over individuals seeking a romantic relationship/being in a new relationship. The long-term complexity of a cancer diagnosis puts stress on any relationship a newer relationship may not be able to handle the uncertainty of the diagnosis. While a cancer diagnosis is not terminal, it had the ability to change life trajectory (such as having children, life-long treatments) placing stress and uncertainty on a new(er) relationship.

Participants with diabetes did not address issues of disclosing to romantic partners in the relationship list, potentially because of the young age of diagnosis or viewing a chronic illness differently. However, one participant did acknowledge the struggle by explaining, "I put boyfriend in both because I have tried both- I think neither plan works. I

tried to delay because to me, it isn't the end of the world. More like nuisance. I don't think it bothers me any more than wearing glasses would bother somebody, but to other people it is worse than cancer". Another participants explained, "If I am dating, I wait". Disclosure of a chronic illness does have a different set of approaches than a non-chronic illness.

Defenbaugh (2013) reports the ability of having a chronic illness and hiding the illness and learning steps to concealment, developing rituals of concealment, and the development of strategies to approach disclosure. In Defenbaugh's discussion of creating a narrative for chronic illness, the issue of isolation is at the fore front. Not sharing about the illness creates an imbalance in the relationship, a hidden identity which takes effort to conceal from the other person.

### **Motivation towards disclosure**

RQ2 asked: *What factors (fear, stigma, need) were motivation towards disclosure?*

Both immediate and delayed disclosure were driven by close relationships and duty to disclose, as seen in the previous question. Discussion from the previous themes can be applied to this research question, specifically in terms of stigma. For participant with diabetes, controlling stigma was a priority in deciding on the disclosure. Participants with Type II diabetes reported the highest levels of stigma while participants with Type I included the need to clarify they had Type I diabetes to reduce stigma.

Stigma provided the key theme in revelation of Type II diabetes. The open-ended responses combined educating people at risk for the disease and reducing embarrassment of having the disease alongside reducing stigma. Responses addressed knowing lifestyle had contributed to the illness and followed by educating others in their lives (such as family and at-risk friends). An increase in health literacy was useful in decreasing the

stigma by allowing for dialogue about the illness. Having information about the illness allows an individual to talk about the illness and answer questions to allow a more fruitful dialogue.

Health literacy for Type I diabetics serves to teach people how the disease was different than Type II, to reduce the stigma. Stigma was discussed as felt after disclosure but also by the participant. Responses included explanation of lifestyle being at fault for causing the illness. Cooperrider and Whitney (1999) explained that while individuals disclose information, learning is often mutual. From the research, education provides a mutual outcome of feeling the need to inform others. Learning how to talk about and disclose the illness required education about the disease to be able to talk about it. Lack of education about the disease for people receiving the disclosure was highlighted in responses through *“we don’t talk about the topic enough”* and *“people don’t know that {difference between Type I and II} means they don’t ask the right questions”*. If education is not present, a person receiving the disclosure is left to draw their own conclusions and assumptions about the illness, creating a false understanding and not allowing the discloser to negotiate face or correct boundaries about the illness.

Fear was not overtly present in the need to disclose. While wanting to understand the illness was present in the open-ended responses, fear was not overtly present. One possible explanation is that for the cancer survivors, the diagnosis is in the past and initial fears are no longer present. For a chronic illness such as diabetes, the fear is part of everyday life and no longer seen as a fear, especially if the illness is well managed. Thus, while stigma was present in delayed or non-disclosure, fear was not as present.

Lack of fear could represent the distance between the study and the initial diagnosis. If fear of the illness is removed or no longer present, fear of disclosure could be removed. If disclosure decisions have been made for several years throughout life changes (new jobs, friends, relationship changes, etc), disclosing health status could no longer be topic of concern and a natural part of the get to know you conversation. If fear of the illness is no longer present, fear of disclosure could also be gone. Braithwaite (1991) found disclosure represents control over the illness and establishment of individuality with the disease.

Need for disclosure was present specifically in the participants diagnosed with Type I diabetes as children. Parents more than children felt obligation to share the children's health status to teachers, coaches, or other adults present in the child's life. This supports previous research which showed parents were often part of the treatment plan, encouraging diligent self-care of their children and helping them to understand the illness (Hummelinick & Pollock, 2006; Vishwanath, 2014). Diabetes was driven by duty to disclose (for safety) followed by need to educate. While both Type I and II discussed duty to inform, the need to educate was centered around wanting friends and family to change behaviors to be healthier and not be diagnosed with the same illness.

### **Differences in Motivation**

The third question asked: *RQ3: Do motivations for disclosure of health status differ between family, friends, coworkers, romantic relational partners or other interpersonal relationship?* While duty to inform and close relationship were the critical reasons for disclosure in both illnesses, other reasons such as desire to educate (diabetes, siblings, immediate), were key. Non-disclosure with friends was a result of privacy and fear of losing



respect. Close family members (parents and spouses/significant others) were immediately closed to for a variety of reasons. As previously explained, part of the reason for immediate disclosure included being present at the diagnosis or the other individual discovering something wrong with the other. Work relationships were discussed under duty or inform over change in ability or needs at work. Close relationships, while necessary, carried a level of risk.

Petronio (2006) found a similar outcome when disclosure was risky and privacy would be lost. Privacy lost ( $n=8$ ) presented an important reason to not disclose. For participants who had visible illnesses, maintaining privacy would not be an issue because it would not be possible. Disclosing illness allowed for a face saving measure to explain the illness or change in ability from the illness. Differences were found in frequency for disclosing to close relationships compared to co-workers and bosses, who were found under delayed or non-disclosure. However, the open-ended responses reshaped this perspective slightly by including need to disclose to non-intimate relationships when necessary. As shown in Table 2, non-disclosure did include both intimate and non-intimate relationships.

Outside of personal relationships, disclosure occurred out of necessity. Need to understand treatments, lifestyle/behavior changes, and inability to hide the disease were cited as a reason for disclosure. Participants diagnosed with diabetes as children needed to disclose for safety reasons. Participants couldn't hide missing work, missing hair from treatment or other physical side effects. As one participant explained, "*don't really tell people unless they see the pump*". Once the medical device is seen, so is the obligation to share health status to educate or simply offer explanation about the situation. For those

able to keep an illness hidden, setting boundaries can be handled differently. If disclosure can be avoided, boundaries do not need to be set.

A clear understanding of motivations for disclosure is not present other than close relationships and out of necessity. Hiding an illness from family an individual lives with becomes nearly impossible, between medical appointments, medication, and devices. Previous research by Westerman, Miller, Reno, and Spates (2015) highlighted the issue by considering the constraints present in understanding motivation behind disclosure. Views on the illness, ability to impact relationship or job ability, laws in place, unease and distrust can all factor into the motivation for disclosure. The results of the current study demonstrate no one size fits all approach to disclosure or boundary creation. The uniqueness of each illness and set of relationships is mirrored in the needs of an individual and the decisions that must take place. Only one participant shared using a therapist to help make these needs, demonstrating individuals are struggling to make these decisions on their own. Needs, social support, ability and education to name a few factors are involved in disclosure and boundary decisions. Moreover, disclosure and boundaries change based on timing and relationships. Privacy boundaries, while present, are influenced by a multitude of factors to impact disclosure.

For individuals with cancer, reasons for self disclosure appeared in every category except for similarity. The only mention of similarity was an open ended response where an individual told their friend who was also diagnosed with cancer. Both having cancer was the reason she sought the individual out to tell. The invasive nature of cancer in all parts of life explains the need to disclose for multiple reasons. While similarity did not show up in the categories, three participants did respond that they would share to other people who

had an illness because of the connection, showing the potential isolation of being the only person with an illness. Parents (mom and dad) appeared most frequently with close relationship and duty to inform.

### **Perception of Risk and Delayed Disclosure**

Research question four asked, *How does the perception of risk of disclosure influence timing of disclosure?* Participants with cancer focused on the need for support and level of risk. Disclosure of Type II diabetes also contained risk of lifestyle judgment. Risk was a reason for not disclosing information, or delaying the disclosure. As one participant explained, *"I don't disclose now unless it will help somebody so I guess I always delay and then tell when necessary"*. Another participant responded, *"I don't tell anybody I am dating until they can handle it"*. Risk during disclosure is aligned with the negative impact disclosure can have on the relationship such as ending or putting the relationship at risk. Risk was aligned with stigma. A stigmatized illness, such as Type II diabetes, increases the perception of the risk of disclosure. However, based on research by Miller (2012), risk was not as common of a response as anticipated.

Miller (2012) found disclosure of cancer risky because of unknown survivorship. One possible explanation for levels of risk not being as present could be that participants were all survivors, many long-term. A second explanation could be increased awareness leading to early diagnosis and new treatment options. More information about the initial diagnosis could have supported levels of risk and furthered understanding. Young participants with cancer reported risk of disclosure to significant others, but not in spouses. As one participant responded, *"Anytime I told someone that I was sick their immediate thoughts were that I was dying so I had to constantly repeat myself and tell them I*

*was not dying*". The need to constantly educate people's misunderstandings of the disease requires significant facework and correction of the incorrect assumptions.

Disclosure relating to Type II diabetes involves risk. More apparent was fear of shame and judgment. As previously discussed, participants with Type II diabetes were less likely to disclose and felt the need to explain the illness. Risk related to judgments about lifestyle, as seen in the previous discussion of fear of stigma in Type II disclosure. Narrative surrounding the disclosure would need to anticipate the misunderstandings to prevent the recipient from creating an incorrect perception about the individual illness. The importance of social support requires a consideration of the balance against the fear of disclosure. Because any illness benefits from social support, fear of disclosing can take away needed avenues of support increasing isolation. Lack of support can cause an individual to take less care of themselves and suffer more effects from the illness (Leung & Chung, 2014).

### **Delayed Disclosure**

The only hypothesis suggested, *Delay of disclosures is correlated with higher risk associated with the outcome of the disclosure*. Perception of risk was seldom reported as a reason for timing of disclosure. Stigma was reported more frequently than risk, though the two are likely related. Risk should relate to the incorrect judgments about an illness that leads to stigma. Goffman (1963) explains a stigmatized individual is deeply discredited and reduced from being a whole person, tainted, or discounted. Risk of stigma after disclosure provides a critical threat to any amount of disclosure. Therefore, Hypothesis one receives only partial support from the research.

Participants with Type I diabetes did not address the concept of risk. For participants diagnosed as children, the chronic nature of the disease influenced the level of risk. As participants claimed, the diabetes and behaviors associated were part of everyday life. Activities that were second nature, such as wearing glasses. Viewing an illness as chronic instead of as the disease places it in the same category as anybody with a chronic illness, positioning the illness as a more normal identity because many people suffer from a variety of chronic illnesses. Participants with Type II did address risk in terms of stigma. Participants shared the need to explain the illness when it was Type I, but those with Type II were less apt to disclose because of ability to keep illness private and feared lifestyle judgment as a cause of their illness. Impression management was apparent, as was the need to clarify the type of diabetes present. The need for impression management was supported by previous research conducted by Stone-Romero, Stone, and Hyatt (2003) report less distrust when a higher ability to control impression management exists.

As discussed in the previous research question, risk and cancer discussions did not take place with the exception of disclosure to new romantic partners. Education became viewed as more important than risk to help others unable to see the person fitting within the expected demographic for the illness.

## **Discussion**

The current study examines implications of the decision-making process during disclosure for diabetes and cancer survivors. The results examine the timing of the disclosure (immediate, delayed, or non-disclosure) evaluating the interaction on the basis of the level of risk. Using the attributes for disclosure categories provided by Derlega et al., (2008) and application of a variety of relationships provided rich data to deconstruct the disclosure process using an open coding framework put forth by the researcher.

As Shim et al., (2011) discovered, many positives come from the ability to disclose and receive social support from others. Benefits include better health outcomes and an improved mental state. However, any disclosure carries the risk of more questions, potential stigma, and needing to explain the reality of the disease while breaking down preconceived beliefs about the illness. Disclosure becomes driven by the need to disclose but contingent on the outcomes and what information needs to be shared. Disclosure includes the element of self and involves the process of educating others. Disclosure became both embraced and loathed by the participants, seen as an unavoidable but necessary process.

As Koenig Kellas, Horstman, Willer and Carr (2015) explain, understanding the impact of disclosure requires examination of the person disclosing as well as the individuals receiving the message. While many of the participants in the current research shared the experience of disclosing and the responses received, further research should explore an understanding of the disclosure process and what occurs before, during, and after the disclosure.

Peterson (2010) found social support as a key reason for disclosure, defining social support as “the various ways in which interactions and social relationship affect physical and physiological well-being” (p. 471). As previous research has stated, strong social support networks are necessary for better health outcomes, as they increase likelihood of adhering to treatment and provide social support.

Brashers, Neidig, and Goldsmith (2004) explain the importance of discussing what is needed from social support after the disclosure. For instance, if the discloser shares information with a co-worker out of obligation, they may not want follow up emotional support. Because the disclosure starts a dynamic change in the relationship, both individuals generate different perspectives on future conversations about the illness. Social support extends Petronio’s conversation on boundary management to include ownership and future conversations about the illness or what kind of future conversation is expected. If a person receiving disclosure is asked to not follow up on the illness or ask questions, the relationship could be in danger. An imbalance of power, knowledge, and inability to emotionally connect to the ill individual exists.

Overall, the findings from this study offer insight on decisions related to disclosure of health information. While disclosure is not always a desired choice, providing knowledge to newly diagnosed, re-diagnosed, or even to family members receiving information about a family member’s illness serves as an important tool in supporting interpersonal and work relationships. Theoretical and practical implications, limitations, future research and a conclusion will be discussed in the following section.

### **Theoretical Implications**

Goffman's theory of face presented a framework for understanding the need for facework during health disclosures. As Cho and Sillars (2015) argued, revealing health conditions constitutes a face-threatening behavior across all cultures. The universal desire to appear as healthy extends to all people and cultures as a valued perception. Using face theory as a framework in health disclosure extends the theory by examining identity and identity creation along with the performance of illness. In the present study, each participant performed illness in a different way such as a pump for insulin or hair loss for cancer. Even between participants with the same illness, a variety of face-saving methods existed. While some participants chose to keep the illness a secret to save face, many used immediate disclosure, creating multiple different sick identities based the person receiving the disclosure.

As Goodwin (1986) explains, identities become shaped as a response to shared narratives. As an individual creates a narrative regarding illness, disclosure and the ability to manage face changes. Illness specific language is learned, questions anticipated and the answers become part of the narrative. The relationship to the receiver is examined in terms of what information to include. Examining facework in tandem with the dialectic process of disclosure (risk versus reward) shifts the need of saving face to needing to find social support. If the disclosure is not well received and face is lost, what ability does the individual have to regain face? Any loss of face risks loss of the anticipated social support from the receiver, possibly removing an important outcome of the disclosure.

Consequently, if health status changes (such as remission), an individual may attempt to save face but if the receiver is not willing to accept the changed identity, the face boundaries shifted. Additionally, an individual could be in treatment for a significant time



with an unknown outcome. An identity related to health status may be in limbo for an extended time, further complicating the healthy/sick identity.

Further research on the potential changing identities could extend the theory to examine facework long term when identity is constantly changing and not under the disclosers control. Continued application of the theory in an uncontrolled setting could create new boundaries for understanding face management. For example, after an illness is cured, physical features could make a person still appear ill, preventing them from recreating a new identity. If people cannot see past the new physical identity, they would still see the individual as sick, ignoring the facework to create the new healthy identity.

The current study contributes to the narrative on facework by examining the performative nature of disclosure. Face-saving involves the “actor” hiding the areas desired to keep private and putting forth a positive self-image. The visible nature of many illnesses negates the possibility of the private self. Challenging the nature of privacy, not keeping private the stigmatized part of the illness could lead to saving face rather than being harmful.

As participants responded in this study, timing and reason for disclosure often related to a face saving need. The findings challenge the notion of having an “on-stage” performance of illness. When the illness does not match audience expectations, the interaction and presentation of self could harm face. For example, a participant with cancer explained, *“I didn’t look sick and that seemed to bother people. Like they were waiting for me to stop hiding”*. The findings encourage a fresh understanding of positive and negative self-concepts and the impact they have on the receiver. Self-concept could be positively impacted from social support. Non-disclosure could also create a sense of negativity

towards the illness. As one participant explained, *“My parents made me feel as though telling people was a bad thing and told me not to post about it on my social networking sites”*.

Non-disclosure (when not the choice of the participant) could create a negative self-identity which needs to be hidden. Non-disclosure could also prevent the creation of narrative about the illness which can prevent an individual from fully comprehending the illness.

**Stigma and facework.** Perceived stigma related to the illness controls the framing and disclosure of information. Underwood (2007) explained face work and disclosure typically surround an attribute that is sensitive to the person disclosing information. As illness changes, sensitivities towards the illness can also change, impacting face work needed to maintain a desired identity. For example, a sexually transmitted infection (STI) becomes an issue when partners initiate sexual activity. Even without symptoms, facework needs to occur as the relationship builds and the risk becomes larger. Because STI status changes (such as a flare up of the illness making it visible or contagious), extending the theory to examine facework in these long term and turbulent environments could provide new insight into identities which (especially those which can't be controlled) change over time.

Disclosure or nondisclosure of an illness provides a further application of Goffman's theory to understand stigma and facework in health disclosure. If disclosure of health status causes conflict in a work setting, supervisors and co-workers could need help saving face. An example of conflict from a participant included not disclosing information until her immune system was compromised and she needed to tell them for her safety. Vickers (1997) argues that companies don't have all of the practical pieces in place to regulate

sharing health status, leading to conflict when attempting to balance accommodation and boundaries.

Westerman et al., (2015) examine the need for training in the place of explicit rules to support employees. Explicit rules could conflict with the illness narrative and create a new narrative for the workplace, not for what the individual wants to disclose. Wittneberg-Lyles and Villagran (2006) found the most common type of workplace disclosure was treatment related (which was true for all disclosures). The second most common was non-disclosure in order to maintain privacy boundaries. White and Wills (2016) contend lack of a workplace script (narrative) can prevent an individual from disclosing at work. Rules, expectations, type of job and co-worker relationships can all influence disclosure. Extending Goffman's work to address health disclosures and the friendship/coworker balance represents a useful tool.

### **Practical Implications**

The findings from the current study offer several practical implications. After a medical diagnosis, information seeking, boundary management, and discussion about the illness are key to understanding a changing life situation. Kim, Lim, and Park (2015) explain that health literacy, or an "individuals' capacity to attain, process, and comprehend the basic health information" is important to understanding and communicating about the illness (p. 1084). Moeini, Maghsodi, Kangavari, Afshari, and Tagh (2016) found lower health literacy correlated with lower self-care.

**Health literacy and education.** A significant finding of the current study was the need to educate others about diabetes and cancer. Before education occurs, health literacy about the topic must be obtained. Disclosure will be hindered if an individual is unable to

talk about the illness and answer questions asked. Unanswered questions can increase stigma and reinforce preconceived notions if appropriate answers are not provided.

Sastry, GhoshDastidar, Adams, and Pebley (2006) argued health literacy leads to social capital, which can be useful during disclosure. Viswanath (2008) explained that health literacy leads to social capital, as the individual has the ability to explain their illness and understand obligations regarding when to disclose.

Social capital emerged particularly in cancer patients. As one participant explained in terms of who she disclosed to:

So this is kinda odd, but my answer to this question is everybody. After a month, I knew what was happening, I told everybody else what was happening. I figured that I am young, not who you would expect to get cancer and it was my job to educate people on what I was going through. I posted on social media and created an account to help people who wanted to follow my journey. I wanted people to know what was going on and I wanted them to check their breasts! So many young women get so much sicker than they need to because they don't think they are at risk.

Creating and having control over the narrative surrounding an illness increases social capital by enabling an individual to have some control over the social interactions surrounding the disease. If literacy is not present, social capital is lost the ability to create a public identity of the illness is lost.

Pleasant, Cabe, Patel, Cosenza, and Cannon (2015) argue two critical issues prevent health literacy. The first is lack of access to medical materials. While a shift to increase accessibility of medication knowledge including simpler explanations of medical terminology exists, much progress still needs to be made. A second issue involves lack of

tools to check for health literacy of patients. While patients respond to medical staff, the patients understand the diagnosis and treatments, little effort exists to test the knowledge.

**Health disclosure at work.** Deciding whether to disclose health status at work is often left to the individual but dependent on the context of the illness. If the illness affects job performance or requires changes to routine, disclosure is unavoidable. An individual is protected from not having to talk about an illness, yet silence does not guarantee continued privacy, especially for an illness (or treatment) with visible signs, such as hair loss or giving oneself an injection. Telling a boss or manager was important for immediate disclosure for participants with cancer because of impacts in the work environment. Individuals with diabetes did not disclose to bosses/managers or coworkers as frequently, because of the ability to conceal the illness.

A potential difference also exists when the illness is considered chronic. As one person commented, “it’s a lot like wearing glasses. I don’t even notice it until something goes wrong”. Goodman, Posner, Huang, Parekh, and Koh (2013) explain that based on the current health and demographic trends, the prevalence of chronic illness will continue to grow and 1 in 4 adults have a chronic condition. Future research should follow up on chronic illness and disclosure to examine difference in reaction. Reactions to disclosure could be different when the illness isn’t new, leading to feelings of being lied to or not believing the seriousness of the illness (because it had not been an issue previously).

Westerman et al., (2015) found in the study that while policies about health are often in place, a rigid set of rules might not allow for boundary creation by the individual. As several participants commented, assurance of ability to do the job or sharing which

aspects of the job could no longer be maintained (such as high amount of travel while on treatment) were key when redefining boundaries in the workplace.

The lack of understanding of illness could become represented as a form of diversity. Allen (1995) explains that diversity in the work place is often limited to a “variety of personal and social bases of identity including race-ethnicity, gender, age, socioeconomic status, religion, sexual orientation, country of origin etc” (p. 144). Framing illness as diversity potentially helps an individual explain differences in abilities related to work, such as a disability. As illnesses become treatable and people find it necessary to work during an illness, health should be treated in the same way as other identities. Linking illness to diversity is more tangible for a chronic illness than a diagnosis like cancer.

To better support individuals disclosing health status, companies would benefit from addressing policies in terms of privacy management and considering what expectations are in place (spoken and unspoken) and to consider how policies control dialogue. As Vickers (1997) argues, taking away control of boundaries could force silence or increase the perception of stigma towards the illness. New policies must allow for an individual to keep the illness private if they are able. Companies need to protect the individual and themselves. Pleasant and Modaff (2016) found that how individuals saw identity determined impacted how and whether to make a request for workplace accommodations. Health literacy, narrative formation, and workplace policies must be viewed together to provide a safe working environment.

**Disclosure as conflict.** Once information has been disclosed, boundaries become shared, creating turbulence and the need for negotiation. Kirshbaum (2012) articulates

health interactions create potential conflict states from risk of disclosure. Disclosure becomes difficult for newly diagnosed individuals to have the knowledge necessary to “solve” for conflict from the disclosure. During immediate disclosure, lack of health literacy leads to lack of ability to solve the problem and provide information about the illness. The findings found that lack of seeking of knowledge came from privacy and fear of losing respect. While motivation for disclosure was not clear, lacking ability to explain the illness could lead to fear of privacy and lack of respect if information about the illness cannot be provided (such as contracting the disease or if it is contagious).

Educating individuals how to talk about the illness becomes a critical part of the diagnosis process. As previously discussed, health literacy remains a key component in talking about the illness. Part of the diagnosis should include personal support on how to talk about the illness in necessary contexts. Anderson (2009) explained that interactions regarding health are prone to conflict because of the high-stress nature of the event. Providing language and metaphor for the narrative could prove useful. Kim, Lim, and Park (2015) argued this need is even great for low-income and low-education individuals, who have less access to knowledge about the disease. Kim, Lim and Park found that low-income and low-education individuals had a lower grasp on the language surrounding the illness and the ability to describe the illness to others. In the current study, participants did not provide enough description of illnesses to find significance in descriptions of illness with education levels. Future research could address the way people describe the illness, which will be discussed later in the manuscript.

Even more concerning, Leung, Cheung, & Chi (2014) found low-income and low-education generated a detrimental effect on treatment outcomes. Fear of being seen as

unintelligent prevented individuals from asking questions during clinic appointments and gaining education/literacy about the disease. Poor health outcomes are a physical result of the misunderstanding. Findings from the current study represented a significant number of high-school only educated participants explaining the struggle to talk about the illness and impacting the disclosure process.

Additionally, the disclosure process needs to be continued as illness is not static: cancer can be in remission, return, go back to remission and return again. A chronic condition like diabetes could have side effects later in life, forcing a chronic illness to intersect with a new diagnosis. Talley (2016) argues the importance of health literacy and providing patients with narratives and metaphors to talk about the illness. Patient education about the illness is significant for helping the patient answer questions and dispelling myths surrounding the illness. For children who are diagnosed, parents and children could have two different narratives, adding an additional layer of language and metaphor to explain the illness at different levels.

A patient blaming themselves for the illness offers disclosures that increase misunderstanding of the illness. Patients need to adjust the narrative as the illness changes. For patients in remission, the fear of cancer returning constitutes a very real fear and the shift from an active cancer patient to a person in remission represents a difficult change in narrative to express adequately.

## **Limitations**

Several limitations exist to the current research. Research design and using the stimulus as an unfocused illness require attention. Additionally, expanding the research to include the target of disclosure at each juncture (immediate and delayed) could provide



insight into how disclosure (as well as boundary management and face work) changes. Reciprocation to the disclosure can alter future disclosure, an important contribution to the process.

Alteration in the research design would assist scholars duplicating the questions. Proposing a set of relationships to have people begin thinking about disclosure could have been seen as the only set of relationships to examine. Participants may have focused on the lists provided and only considered each relationship listed, not thinking about other people in their lives. An unlimited list contributes to participant fatigue, and cause high numbers of dropout if the first list (immediate disclosure) was lengthy. For participants diagnosed as children, the question may not have been seen as relevant or lacked certainty in the answer.

Moreover, a significant number of participants failed to indicate the reasons for disclosure. After entering relationships in the reasons for disclosure category (i. e. trust, duty to inform), participants did not respond in the open-ended question box. Potentially, this was seen as a duplicate question or it may have been difficult to complete boxes on a mobile phone. Additionally, if language to talk about the reasons was lacking, the narrative may not exist.

Data was fractured due to a viewing a question as duplicated. Participants were asked as the start to list the people they had disclosed to, including a partially constructed list. Participants possibly thought they had answered the question already, choosing not to answer the question again.

Research design would be improved by asking before each timeframe to list disclosures (people) and then place in the attribute(trust, duty to inform) categories. The

first relationships in each category likely represent the most emotionally charged disclosures, both positive and negative. A self curated list allows for each individual to reflect on the relationship without any influence from the research design. Allowing individual to self-curate allows for relationships not discovered in previous research to emerge.

For individuals diagnosed as children rather than adults, recalling disclosure seemed more difficult because relationships changed more frequently and included more levels of interaction, such as a new teacher each year, friends and subsequently friends' parents. Initial narrative on the disease was not created by the child, but the parents. For these participants, accuracy of memory is likely to be what was told to them rather than a remembered experience.

Conducting individual interviews allows for more developed study. Allowing voices to be heard gives the chance for creating of the health narrative. As Wang (2014) explains, narrative allows a participant to fully explain their illness by sharing the emotional story and allowing them to frame it in their own voice – not the confines put forth by the researcher. Because so few participants went into depth about their illness, hearing the narrative creation could further explain issues of health literacy which became a key factor in disclosure.

The results provide a diversity of responses based on the illness, age of diagnosis, and current age. Young adults and elderly have very different social circles, family members, and work experience which created very different results based on the outcomes of the survey. Young adults commented on need for education, a way to prevent friends from suffering from a potential disease. For participants with cancer who were married,

telling a spouse was an immediate disclosure or the spouse was present when the formal diagnosis was received. For young adults with cancer delay or hesitancy to tell a significant other about the previous diagnosis was present. As one participant explained, "*I put boyfriend in both because i have tried both - i think neither plan works.*" Future research could focus on romantic relationships and how the narrative changes based on previous responses to the illness.

A more focused group of participants and stricter demographic requirements would allow for depth of specific groups and experiences. For example, surviving childhood or young adult cancer provides a very different perspective than an older person with cancer. Disclosing an illness as a young adult contains a different set of risk factors which should be addressed. Starting college, finding a career, finding a romantic partner and deciding on children are more likely to effect young adults than older. Being diagnosed at the beginning of life rather than near the end contains a different set of behaviors and future lifestyle choices which would involve very different life experiences. An older adult would have to decide on early retirement or how to tell adult children, very different life stages than a young adult.

Initially, the designed research tool addressed young adults with cancer. In attempt to conduct a study that would allow for comparison between groups, the age restriction was lifted and a comparison group, diabetics, was added. Because of this, the first question that asks individuals to start thinking about who they disclose to could have included more prompts, such as children and more about non-family and work related friends. While participants were still able to include these individuals in later questions, the initial

question could have restricted their thoughts on who to include in later questions. Future research design could address chronic/non-chronic illnesses as they are viewed differently.

### **Future Research**

Future research should continue to explore elements of disclosure in health related interactions. Understanding the interpersonal process of disclosure benefits the sender and the receiver, providing both with tools necessary to understand boundary management and face saving behaviors. Creating a health narrative which allows for reciprocity permits the receiver to create a narrative to the disclosure, reducing the stress over boundary creation.

**Work related disclosure.** Research should continue into the handling of disclosure at work – not only with bosses and coworkers but people outside of work such as clients or students. While the Americans with Disabilities Act (ADA) requires accommodations for an individual, the request for accommodations may fall outside the desired boundaries of disclosure. ADA accommodation requires an identity shift to illness and disability which could increase feelings of stigmatization. Consequently, boundaries of information ownership become more confusing after disclosure as the extended audience possesses different legal boundaries than a boss or co-worker. Co-workers feeling the need to look out for themselves could share information without considering boundaries set by the discloser. Future research should examine disclosure connected to clients or other individuals external to the company. Petronio (2002) explains boundaries become turbulent when an individual is no longer able to coordinate the boundaries, which would be true in these legally unprotected situations. Legally, an individual needs to think about disclosure in terms of what information is shared to receive the required accommodations,

such as needing to disclose not being able to work mornings or afternoons after a medication is consumed or the need to work from home after chemotherapy. If an individual is out sick receiving treatment and the client asks a manager about the individual, pre-determined responses can be important so the information stays internal – but in a manner where the working relationship is not put in jeopardy. Control over the narrative receivers create (to provide to clients) should receive consideration.

**Impact on receiver.** Future research should focus on both members of the disclosure. As Keonig Kellas et al., (2015) points out, little research is known about the effect of disclosure beyond the sender. Research should focus on emotional and support reactions for the receiver, or how the narrative changes based on reactions. Additionally, research examining both individuals could focus on boundary setting and framework. Influence on the narrative from disclosures could provide information on the process of constructing the narrative. Boundaries viewed from the point of the receiver could help understand how the receiver negotiates the boundaries of the disclosure (Petronio, 2004). For example, if an individual discloses and tells the receiver, “you are the only person I am telling”, clear boundaries and more importantly a significant burden in support and care taking placed upon the receiver.

### **Conclusion**

Greene et al., (2012) represents disclosure of health status as creating a dialectical tension of balancing the risk and reward of self-disclosure. Individuals with an illness feel stigmatized because of the illness or take on the identify of a sick person. Through the use of frequencies and narratives, this study offered an exploration of the reasons for the

decision of timing and choice of target for disclosure. Key to the outcome of disclosure was health literacy and the ability to create narrative for the disclosure.

Focusing on the relationship and the intention of the disclosure allows for education to occur for both parties. While traditional reciprocity might be missing, helping diagnosed individuals create a two-way conversation could be helpful during disclosure and boundary creation. Finding ways to create a supportive environment benefit the social support required during turbulent times. The current study allows for continued understanding of the need to examine the what, how and timing of disclosures, creating a healthy, supportive environment for all.

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## APPENDIX A: Recruitment, Consent, and Survey

### Recruitment

Hello,

My name is Jessica Samens and I am a doctoral student at University of Wisconsin, Milwaukee. I am conducting research examining disclosure of health status in different relationships. If you are a cancer survivor or diabetic, you are invited to participate. If you are interested, please click the link below to read the consent materials. You must be 18 years or older to participate. If you have any questions, please contact the researcher, Jessica Samens at [jsamens@uwm.edu](mailto:jsamens@uwm.edu).

Thank you,  
Jessica Samens

### Consent Form

#### University of Wisconsin – Milwaukee Consent to Participate in Online Survey Research

**Study Title:** How Individuals Disclose Health Information

**Person Responsible for Research:** Jessica Samens

**Study Description:** The purpose of this research study is to study the timing of disclosure of health status. Approximately 100 subjects will participate in this study. If you agree to participate, you will be asked to complete an online survey that will take approximately 20 minutes to complete. The questions will ask you to think about whom and when you disclosed your health status and why the decision was made and those you chose not to disclose the information to.

**Risks / Benefits:** Risks to participants are considered minimal. Risks include recalling the experience of remembering the disclosures and any negative memories that were involved. Collection of data and survey responses using the internet involves the same risks that a person would encounter in everyday use of the internet, such as breach of confidentiality. While the researchers have taken every reasonable step to protect your confidentiality, there is always the possibility of interception or hacking of the data by third parties that is not under the control of the research team. There will be no costs for

participating. Benefits of participating include a further understanding of why and when people choose to disclose information about their illness.

**Limits to Confidentiality:** Identifying information such as your name, email address, and the Internet Protocol (IP) address of this computer will not be asked or available to the researchers. Data will be retained on the Qualtrics website server for one year and will be deleted by the research staff after this time. However, data may exist on backups or server logs beyond the timeframe of this research project. Data transferred from the survey site will be saved on a password protected computer for two years. Only the principal investigator, Jessica Samens will have access to the data collected by this study. However, the Institutional Review Board at UW-Milwaukee or appropriate federal agencies like the Office for Human Research Protections may review this study's records.

**Voluntary Participation:** Your participation in this study is voluntary. You may choose to not answer any of the questions or withdraw from this study at any time without penalty. Your decision will not change any present or future relationship with the University of Wisconsin Milwaukee.

**Who do I contact for questions about the study:** For more information about the study or study procedures, contact Jessica Samens at [jsamens@uwm.edu](mailto:jsamens@uwm.edu).

**Who do I contact for questions about my rights or complaints towards my treatment as a research subject?** Contact the UWM IRB at 414-229-3173 or [irbinfo@uwm.edu](mailto:irbinfo@uwm.edu)

**Research Subject's Consent to Participate in Research:** By entering this survey, you are indicating that you have read the consent form, you are age 18 or older and that you voluntarily agree to participate in this research study.

Thank you!

- Yes, I agree
- I do not wish to participate

## Survey

Q1: I am a

- Cancer survivor (please specify type) \_\_\_\_\_
- Diabetic - Type 1
- Diabetic - Type 2
- None of the above

Q 2: Please describe your illness - include details of when diagnosed and how it impacts your life, and anything else that could be important to disclosing information about illness to the people in your life.

Q 3: The following question asks you to begin thinking about who you have disclosed information about your illness to. You will be asked to consider who you disclosed your illness to immediately, who you delayed telling, and individuals you decided not to disclose to. You will have the chance to add more people later in the survey and to provide explanation. For this question, you can drag and drop relationships into the disclosure categories. You can add more relationships in the follow up questions.

Immediate Disclosure	Delayed Disclosure	Did not Disclose
<input type="checkbox"/> _____ Mother	<input type="checkbox"/> _____ Mother	<input type="checkbox"/> _____ Mother
<input type="checkbox"/> _____ Father	<input type="checkbox"/> _____ Father	<input type="checkbox"/> _____ Father
<input type="checkbox"/> _____ Boss	<input type="checkbox"/> _____ Boss	<input type="checkbox"/> _____ Boss
<input type="checkbox"/> _____ Coworker	<input type="checkbox"/> _____ Coworker	<input type="checkbox"/> _____ Coworker
<input type="checkbox"/> _____ Significant other	<input type="checkbox"/> _____ Significant other	<input type="checkbox"/> _____ Significant other
<input type="checkbox"/> _____ Sibling (specify)	<input type="checkbox"/> _____ Sibling (specify)	<input type="checkbox"/> _____ Sibling (specify)
<input type="checkbox"/> _____ Other relationship - please specify relationship	<input type="checkbox"/> _____ Other relationship - please specify relationship	<input type="checkbox"/> _____ Other relationship - please specify relationship
<input type="checkbox"/> _____ Other relationship	<input type="checkbox"/> _____ Other relationship	<input type="checkbox"/> _____ Other relationship
<input type="checkbox"/> _____ Other relationship	<input type="checkbox"/> _____ Other relationship	<input type="checkbox"/> _____ Other relationship
<input type="checkbox"/> _____ Other relationship	<input type="checkbox"/> _____ Other relationship	<input type="checkbox"/> _____ Other relationship

Q4: The following questions will ask about reasons for disclosure. Think of the people you disclosed to immediately and why. For example, If you shared with your mother because of "duty to inform" and "close relationship", enter mother next to both categories. You will be asked to do the same for those with delayed disclosure on the next page.

	Relationship	Relationship	Relationship	Relationship
Close Relationship	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Trust	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Seeking to Help	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Duty to Inform	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Similarity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Availability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other person asked	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other person involved	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Catharsis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Educate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Increase	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

intimacy or  
closeness

Self-  
Clarification                                               

Q5: Please offer explanation in more detail for those you disclosed to immediately. Include any additional details, such as requests ("please don't tell other people") or if there was any regret in disclosing information. Be as specific as possible.

Q6: The following questions will ask about reasons for delayed disclosure. Think of the people you disclosed to some time after the diagnosis and why. For example, If you shared with your mother because of "duty to inform" and "close relationship", enter mother next to both categories. You will have the chance to explain why the disclosure was delayed after this question.

	Relationship	Relationship	Relationship	Relationship
Close Relationship	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Trust	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Seeking to Help	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Duty to Inform	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Similarity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Availability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other person asked	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other person involved	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Catharsis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Educate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Increase intimacy or closeness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Self-Clarification	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q7: Please offer explanation in more detail for those you chose to wait to disclose. Include any additional details, such as requests ("please don't tell other people") or if there was any regret in disclosing or waiting to disclose information. Please be as specific as possible.

Q8: The following questions will ask about those you have delayed disclosure to - think of the people you chose not to disclose to and the reason why. For example, enter "father" if you chose not to disclose to him for any reason.

	Relationship	Relationship	Relationship	Relationship
Protecting the other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fear of losing respect	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Privacy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Superficial Relationship	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Self-blame/Low self-esteem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dissimilarity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Would put relationship at risk	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other can't help	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q9: Please offer explanation in more detail for those you chose not to disclose. Include any additional details, such as regret in not telling or experiences that caused you not to disclose.

Q10: Any additional information you would like to share about disclosure or the disclosure process related to the previous questions or thoughts you would like to share?

Q11: I am

- Male
- Female
- Prefer not to answer

Q12: Age

Q13 :Approximate date and prognosis of original diagnosis

Q14: Age at diagnosis

- Q15: Education level
- High School
  - College/University
  - Post-Graduate



## APPENDIX B: Definitions

**Table 1** Definitions of attributes (Derlega, et al., 2008)

Attribute	Definition
Close relationship	Being in an emotionally close relationship
Trust	Having a relationship built on trust
Duty to Inform	Wanting to have an open and honest relationship; important information about the self that the other needs to know
Similarity	The other person and the individual disclosing have something in common
Availability	Target was chosen mainly because of situational or proximal availability
Other asked	The other asks or demands disclosure
Involved	Disclosing because target is involved in the situation
Catharsis	Emotional relief or release of pent of feelings
Educate	To help the other be better educated about certain matters
Increase Intimacy	Increase intimacy or closeness with the other person and encourage reciprocity
Self-Clarification	Increase clarity and self-understanding: put thoughts and feelings into clearer focus
Nondisclosure Attributes	
Protecting the Other	Concealing certain information to avoid hurting the target

Concern about losing respect	Not disclosing out of fear that the other person would think less of them
Privacy	Not disclosing to maintain one's privacy and to avoid gossip and information dissemination
Self-blame/Low self-esteem	Shame, self-blame, or low self-esteem relating to the topic of disclosure
Other cannot be helpful	Avoiding disclosure to a target because that person is unable to provide needed assistance
Putting the relationship at risk	Concern that revealing the information would weaken or maybe end a relationship
Difficulty	No common ground exists with the other person so disclosure is avoided

### APPENDIX C: Results Tables

The following tables include a tally and percentage of responses for each timing category.

Cancer *n*= 36

Diabetes *n*= 29

**Table 1** Cancer: Immediate Disclosure

	Mom	Dad	Significant Other	Co-worker/s	Boss/ Manager
Close Relationship	12 33%	7 19%	6 16%	1 2.7%	1 2.7%
Trust	4 11%	1 2.7%	3 8%	2 5%	2 5%
Seeking help	2 5%	2 5%	1 2.7%	1 2.7%	1 2.7%
Duty to inform	5 14%	3 8%	4 11%	2 5%	4 11%
Similarity					
Availability	1 2.7%		2 5%	1 2.7%	
Other Person asked			1 2.7%	1 2.7%	
Other person involved			3 8%		
Catharsis			1 2.7%		
Educate					
Increase Intimacy or closeness			2 5%		
Self-Clarification			1 2.7%		2 5%

**Table 2** Cancer: Delayed Disclosures

	Friends	Co-Workers	Children	Siblings
Close Relationship	1 2.7%	1 2.7%	2 5%	
Trust	2 5%	1 2.7%		
Seeking help			1 2.7%	
Duty to inform	4 11%	5 14%	3 8%	2 5%
Similarity				
Availability				

Other Person asked	1 2.7%	2 5%		
Other person involved	1 2.7%			
Catharsis				
Educate	3 8%		2 5%	1 2.7%
Increase Intimacy or closeness	1 2.7%			
Self-Clarification			1 2.7%	1 2.7%

**Table 3** Cancer, Nondisclosure

	Friends	Co-Worker	Boyfriend	Siblings
Protecting the other	2 5%			1 2.7%
Fear of losing respect				
Privacy	2 5%	2 5%	1 2.7%	1 2.7%
Superficial relationships		1 2.7%	1 2.7%	
Self Blame/Low Self-esteem				
Dissimilarity	2 5%	2 5%	1 2.7%	
Would put relationship at risk				
Other can't help				1 2.7%

**Table 4** Diabetes – Immediate Disclosure

	Mom	Dad	Sig Other	Sibling
Close Relationship	6 21%	5 17%	6 21%	1 3&
Trust			1 3%	
Seeking help			2 7%	

Duty to inform	2 7%	1 3%	4 13.7	5 17%
Similarity		1 3%		
Availability			2 7%	
Other Person asked				1 3%
Other person involved	3 10%	2 7%		
Catharsis		1 3%	1 3%	
Educate	1 3%	1 3%		3 10%
Increase Intimacy or closeness				
Self-Clarification				

**Table 5** Diabetes – Delayed Disclosure

	Mom	Friends	Teacher	Siblings
Close Relationship	2 7%	2 7%		1 3%
Trust	1 3%	1 3%		
Seeking help				
Duty to inform	2 7%	2 7%	4 13.7%	2 7%
Similarity				
Availability				
Other Person asked				
Other person involved				
Catharsis				
Educate		2 7%	1 3%	1 3%
Increase Intimacy or closeness		1 3%		
Self-Clarification				

**Table 6** Diabetes, Nondisclosure

	<b>Acquaintances</b>	<b>Work</b>	<b>New Friends</b>	<b>Best friends</b>
Protecting the other	1 3%			1 3%
Fear of losing respect		1 3%		1 3%
Privacy	1 3%	1 3%	1 3%	
Superficial relationships	1 3%			
Self Blame/Low Self-esteem				
Dissimilarity				
Would put relationship at risk				
Other can't help				

## Jessica M. Samens

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Current Positions    Instructor, Assistant Director of Forensics, Bethel University  
Adjunct Assistant Professor, St Mary's University Minnesota  
Doctoral student, University of Wisconsin - Milwaukee

### Education

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*Doctoral Student*

University of Wisconsin, Milwaukee 2013-present  
Health Communication

*Master of Arts*

Minnesota State University, Mankato 2004- 2006  
Speech Communication

*Bachelor of Arts*

Winona State University, Winona, MN 2004  
Major: Communication Studies  
Minor: Special Education

### Positions

---

Instructor and Assistant Director of Forensics 2009- present  
Department of Communication Studies  
Bethel University

Associate Professor, Curriculum Developer, Summer 2012 to present  
Department of Organizational Leadership  
St Mary's University, Minnesota

Instructor, 2006-2009  
Department of Speech Communication  
Minnesota State University, Mankato

Graduate Teaching Assistant, 2004-2006  
Department of Speech Communication  
Minnesota State University, Mankato

Graduate Forensics Coach, 2004-2006  
Department of Speech Communication  
Minnesota State University, Mankato

### Courses Taught

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Fundamental of Speech Communication  
Perspectives of Communication Theory  
Research Methods  
Advanced Public Speaking  
Oral Interpretation of Literature  
Basic Communication  
Public Speaking  
Interpersonal Communication  
Public Speaking for Non-Native Speakers  
Nonverbal Communication  
Basic Communication [online]  
Virtual Communication [online]  
Communication for Technical Professionals  
Introduction to Liberal Arts  
Introduction to Life at Bethel  
Forensics Lab  
Business Communication for Professionals  
Senior Seminar, Communication  
Public Presentations (MA level)  
Collaboration and Conflict (MA level)  
Communication and Presentations (MA level)  
Ethics and Research (MA level)

### **Awards, Honors, and Recognition**

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“Making Connections: Discovering the Link between Popular Culture and the Basic Course.” The Melissa Beal Award, Basic Course Interest Group, 2012

“Making connections: Supporting the non-native speaker of english in the classroom. Paper Presentation, Instructional Resources Group, Top Panel, 2012.

### **Research and Presentations**

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Samens, J. (2015) *Online Student Presentation Methodology: Debating Best Practices when Assigning Presentations in Online Communication Classes*. Presentation at the Communication Theater Arts Minnesota annual conference.

Samens, J. (2015). *Students in Suits: Exploring Competitive Speech and the Halo Effect*. Presentation at the Communication Theater Arts Minnesota annual conference.

Samens, J. (2014). *Finding GRIT in forensics*. Presentation at the Communication Theater Arts Minnesota Conference.



- Samens, J. (2014). *Encouraging voices in the classroom: The unheard voices of ELL students*. Presentation for the Intercultural Communication Division, Central States Communication Association.
- Walker, J., Brennan, N., & Samens, J. (2014) *A new method using online comment analysis as the vehicle to elevate a new scholarship based on conference forums*. Presentation on Post-baby bodes and the ways they unite and divide women. Paper Presentation, Communication Theory Interest Group, Central States Communication Association
- Samens, J. (2012). *"Making connections: Discovering the link between popular culture and the basic course"* Paper presentation, Basic Course Interest Group.
- Samens, J. (2012) *"Making connections: Supporting the non-native speaker of english in the classroom*. Paper Presentation, Instructional Resources Group, Top Panel.
- Samens, J. (2012) *"The pedagogy behind practice: Uniting competitive forensics norms with the public speaking curriculum"* Paper presentation, Argumentation and Forensics.
- Samens, J. (2011) *"The Bloomington Recommendations"* Paper presentation at the 2011 Individual Events Conference, Bloomington, MN.
- Samens, J. (2011). *"Current research in argumentation and forensics"* Panel Respondent, Argumentation and Forensics Interest Group.
- Samens, J. (2010). *"Help! I need a new idea!"* Panel Chair and presenter, Adjunct and Temporary Faculty Caucus.
- Samens, K. (2008) *"The usage of popular culture in communication classes: Theories, methods, and artifacts of popular culture"* Panel Participant, Instructional Resources.
- Samens, J. (2008) *"Basic course and civic engagement: Beyond the classroom. State of Minnesota Showcase program*. Panel Participant, Central States Advisory Council.
- Samens, J. (2008) *"No, I am not a student: Pedagogical strategies and challenges of being a young instructor"* Panel Participant, Communication Education.
- Samens, J. (2008) *"Queer pedagogy as an activist's tool: Incorporation of queer pedagogy in communication education"* Panel Chair, Communication Education.
- Samens, J. (2007) *"Flying solo: Graduate students teaching upper level courses"* Panel

Participant, Communication Education.

Samens, J. (2007) "*Blurring the lines: An examination of Ethical Dilemmas*" Participant and Chair, Freedom and Responsibilities of Speech.

Samens, J. (2007) "*Beyond the classroom: Basic course and civic engagement*" Member of panel presentation, Basic Course Division.

Samens, J. (2006) "*Standpoint Theory: How perceptions are formed*" Activity presented, Great Ideas for Teaching Speech.

Samens, J. (2006) "*Communication apprehension in the classroom: A qualitative approach to teacher immediacy and classroom climate*" Paper presented at the Central States Communication Association Conference, Graduate Caucus.

Samens, J. (2005) "*Normalizing Expectations? Sexuality and Disability in Professional and Embodied Discourse*" Paper presented at the Feminist Research Conference in Mankato, MN.

Samens, J. (2004, November). *But what if they laugh at me? An examination of the Effects of Peer Coaching on Team Morale.* Paper presented at the annual meeting of the National Communication Association, Chicago, IL.

### **Forensics Experience**

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Assistant Director of Forensics, Bethel University Fall 2009- to present

Director of Forensics (Acting) Bethel University – Spring 2011

Minnesota State University Graduate Coach, August 2004 to May 2006

Winona State University Forensics Coach, 2003-2004

### **Service**

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#### *Departmental*

Chair of Scholarship Committee  
Fall 2014 to present

#### *University*

Member, ESL Task Force Committee  
Fall 2010 to present  
Professional Development Committee

Fall 2016 to present

*Organizational Memberships*

National Communication Association (NCA) member

November 2004 to present

Central States Communication Association 2005 to present

Pi Kappa Delta (PKD)

National Forensics Honorary, March 2001 to present

Graduate Advisory Committee (GAC)

Minnesota State University, Mankato, August 2004 to May 2006

**Review Boards**

National Communication Association Disability Caucus Paper reviewer. March, 2005.

Central States Communication Association – Various, Fall 2005 to present

Communication Theater Arts Minnesota – Various, Spring 2011 to present