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## BALLOONS, BREADCRUMBS, AND SPOONS: EMERGING ADULTS' PRIVACY NEGOTIATION AND MANAGEMENT OF THE (NON)DISCLOSURE OF CHRONIC ILLNESS-RELATED INFORMATION WITH A FRIEND

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BALLOONS, BREADCRUMBS, AND SPOONS: EMERGING ADULTS' PRIVACY  
NEGOTIATION AND MANAGEMENT OF THE (NON)DISCLOSURE OF CHRONIC  
ILLNESS-RELATED INFORMATION WITH A FRIEND

by

Robert D. Hall

A DISSERTATION

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Major: Communication Studies

Under the Supervision of Professor Dawn O. Braithwaite

Lincoln, Nebraska

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Robert D. Hall, Ph.D.

University of Nebraska-Lincoln, 2022

Advisor: Dawn O. Braithwaite

Emerging adults (EAs) experience many changes throughout this life-stage, characterized by self-focus, identity explorations, instability, in-betweenness, and possibilities of optimism (Arnett, 2014). As EAs transition from home of origin into independence, they may place more reliance on social networks apart from their family of origin (e.g., friends, Rawlins, 2009). Yet, chronically ill EAs may experience complications due to the biographical disruption, or interference of expectations in one's life (Bury, 1982), particularly given that chronic illness is typically viewed as an elderly-related issue rather than occurring with youth (Kundrat & Nussbaum, 2003). Through transitions in the EA life-stage, EAs with chronic illness may forgo sharing chronic illness-related information or withhold expressed desire for social support to appear more "normal" to fit in with their peers (Spencer et al., 2019). Thus, I centered the present study in Petronio's (2002) Communication Privacy Management (CPM) theory to understand how EAs interact and negotiate (non)disclosure of chronic illness-related information with a friend.

In the present interpretive and qualitative study, I analyzed and described how EAs interacted and negotiated the process of (non)disclosure of their chronic illness-related information with a friend. Data were 15 in-depth interviews and 15 book cover

images to represent the experiences of EAs with chronic illness. In the results, I describe and explain how participants (a) engaged criteria for disclosure and identified the confidants of their disclosure, (b) created boundary rules around their chronic illness-related information, (c) perceived their friends' role/non-role in chronic illness management, and (d) made sense of their chronic illness-related information management processes.

I contribute four theoretical insights regarding CPM: (a) expanding confidant typology, (b) deconstructing disclosure criteria, (c) demonstrating dialectical tensions of private information disclosure, and (d) developing CPM concepts through metaphorical insights. I also offer two main practical implications: (a) creating a resource for EAs with chronic illness and (b) offering a strategy for arts-based therapeutic practice for those working with EAs experiencing biographic disruption.

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## **CHAPTER ONE: ARGUMENT FOR THE PRESENT STUDY**

### **RATIONALE**

Throughout our lives, we make decisions about sharing information. Sometimes, we share our information openly while keeping information to ourselves in other situations and we consider a wide variety of factors in making the decision to reveal or conceal information. No matter the particular interaction or relationship, we consider sensitive information to be a part of privacy. According to Petronio (2002), privacy is the belief that we have a right to own our private information. Private information, then, is any personal information that carries some dimension of riskiness, meaning that sharing such information could carry some type of consequence. Therefore, private information slides along a continuum of revealing and concealing dependent on many factors, such as types of relationships, cultural norms, and gendered expectations (Petronio, 2000).

Within personal relationships, people continually consider and make choices concerning how to negotiate both revealing and concealing private information (Rosenfeld, 2000). Those who share their private information with others are known as confiders (Hahn, 2020). In families, confiders make decisions to disclose private information based on assessments of the confidant, or receiver of private information, as well (Petronio, 2002). Regarding the confidant, confiders assess the openness and relevance private disclosures, for example, with issues of sexuality and the timing of disclosures or whether to allow family members access to certain private information altogether (Lannutti, 2013), or with social media access for family members (Child & Westermann, 2013). While researchers have well-documented that families manage many privacy issues throughout the family system (Petronio, 2013, 2018; Plander, 2013; Toller

& McBride, 2013), other interpersonal relationships, such as friendship, are not as well represented in the literature, despite the fact that individuals often disclose sensitive private information to their friends (Rickwood et al., 2005; Venetis et al., 2018).

Disclosure processes with friends are not well understood, particularly in emerging adulthood (EA) populations when friends become a pivotal relationship for social support (Buote et al., 2007), which was the central focus for my work in the present study.

The emerging adult (EA) is an individual in the stage of life originally conceptualized by Arnett (2000, 2014) as occurring from ages 18-25. Although EA only occurs in cultures that include a period of independent exploration from 18-25, Arnett (2014) further identified that EAs are characterized by self-focus, identity explorations, instability, feelings of in-betweenness, and possibilities optimism. Most of the characteristics of the EA come from “the feeling of in-betweenness” as the “feeling of being no longer adolescent but yet fully adult, is rooted in the changes taking place in their relationships,” particularly with parental figures (p. 49). Through the transition of emerging adulthood, the EA experiences a process of deindividuation in which young adults form stricter boundaries and rules around their private information from their family (Petronio, 1994; Petronio, 2002; Youniss & Smollar, 1985). When considering life transitions at this pivotal developmental stage, the physical and relational health of the EA also transitions. Although some researchers explored how EAs manage a caretaking role for their parents with a chronic illness (e.g., Thompson et al., 2017), research on the EA’s own health has remained relatively unexplored in relational and health communication research, potentially due, at least in part, to the underrepresentation of

this demographic in congruence with stigmatizing perceptions of chronic illness as an aspect of aging or elderly populations (Kundrat & Nussbaum, 2003).

Despite knowing that individuals often disclose mental and chronic conditions with their friends, researchers have not fully examined these disclosure processes, particularly regarding non-mental chronic conditions (Venetis et al., 2018; Rickwood et al., 2005). Researchers reported that ineffective management of chronic conditions during the EA period could bear consequences, but researchers have not fully considered the management of this health-related information outside of EAs with HIV/AIDS (Miles et al., 2004; Nasr et al., 1992; Ryscavage et al., 2016). Taking all of this into account, my central purpose in this dissertation study was to understand how emerging adults negotiate and manage the (non)disclosure of chronic illness-related information with a friend. To address my goals for this study, to follow, I examine (a) chronic illness in emerging adults, (b) interaction in friendship relationships, and (c) communication privacy management theory. I first explore the nature of chronic illness to understand its significance in the present study.

### **Chronic Illness and the Emerging Adult**

Scholars estimated that 20-30% of adolescents have a chronic illness—one that lasts more than six months (Yeo & Sawyer, 2005)—yet such information about chronic illness between adolescence and adulthood are scant. However, research on EAs with non-mental chronic conditions<sup>1</sup> is particularly important as those growing up with a

---

<sup>1</sup> Although distinguishing between mental and chronic health could be interpreted as advancing the mind/body split mythos (for a review, see Bracken, 2002; Gatchel, 2004), I make the distinction between the conditions here. I am not arguing that the mind and body exist separately from each other as in traditional Cartesian medical philosophy (Greer, 2003). Rather, I implement a biopsychosocial approach in those conditions and/or illnesses manifest together from both biological and social influences (Gatchel,

chronic illness (e.g., diabetes, asthma) often rely on their parents for support and care, and transitions to independence during the EA stage of life are often underdeveloped for effective chronic illness treatment (Peters et al., 2011). Researchers noted that individuals who grew up ill, such as an EA with a chronic illness, may be better acclimated than those with a later onset of illness (Engman, 2019), and researchers devoted much effort into studying the period of transition between adolescence regarding the most effective transition from pediatric to adult-oriented care (Miles et al., 2004; Nasr et al., 1992; Ryscavage et al., 2016). Most recently, researchers described the pivotal role of peers and friends when managing chronic illness through the transition from adolescence into EA (Newman et al., 2016; Spencer et al., 2019). Although scholars explained that friends may influence an EA's chronic illness management (Newman et al., 2016), other researchers described how EAs with chronic illness “justify their apparent disengagement in academic and social life...to ensure friendships were not compromised” or resist their body's chronic illness symptoms to maintain a “typical” social life (Spencer et al., 2019, p. 10). Taken together, scholars studying EAs, chronic illness, and friendship demonstrated how normative life transition expectations affect the management of chronic illness particularly when considering the influence of interpersonal relationships

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2004). However, grant-funding agencies and governmental bodies continue to discuss mental and chronic illnesses as separate illnesses, yet usually comorbid (Canadian Mental Health Association, 2008), and sometimes label mental illnesses as chronic (e.g., chronic depression), while explicitly chronic conditions typically exclude a “chronic” precursor (e.g., arthritis) (National Institute of Mental Health, 2015). In other words, while all mental illness may be considered chronic, not all chronic illness may be considered mental illness (Centers for Disease Control and Prevention, 2012). Additionally, mental and chronic illnesses may differ in their stigmatization, and the severity of stigmatization often varies according to the specific illness in either category (Joachim & Acorn, 2001; Weiss et al., 2006). Scambler (2009) also noted that mental illness has received more considerable attention in research compared to chronic conditions. Furthermore, with perspectives of emerging adults as the focus of the present study, information from grant-funding and governmental agencies is rather scant outside of mental health, smoking behaviors, obesity, and diabetes (Centers for Disease Control and Prevention, 2019). Therefore, when stating “chronic illness” throughout this study, I am referring to chronic-non-mental conditions to better understand the disclosure-related issues faced by emerging adults with such conditions.

through this life transition. Thus, in this section, I discuss (a) chronic illness and biographical disruption and (b) emerging adulthood and chronic illness.

### **Chronic Illness and Biographical Disruption**

I next consider chronic illness as biographical disruption. Bury (1982) described chronic illness as a biographical disruption in the sense that “the structures of everyday life and the forms of knowledge which underpin them are disrupted” (p. 169). Particularly in youth, issues of physical pain and suffering related to chronic illness may seem improbable due to the associations chronic illness has with aging populations (Bury, 1982; Kundrat & Nussbaum, 2003) making the presence of chronic illness in the EA stage of life particularly disruptive. As EAs transition through this developmental stage, they foster their own social networks and may rely more on these newer networks than previous relationships such as family (Heinze et al., 2015). However, with chronic illness, individuals may ignore or dismiss the onset of symptoms as the acknowledgement of chronic illness “involves the initiation into a new social arena” that contradicts previous expectations for the life-course (Bury, 1982, p. 170).

Considering chronic illness as a biographical disruption complicates issues of identity. Individuals experiencing chronic illness often manage a both positive and negative issues of identity management. On one hand, individuals with chronic illnesses often struggle with the legitimacy of their illness due to the lack of symptoms physically visible to others (Defenbaugh, 2013). On the other hand, individuals with chronic illness do not necessarily have to disclose their illness to others due to invisibility (Horan et al., 2009). In either case, individuals negotiate issues of a stigmatized identity through their chronic illness. While benefits of discussing a chronic illness with others include reduced

stigma and support from peers (Corrigan & Matthews, 2003), responses to disclosures of stigmatized identities are often uncertain and may include avoidance and discrimination (Corbière et al., 2012). Thus, those faced with chronic conditions may conceal their ill identity to avoid stigmatization.

While some researchers noted that concealment was often associated with negative outcomes such as increased psychological distress (Quinn & Chaudoir, 2009; Sedlovskaya et al., 2013), other researchers more recently described concealment as a more nuanced issue that was neither inherently good nor bad (Cook et al., 2017). While individuals withholding chronic illness-related information from healthcare professionals may exacerbate symptomology and decrease quality of life (Earnshaw & Quinn, 2011), they may also cope through concealment to “avoid negative interpersonal interactions or becoming a target of bias and discrimination” (Cook et al., 2016, p. 83). Cook et al. (2017) summarized that people living with chronic illness navigate a complex identity in which disclosure could result in positive or negative relational outcomes. They further described that disclosure-based decisions surrounding chronic illness stem from a cost-benefit ratio weighing the associated perceived benefits and risks of disclosing the ill identity with others. When considering the EA, however, issues of disclosure-concealment may become even more nuanced.

### **Emerging Adulthood and Chronic Illness**

Prior to the EA life-stage, parents tend to play a more active role in the lives of their children, including the management of their health. Intuitively, young people (i.e., children and adolescents who are not yet EAs) with chronic illness focus more on peer relationships and adapting to stressors at school when compared to adults with chronic

illness, and these nuances across the lifespan demonstrate the unique developmental stressors one must navigate when facing chronic illness (Taylor et al., 2008). When discussing chronic illness in adolescents specifically, La Greca (1992) reported that friends tend to provide support through more of a “companionship” role than family who provide support through a “tangible” resource provision role such as access to healthcare resources. With the focus on peer relationships, researchers noted that young people who experience support from friends may have increased chronic illness treatment compliance (Kyngäs et al., 2002; Kyngäs & Rissanen, 2001), easier adjustment to school-related activities (Dockett, 2004), and more effective self-management of the chronic illness (Sawyer & Aroni, 2005). As such, when friends do not appear supportive, adolescents with chronic illness may isolate themselves from or avoid social interaction with friends, which could result in increased psychological distress (Forgeron et al., 2011). Those who experience a lack of support from friends and family in later adolescence and EA also experience increased issues of identity development and psychological distress (Bowlby, 2011; Thyberg, 2018). However, as young people continue to develop over time, the ways they interact and manage chronic illness also changes.

In emerging adulthood, people tend to rely on friendships not only for social support generally (Rawlins, 2009), but also health-related support and decision-making. More often in EA, however, are those situations when persons disclose health conditions, such as mental illness, to friends rather than to family (Venetis et al., 2018; Rickwood et al., 2005). In fact, friends who are more accepting and are perceived as friends can help ameliorate the effects of ADHD (attention-deficit hyperactivity disorder) in EAs transitioning into college (Khalis et al., 2018). Outside of mental illnesses, researchers are



beginning to identify relationships between friendship and non-mental chronic conditions in EA populations, particularly in diabetes research (Helgeson et al., 2015). In the most serious instances, friends may serve as informal healthcare advocates to provide emotional support, interpretations, and navigation of healthcare decision-making (Petronio et al., 2004). Given how researchers have placed friends as a key relationship in tandem with chronic illness and other health-related research regarding EAs, I now turn to a discussion about interaction in friendship relationships to highlight the key aspects of this relationship as it pertains to the present study.

### **Interaction in Friendship Relationships**

There may be no more ubiquitous relationship than friendship. Although friendships relationships vary in intensity, proximity, and similarity, most, if not all, people experience friendship to some degree as they are culturally universal relationships (Parks, 2011). The friendship relationship has been described as “the pinnacle of human experience” in terms of intimacy (McAdams, 1997, p. 157). Yet, without communication, individuals fail to build and maintain the pivotal friendship relationships in their lives. In this section, I provide (a) my perspective on communication, (b) the conceptualization of friendship in the present study, (c) the characteristics of the friendship relationship, and (d) the functions of friendship.

### **Perspective on Communication**

My perspective concerning friendship in this present study was centered in a constitutive perspective on communication, which “asks how communication defines, or constructs, the social world, including ourselves and our personal relationships” in which “persons and relationships are not analytically separable from communication” (Baxter,

2004, p. 3). In the context of friendships, which are constituted in communication (Sias & Bartoo, 2007), EAs articulate their own identity in relation to their friendship relationship through connection and separation (Anthony & McCabe, 2015) as “a friend constitutes ‘another self’” (Rawlins, 2009, p. 6). While friendships play this role across life stages, it is particularly important in emerging adulthood because of the desire for autonomy co-occurring with a desire for connection (Baxter & Montgomery, 1996) in this life-stage embodied through the experience of separating oneself from their parents while building their own relationships with peers (Arnett, 2007). In this sense, EAs co-construct their sense of self through their interactions and relationships with others, creating what Wilmot (1995) conceptualized the non-separable self-other-relationship triad. More recently, constitutive scholars further placed communication as the agent of power and action in creating identity and relationships with Baxter (2014) describing that “communication can construct the social world through the consequential effects it has in shaping outcomes of a variety of kinds” (p. 37). However, the friendship relationship better embodies Wilmot’s (1995) perspective of “Paradigm III” in which communication is “the joint product of two persons in relation” that “opens our eyes to (1) the transformative potential of communication and (2) seeing dialogue, not monologue, as the heart of the process” (p. 53). Within this perspective, the self-other-relationship is considered nonseparable due to the transformative role that communication plays as conjointly created between the self and other to form the relationship. Without communication, the relationship is never created or dissolves in the absence of communication. To further understand the relational context of the present study, I next describe the friendship relationship.

### **Conceptualization of Friendship in the Present Study**

Individuals often come to their friendships in emerging adulthood with some aspect of identity, although when friends first influence socialization varies by culture (Arnett, 1995). In considering Grusec's (2002) conceptualization of socialization as how "individuals are assisted in the acquisition of skills necessary to function as members of their social group" (p. 143), the EA, especially in Western culture, goes through a period of socialization often through trade school and college (Arnett, 2007). However, EAs experience less socialization from friends than in adolescence, although EA friendships are often more intimate (Arnett, 2007) due to the increase in selective association of interacting with individuals more akin to oneself (Rose, 2002). However, this view of friendship was normative, and, as noted earlier, EAs with chronic illness are likely to experience a disruption of normative developmental expectations (Bury, 1982) despite a desire for similar development treatment as their non-chronically ill peers (Taylor et al., 2008). Therefore, it was imperative to consider the normative emerging adulthood trajectory as EAs shifted their intimacy toward friendships to understand key differences in friendship experiences, and this was one of my goals in the present study,

Researchers described the friendship relationship as one that contributes to an individual's relational, mental, and physical well-being (Anderson & Fowers, 2019), and yet how persons form, maintain, and understand friendship processes regarding chronic illness has remained relatively unexamined compared to other personal relationships such as marriage and other romantic relationships. Given the centrality of friendship to understanding disclosures regarding chronic illness, I next provide my conceptualization of the friendship relationship.

Although one could argue that all friendships are different, scholars historically agree on three key characteristics of friendships: voluntariness, equality, and a lack of institutional ties (Bliezner & Adams, 1992; Fehr, 1996; Rawlins, 2009). Friendships also differ throughout the lifespan with the most visible influence of friends occurring during school-aged years and dwindling over time, yet becomes more intimate longitudinally (Arnett, 2007). Despite these developmental differences, the three main characteristics remain central to most conceptualizations of friendship. To fully understand the friendship relationship in the present study, I next describe the three dimensions of friendship: (a) voluntary, (b) equality, and (c) sexual intimacy.

**Voluntary Dimension of Friendship.** First, friendship scholars agree that one of the main defining characteristics of a friendship is the voluntary nature of being a friend (Fehr, 1996; Rawlins, 2009). Scholars defining the friendship relationship over decades of scholarship consistently included some dimension of “voluntariness” when describing a friend, whether explicitly (e.g., voluntary interdependence, Hays, 1984; voluntary or unconstrained interaction, Wright, 1984) or implicitly (e.g., spontaneously, Hartup, 1977; reciprocity, Reisman, 1979). Original conceptualizations of the voluntary nature of friendships include a lack of obligation and a freedom of choice, meaning that the relationship is free from overt dependence, coercion, and the ability to seek others to fulfill the relational needs (Palisi & Ransford, 1987). However, scholars studying friendship now describe the voluntary nature of friendships based solely around the selection or choice of an individual to be a friend (Adams & Blieszner, 1994). Although family members may also lack blood and legal ties, these individuals are often given a non-friendship label as to reinforce the standard of family processes (e.g.,

fictive/voluntary kin, Braithwaite et al., 2010). Even in situations when friends function in family roles (e.g., when a family of origin may reject a child over a stigmatized identity, Lewis, 2011), many issues, such as achieving emotional or physical intimacy, become more complex (Nardi, 1992). Thus, understanding the voluntary nature of friendship is important to my work in the present study because when disclosing sensitive information to a relational other, the confider must ascertain the consequences of disclosure that could include a lost or diminished relationship (Petronio, 2002). Regarding chronic illness, Hall (2020) described that the voluntary nature of the friendship may contribute to one's decision-making about stigmatized health-related disclosures. However, in defining a friendship, scholars note that being voluntary is just one aspect of the relationship as equality is a second key tenet of a friendship relationship.

**Equality Dimension of Friendship.** Second, in a friendship relationship, individuals generally perceive equality surrounding the relationship (Fehr, 1996). Although each friend may have a different cultural background (i.e., different socio-economic status, race, and/or sexual orientation which may constitute societal inequalities), equality in a friendship normally exists outside of these power dimensions as “friends treat each other as equals with regard to their common pursuits” (Rawlins, 2009, p. 179). As Rawlins (1992) explained, friends “tend to emphasize the personal attributes and styles of interaction that make them appear more or less equal to each other,” and that relationships in which exploitation or manipulation may be present would not be true friendship (p. 12). In other words, friends do not claim or emphasize superiority in the relationships (Reisman, 1979) despite societal markers of power. This is

not to say that friends are identical people. Rather, friends allow for the both the independent and dependent self to co-exist in the relationship (Rawlins, 2009). Some researchers describe that if inequalities exist, friends may try to alleviate them or leave the friendship altogether (Fehr, 1996) noting that without equality and striving for each friends' beneficence, the friendship fails to exist (Telfer, 1971). Nonetheless, those in equitable friendships do perceive more relational satisfaction as opposed to those individuals in unequal friendships (Berg, 1984).

Thus, equality is a pivotal tenet of a friendship relationship that may not present in other relationships (e.g., power discourses in family, e.g., Suter & Seurer, 2018). In the present study, understanding equality is important because as EAs navigate their chronic illness experience, they continually try to fit in with their friends for some degree of perceived normalcy (Spencer et al., 2019). While trying to build their autonomy, EAs may ignore or disregard their chronic illness symptoms (Spencer et al., 2019) to garner equal treatment as their friends (Taylor et al., 2008). However, in defining friendship, the voluntary and equality dimensions do not address the sexual intimacy dimension of friendships.

**Sexual Intimacy Dimension of Friendship.** Third, the final unique aspect of friendship is the lack sexual intimacy in most friendship relationships (Fehr, 1996; Rawlins, 2009). Rawlins (2009) described that a friendship including sexual intimacy moves into a new type of relationship described as "friends-with-benefits" in which the interactants may have physical sexual encounters with one another. He distinguishes these types of relationships because the expression of sex (or lack thereof) into a relationship inherently changes the dynamics of the relationship, particularly with friends.

However, the dynamics of sexual intimacy perceived in friendships has changed over time. One limitation of the past literature was the assumption that cross-sex friendships always have a type of sexual tension, particularly coming from men (Bleske-Rechek & Buss, 2001). However, in his study of hetero- and homosexual friends, Byron (2016) found that although individuals do contemplate the riskiness of adding a sexual intimacy with their friends, friends can sometimes fill roles of sexual experimentation, sexual health advocacy, and sexual identity support. Thus, even though researchers historically eliminated sexual intimacy from friendship, modern friendship scholars note that “friendship and sex are not diametrically opposed” (Roach, 2012, p. 45). In this present study, then, I do not qualify friendships regarding sexual intimacy particularly as EAs with chronic illness may be seeking other kinds of support from their friends. However, the idea of the friendship relationship has been traditionally rooted throughout the dimensions of voluntariness, equality, and intimacy, yet what constitutes these categorical differences continues to blur over time, particularly in how friendships function. Therefore, I next discuss the functions of friendship to illuminate the nuances of the lived experiences of friendship relationships.

### **Functions of Friendship**

Certainly, friends play numerous roles throughout one’s life. Traditionally, researchers considered friendship through a strict lens of “*gemeinschaft*,” or personal relationships in which community and commonalities are emphasized, as opposed to “*gesellschaft*,” or role relationships in which the self and societal preoccupations are emphasized (Bochner, 1984). However, researchers now acknowledge the idea of friendships as “blended” which describes how friends can be both personal and role

relationships at the same time (Bridge & Baxter, 1992). Thus, I will describe the functions of friendships in terms of (a) the friendship relationship as a support system, (b) how friends may function as kin, and (c) the role friends play in decision-making and health. In first understanding the balance of the personal and the role functions of friendship, I provide an overview for how friends function as a support system.

First, researchers have long considered social support to be a key function of the friendship relationship (Helsen et al., 2000; Procidano & Heller, 1983; Walen & Lachman, 2000). Researchers found that, in general, individuals rate supportive interactions (i.e., understanding, reliance, and openness) higher with friends than family potentially due to the voluntary relationship (Lee & Szinovacz, 2016). Friends may serve as a buffer in instances of emotional turmoil to serve an emotional support role (e.g., poly-victimization for women, Crush et al., 2018; HIV-status for men, Lee et al., 2015). In some instances, women in particular may respond to stressful environments as “tend-and-befriend” rather than “fight-or-flight” to serve as a preventative buffer and network to on whom to rely when faced with stressful encounters (Taylor et al., 2000). Friends may also provide tangible support particularly as they may be more attuned to their friend’s experiences of stress and/or trauma, effectively being “well-placed to provide unsolicited [tangible] social support” such as gift-giving, preparing meals, and sharing information when such things were not necessarily requested (Sias & Bartoo, 2007, p. 461). Sometimes, friends may provide instrumental support when they serve as informal healthcare advocates in which they may help healthcare workers provide necessarily information to the patient and vice versa (Petronio et al., 2004).



In further considering friends as social support in the present study, friends can fulfill a function in our lives known as a “behavioral vaccine” which relies on the premise that “an individual’s physical and mental health is framed by [their] social environment” (Sias & Bartoo, 2007, p. 456). Here, friends serve various supportive functions based on the needs of the chronically ill individual despite not being able to treat the illness itself (Sias & Bartoo, 2007). Despite their inability to treat the illness, the friendship relationship may become more intimate when an individual receives social support in the face of illness (Sias & Cahill, 1998). Although EAs may receive various types of support from their friends post-disclosure of chronic illness (e.g., rides to doctor’s appointments), EAs continually report fear of rejection and a lack of acceptance as reasons for continued concealment (Kaushansky et al., 2017). While friends may provide avenues for support regarding chronic illness, there are still many risks in seeking such support through disclosure of chronic illness-related information. Nonetheless, in addition to emotional, tangible, and instrumental social support, friends can also serve a uniquely personal function.

Seconds, sometimes individuals identify friends as “like family,” in which they serve a role similar or identical to that of familial relationships (Messner, 1992; Nardi, 1992). When conceptualizing friends as family-like, researchers often positioned the friendship as a substitute for the family-of-origin (Nelson, 2014) or as voluntary kin, of which some scholars described as having a root of friendship (Braithwaite et al., 2016). For example, Braithwaite et al. (2010) found that friends may function as family out of convenience in which the family-of-origin was unavailable or inaccessible geographically or for a period of time. In addition, sometimes friends filled roles that family members

cannot. For example, Myroniuk et al. (2017) found that individuals from Malawi—a country with a family-focused culture—would be more likely to ask their friends for support during a crisis than family. Additionally, close friends often remain close in the face of negative events while other relationships may deteriorate (e.g., bullying and cyberbullying experiences, Coyle et al., 2019). Friends may also be the primary relationship with whom EAs share chronic illness if family members were unsupportive (Bowlby, 2011). However, researchers demonstrated that family and spousal relationships often influenced health decision-making (e.g., family influence cancer treatment decision-making, Krieger, 2014; partner influence in cancer treatment decision-making, Palmer-Wackerly et al., 2017), yet, given the central role of the friendship relationship through life, friends may also play a role in health decision-making and disclosure processes.

Third, while friends serve a role of “informally linking groups, institutions, and cultures,” they are also essential for individual and relational well-being (Parks, 2011, p. 367). In fact, if persons perceive their peers to be more approving of us, depressive symptomology decreases (Zimmer-Gembeck et al., 2007). Furthermore, researchers argue that friends are a key relationship for influencing mental health, including decision-making (Venetis et al., 2018) and effects of social strain (Walen & Lachman, 2000), yet this influence tends to be inconsistent when discussing age (e.g., peers may not play as big of a role in buffering depressive symptomology as hypothesized as individuals age, see Pössel et al., 2018). However, some researchers emphasize that the role of the friendship becomes increasingly important with age, particularly as individuals seek social support for more physically chronic conditions (Heinze et al., 2015). Although

friendship was a pivotal relationship in which individuals invest relational energy and that these relationships have effects on relational and physical well-being, the conversations in which these processes occurred remains relatively unexamined.

Researchers interested in EA populations and health examined how friends aid in reducing psychological distress for EAs who experienced abuse (Dion et al., 2016) and violence in their adolescent years (Heinze et al., 2018). Researchers also found that friends may exacerbate our depression symptoms (Moses, 2010), particularly if an individual's attachment style was more anxious (Chow & Ruhl, 2014), showing that the friendship relationship affects mental health throughout emerging adulthood. However, these researchers did not examine the disclosure of these phenomena, but rather the presence of friends during tumultuous life circumstances. When considering disclosure, though, EAs may feel more comfortable discussing various health-related topics with their friends than family members or other close relational others (e.g., safe sex, Lefkowitz et al., 2004). Researchers found that EAs tend to be more open to various disclosures when compared with older populations given the accessibility of social networking sites to maintain connections (Davis, 2012; Peter et al., 2005), relieve feelings of loneliness (Hood et al., 2018), and increase overall perceptions of happiness (Manago & Vaughn, 2015) and general well-being (e.g., self-esteem, Valkenburg et al., 2006; decreased psychological distress, Szwedo et al., 2012). However, when considering chronic illness, researchers found that EAs who withhold information about their illness may experience increased isolation and frustration from friends (Thompson et al., 2012), yet disclosure about risky health behaviors serve as a protective factor from engaging in such behaviors in the future (Urry et al., 2011). Some researchers contrarily reported that

some EAs experienced increased bullying and stigma from peers knowing of chronic conditions (Moses, 2010; Roosta et al., 2010), yet withholding disclosure may prevent psychological distress in some instances (e.g., sexual orientation, Shilo & Savaya, 2011). Thus, researchers discussing the friendship relationship in tandem with decision-making, support, and disclosure regarding health-related topics have started to show the complex friendship role throughout emerging adulthood.

In emerging adulthood, researchers have begun to examine communicative processes regarding mental health disclosure with a friend to seek social support (Rickwood et al., 2005), further exemplifying the pivotal role that friends may serve as social support in health journeys. For example, researchers found that friends disclose mental health conditions or concerns based on information assessment (e.g., reactions to stigma, visibility of symptoms, preparedness for diagnosis, and relevance to the relationship), relational closeness (e.g., openness, comfortability, confidence, resource provision, interest), and efficacy (e.g., ability, desire, and certainty to share mental health information) (Venetis et al., 2018), showing that social support and disclosure-seeking behaviors may come with caveats in discussing health issues with a friend. Because of the inherent equality and trustworthiness in most friendship relationships, disclosing private information may be predetermined by the standards of the relationship (Caughlin et al., 2009; Venetis et al., 2012). While EAs may have many friends, they tend to tell very few friends about their chronic illness (Kaushansky et al., 2017). For example, EAs may disclose to friends that have made their own chronic illness known (Kaushansky et al., 2017), demonstrating reciprocity and similarity to be key criteria for disclosing sensitive, private information (Petronio, 2002) particularly in friendships (Rawlins,

2009). When discussing other aspects of health, researchers noted the beneficial role that friends tend to play throughout life.

Disclosure in the friendship may be risky, however, because of the voluntary nature of friendship. As “friends voluntarily navigate private moral visions and alternative spaces for performing social lives,” the delineation between acceptable and unacceptable disclosure is socially constructed between the friends (Rawlins, 2009, p. 185). Friends may keep some information private for relational maintenance (Rachels, 1975), but withholding some aspects of information, such as that which may be disclosed with a psychiatrist, may also aid in relational maintenance (Reiman, 1976). Parks (1995) described the myth that in order to become closer or more intimate with a relational other (e.g., a friend), one must self-disclose personal information. Although individuals reported self-disclosure to be a primary indicator of relational closeness with a friend (Parks & Floyd, 1996), Petronio (2002) described that disclosure is risky in any relationship. When considering chronic conditions, Defenbaugh (2013) noted that disclosure of the illness could exacerbate experiences of stigma. Nonetheless, there are cultural expectations that “we embrace the responsibility to protect our friends’ and our own privacy, areas of vulnerability, and threats to dignity” (Rawlins, 2009, p. 57-58). This shows that one’s commitment to a friendship carries an expectation in being part of mutual support system, particularly for chronic illness.

When considering health-related information, friends can improve quality of life through disclosure and illness management manners. However, trusting a voluntary relationship with such sensitive information may seem counterintuitive due to the riskiness at play with cultural dimensions of chronic illness stigmatization (Cardillo,

2010), particularly as experiences of many chronic illnesses are invisible or “subjective experiences” (Donoghue & Siegel, 1992, p. 7) in which one’s peers must take one’s experience of illness at their word. When facing this subjective experience stigma, Thyberg (2018) described her experience of living with fibromyalgia as she “tried desperately to keep up appearances and hide just how badly [she] felt,” feeling incredibly self-conscious and socially burdensome to her peers because of her chronic illness symptoms (p. 36). Despite the amount of stigma and isolation experienced by EAs experiencing chronic conditions, researchers have yet to fully examine and consider how these individuals disclose such experiences and its effects on both physical and relational health. Furthermore, while individuals continue to describe the pivotal role of the friendship relationship throughout the EA life-stage and chronic illness experience, the importance of this relationship has not been well-understood when compared to other relationships such as parents (Heinze et al., 2015). Thus, I considered communication privacy management theory the best theory to help me further explore the nuanced aspects regarding the disclosure of private information to further understand the phenomenon of health disclosure between friends.

### **Communication Privacy Management Theory**

Throughout decades of scholarly endeavors, researchers have come to understand disclosure as a pivotal part of the communication discipline. Beginning with Jourard’s (1971) original conceptualization of self-disclosure and continuing into Altman and Taylor’s (1973) original theorizing of disclosure in social penetration theory, the phenomenon of self-disclosure has evolved over time. More recently, this phenomenon underwent a significant linguistic shift, removing “self-” from “disclosure” in order to

reflect that disclosure is more complex than a one-time, one-person phenomenon (Petronio, 2004). Thus, the most current, and perhaps most studied (Braithwaite et al., 2015; Braithwaite et al., 2018) theoretical perspective of disclosure is communication privacy management theory (CPM) showing that disclosure remains a central construct of the communication discipline.

Sandra Petronio, the author of CPM, first theorized disclosure through the communication boundary management theoretical model (Petronio, 1991). She began this work because of her frustration with the limits of disclosure scholarship because researchers considered self-disclosure as a goal, not a process that included “what is disclosed, the private information, and how it is disclosed” (Petronio, 2004, p. 196). In her initial articulation of the theory, she focused primarily on how couples manage a dialectical tension between the need for disclosure and the need for privacy (Petronio, 1991). Throughout her first iteration, Petronio (1991) described various prerequisites for disclosure (e.g., gender, culture, privacy orientation) that influence decisions regarding revealing private information. Despite her initial focus on a family-oriented model, Petronio continued to study privacy not only in the family context (e.g., parental privacy invasion, Petronio, 1994), but also interpersonal (e.g., negotiating boundaries, Petronio et al., 1998) and health (e.g., nursing home care, Petronio & Kovach, 1997) contexts as well.

As she developed the theory that she called CPM (Petronio, 2002), she expanded from a boundary management model to a theory about disclosure because “the theory was explaining privacy management, not just the way boundaries functioned in general” (Petronio, 2004, p. 201). Her reconceptualization of the name of her theory allowed for a

more consistent use of the theory rather than as something authors cited when generally discussing family-related processes. To implement this change, she created the full theory of communication privacy management theory, completely dropping “boundary” from the theory’s namesake. Within her theory, Petronio (2002) provided five main suppositions of CPM: (a) private information, (b) privacy boundaries, (c) control and ownership, (d) rule-based management system, and (e) privacy management dialectics. I detail each supposition below to provide an overview of the theoretical lens I proposed to guide my work in the present study.

### **Five Suppositions of CPM**

First, Petronio (2002) described her first supposition surrounding CPM through defining her focus on private information. Here, Petronio centered her theory around private disclosure which she conceptualized as the “*process of telling and reflects the content of private information about others and us,*” which allowed for a focus on the communicative process of disclosure rather than revelations of self (Petronio, 2002, p. 6, *emphasis in original*). In her theory, Petronio used Goodstein and Reinecker’s (1974) definition of private information as “information about oneself that is rather private or intimate and is disclosed under special circumstances” (p. 51). Thus, Petronio’s (2002) conceptualization of privacy directly responded to Parks’ (1995) critique of self-disclosure as a process to achieve intimacy by noting the considerable risks associated with disclosing private information. Through a focus on private information disclosure, Petronio (2002) noted that not all private disclosures lead to intimacy, nor should private information be disclosed simply for the goal of achieving intimacy. This turn in



disclosure and privacy theorizing allowed Petronio to expand on her original boundary metaphor.

Second, Petronio (2002) discussed her boundary metaphor to describe the flow of private information between interactants. At this point, Petronio defined privacy as “the feeling that one has the right to own private information, either personally or collectively” and that “boundaries mark ownership lines for individuals” (p. 6).

Regarding boundaries, an individual may have permeable (easily broken) or impregnable (difficult to open) boundaries which may be clearly stated or ambiguous in the interaction. Regarding EAs, Petronio described deindividuation as the process in which EAs become more autonomous and seek more control over their private information. Throughout deindividuation, EAs may shift their boundary coordination to more frequently exclude their parental figures. This is particularly concerning as EAs struggle to gain autonomous decision-making regarding chronic illness while perhaps relying on parental figures for guidance, tangible resources, and illness management (Helgeson et al., 2008). Here, EAs may feel a sense of responsibility for general illness management, yet keep day-to-day information more private with personal networks, such as friends (Diaz-Gonzalez de Ferris, 2011). Throughout the navigation of these boundaries, EAs are consistently navigating the ownership of their private information.

Third, Petronio (2002) discussed control and ownership as an inherent aspect of the privacy management process. She noted that in the United States “we equate preserving privacy with maintaining personal dignity and autonomy and with safeguarding the self” (p. 9). She argued that privacy, then, is seen as something an individual owns as though privacy were a tangible or tradable good. People often get to

decide what to do with their information, with whom to share it with, if anyone, and how further management of the information is to be negotiated. When individuals did not get to decide the disclosure process as the case of withholding genetic results (Petronio & Gaff, 2010), they described the co-owner of the private information as compromising of their privacy. When an individual share private information with someone else, Petronio (2002) described that the interactants are now co-owners of this information. Co-owners now hold the private information as a shared good, and the interactants negotiate, implicitly or explicitly, how to further reveal or conceal the private information. In this negotiation, the co-owners make many decisions about management of the private information based on various rules.

Fourth, Petronio (2002) described that deciphering disclosure decisions of private information uses a rules-based management system. Here, co-owners negotiate and re-negotiate rules of how to manage private information disclosure. Petronio described that “there is an expected guardianship of the information often assumed by” the co-owners of the private information (p. 11). This expected guardianship could lead to explicit or implicit coordination of boundaries of future disclosure or, if violations occurred, re-negotiation and creation of rules surrounding a violated or turbulent boundary. Perhaps this explains why individuals are careful about disclosing private health information with friends (Venetis et al., 2018) as the extensive criteria to be considered a confidant for disclosure may explain often implicit boundary coordination (Hall, 2020). These exemplars of the difficult decisions in navigating private information disclosure highlight the dialectal aspects of CPM.

Fifth, Petronio (2002) described how her theory is dialectical in nature. Although an individual will likely never be completely on one end of the concealing-revealing dialectical tension (Petronio, 2000), individuals manage this tension whenever facing decisions regarding private information disclosure. Not to be confused with other major dialectical theories of communication (e.g., relational dialectics theory, Baxter & Montgomery, 1996; relational dialectics theory 2.0, Baxter, 2011), Petronio (2002) described the dialectic tensions of CPM as “the forces pulling between and with the needs of being both private through concealing and public through revealing” (p. 12). Rather than simply saying disclosure is either private or not, Petronio (2002) described “that privacy and disclosure are distinct opposites having distinct features from one another that function in incompatible ways” (p. 13). However, she described how the concepts are dependent on one another, as disclosure does not exist without privacy, and privacy only occurs in the absence of disclosure. Thus, she argued that privacy and disclosure are not dualistic tensions, but dialectic tensions due to the unity needed for the existence of the phenomena. Relevant to the present study, researchers established that EAs struggle with issues of concealing and revealing chronic health disclosures with friends in considering socialization (Spencer et al., 2019) and supportive needs (Kaushansky et al., 2017). As such, Petronio’s (2002) CPM theory provides the best theoretical framework through which to consider the phenomenon of my inquiry due to the theory’s applicability to emerging adulthood and chronic illness.

Scholars continue to build, expand, and apply communication privacy management theory throughout the communication discipline (e.g., Petronio & Durham, 2015; Petronio, 2018) and beyond (e.g., family studies, Petronio, 2010; healthcare,

Ngwenya et al., 2015; technology, Frampton & Child, 2013). Because researchers have studied and expanded many aspects of CPM throughout the years, CPM remains a central theory for researching phenomenon-related disclosures. Because my purpose in the present study was to understand how EAs manage disclosures with their friends regarding chronic illness-related information, certain concepts of CPM are particularly prescient within my inquiry to fully understand the decisions EAs make in both disclosing their chronic illness-related information and managing the co-ownership of the private information. To understand the decision-making of disclosures and reactions to the disclosure, I (a) describe the criteria for disclosure, (b) explore confidants of the disclosure, and (c) delve into the negotiation of privacy rules between interactants of the disclosure. Thus, in order to understand how individuals make decisions to disclose chronic illness-related information, I first explain the criteria for disclosure.

### **Criteria for Disclosure**

Petronio (2002) initially conceptualized a list of five separate criteria for disclosure: expectations and practices of gender identity in disclosure; the socialized norms of a culture's orientation of privacy; the motivations to control, express, and/or protect; the context in the sense of the social and physical environment; a risk-benefit ratio analysis regarding feelings of vulnerability and the advantages of disclosure. However, her later conceptualization of the criteria disclosure condenses these criteria into two categories: (a) core criteria and (b) catalyst criteria. Petronio (2013) defines core criteria as the criteria that "reflect the stable gauges used to make choices about privacy rules" and includes privacy orientations, gender, and culture (p. 10) while catalyst criteria are those that "tend to trigger privacy rule changes" and includes context, motivations,

and risk-benefit ratios (p. 10). To understand these further, I next describe each criterion in depth.

**Core Criteria.** For Petronio and Durham (2015), the core criterion is the more stable of the two categories, operating in the background as part of someone's socialized experiences. Within the core criterion are dimensions of privacy orientations, gender, and culture. Typically, researchers consider privacy orientations, or how open or a closed a one may be toward private information, to be a family-related privacy concept as disclosures of private information provide markers for group membership inclusion or exclusion (Serewicz & Canary, 2008). For example, Donovan et al. (2016) found that EAs reported higher relational quality when their parents were more open about private information in a peer-like fashion. Many researchers found relationships between privacy orientations and parent-child disclosure (e.g., Hammonds, 2015) and multi-generational communication (e.g., Child et al., 2015), and these disclosures span health-related topics as well. Overall, researchers found consistent links to privacy orientation and cancer such that high conversation-oriented families with more permeability tend to communicate more openly about genetic cancer risks (Rauscher et al., 2015). However, in studies regarding parent-adolescent conversations about health topics, adolescents do conceal some health-related information (e.g., sex, smoking, drinking) from their parents for various reasons (e.g., embarrassment, awkwardness) which shows some of the emerging tensions regarding the deindividuation process characteristic of EAs (Ebersole & Hernandez, 2016). In fact, researchers found that disclosure about sexual health-related topics, such as a vasectomy, can occur more to friends than to family in non-adolescent populations (Rauscher & Durham, 2015). Therefore, understanding privacy orientations

could illustrate the process of disclosure between friends. However, gender also plays a role in disclosure processes.

Throughout the years, Petronio (2002, 2018; Petronio & Durham 2015; Petronio et al., 1984) described how men and women have different styles of disclosure. In summarizing this literature, researchers described how women are more likely to disclose private information to either men or women while men typically only disclose women. However, researchers are beginning to challenge this gender dynamic in CPM research. For example, in their study on women with fibromyalgia in the workplace, Hall and Miller-Ott (2019) found that the gender of the confidant was not as relevant in disclosure or concealment of the illness, but the stigma of fibromyalgia as a feminine illness that further perpetuated the “weak woman” narrative cut across male and female colleagues. Helens-Hart (2017), however, noted that females with minority sexual identities face repercussions in the workplace whether they disclose or conceal their identities particularly in male-dominated workforces. In both studies, participants reported termination due to their marginalized gender-laden identities. Thus, although gender and disclosure may be more nuanced than initially conceptualized, issues surrounding gender continue to appear in CPM-related studies. This could be due to the cultural dimensions in which individuals disclose private information.

In her original description of culture, Petronio (2002) took a more macro-level approach to how culture affects disclosure (e.g., high-power distance cultures vs. low-power distance cultures). More recently, however, researchers started examining the interaction of macro- and micro-level cultural discourses on disclosure. For example, Rubinsky (2018) described the interplay of how macro-level perceptions of sexuality

shapes micro-level family orientations toward polyamorous individuals in the family, showing that culture goes beyond macro-level standards for disclosure. However, people consider more than core aspects of the self when considering criteria for disclosure when faced with changing circumstances.

**Catalyst Criteria.** Petronio (2002; Petronio & Durham, 2015) considered catalyst criterion as those instances when privacy rules change due to responses of the needs of the interactants. Within the catalyst criterion, Petronio & Durham (2015) incorporate Petronio's (2002) original concepts of context, motivation, and the risk-benefit ratio. Through these concepts, researchers find that catalyst criteria are more flexible. For example, context, or situational features, may take precedent over any core criteria when presented with abnormal circumstances (Steuber & McLaren, 2015). That is, in a given circumstance, an individual may consider the situation over the gender, culture, or privacy orientation of themselves or the relational other. Often, these changes come from external factors, often conceptualized by the onset or experience of an illness or disability (Petronio, 2002, 2013; Braithwaite, 1991). Researchers are beginning to uncover more nuanced explanations of situational features, finding that the management of the chronic health-related information in the family may clash with general family privacy orientations (Rafferty et al., 2019).

Further, situational factors may also interact with motivations for disclosure. For example, in their study on how parents manage private information about their chronically illness children, Rafferty et al. (2019) described how parents constructed a "new normal" as motivated by "the ongoing demands and changes associated with providing constant medical attention to their sick child" (p. 103). Through the adjustment

of caring for a child with a chronic illness, parents' motivation for adjustment resulted in seeking the best care, building a support network, and managing their emotional labor in response to the biographical disruption of the chronic illness. Thus, the situation of a biographical disruption of chronic illness changes the dynamics of intimate others, and this could hold true for non-familial relational others as well, particularly as adolescents transition into emerging adulthood, and was of interest in the present study.

However, researchers examined relatively little concerning non-familial relationships when considering chronic illness and chronic illness disclosure regarding EAs. Researchers acknowledged that the period of adolescent-emerging adulthood transition is rife with change, and through this transition, EAs may begin relying more on their friends for social support and management of chronic illness (Heinze et al., 2015; Peters et al., 2011). Researchers also showed that individuals do disclose their stigmatized health issues and concerns with their friends (Butler, 2016; Venetis et al., 2018). However, specific identification of criteria between friends regarding chronic illness disclosure is not well understood, yet may aid in providing guidelines for more effective management of chronic illness in the EA population. Thus, I posed the following research question (Note: all RQs are summarized in Table 1, p. 44):

**RQ1:** What criteria do emerging adults with chronic illness use in determining an appropriate friend to whom to reveal private information about chronic illness?

### **Confidants of Disclosure**

As Petronio (2002) described, "once disclosure takes place, the mutuality of the experience makes an impression on both the sender and the recipient" (p. 110). Here, confidants are the receivers of a private information disclosure. A confidant fulfills this



role after the disclosure of private information, in which confidants also manage a privacy boundary. Often, confiders of private information consider the characteristics of the confidant as outlined in the criteria section. However, confidants vary in how they respond to such disclosures. Therefore, In the next section I provide an overview of the three types of confidants as described by Petronio (2002): (a) deliberate confidant, (b) inferential confidant, and (c) reluctant confidant. After I provide the overview for each type of confidant, I consider how researchers have applied confidants in health-related contexts.

**Deliberate Confidant.** First, Petronio (2002) defines a deliberate confidant as someone who solicits the private information from a discloser. The most common relationship cited as a deliberate confidant is the therapist-patient relationship, particularly in reciprocity, as “therapists talk about problematic areas of their [own] lives, thereby enabling clients to accomplish the goals of therapy” (p. 113). In intimate personal relationships, individuals may also fulfil the role of a deliberate confidant. For example, Shin (2019) found that adolescent children often act a deliberate confidant for their mothers in Mexican immigrant families. In this role, the children would directly solicit private information from their mothers to provide social support through tangible and emotional means. Shin noted that this deliberate confidant role shifted the perception of the mother-adolescent relationship to more of a friend-friend relationship. In fact, researchers continually associate the deliberate confidant with the idea of friendship (e.g., DiVerniero & Hosek, 2011) in tandem with social support, which further supports the idea that social support is a key tenet of friendship (Fehr, 1996; Rawlins, 2009) as a deliberate confidant goes out of their way to seek information on their own accord

(Petronio, 2002). Thus, considering the deliberate confidant role of a receiver of private information may shed further light on processes of chronic illness-related information disclosure between friends, especially as researchers described the friendship relationship as one that contributes to an individual's relational, mental, and physical well-being (Anderson & Fowers, 2019). Friends may fulfill this confidant role through well-being checks and deliberate information-seeking strategies. In the present study, I asked participants to describe the circumstances surrounding the initial and continued disclosure of their chronic illness-related information so that I could identify experiences of friends enacting a deliberate confidant role through asking about the illness. Despite the (potential) presence of a reluctant confidant in the disclosure process, the role most commonly associated with friendship may be the inferential confidant.

**Inferential Confidant.** Second, an inferential confidant is the individual a discloser would expect to share private information with “because it is fundamental to the relational definition” (Petronio, 2002, p. 111). When forming friendships, people typically define their relationship as voluntary and equal with no blood or legal relation or sexual intimacy (Fehr, 1996). Thus, the fundamental definition of the friendship relationship is one that “involves concern for the other person for his or her own sake” (Rawlins, 2009, p. 5). Based on this conceptualization of friendship, a friend would expect to hear various private information disclosures from a friend due to the desire for mutual well-being fundamental to the relationship. Perhaps this was why a friend would be a primary individual for whom EAs disclose stigmatized health information (Venetis et al., 2018), and could explain why friends contribute substantially to overall well-being for EAs (Anderson & Fowers, 2019). Thus, further investigation into how confiders

identify and ultimately disclose their private information with an inferential confidant could provide substantial knowledge for how emerging adults could better manage their quality of life, particularly in the face of changing chronic illness management. In the present study, I asked participants about their perceptions of their friends' role in receiving the information, particularly noting if their friend enacted an inferential confidant role in being supportive and receptive to the initial and continued disclosures of chronic illness-related information. Nonetheless, situations may arise in which a friend does not want to receive or hear private information, and thus requires explanation.

**Reluctant Confidant.** Third, Petronio (2002) conceptualized a reluctant confidant as someone who would not desire or expect to be a receiver of a disclosure, but receives a discloser's private information nonetheless. Although Petronio (2002) initially conceptualized reluctant confidants as a captive audience and surprised in receiving private information disclosures (e.g., a stranger on an airplane) or as a close relational other who becomes reluctant (Petronio, 1999), researchers expanded the reluctant confidant to include close relational others. For example, in their study of college students enacting various roles as confidants, McBride and Bergen (2008) found that friends sometimes exhibit behaviors of a reluctant confidant (e.g., questioning, doing/saying nothing, expressing disapproval) when they are unsure how to handle a disclosure, uncomfortable with a disclosure, or received private information described as shocking, but not necessarily unwanted. Because being a reluctant confidant is usually stressful, and the involuntary nature of private information disclosures to a reluctant confidant can cause relational strain between interactants (O'Mara & Schrod, 2017). Despite the presence of reluctant confidants in friendships, McBride and Bergen (2008)

reported that the EAs in their sample did not end their friendships, but rather redefined rules and boundaries of private information disclosure. For example, they found that some friends decided to build boundaries around certain topics that they would not further discuss in their relationship with the discloser. Even though the cultural expectations of friendship may incorporate a willingness “to accept any type of disclosure and such disclosures should minimally affect the friendship,” researchers have not addressed issues of chronic illness disclosure in this manner (McBride & Bergen, 2008, p. 56). Although McBride and Bergen addressed traumatic events (e.g., suicidal ideation), explicit investigation regarding reluctant confidants and chronic illness is merited as EAs seek social support and general well-being with their friends. In the present study I sought to understand how EAs describe reluctant confidants in their experience of disclosing chronic illness-related information.

**Applications of Confidants.** When describing the specific type of confidant within a given study, researchers identified various results for both relational and health well-being. Individuals enacting a deliberate confidant role may experience more long-term relational dependency from the discloser (Shin, 2019); inferential confidants are expected to be willing and comfortable with various disclosures from a close relational other (Pederson & McLaren, 2015); reluctant confidants may report negative changes in relationships (McBride & Bergen, 2008) or additional stress and/or relational strain (O’Mara & Schrod, 2017). In addition, the type of confidant experienced at a particular disclosure episode may influence future disclosures of private information as private information disclosure is a self-correcting system for navigating privacy issues (Petronio, 2002). This would be particularly important in the context of discussing health related

information because friends sometimes do not want to hear certain private disclosures and may redefine the boundaries of the relationship in what can or cannot be shared (McBride & Bergen, 2008).

Recently, researchers started looking at decision-making more explicitly when considering a confidant through a CPM lens. For example, Wilson et al. (2019) found that female veterans consider various aspects of both relational quality and anticipated response when deciding to disclose mental health issues with family and friends. The authors found that their participants disclosed with confidants perceived as more expert and honest while withholding from confidants who were unable to listen. Other CPM researchers noted that friends may be a key source of support for a parent with a child who has autism spectrum disorder while placing emphasis on proximity and interactivity rather than relational quality (Hays & Butauski, 2018). Furthermore, researchers not working with a particular theory found friends and family who may have negative attitudes toward mental health may also influence disclosure decision-making (Bogen-Johnston et al., 2017), positioning relational role or quality as secondary.

Overall, the findings regarding confidants in the disclosure process are largely inconclusive in a general sense when considering chronic illness. What seems to work in a mental health context regarding disclosure decision-making (Pahwa et al., 2017; Venetis et al., 2018) and privacy (Wilson et al., 2019) did not fully capture the experience of disclosure decision-making in a chronic illness context (e.g., cancer, Magsamen-Conrad et al., 2019) or developmental disorder context (e.g., autism, Hays & Butauski, 2017). Yet other scholars found relational quality and anticipated response was a strong indicator for disclosure in a prostate cancer context (e.g., “strong ties,” Brown et al.,

2016) and HIV context (Catona et al., 2016). Other scholars recommended direct disclosure regardless of relationship (e.g., infertility, Steuber & High, 2015), while no differences may be found regarding relational quality for individuals who are elderly and chronically ill (Checton & Greene, 2015).

Throughout the literature on making decisions about disclosure, scholars have largely found inconsistent results regarding relationship quality and anticipated response. However, one consistency that researchers seem to have found regarding EAs was the role of friendship in disclosing health-related information. Researchers continually reported that EAs disclose their mental health to friends (Butler, 2016; Venetis et al., 2018) and to their parents when they act like friends. Knowing this, I asked the following research question:

**RQ2a:** What are the characteristics that emerging adults with chronic illness identify in friends they choose as confidants?

Additionally, because unwanted, risky, or surprising disclosures may change the communication, and thus the relationship, in friendships (McBride & Bergen, 2008), I posed the following research question:

**RQ2b:** What changes, if any, in the friendship relationship do emerging adults with chronic illness describe with a confidant post-disclosure of chronic illness-related information?

Sometimes EAs disclose more to their friends because of the deindividuation process (Petronio, 2002), and this may be done to receive tangible, emotional, and/or informational support from their friends (Sias & Bartoo, 2007; Kaushansky et al., 2017). In considering these reasons for disclosure, I considered the following research question:

**RQ2c:** What changes, if any, in illness management do emerging adults with chronic illness describe post-disclosure of chronic illness-related information to the confidant?

If a disclosure is unwanted, especially risky, or surprising (McBride & Bergen, 2008) and/or a boundary is violated, future management of the private information must be re-negotiated between co-owners of the information (Petronio, 2002). In considering how reactions to the primary disclosure of private information from a confidant can shape future (non)disclosures of private information, I asked the following research question:

**RQ3:** How, if at all, did the type of confidant with whom emerging adults with chronic illness change future (non)disclosures of chronic illness-related information?

Given the variations among the types of confidants, coordinating boundaries between interactants is no simple feat. Thus, I next describe boundary linkage rules in order to further query how EA friends disclose private, chronic health information with another friend.

### **Privacy Rule Negotiation**

In the confider-confidant dyad, boundaries can become messy when there is a lack of privacy rule negotiation (Petronio, 2002). Although private information disclosure is not an inherently two-person phenomenon (e.g., communal boundaries of families, friend groups, and workplaces, Petronio, 2002), it is outside the realm of my study to account for all individuals involved in a disclosure as the focus of this study was the dyadic exchange between confider-confidant. Depending on the riskiness of private information, friends may perceive ownership differently. If a confider deemed the private

information as particularly risky, they viewed the confidant having less ownership of the private information, while the inverse was true for less risky private information (Kennedy-Lightsey et al., 2012). Generally speaking, researchers found that if the information is riskier, the confider may create more explicit rules, while less risky information likely carried implicit rules (Venetis et al., 2012). Nonetheless, disclosures of health-related information were often expected to remain between the interactants with confidants withholding such information from third parties (Venetis et al., 2012). Given the various expected outcomes of disclosures, confiders may enact privacy rules to govern the co-ownership of private information.

Petronio (2002) described that confiders of private information typically make either explicit or implicit rules. With explicit rules, the confider may give disclosure warnings, or phrases that explicitly define the parameters of co-ownership in future disclosures between the interactants and/or third parties. Regarding health-related information, researchers found that confiders not only explicitly mark such information more often, but confidants are more likely to keep this information more secretive regardless of the explicit/implicit coordination (Venetis et al., 2012). Nonetheless, a confidant's further revelation of private disclosures does occur regardless of coordination type, although this may be dependent on the topic of disclosure or perception of ownership (Kennedy-Lightsey et al., 2013; Venetis et al., 2012). For example, Kennedy-Lightsey et al. (2013) found that without conversations including explicit disclosure warnings and degree of risk, confidants may perceive higher levels of ownership of the private information, which may lead to revealing such information to third party individuals. However, when a discloser enacts explicit rules with a relationally close



confidant (e.g., friends), the confidant may feel negatively challenged in terms of their relational intimacy and trustworthiness (Caughlin et al., 2009; Venetis et al., 2012). Thus, EAs disclosing and receiving chronic illness-related information with friends may struggle in effectively coordinating either explicit or implicit boundaries due to the nuances of the disclosure event. In reflecting on the complexity of explicit/implicit rule negotiation, friendship, and chronic conditions, I now turn to my pilot studies for this dissertation to further enlighten the messiness that is privacy rule coordination and provide my next research question for the present study.

### **Pilot Studies**

Prior to this study, I undertook two studies on disclosure between friends about health conditions. In my first study (Hall, 2020) I explored how friends decide to disclose their mental health condition(s) or concern(s) with another friend. In the second study (Hall, 2021), I repeated the focus of the first study, but from a confidant's perspective while expanding the participant criteria to include both mental and chronic health. In the second study, despite expanding the criteria, I only found one participant who received a disclosure regarding non-mental chronic health, which led to my present study focusing on chronic illness to more fully understand the phenomenon of the disclosure of chronic illness-related information. As I considered the findings, I asked myself, "Why am I not getting participants with non-mental chronic conditions?"

Throughout both studies, results were comparable. I found trustworthiness to be a key tenet of friendship that led to disclosure, and confidants reported feeling like they received the private disclosure due to their trustworthiness as a friend, which were common findings among other studies of this nature (Kaushansky et al., 2017). The

interactants built their mutual trust upon previous disclosures, the management of the information post-disclosure, and relational histories. A key finding from the studies was that confidants seemed to build strict criteria for selecting a confidant prior to the disclosure. These criteria for selection mitigated much of anxieties of the disclosure process, which led to more surprising results in terms of privacy rule creation.

More often than not, the participants in both studies reported implicit boundary coordination as opposed to explicit boundary coordination. I struggled to interpret this finding in light of previous research on health-related information and disclosure processes. First, I was surprised to not find more instances of explicit negotiation and that confidants would maintain better secrecy of this private health-related disclosure (Venetis et al., 2012). Instead, I found ample evidence for the contrary in both cases. Perhaps explained by similar conditions under Steuber and McLaren's (2015) study, the nature of the friendship and strict selection criteria for disclosure may have mitigated a discloser's anxiety enough that explicit boundaries were deemed unnecessary or extraneous. Despite this, confidants reported often telling someone else about the disclosure, typically a close-relational other (e.g., parent). In discovering this phenomenon, I was left with only inklings and hunches about these disclosure processes. One possible explanation could be that my participants were mostly college students who likely had ample mental health resources on college campuses (e.g., availability of counseling, Eisenberg, 2019). This could also explain why I struggled to find individuals who experienced receiving non-mental chronic information from a friend, particularly as a friend can sometimes exacerbate experiences of stigma (Moses, 2010). I knew that investigating non-mental chronic health issues among the EA population could aid in understanding the

phenomenon of living with an underrepresented health issue during a period of life transition.

In these two previous studies, I conceptualized the criteria for disclosure under Petronio's (2002) original descriptions of the criteria. In the present study, I conceptualized the criteria under the updated descriptions for criteria of disclosure described earlier in this chapter: core and catalyst criteria (Petronio, 2013; Petronio & Durham, 2015). In the extant literature, researchers often conceptualized the disclosure criteria into the original distinct types, even if they describe core and catalyst criteria in the front end of the manuscript (e.g., Smith & Brunner, 2017). In the present study, I innovated language for the interview protocol to embody the updated concepts and reflected a more nuanced understanding of the disclosure criteria (as I explain further in Chapter Two). I adjusted the language in these portions of the interview to garner a better understanding of an often-non-discussed health issue among EAs.

Within the previous studies, I did not probe participants regarding their negotiation of privacy rules. As was somewhat typical in open-ended studies of CPM and privacy rules, I asked participants how they managed the information post-disclosure by asking: "Once you told your friend about your mental health, what, if anything, did you tell them about what they could and couldn't do/say with the information?" for disclosures or "Once your friend told you this information, what, if anything, did they tell you about what you could and couldn't do/say with the information they gave you?" for confidants. In a similar vein, Smith and Brunner (2017) asked their participants: "Would you expect the private information you shared to remain confidential? If so, how would you make sure that information remains confidential? Please describe in two to three

sentences” (p. 442). In my own studies and from the work of other researchers (e.g., Smith & Brunner, 2017; Steuber & McLaren, 2015), researchers continually found individuals created implicit rules more often than explicit rules when studying friendship. However, when considering EAs and chronic illness, the lack of resources and regular exposure to chronic illness in EA populations could further challenge how EAs manage and navigate their (non)disclosure of their chronic illness-related information (Thyberg, 2018).

Therefore, the focus of the present study shifted from mental illness-related information to chronic illness-related information. From my studies, I found that confiders reported creating implicit rules, and confidants reported a lack of explicit rules regarding mental health. However, the availability of mental health resources and consistent exposure to mental health may have contributed to a sense of normalcy or ordinariness for EAs. Thus, my focus in the present study differed significantly in conceptualization of CPM and health conditions through both updated CPM terminology and further investigation of chronic illness-related information. By more thoroughly exploring the privacy rule negotiation of chronic illness as I describe in Chapter Two, I sought to build a more thorough understanding of what the actual process of privacy rule negotiation may look like for EAs with chronic illness. Therefore, I asked the following research question:

**RQ4:** What, privacy rules, if any do emerging adults with chronic illness negotiate with a confidant when disclosing chronic illness-related information?

### **Making Sense of Disclosure**

To further understand how and why EAs disclose their chronic health-related information with a friend, I seek to extend CPM through a sense-making approach (Dervin, 2000). Dervin's (2000) sense-making approach rests on the idea that information is "made and unmade in communication," meaning:

That we create an information system to assist people in designing their own information and, in particular, in sharing with each other the ways in which they have struggled individually and collectively to both create order out of chaos and create chaos out of order when order restricts or constrains them (p. 43).

In creating such a system, individuals can make sense of the incompleteness of their story and/or personal myth to work through the chaos of their own experiences. Here, when how one views the world is inconsistent with how one comes to understand something, the incongruence between oneself in the past and oneself in the present can pose problems in the understanding of "self." In other words, when engaging with the sense-making approach, a researcher asks: "How can we bridge gaps in our existence?"

This perspective is well suited for my work in the present study particularly through the lens of biographical disruption (Bury, 1982). Since chronic illness carries a perception associated with those in older populations (Kundrat & Nussbaum, 2003), researchers have found strong tendencies of biographical disruption for EAs, such as concealing symptoms to appear "normal" with their peers (Spencer et al., 2019). As such, the EA may have certain expectations for what it means to be "young," yet experiencing the onset and/or continued management of a chronic illness or illnesses may not make

sense in this life stage. EAs may then decide to disclose or withhold information from their friends to seek support or maintain a façade of normalcy. While some models and studies of disclosure consider the events leading up to and during health-related disclosure (e.g., Greene, 2009; Magsamen-Conrad et al., 2019), how individuals make sense of the entire disclosure process has not been as well documented. I next discuss arts-based research approaches (ABR) as a method that lends itself particularly well to issues of sense-making processes in health-related research (Douglas & Carless, 2018).

### **Arts-Based Research**

Broadly speaking, ABR is neither exclusively art nor exclusively science, but rather the “intersection of art and science” (Leavy, 2018, p. 3). Through this perspective, Gerber et al. (2012) describe the main philosophical tenet of ABR as it “recognizes art has been able to convey truth(s) or bring about awareness (both knowledge of the self and of others)” and “recognizes the use of arts is critical in achieving self-other knowledge” (p. 41). Thus, researchers using ABR do not place (social) scientific or artistic inquiry as inherently better than the other. Rather, both are necessary in capturing the reality of the human experience.

In the uncertainty and constant flux of human experience, ABR can help people make sense of chaos. Researchers engaging with ABR are particularly poised for helping others make sense of the seemingly chaotic as “a turning point to a new self-organization” such that “we would not fear [chaos] as much as we do” (Krahnke & Gudmundson, 2018, p. 565). For those EAs experiencing the turbulent issues in the onset and/or management of chronic illness, ABR may be particularly useful in helping them understand their decision-making and experiences throughout their illness journey.

Particularly as chronic illness disrupts daily life and the typical rules by which we live (Bury, 1982), ABR is a pivotal area of inquiry for scholars to further understand and assist in the sense-making process of chronic illness disclosure.

Researchers have actively used ABR in various facets of health-related research, describing the arts as essential to understanding health-related issues (Cox & Boydell, 2015; Hodgins & Boydell, 2014). In their review of the ABR health-related literature, Boydell et al. (2012a) found three main rationales for using ABR in health-related research: (a) providing a richer description of the qualitative data, (b) emphasize the participants' lived experience and the meaning of their experience, and (c) focus on contextual factors that can improve our understanding of the phenomena under inquiry. Researchers described past studies using health related ABR included visual, literary, and performance arts (Fraser & al Sayah, 2011) with photography and theatre as the most common genres used in the literature (Boydell et al., 2012a). Via the use of these ABR methods and arts-based interventions, researchers have found positive mental health outcomes for those EAs who participant in the interventions (Smriti et al., 2022). Often, these interventions allow participants to express their lived experiences to make sense of complex and sometimes difficult life experiences (Shemer & Shahar, 2022). Because EAs with chronic illness experience biographic disruption, dilemmas in seeking support, and potential difficulty in managing their chronic illness-related information, I considered the following research question:

**RQ5:** How do emerging adults make sense of the (non)disclosure process regarding their chronic illness-related information?

**Table 1: Summary of Research Questions**

<b>Summary of Research Questions</b>
<b>RQ1:</b> What criteria do emerging adults with chronic illness use in determining an appropriate friend to whom to reveal private information about chronic illness?
<b>RQ2a:</b> What are the characteristics that emerging adults with chronic illness identify in friends they choose as confidants?
<b>RQ2b:</b> What changes, if any, in the friendship relationship do emerging adults with chronic illness describe with a confidant post-disclosure of chronic illness-related information?
<b>RQ2c:</b> What changes, if any, in illness management do emerging adults with chronic illness describe post-disclosure of chronic illness-related information to the confidant?
<b>RQ3:</b> How, if at all, did the type of confidant with whom emerging adults with chronic illness change future (non)disclosures of chronic illness-related information?
<b>RQ4:</b> What, privacy rules, if any, do emerging adults with chronic illness negotiate with a confidant when disclosing chronic illness-related information?
<b>RQ5:</b> How do emerging adults make sense of the (non)disclosure process regarding their chronic illness-related information?



## CHAPTER TWO: METHOD

### Rationale for Paradigm and Method

My goal in undertaking this study was to better understand the processes of disclosure with a friend regarding chronic illness-related information during a life-stage filled with relational and health transitions. To best investigate this phenomenon, in this chapter I explain my use of the interpretive paradigm and qualitative methods in the present study. In doing so, I (a) describe the relevance of the interpretative paradigm to my inquiry, (b) explain my use of qualitative methodology in conducting my study, (c) review my data collection and procedures, and (d) discuss my data analysis and verification strategies regarding my results. First, I describe the relevance of the interpretive paradigm to this study.

### Paradigmatic Assumptions

Those working from an interpretive paradigm believe that human action is a purposive, meaning-making process (Baxter & Babbie, 2004). Interpretive researchers investigate people's subjective experiences, focusing on the local knowledge and meaning-making processes of a specific group and/or phenomenon (Baxter & Babbie, 2004). Their inquiries reject the notion of objectivity as an individual can "never exist or work completely *separate*...from the things that we study" (Lindlof & Taylor, 2018, p. 12, *emphasis in original*). Researchers working from the interpretive paradigm focus their inquiry primarily on the fact that human action has purpose, the act of inquiry itself is a production of meaning, and that there is no social world "out there," focusing on meaning-making processes of the interactants in a social world. For the present study, I sought to understand EAs' (non)disclosure of their chronic illness-related information

with a friend and make sense of these disclosures. I examined the social worlds of the participants to understand how they perceived and made sense of their lived realities, or subjectivities, building a better understanding of the nuances that exist in such a phenomenon. Centered in communication through disclosure processes, working from the interpretive paradigm was particularly useful for understanding the communication-based inquiry in my study (Putnam, 1983).

**Interpretive Paradigm in the Communication Discipline.** Specifically within the communication discipline, the interpretive researcher is “committed to a detailed understanding of how particular social realities are produced and maintained through the everyday practices of individuals, relational parties, families, and so on” with a bend toward “the native’s point of view” (Braithwaite et al., 2015, p. 9). In tandem with Baxter and Babbie’s (2004) conceptualization of interpretive research, Braithwaite et al. (2018) noted that interpretive communication researchers often work from a sensitizing perspective in which they place communication theory “at play with the point of view of the perspectives of the participants and the interpretations of the researcher” (p. 6). Interpretivists working from this sensitizing perspective view theories as resources from which to draw insight in making sense of participants’ lived experiences (Lindlof & Taylor, 2018). In designing my study within a CPM theoretical lens (Petronio, 2002), I used the terminology and ample research on CPM-related concepts as a starting place and resource from which to understand how EAs disclose chronic illness-related information with a friend. With CPM as a theoretical resource, I was better equipped to investigate issues of disclosure as CPM is an ideal fit for considering disclosure-based inquiry.

Petronio and Durham (2015) described how CPM is used by scholars of both interpretive and post-positivist paradigms because Petronio (2002) did not develop her theory with a certain paradigm or methodology in mind. Thus, in the present study, I sought to understand the rule-based, sense-making processes inherently involved with disclosure of chronic illness-related information and social attitudes toward illness (Duggan, 2019). In developing my study, I used CPM as a guiding theoretical framework to construct my semi-structured interview guide and analyze my results (Lindlof & Taylor, 2018), keeping in mind the especially risky privacy issues and stigmatization surrounding chronic illness-related information (Cardillo, 2010). In further noting my role as the researcher in this present study, I will next provide my reflexivity.

**Reflexivity.** In describing how to analyze “good” qualitative research, Tracy (2010) provided a criterion of sincerity through which “the research is marked by honesty and transparency about the researcher’s biases, goals, and foibles” and “about how these played a role in the methods, joys, and mistakes of the research” (p. 841). One method for demonstrating sincerity is through a reflexivity statement, which Suter (2016) described as “the inclusion of (re)positionings of the author’s self in relation to or as embodied in the project” (p. 3). At the time of this present study, I am a 29-year-old, cisgender, homosexual, white man from a primarily middle-class background working on an advanced degree in Communication Studies. Personally, I do not have a chronic condition, but I have family members with chronic illnesses with various degrees of symptoms and symptom severity ranging in age from 24-75. With my background, I know that I have had privileged access to healthcare that may not be afforded to everyone. I have also witnessed the effects of chronic illness second-hand through my

family members' experiences. In acknowledging these aspects of my subjectivity, I knew that my own experiences and what I considered to be knowledge would be challenged. I came to know EAs with chronic conditions as a unique population that informed my understanding of what Wentz-Hahn (2020) described as “context, experiences, meaning making, and theory” (p. 48). To be transparent about the goals of this present study, I explain my future goals more in Chapter Five. As I next describe my methodological considerations, I will describe incorporating my interpretive perspective in tandem with the qualitative data I carried out in the present study.

### **Methodological Considerations**

Through the interpretive paradigm I focused on how social actors in the present study embodied the *what* and *how* of meanings through language and action (Schwandt, 1998). Much of the interpretive perspective comes from hermeneutics, or the study/interpretation of text(s), and *Verstehen*, or the “ability to *imagine* the felt, lived experience of another as a prerequisite for *understanding* it” (Lindlof & Taylor, 2018, p. 52, *emphasis in original*). Researchers have incorporated qualitative methods to study various aspects of health due with the goal of garnering insight into the real-world experiences and perspectives of the health of their participants (Braun & Clarke, 2014).

A researcher using interviews elicits participant observation, feelings, and sense-making of their world(s) (Merriam & Tisdell, 2016). As Patton (2015) described, “we interview people to find out from them [the participants] those things we cannot directly observe” and thus “the purpose of interviewing, then, is to allow us to enter into the other person’s perspective” (p. 426). In my study, I sought to learn how EAs managed and navigated the (non)disclosure of chronic illness-related information with their friends.

The strength of my approach was in its qualitative methodology with the capacity to capture revelations and meanings of chronic illness (Duggan, 2019). In this way, I allowed for each participant to reflect on their lived experiences that occurred in the most naturalistic manner possible.

I used a semi-structured interview (Lindlof & Taylor, 2018) that included both (a) open-ended questioning and (b) the creation of an artifact in the form of a book cover, based on Tracy and Redden's (2015) work on drawings and metaphors (I detail these further later in this chapter). Creswell (2016) described the prevalence of interviews for collecting qualitative data, especially because a researcher using such a method "attempts to understand the world from the [participants'] points of view, to unfold the meaning of their experiences," and "to uncover their lived world prior to scientific explanations" (Brinkmann & Kvale, 2015, p. 3). I used a semi-structured interview guide to engage in a more conversational tone (Brinkmann & Kvale, 2015) and flexibility (Lindlof & Taylor, 2018) during the interview process. In using a semi-structured interview, I came to each interview with a prepared interview guide that allowed for flexibility during the interview. Because of the semi-structured interview format, I easily shuffled questions throughout the interview and probed for more information as needed, providing a natural discursive flow to the research experience (Rowley et al., 2012). Now that I described my methodological considerations of the study, I next describe my procedures of the present study regarding (a) recruitment, (b) participants, and (c) the semi-structured interview guide.

## Procedures

### Recruitment

First, in keeping with the goals of my study, and after I received IRB approval, I used purposive sampling to locate my participants and identify individuals most likely to embody and experience my phenomenon of inquiry: an EA with a chronic condition who has shared that information with a friend (Schwandt, 1997). To best understand how EAs navigate chronic illness-related information disclosure with their friends, my participants needed to meet three criteria to be in the sample (Lindlof & Taylor, 2018). First, participants must have been 19-29 years old to be considered both an EA and a legal adult in the state I performed the research (Neb. Rev. Stat. § 43-2101). Second, participants self-reported a chronic illness as conceptualized in Chapter One as including chronic illnesses except mental illness. Third, participants must have disclosed their chronic illness to a friend at least six months prior to the interview. Researchers estimated it could take anywhere from 160 hours across 10 days (Altman & Haythorn, 1965) to over 200 hours over six weeks to become good or best friends (Hall, 2019). I chose a six-month time frame to account for the beginning of the friendship, the disclosure of the chronic illness-related information, and the present day.

Second, I recruited the participants in the present study via electronic and online methods. Although my original plan was to do more in-person and location-based recruitment and interviewing, due to the constraints in place by the COVID-19 pandemic during which the present study occurred, I recruited participants mainly through online and mediated communication methods (e.g., reddit, the Communication Research and Theory Network (CommNotes), electronic kiosks, e-mail, online support groups, UNL's

Department of Communication Studies' research website) in addition to my personal social media networks (e.g., Facebook, Twitter). For any electronic domain I did not control, I asked and waited for approval prior to posting any recruitment material in those spaces. Regardless of the method of recruitment, participants were required to contact me via e-mail to express interest of participation in the study.

One important question for any researcher is how much data to collect. Although some qualitative researchers would call for some form of data or theoretical saturation in their protocol, Braun and Clarke (2019b) explicitly noted that such a standard is more neo-positivist than and incongruent with interpretive-qualitative methodology such as the reflexive thematic analysis (Braun & Clarke, 2006, 2019a) I used to interpret my data in this study. Many qualitative researchers argued about the specific number of participants needed to claim theoretical saturation (as little as 5, Creswell, 2002; as many as 60, Bernard, 2000). However, in refuting the theoretical saturation standard of qualitative research, Braun and Clarke (2019b) claimed, "meaning requires *interpretation*" such that attempting to "find" the inherent meaning in the data would reject "the intersection of the data and the researcher's contextual and theoretically embedded interpretive practices" (p. 10, *emphasis in original*). To best reflect my approach to the interpretive paradigm in these methods, I used reflexive thematic analysis meaning to determine my recruitment. In other words, I determined the quality of my results in whether my interpretations "tell a compelling, coherent and useful story in relation to the research question[s]" and "offer useful insights that speak to the topic in relation to context and sample" (Braun & Clarke, 2019b). To ensure the quality of my results, I used the concept of information power.

In their attempts to further address issues of sample size and saturation in qualitative studies, Malterud et al. (2016) created the concept of information power describing that as a sample holds more relevant information to the inquiry, the less participants are needed to reach the study's goal. In considering information power, the authors described five dimensions of a study to consider for "guessing" the appropriate number to reach in a qualitative inquiry: study aim, sample specificity, use of established theory, quality of dialogue, and analysis strategy. In the present study, I had specific study aim (i.e., exploring how emerging adults disclose chronic illness-related information with a friend) and sample (i.e., 19-29 years old, have a chronic illness, and told a friend of their chronic illness at least 6 months ago), established theory (CPM as a widely used theory, Braithwaite et al., 2015), and strong quality of dialogue (see Appendix A for the interview materials), and analytic tools to best understand the phenomenon of the present study that I discuss later in this chapter. Because of the narrower approach of each of Malterud et al.'s (2016), coupled with the significant challenges of recruiting participants during the Covid-19 pandemic and that my inquiry emphasized a need for rigorous participation from the participants through both the interview and book cover creation described later in this study. Thus, in knowing and reflecting on the nature of my study, I successfully recruited and interviewed 15 participants for the present study whose perspectives were represented in interviews of 45-125 minutes in length ( $M=50.87$  minutes), 503 pages of double-spaced interview transcriptions, and 15 book cover images for analysis.



## Participants

Second, I now describe the participants in the present study. Of the 15 participants in this study, 11 self-identified as female, 3 identified as male, and 1 identified as non-binary. The participants were ages 20-28 ( $M=23.91$ ). The participants self-identified as predominately white ( $n=11$ ) with the other participants identifying as Hispanic/Latinx ( $n=2$ ) or biracial (Black/white,  $n=1$ ; Middle Eastern/white,  $n=1$ ). Regarding their chronic conditions, participants described the length of their diagnosis ranging from 3 months<sup>2</sup> to fourteen years ( $M=6.66$  years). Of the conditions represented by the participants in this study, asthma ( $n=2$ ) Chron's disease ( $n=2$ ), and postural tachycardia syndrome (POTS) ( $n=2$ ) were the only conditions with more than one participant self-identifying as diagnosed with that condition. The other conditions reported by the participants in this study were: ankylosing spondylitis (AS), autonomic neuropathy, chronic fatigue syndrome, coinfection of bartonella and babesia, connective tissue disorder, dysautonomia, Ehlers-Danlos syndrome (EDS), endometriosis, fibromyalgia, fructose malabsorption, Hashimoto's disease, inflammatory bowel disease, irritable bowel syndrome, mast cell activation syndrome, peripheral neuropathies, polycystic ovary syndrome (PCOS), psoriatic arthritis, Sjogren's syndrome, small intestine bacterial overgrowth (SIBO), and systemic lupus erythematosus (SLE)<sup>3</sup>. Now that I described the participants from the study, I next describe the interview procedures from the present study.

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<sup>2</sup> Although not all participants had a diagnosed chronic condition six months prior to the interview, they had been through the diagnostic process to receive chronic illness diagnosis. In noting the often-lengthy process to receive a chronic illness diagnosis (e.g., Martín et al., 2014), the participants in this study only needed to have shared chronic illness-related information with a friend 6 months prior to the interview.

<sup>3</sup> There are more chronic conditions than participants in the study. This is not surprising given that nearly one third of all chronically ill individuals experience comorbidities—occurrence of multiple chronic illnesses in one person (Boersma et al., 2020).

## **Interview Procedures**

To best understand the experiences EAs and the (non)disclosure of chronic illness-related information with a friend, I engaged with the participants using a semi-structured interview guide (Appendix A) (Lindlof & Taylor, 2018). Given constraints placed by IRB to keep researchers and participants safe during the COVID-19 pandemic at the time I collected the data in this present study, I interviewed participants via online mediated technologies (e.g., Skype, Zoom) based on participant preference. I undertook the semi-structured interview in two parts: (a) demographic and open-ended questions and (b) the creation of a book cover prior to the interview and discussion of the book cover during the interview.

I created the first part of the semi-structured interview guide using CPM (Petronio, 2002) as a sensitizing framework (Bowen, 2006) to build open-ended questions that provide me with a frame of reference for interpreting my participants' experiences (Marsiglio, 2004). In this way, I asked the participants structured demographic questions, followed by questions about participants' experience of disclosing their chronic illness-related information with a friend. I asked further questions regarding their experiences, decision-making, and management of information (see Appendix A).

The second part of the interview was originally to be an updated version of what I called the Talk and Text Thematic Analysis, or 3TA, developed in my second pilot study (Hall, 2021). I originally planned to create a co-constructed artifact in a face-to-face interview with the participants, asking them questions about the piece with a participant reflection (Tracy, 2019) to co-analyze the results. However, due to the constraints

stemming from the COVID-19 pandemic restricting in-person research, I turned to Tracy and Redden's (2015) drawing as metaphor model.

Originally designed for metaphorical organizational research, Tracy and Redden (2015) described their model of drawing and metaphor analysis as a method that helps in "empirical value, power-sharing and collaboration...and enhanced representation" (p. 240). In this method, the interviewer would ask the participant to draw the representation of the phenomenon under inquiry. For example, Tracy et al. (2006) asked their participants to draw the feeling of being bullied in the workplace. In their model, the authors argued that the empirical value of drawing and metaphor analysis helps access both tacit and collective assumptions. In this way, the authors further described drawing as an effective method of triangulation because the picture required further interpretation and explanation from participants in which the researcher probed and found further meaning making. In citing Papa and Singhal's (2007) participatory work with oppressed communities, Tracy and Redden (2015) noted that drawing opens the dialogue for participant collaboration "as they are asked to help generate material for analysis and consideration" (p. 244). By allowing participants to create and offer interpretations of their creations, the researchers were more equipped to understand and tell the participants' stories. Finally, the material produced from participant drawings was seen as more transferrable in the sense that participants were more equipped to process, comprehend, and make decisions about creating art (Meyer, 1991), and the process of creating visual art made the research experience more memorable and interesting for both participants, researchers, and those who view the work (Tracy & Redden, 2015).

In tandem with Tracy and Redden's (2015) model, I drew inspiration from Moore's dissertation (2016) and subsequent publication (2017) for the present study when asking the participants to reflect on their experiences of sharing their chronic illness-related information with a friend. While Moore developed her protocol with a modified version of McAdams' (1997) life story interview to create a table of contents based on participant experiences, I asked participants to create a book cover including a title and design. Moore (2016) created a detailed prompt and worksheet to elicit information from participants prior to the interview. In noting the success of Moore's work in collecting thick, descriptive data, I provided participants in the present study with a prompt prior to the interview. After participants in this present study provided their informed consent, I sent participants a response inclusive of the following prompt:

To get you thinking about your experience of sharing chronic illness-related information with a friend, I would like you to design a book cover that best captures your experience. In doing so, reflect on your experiences and provide a title that best describes this experience. Additionally, I invite you to create the cover design for this book. Keep in mind that you do not have to be creative to do this as I am not looking for you to build a masterpiece. You can draw an image or multiple images, describe what you would like to see on this book cover, use stickpersons to represent what you envision, or any other method of creation to best show what your experience has been like in sharing chronic illness-related information with a friend. You are not limited in how you want to make this book cover. I will give you some time to work on this and a template to work from if you would like. Please feel free to ask me questions at [robert.hall@huskers.unl.edu](mailto:robert.hall@huskers.unl.edu). Once you send me

your completed piece, we will set up our interview. During the interview, I will ask you some questions about your design so we can best make sense of your artistry. In Appendix B, I include the template and instructions for creating the book cover to aid participants in the present study in their creative process. I informed the participants in the present study that they were welcome to use or not use this template, create their own template, or send descriptions of what they wanted to see on their book cover. Once each participant in the present study sent me their completed book cover via email, I scheduled an interview with them to be held via online media. In the interview, I asked participants in the present study about their book cover they created prior to the interview including the meaning of, suitable audience for, and importance of their book cover (see “Book Cover Design,” Appendix A). I informed the participants in the present study that they were welcome to change any part of the title and artistic design at any time before, during, or after the interview.

### **Data Analysis and Verification**

I analyzed these data from the present study in two parts. I started with an analysis of the open-ended interview portions of the transcript, followed by an analysis of the data collected with the book covers. To transcribe interviews, I used transcription services (e.g., Transcription Panda, rev) to assist in this process. Through the transcription process, I made sure to remove all identifying information and give participants pseudonyms to protect participant confidentiality<sup>4</sup>. To analyze the transcripts, I used Braun and Clarke’s (2019a) reflexive thematic analysis to analyze these data from the

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<sup>4</sup> In the results of the present study, participants will only be identified via their interview number. Due to the intersectional identities of sex, age, and occurrence comorbid chronic conditions, I use the interview number to reference the participants to minimize risk of the participants in this study.

open-ended questions. Keeping in line with reflexive thematic analysis, I ensured to be theoretically flexible, emphasizing the interpretive paradigm in considering the subjectivity of the researcher, recursive meaning-making of participant experiences, and reflecting on the larger implications of and engaging with the data (Braun & Clarke, 2019a). In the present study, I used reflexive thematic analysis to analyze the (a) open-ended interview data and (b) book covers.

### **Open-Ended Interview Data Analysis**

Along with the first step in Braun and Clarke's (2019a) reflexive thematic analysis, is I familiarized myself with the data through reading and re-reading the data from the interviews in aggregate form to be fully familiar with the data. Second, I engaged in the coding stage during which I interacted with, asked questions about, and made comparisons among the data, building and developing concepts as articulated by the participants and described through my interpretive lens (Corbin & Strauss, 2008). Specifically, I looked for phenomena that appeared relevant to addressing the research questions and what the participants in this present study offered in the interview to organize into themes at the next stage (Braun & Clarke, 2006; Lindlof & Taylor, 2018). The third step is generating initial themes, and I incorporated Owen's (1984) criteria for thematic inclusion: recurrence (i.e., similar meanings identified throughout the data), repetition (i.e., similar or identical key words and/or phrases throughout the data), and forcefulness (i.e., participant emphasis given to specific discourse(s)). To identify a recurrent theme, I looked for at least two instances of similar meaning throughout the data even though participants in the present study may have used different words. To find a repetitive theme, I looked for repeated words, phrases, and/or sentences throughout the

data. Because forceful themes are noted through their nonverbal attributes (e.g., vocal tone, volume, and pauses, Owen, 1984) and because I did not transcribe all interviews personally, I made notes during the interview and, as needed, went back and listened to the audio recordings to effectively capture the idea(s) the participant in the present study nonverbally emphasized, the nonverbal behavior that I noted as particularly stressed by the participants, and a time-stamp to review the phrasing during analysis.

The fourth step is reviewing the themes in which I made sure that the thematic scheme “‘accurately’ reflects the meanings evident in the data set as a whole,” checking that my “‘accurate representation’” of the data represented my “‘theoretical and analytic approach’” (Braun & Clarke, 2006, p. 91). Here, I invoked both emic, the participants’ sense-making of their lived experiences, and etic, my knowledge and application of CPM, analytical perspectives for analysis (Lindlof & Taylor, 2018). This means that I looked for the criteria that participants in the present study used to make their decisions about disclosing their chronic illness-related information with their friend, the characteristics of confidants as determined by the participants, changes in information and illness management between friends, and the privacy rules negotiated by the participant and the friend as described by the participants.

In keeping with this emic and etic “‘iterative nature’” of reflexive thematic analysis (Braun & Clarke, 2019a, p. 593), in the fifth step, defining and naming themes (Braun & Clarke, 2006), I used in vivo quotes coupled with theoretical concepts to best articulate the full story of these data. I used exemplars as a method for illustrating the themes (Tracy, 2019) while explaining these data through a CPM lens to best make sense of the theoretical phenomenon. I chose exemplars that best capture the heart of the theme to

show participant experiences in the present study rather than tell the reader about them (Padgett, 2012). After defining and naming themes, I performed data verification strategies (described later in this chapter) prior to completing the final step of thematic analysis in which the researcher writes the report.

### **Book Cover Data Analysis**

To analyze the book covers, I used a more inductive, or emic, approach of reflexive thematic analysis, to understand the data “from the actor’s point of view” which “is context-specific” (Tracy, 2019, p. 26). Here, the “actors” were the participants in the present study as they created the book cover, and, in noting that I could never fully remove myself from the analysis (Yerby, 1995), I was aware that I was unable to fully remove my etic, or theoretical knowledge, from the analysis (Burr, 2015). Thus, to accomplish the analysis of the book covers, I analyzed the book covers and the transcriptions from this part of the interviews in this present study using Owen’s (1984) criteria for thematic development through identifying (a) recurring meanings, (b) repeated key words and/or phrases, and (c) emphasized ideas and/or discourses throughout the data. Although my own CPM lens informed the interpretation of these data, I did not create “a priori” categories for the results from these data in the present study. In other words, should the findings from these data fit within a CPM framework, I described them in such a manner. However, because participants were likely not attuned to this etic perspective, I analyzed these data openly to identify recurring, repeating, and forceful themes (Owen, 1984). After identifying the thematic landscape of the book covers, I moved to my verification strategies of the preliminary results of the present study.



## Data Verification Strategies

Many interpretive researchers rejected the notions of “reliability” and “validity” attempts for a researcher to remain objective and rather let the findings stand on their own (Lindlof & Taylor, 2018; Merriam & Tisdell, 2016; Tracy, 2019). While some interpretive researchers discussed using aspects of reliability and validity (e.g., Lindlof & Taylor, 2018; Merriam & Tisdell, 2016), other researchers worked to redefine the means by which interpretive researchers evaluate what is “good” research through engaging in verification of results (Braithwaite et al., 2014; Tracy, 2019). In my verification procedures, I next discuss the two methods in which I used to verify my data: (a) data conferencing and (b) member reflections.

The first step I took in verifying my data was engaging in a data conference, a term developed in my research community (Braithwaite et al. 2014, 2017) and sometimes referred to as peer examination (Merriam & Tisdell, 2016) or peer debriefing (Guba & Lincoln, 1989, Spall, 1998). Braithwaite et al. (2017) described data conferencing as a process of eliciting feedback on preliminary results from academic or scholarly peers. To perform the data conference for this present study, I first completed my initial analysis and generated a handout with my preliminary findings including sample exemplars from these data, overview of my methodology, and participant demographics. After preparing these materials, I invited scholars to attend a meeting who were expert in some aspect of this study (i.e., CPM, disclosure, friendship, emerging adults, and/or chronic illness, qualitative methods) to “provide thorough assessment of the procedures and findings” and engaged in critical feedback, challenging the initial results as needed (Braithwaite et al., 2017, p. 1). At the meeting, I discussed my findings with the attending scholars and

informed them about my decision-making processes of creating these initial results. After my discussion, I invited the scholars to question and provide feedback on the initial results. After the data conference, I took my colleagues' feedback and re-worked the results as necessary for the best representation of these data. After completing the data conference, I performed my next step in verifying my results through a member reflection with the participants in this present study.

Traditionally known as member checks (Creswell, 2009), I incorporated member reflections in the present study to “allow for sharing and dialoguing with participants about the study’s findings, providing opportunities for questions, critique, feedback, affirmation, and even collaboration” (Tracy, 2010, p. 844). Tracy (2019) differentiated member reflections from member checks primarily in the purposes of each method. Whereas member checks were used to validate results, member reflections went beyond this to also invite further inquiry from participants and enhance the credibility of the findings. For member reflections in my study, I sent all participants a brief overview of the findings from the open-ended questions with exemplar book covers so the participants can then “react, agree, or point out problems with the analysis” (p. 278). For the present study, this is especially important as participants created the book cover from their lived experiences, which made the participants a co-researcher (Roulston, 2010) in the sense that they both created and co-analyzed the data while also expanding and/or affirming the findings from my analysis.

In eliciting reflections from my participants, I sent participants who agreed (n=14) to participate in the member reflection an email with a document containing a summary of the results from the open-ended interviews and data conferencing with exemplars. In

sending these results, I provided instructions to the participants in the present study to review the document and consider the following questions: “Did I get this right in terms of your experience sharing your chronic illness-related information with your friend? Why or why not?” and, “How well do these results I have shared capture your experiences as a person who has shared chronic illness-related information with a friend? Why or why not?” As I asked these questions, I elicited participant feedback on the representation of the results regarding the main ideas of the study. After receiving the participants’ feedback (n=9), I analyzed these responses to note themes in the feedback for the present study. With the member reflections, the participants in this study largely affirmed the findings of the study. Some of the participants in the present study commented on others’ differing experiences, but overall, they found the results to be representative of their lived experiences.

After I completed all analysis and verification strategies, I finished my reflexive thematic analysis with the sixth step: writing the report (Braun & Clarke, 2019a). Through the analysis and verification strategies, I collected exemplars to highlight themes, made arguments for my decisions in explaining my results, and garnered initial feedback from various sources to organize and present my findings of these data in the following chapters.

## CHAPTER THREE: RESULTS

### Summary and Overview of Dissertation Results

In the present study, my goal was to better understand the processes of disclosure with a friend regarding chronic illness-related information during emerging adulthood. Specifically, I examined how individuals made decisions negotiating and managing their chronic illness-related information with a friend. In my study, I focused on five research questions:

**RQ1:** What criteria do emerging adults with chronic illness use in determining an appropriate friend to whom to reveal private information about chronic illness?

**RQ2a:** What are the characteristics that emerging adults with chronic illness identify in friends they choose as confidants?

**RQ2b:** What changes, if any, in the friendship relationship do emerging adults with chronic illness describe with a confidant post-disclosure of chronic illness-related information?

**RQ2c:** What changes, if any, in illness management do emerging adults with chronic illness describe post-disclosure of chronic illness-related information to the confidant?

**RQ3:** How, if at all, did the type of confidant with whom emerging adults with chronic illness change future (non)disclosures of chronic illness-related information?

**RQ4:** What, privacy rules, if any, do emerging adults with chronic illness negotiate with a confidant when disclosing chronic illness-related information?

**RQ5:** How do emerging adults make sense of their decision to disclose and/or withhold their private, chronic illness-related information?

In this chapter, I will (a) provide an overview of the two results chapters, (b) detail my results regarding RQs 1-4, and (c) present my conclusions for the main findings of this chapter. As such, I will first begin with an overview of the two results chapters.

### **Overview of Results Chapters**

Throughout Chapter Three, I address my first four research questions. In these, I sought to understand how individuals decided with which friend to share their chronic illness-related information. In using CPM as a sensitizing theory in my data analysis, I found common threads of my participants' decisions to disclose using the contextual criterion through (a) abnormal circumstances and (b) relational history to answer RQ1. Regarding RQ2b and RQ2c, I identified in the participants' responses how they (a) perceived their friendships grew stronger post-disclosure and (b) were satisfied by their friends' minimal or as-needed involvement in their chronic illness symptom management. Once participants had disclosed with their friend, I identified three types of confidants my participants experienced: (a) inferential, (b) deliberate, and (c) consequential, answering RQ2a and RQ3. While negotiating the flow of private information disclosure and answer RQ4, I found both (a) implicit and (b) explicit privacy rules in the participants' discourse. At the end of Chapter Three, I will provide a brief summary and conclusions based on these results.

In Chapter Four, I explore my RQ5 concerning how EAs make sense of the disclosure of their chronic illness-related information with their friend. In this chapter, through using arts-based research methodology, I explore how the participants in the

present study made sense of sharing their chronic illness-related information with a friend through two metaphorical themes: (a) privacy-related metaphors and (b) chronic illness management-related metaphors. I present several exemplars in each theme of the Chapter Four results section that best showcase the main ideas of these findings. With the book covers, I add *in vivo* quotations from the interviews and written responses from the participants to further illustrate how the participants explored making sense of the disclosure of chronic illness-related information with a friend. Finally, I end Chapter Four with a brief summary and discussion.

In the final chapter, Chapter Five, I discuss my dissertation. In this chapter I will first provide a summary of my results and discuss my major findings including (a) theoretical insights of disclosure, (b) nuances of disclosure and friendship, and (c) implications for practical uses of the results. Second, I will discuss the strengths and limitations of my dissertation study. Third, I end Chapter 5 with insights into future inquiry regarding disclosure, friendship, and chronic illness. To begin this sequence of chapters, I will now discuss my findings regarding RQs 1-4.

### **Overview of Chapter Three Results**

My goal for Chapter Three was to answer RQs 1-4:

**RQ1:** What criteria do emerging adults with chronic illness use in determining an appropriate friend to whom to reveal private information about chronic illness?

**RQ2a:** What are the characteristics that emerging adults with chronic illness identify in friends they choose as confidants?

**RQ2b:** What changes, if any, in the friendship relationship do emerging adults with chronic illness describe with a confidant post-disclosure of chronic illness-related information?

**RQ2c:** What changes, if any, in illness management do emerging adults with chronic illness describe post-disclosure of chronic illness-related information to the confidant?

**RQ3:** How, if at all, did the type of confidant with whom emerging adults with chronic illness change future (non)disclosures of chronic illness-related information?

**RQ4:** What, privacy rules, if any, do emerging adults with chronic illness negotiate with a confidant when disclosing chronic illness-related information?

I used CPM (Petronio, 2002) as a sensitizing framework (Bowen, 2006) and Owen's (1984) criteria for identifying and developing the themes of my findings in the present study. Through analysis of these present data, I found the participants' decisions to disclose I heard using the contextual criterion through (a) relational history and (b) non-relational circumstances. Once the participants in the present study shared their chronic illness-related information with their friend, I identified how these participants experienced (a) deepening of the friendship and (b) satisfaction by their friends' involvement in their chronic illness symptom management. Through analyzing the participants' descriptions of their friends receiving their chronic illness-related information, I identified three types of confidants my participants experienced: (a) inferential, (b) deliberate, and (c) consequential. While negotiating the flow of private information disclosure, I found both (a) implicit and (b) explicit privacy rules through my

participants' discourse. To start, I will discuss findings related to RQ1: "What criteria do emerging adults with chronic illness use in determining an appropriate friend to whom to reveal private information about chronic illness?"

### **Criteria for Disclosure of Chronic Illness-Related Information with a Friend:**

#### **Context and Privacy Orientation**

To answer RQ1, I examined these data for how my participants described their decisions to share their chronic illness-related information with their friend. To find an answer to RQ1, I first asked my participants to "Tell me the story about when you first told [friend's name] about your chronic illness, describing, as best as you can recall, what you and [friend's name] did and said in this situation." I further probed my participants on the criteria they used to decide to share their chronic illness-related information with their friend by asking, "What was it about [friend's name] influenced your decision of telling them about your chronic illness?", "What circumstances led to the decision to tell [friend's name] about your chronic illness?", and, "What motivated you to disclose your chronic illness to [friend's name]?" Through analyzing my participants' responses, I identified two types of criteria the participants used to decide to share their chronic illness-related information with a friend: (a) contextual criterion based on relational history and non-relational circumstances and (b) privacy orientation criterion based on previous experience(s) (see Table 2) (see pages 25-29 for the discussion of disclosure criteria). In discussing these findings, I will first discuss the contextual criterion.



**Table 2: Criteria for Disclosure of Chronic Illness-Related Information with a Friend: Context and Privacy Orientation**

<b>Criteria for Disclosure of Chronic Illness-Related Information with a Friend: Context and Privacy Orientation</b>
<b>A. The Contextual Criterion for Disclosure of Chronic Illness-Related Information with a Friend</b>
1. <b>Abnormal Circumstances</b> (events that were deemed unusual either at the EA life stage or at a societal level)
<i>a. Diagnostic process</i>
<i>b. COVID-19 Pandemic</i>
2. <b>Relational History</b> (considered their interactions/observed interactions of their friend in the past)
<i>a. considered the attitudes, characteristics, and demeanor of their friend</i>
<b>B. Privacy Orientations</b> (one's general regarding for their private information)
1. <b>Medical Necessity</b> (shared with others in case of an emergency)
<i>a. More severe/common symptoms</i>
2. <b>Non-Disruptive Condition</b> (felt like their chronic illness symptoms were not frequent/severe enough to be disruptive)
<i>a. Less severe/frequent symptoms</i>

### **The Contextual Criterion for Disclosure of Chronic Illness-Related Information with a Friend**

I will first explore how the participants described their friend as someone they identified could receive information regarding chronic illness-related information based on context. Specifically, I will discuss how (a) abnormal circumstances and (b) relational history both provided a context through which participants qualified their friend as worthy to receive their chronic illness-related information with their friend. I will first discuss the context of abnormal circumstances.

**Abnormal circumstances.** Petronio (2002) originally conceptualized context as a catalyst criterion in which abnormal circumstances (e.g., life circumstances, traumatic events) lead to a change in privacy management. In my analysis of these data, I found

participants describing both (a) the diagnostic process and (b) the COVID-19 pandemic as contextual criteria for disclosure. In each of these instances, these participants perceived a need to share their chronic illness-related information with their friend.

First, in acknowledging that the diagnosis of a chronic condition is disruptive to the EA life stage (Bury, 1982), some participants described that their friend was present through the diagnostic process. Here, participants in the present study perceived a necessity to explain the abnormal circumstance of experiencing a chronic illness diagnosis as an EA with their friend. For example, one participant described why the first told their friend of their chronic illness-related information:

Just the fact that they're so involved in my life, and they are one of my best friends and knew that I was going to the doctor and kind of going through this mystery of what was going on. And so they were part of the journey. And so that fact—and also the fact that we are so close, it was kind of like, “Hey! This is going with me. I want you to be aware that X, Y, Z is happening, so you know that that's something that I'm going through.” (1: 217-223)<sup>5</sup>

While this participant's friend was along for the journey of the participant's diagnosis of their chronic illness, and thus living alongside the biographical disruption of being an EA with a chronic condition, not all participants had this same experience in terms of abnormal circumstance. I discovered how the COVID-19 pandemic, an abnormal circumstance, influenced some of the participants to share their chronic illness-related information with their friend. While the experience of a chronic illness as an EA is disruptive itself, the additional stress of living through the COVID-19 pandemic as an

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<sup>5</sup> Numbers in parentheses describe the interview number and lines of the transcript from the interview.

immunocompromised individual further motivated some participants' decisions to share their private information with a friend. One participant described:

So, the whole reason I told him was very much related to COVID-19. It kind of ties into my book cover, too. So, I was just panicking about this whole thing. I knew what it meant for me, because if I get a cold it takes me three to six weeks to get over it and then a few more months of lasting symptoms. So, when this thing came about, I was like, oh, my gosh, this is terrifying. He was like, you don't need to worry. You're young and healthy. We're going to be fine. A direct quote he said, "t's just the old people who are going to get it and die, and the people with no immune systems who are going to get it and die." I was like, well, here's the thing, I don't have an immune system, so thank you. Then I explained what that meant and what my Lupus is and all that. (5:198-206)

Throughout the interviews in the present study, participants highlighted the idea of abnormal circumstances explained through the contextual criterion in CPM (Petronio, 2002). When people experience abnormal circumstances regarding their private information, they create new privacy expectations (Petronio, 2002). In the first exemplar, the participant described their frequent doctor visits with their friend to let them know of the changes regarding life circumstances. In the second exemplar, the participant described how the onset of a traumatic event as an immunocompromised individual was a key influence in the disclosure of their chronic illness-related information with their friend. As such, I related these participants considering abnormal circumstances as exemplary of the contextual criterion as a *catalyst criterion* in that the participants responded to needed change (Petronio & Durham, 2015; Petronio et al., 2022). While I

found that some of the participants in this present study highlighted abnormal circumstances as a key criterion for disclosure, other participants described context as more of a quality of the friendship than a response to change.

**Relational history.** The second part of contextual criterion I found in these data involved relational history. In this way, I described how the participants' responses illustrated context in a more stable, core criterion manner regarding the relational history with their friends (Petronio & Durham, 2015; Petronio et al., 2022). Through analyzing these data, I found several participants described *characteristics* of their friend rather than *circumstances* of the friendship as the criterion for disclosure. In what I described as relational history, these participants evaluated their past interactions with their friend when deciding whether to disclose their chronic illness-related information with their friend. For example, as one participant explained:

She's not judgmental. I'd bet, out of all of my friends, she's almost the most level-headed person I know. She'll call me out if I'm overthinking something. We got really, really close once I switched labs because my advisor left. Also, I just wanted to know what her thoughts were since she studies this stuff. But it's interesting, because most of my dietician friends don't know, and then the gut people don't know. It's like no one knows. They think I have Celiac disease, which I'm like, "no, I just can't have wheat, but I can eat all the gluten." So, I chose her because I do value her opinion a lot and, she listens, actually listens, instead of just listening and then just saying stuff to provide information when it's like you don't really know. (6: 178-186)

Another participant described the characteristics of their friend as the criterion for disclosing their chronic illness-related information with the friend:

I mean, she's just a very...what's the word I'm looking for? She's very respectful of other people's information, and the things that are happening in their lives. And so, I mean I wouldn't mind if she ever told someone, "Oh my God, my best friend has AS!" I wouldn't care at all. But that's not something she just would do. And I just know that about her. (4: 218-222)

I found in these participants' discourses descriptions of the characteristics of their friend and past discussions as criteria through which their friend was deemed able and worthy to receive the participants' chronic health-related information. The participants compared these friends as unique from other friendships in several ways: attitude, demeanor, and past experiences. Through these exemplars, I related the participants' responses in the present study to the equality dimension of friendship because the responses exemplified in relational history served as a contextual criterion to share the private information (Rawlins, 2009). Here, even though the friends may have had unequal positions of power and unique experiences in considering (dis)ability, there was no claim of superiority and an emphasis on maintaining similarities for the friendship to continue (see Rawlins, 1992).

When considering relational history, I propose that the participants' discourse in the present study complicate our understanding of the contextual criterion as purely a type of catalyst criterion. When concerning relational history, I found that participants described something closer to the core criterion (i.e., more stable, long-term characteristics) of their friend rather than a catalyst criterion (i.e., responding to changing

circumstances) as their reason for disclosing their chronic illness-related information (Petronio & Durham, 2015; Petronio et al., 2022). Yet, in analyzing these present data, I did not identify any instance of the previously theorized core criteria for disclosure (i.e., privacy orientations, gender, culture, Petronio & Durham, 2015; Petronio et al., 2022) when participants described the characteristics of their friend as the reason they could disclose their chronic illness-related information with their friend. Thus, while I found some participants in the present study embodied the theoretical notion of the contextual criterion as a catalyst criterion, others showed that the relationship itself, as a contextual criterion, is enough of an established, core criterion for disclosure.

In her original conceptualization of the contextual criterion, Petronio (2002) described the contextual criterion through two dimensions: the social environment and the physical setting. While abnormal circumstances may have influenced a participant's decisions to disclose their chronic illness-related information with their friend (e.g., diagnostic process, the COVID-19 pandemic), there were times when the context of the relational history alone were deemed enough context for disclosure of chronic illness-related information with a friend. While context and relationships may adjust or change over time, the communicative actions that constituted the participant's friendship relationship influenced interactions surrounding sharing chronic illness-related information with their friend in these present data. While some participants in the present study highlighted contexts as the primary criteria for disclosure, others described their orientation toward their chronic illness as the reason to share their chronic illness-related information with their friend as I discuss to follow. Thus, I will next discuss the privacy orientation criterion for disclosure.

## **The Privacy Orientation Criterion for Disclosure of Chronic Illness-Related Information with a Friend**

The second criterion for disclosure, privacy orientations, refers to one's general attitude regarding their private information (Petronio, 2013). When deciding to share their chronic illness-related information with a friend, I found that some participants primarily considered how open or closed they were regarding their chronic illness. In the interviews, I found privacy orientation as a criterion for disclosure in these present data only when participants were more *open* about sharing their chronic illness-related information with others. Sometimes, participants in the present study perceived this was out of medical necessity. For example, one participant described:

Yeah, I mean, I'm a pretty open person in general about [my chronic illness], whether it's with friends or others, just because my condition, like, when I get flares, I can pass out or randomly just throw up somewhere. So, I have to kind of tell people. But at that time, I do think I had more choice. But it was also more of just like the expectations of the relationship. We all talk about everything anyway. So, it wasn't so much, "Oh, do I want to tell her or not." It was just like, "yeah, of course. Why wouldn't I tell her?" But outside of that relationship, I would say there's less choice, I guess. (8: 235-241)

While this participant mentioned their relational history with their friend, they focused on their orientation toward their condition as the criterion for disclosure. Because of how this participant perceived their condition—largely results from the side effects of the chronic illness—they had a more open privacy orientation regarding their chronic illness.

However, not all participants I identified as using the privacy orientation criterion in this present study described medical necessity. Sometimes, participants perceived their chronic illness was not particularly disruptive to their daily functioning. For example, one participant described:

I'm not embarrassed about [my chronic illness] or afraid about it. My chronic illness...it doesn't bother me. It doesn't affect me on a day-to-day basis. I think when I was younger, I used to kind of...especially when I first got diagnosed, I thought, "It's a part of me and it defines who I am." I think it's because there were certain opportunities that became closed off to me, and I kind of was resentful for that. But I think over time, especially as I've gotten more comfortable with having a chronic illness, I've come to accept what it is for me. That it's just a part of me. It's not something that defines me as a person. It's just something...I mean, shit happens. Everybody has to deal with it. Everybody has their own problems. This is my problem. (2: 322-332)

Although this participant described the experience of biographical disruption—their chronic illness disrupting their identity—in the past (Bury, 1982), they normalized their condition as a part of their identity. As such, they acknowledged that their chronic illness did not affect them daily, which could have privileged them toward a more open privacy orientation. When considering chronic illness, the experience of stigma could influence one's decisions to disclose (Defenbaugh, 2013). When participants perceived they did not experience their chronic illness symptoms as frequently or severely as other chronic conditions, I found how participants subsequently maintained an open privacy orientation surrounding their chronic illness.



In this section, I discussed the two criteria for disclosure I heard in the discourse of participants in the present study: (a) context and (b) privacy orientation. Within context, I described the two findings of (a) abnormal circumstances and (b) relational history that related to how EAs decided to share their chronic illness with a friend in changing environments and a stable social relationship. Regarding privacy orientations, I described how I heard in the participants' experiences that their chronic illness influenced their decisions to share their chronic illness-related information with their friend. Now that I discussed the criteria for participants' disclosures, I next discuss how EAs perceived and negotiated their relationship and chronic illness management post-disclosure with their friend in the present study.

### **Consequences of the Disclosure of Chronic Illness-Related Information with a Friend**

To answer RQ2b and RQ2c (see Table 3), I examined how the participants described (a) both their relationship and (b) management of their chronic illness post-disclosure of their chronic illness-related information with their friend. To address RQ2b, I asked my participants questions such as, "How satisfied do you feel about your experience of sharing this information with your friend overall?" and "How do you think sharing this information with your friend affected your friendship, if at all?" To address RQ2c, I asked my participants questions such as, "After telling your friend about your chronic illness, how did your overall well-being in terms of your chronic illness change, if at all?", "How involved, if at all, would you say is your friend in helping you manage your symptoms?", and "How, if at all, has your management of your chronic illness changed since sharing this information with your friend?" Through the participants'

responses, I learned about their perceptions regarding their relationship and chronic illness management through two main themes I identified in these present data: (a) deepening the friendship relationship and (b) minimal or as-needed involvement (see Table 3). I will first describe the participants' friendship relationship.

**Table 3: Consequences of the Disclosure of Chronic Illness-Related Information with a Friend**

<b>Consequences of the Disclosure of Chronic Illness-Related Information with a Friend</b> (post-disclosure, individuals described their relationship with their friend and their management of their chronic illness)
<b>A. Deepening the Friendship Relationship</b> (increased feelings of intimacy and relational closeness with their friend)
1. Positive Experiences
2. Bias of Intimacy
<b>B. Minimal or As-Needed Involvement</b> (largely desired emotional social support from their friends)
1. Chronic illness as individual
2. Emotional social support

### **Deepening the Friendship Relationship**

All of the participants taking part in the present study experienced a deepening of their friendship relationship, or, in other words, I found each participant described increased feelings of intimacy with their friend post-disclosure of chronic illness-related information. In my analysis of these data, I found none of the participants' friendships remained static—there was a change in a positive direction. For example, Participant 3 explained how, “I think it really changed our friendship a lot...we definitely became instantly more connected, a lot more intimate in the friend way just being able to share stuff” (3: 386-387). Additionally, Participant 7 explained:

I think it deepened it for sure. I think anytime you disclose something and it's a personal thing, especially an unreadable personal thing, it takes trust and vulnerability that obviously when handled well, like I think she did, can advance a relationship in a positive way and I think it did just that, made us closer. (7: 366-369)

In this way, these participants echoed the sentiments of those from the study. The participants in this present study all described feeling closer with their friend post-disclosure of their chronic illness-related information. Thus, it is perhaps unsurprising that when friends were more receptive and supportive when receiving private information, the feeling of relational intimacy grows closer.

While these present results may show a bias toward intimacy inherently present when disclosing private information (Parks, 1995), it is important to note that not all disclosures in relational life are positive. Although the participants in the present study did not elaborate on negative experiences, several mentioned that not all people may be as receptive to receiving chronic illness-related information. For example, Participant 3 described how “the people that have given me weird reactions are the people that knew me as a healthy person” (3: 538-539). The participants in this present study may have experienced more positive relational development because of their careful consideration of the qualities of their confidant and necessary changes in their environment, much like the criteria for disclosure I previously discussed. While I found overall increased intimacy in participants’ friendships, I also identified overall satisfaction with the role of the participants’ friends regarding chronic illness management.

### **Minimal or As-Needed Involvement**

Overall, I found the participants in the present study largely described their chronic illness as an individual experience, perhaps due to the experience of biographic disruption (Bury, 1982). Nonetheless, in my analysis of these data, I discovered that the participants were generally satisfied with how their friends fulfilled their role in the management of the participant's chronic illness(es) post-disclosure. While participants in the present study described various scenarios of how friends witnessed symptoms of the participants' chronic illness(es), I found that the participants mostly described their friends' support in terms of emotional social support (Cutrona & Suhr, 1992) and on an as-needed basis. For example, one participant described their perceptions concerning their friends' involvement in the management of their chronic illness in a discussion with me:

Interviewer: How involved, if at all, would you say he [your friend] was in helping you manage any aspect of your symptoms?

Participant 2: No, not really involved at all.

Interviewer: And how satisfied are you with that aspect of it?

Participant 2: I'm perfectly satisfied. I can take care of myself. I don't need him to take care of that for me. I don't need a shoulder to cry on. I'm okay.

Interviewer: If it comes up, how responsive would you say he is to your concerns about your Chron's Disease?

Participant 2: I feel like if it came up, he'd definitely be willing to talk about it with me and have a conversation. I feel like he would be open to speaking more about it if I wanted to speak about it like I said. But he's not pushy. So, I'm not

worried about, like I said, I'm not worried about him pushing me for information or making me speak when I don't feel like I want to talk about it. (2: 348-359)

Another participant echoed this sentiment of the individual experience of their chronic illness while feeling satisfied about their friend's role:

I'd say on a pretty casual level. Just because if it has been four or five years now since I've got diagnosed, I would say I'm pretty adept at handling a lot of it by myself. I would say she mostly helps with just the emotional, mental pieces of it—just sort of being someone to kind of hear me out when I'm like, “Oh, my shoulders really hurt...” etc. Just being an affirmative ear in the sense of like, “Oh, yeah, that does suck. Come sit on the couch with me and watch TV and try and wait for your ibuprofen to kick in.” You know? Stuff like that. So, I definitely look at it as an emotional, social kind...rather than the actual physical self-care. (10: 551-558)

Through these examples, the participants in the present study described how they were satisfied with their friends only intervening on an as-needed basis for their chronic illness. Additionally, when they asked their friend for support, they elicited emotional social support. While Helgeson et al. (2015) reported that EAs experiencing diabetes found their friends to be less supportive than those without diabetes, the participants in the present study described how the support on an as-needed basis was the desired frequency of support. When taken into consideration with participants' experiences from the present study, indicating a lack of support may be a premature evaluation since I identified participants' overall satisfaction with their friends' minimal/as-needed approach to emotional social support. This could also help explain why Helgeson et al.

(2015) found that friendship support was not a predictor on the well-being for youth with diabetes since the participants in the present study described not wanting their friends involved in the direct management of symptoms.

Thus far, via the analysis of these present data, I showed (a) careful consideration of criteria through which to disclose their chronic illness-related information with a friend regarding abnormal events and relational history and (b) positive experiences of relational development and chronic illness support post-disclosure. Understanding these findings, I now consider the participants' perceptions in the present study regarding how their friends received their private information in the friend's role as confidant through the disclosure process.

### **Types of Confidants regarding the Disclosure of Chronic Illness-Related Information with Friends**

To answer RQ3, I looked for how participants in the present study described their friends as confidants, or receivers of private information (Petronio, 2002; Petronio & Durham, 2015; Petronio et al., 2022), of their chronic illness-related information (see Table 4). Like with RQ1, I asked my participants to "Tell me the story about when you first told [friend's name] about your chronic illness, describing, as best as you can recall, what you and [friend's name] did and said in this situation" to answer RQ3. I further probed my participants on the reactions of their friends by asking, "How did your friend react to receiving this information?", "What did your friend do or say after receiving this information?", and "How have you and your friend discussed this information about your chronic illness since the first time you revealed you discussed this with them?" Through my participants' responses, I organized my participants' responses into three types of

confidants they experienced when sharing their chronic illness-related information with a friend: (a) inferential, (b) deliberate, and (c) consequential confidants (see Table 4 and a description of these types of confidants on pages 29-34). With these findings, I will first discuss inferential confidants.

**Table 4: Types of Confidants regarding the Disclosure of Chronic Illness-Related Information with Friends**

<b>Types of Confidants regarding the Disclosure of Chronic Illness-Related Information with Friends</b>
<b>A. Inferential Confidant</b> (those expected to receive the disclosure)
1. Related to the Relational History Contextual Criterion
2. Affirms Petronio's (2002) Conceptualization
<b>B. Deliberate Confidant</b> (those soliciting the disclosure of information)
1. Only Identified after the Initial Disclosure
2. Only Discussed Chronic Illness-Related Information
<b>C. Consequential Confidant</b> (those receiving the disclosure based on unpredictable circumstance)
1. Expands Typology
2. Chronic Illness Symptoms Lead to Disclosure

### **Inferential Confidant**

First, inferential confidants are those we would expect to receive our private information disclosure “because it is fundamental to the relational definition” (Petronio, 2002, p. 111). Based on this definition, I found significant overlap in these present data between the theme of *relational history* and the *inferential confidant*. In this sense, participants I identified as using relational history (i.e., the characteristics of and past interactions with a friend) as the contextual criterion for disclosure also described their friend as willing and able to receive their chronic illness-related information. When Participant 1 described their friend's involvement in their personal life and diagnostic journey, they described that the *closeness* of their friendship gave an expectation of the

friend to receive their private information. In this way, their friend affirmed this perception with their reaction. Participant 1 described:

[He was] just very, “Oh, I’m so sorry. If there’s anything I can do…” Like I was saying before, “You can always come to me if you need an ear or something.” It’s one of those situations where there’s really not anything that they can do other than just be there...and listen to me complain or something. They were pretty receptive to that. (1: 243-246)

Additionally, Participant 6 described their friend’s nonjudgmental past, level-headedness, and listening behaviors learned over time. In this way, Participant 6 also described how they had been going through a diagnostic experience like Participant 1. Because Participant 6 previously thought they had a chronic illness related to their digestive system, their friend already knew about their restricted diet. However, when officially telling their friend of their diagnosis of SIBO (Small Intestine Bacterial Overgrowth), they described how their friend was receptive of that information:

Her initial reaction was, I've heard about it, but tell me more...Then after I kind of...I sent her the link and then afterwards, she's like, oh, no. Because the SIBO is actually a 50% recurrence rate. I was on antibiotics for two weeks, three times a day to basically kill off my gut bacteria. Then at the same time, with the fructose malabsorption, I sent her more information...she's like, “So what *can* you eat?” Because the list of what I can't eat was longer than what I can eat. So, I think when you hear it, you don't think it's as bad as Chron's or UC...I think the part where she realized it sucks is there's no treatments for it. (6: 217-225)



Through this example and the relational history exemplar, Participant 6 showed how they took into consideration their relational history as way to gauge whether their friend would be receptive to receiving the disclosure.

Shown through both of these exemplars, participants describing their friends to be what I considered inferential confidants also utilized relational history as the primary criterion for sharing their chronic illness-related information with their friend. In this way, my analysis of the discourse of the participants in this present study further exemplified how Petronio's (2002) conceptualization of the inferential confidant are those who are expected to receive the private information of the disclosure especially as "the inferential confidant role is connected the relational context" (p. 116). Here, because of the fundamental definition of friendship, I found participants in the present study described their friends as willing and able to receive their chronic illness-related information. Additionally, these exemplars came from parts of the interview where participants described their friends' reactions immediately after the initial disclosure of private information. While I found inferential confidants in the participants' experiences during the initial disclosure process of their chronic illness-related information, I identified some of the participants' confidants following initial disclosure of their chronic illness-related information.

### **Deliberate Confidant**

The second type of confidant is the deliberate confidant, which Petronio (2002) described as those who solicit private information disclosure from the owner of the private information. In this way, the deliberate confidant is often conceptualized as trying to probe for more information to garner the initial disclosure (e.g., therapists probing

clients for personal information). However, what I heard from the participants in this present study was not a description of deliberate confidants in terms of the initial disclosure event. Instead, participants in the present study explained that their friends would initiate conversations regarding their chronic illness in interactions that occurred after the initial disclosure of their chronic illness-related information. For example, Participant 4 described:

Yeah, it's usually whenever...most always she checks in on me. And she's like, "How are you feeling today? Are you tired? Is your brain working?" Because sometimes my brain doesn't work. Yeah, she's just always checking in on me and making sure I'm okay. Very rarely do I just bring it up to her and be like, "I feel terrible today." Yeah, she's kind of like my mom [laughs]...So I think it depends on how I'm feeling. But on average, [we talk about my AS] probably once a week, maybe once every two weeks. (4: 312-316)

Additionally, Participant 3 described how their friend brought up the topic of dietary needs:

So, when we first moved in together, she was like, "Okay, will you write on the refrigerator all of the things that you don't eat." Because I'm allergic to some things, but then there were also things that I try not to eat a lot of because I've read the books and stuff like that so...I try to limit gluten—stuff like that. So she was, "Just write on the refrigerator then I know if I'm cooking for the two of us what to leave out. (3: 165-169)

With these exemplars in mind, I discovered how participants reacted to their friends deliberately soliciting chronic illness-related information from the participant (e.g.,

general well-being, dietary needs). While I described participants as generally satisfied by their friends' minimal or as-needed involvement in the management of their chronic illness earlier, these participants in the also described being incredibly satisfied with how their friends solicited private information. However, it is important to note that soliciting private information was not necessarily a daily occurrence, but rather episodic, for instance, bi-weekly check-ins or instances concerning shared meals. I found deliberate confidants in the participants' discourse when their friend may check-in if they are showing symptoms and when shared activities, such as a going out on a weekend, could affect the participant. In this way, I identified participants receiving as-needed social support from deliberate confidants, but in a more instrumental, or providing physical resources, supportive role (Cutrona & Suhr, 1992). As such, friends fulfilling a deliberate confidant role on an as-needed basis were still perceived in a positive manner. Thus, while some confidants sought out a participant's chronic illness-related information, other confidants happened to experience a circumstance of chronic illness symptoms, learning of the participant's chronic illness-related information as a result.

### **Consequential Confidant**

I identified the third type of confidant based on these present data as a consequential confidant While Petronio (2002) categorized confidants into three broad categories of inferential, deliberate, and reluctant, one participant (Participant 13) described such a forceful experience of initial disclosure during the interview portion of the present study that it warranted consideration here (see Owen, 1984). In Chapter Four, I further discuss how friends may receive disclosure of chronic illness-related information because of circumstance, but those responses occurred during the discussion

of participants' book covers in the present study. However, the responses that the participants provided throughout the present inquiry regarding what I identified as the consequential confidant helped to inform this new category of confidants for CPM.

In this study, when a friend was a consequential confidant, the friend did not necessarily expect to receive the private information like an inferential confidant, did not ask for the private information like a deliberate confidant, nor were they unable or unwilling to receive the information like a reluctant confidant (Petronio, 2002). Instead, the consequential type of confidant received private information resulting from circumstance. Participant 13 described their initial disclosure of their chronic illness-related information with their friend as follows:

It was a week after we moved in, so it was the first time [my friend] had seen me have a full episode. Other times, if I was having joint pain... [my friend] didn't know it was happening...Before then [the initial disclosure], if I were having problems, I would usually just say, "My joints hurt," or, "I have a fever...I can't come out." It was the first time [my friend] had seen the first extent of it. [I had passed out in our house and] I remember her sitting down with me and helping me up eventually. She's like, "Is there anything I can get for you? Can I help you fix this right now?" I was like, "No, I just have to wait for it to go away." She ended up not going out and staying home with me. We watched a movie or something together. That was just a really bad pain night. It was the first time that I was forced to tell [her] what was going on...and realized I could tell her about what was happening, which was good. Before I had just been dealing with it by myself, which honestly was not great for my mental health. It meant a lot moving

forward, too, just living in the same house with [her]. Having nights where I just couldn't get out of bed, she understood what was happening and so would check on me. She took to calling both of us the grannies of our apartment because she likes not going out too. It was funny. I could laugh at it too. (13: 208-224)

Prior to this episode, this participant stressed they had not planned on sharing information regarding their chronic illness-related information with their friend. However, due to experiencing a symptom of their chronic illness with their friend present, the illness revealed itself to their friend. Since this initial disclosure, the participant described how their friend has been supportive in various ways, especially meeting the social needs that may be hindered due to biographical disruption of EAs (Bury, 1982; Spencer et al., 2019).

Furthermore, I found this participant's initial disclosure is largely void of criteria for disclosure. In this sense, the participant did not fully consider core or catalyst criteria because they had not planned on sharing their chronic illness-related information with their friend. While the onset of a severe symptom of chronic illness may be an abnormal circumstance, with the way in which previous participants in this study described this criterion as related explicitly to biographic disruption and COVID-19, this participant's experience did not fall under that theme because they did not necessarily plan or have the choice to share their chronic illness-related information with their friend. As such, this participant's (and some of the participants in Chapter Four) exemplar allowed me to conceptualize more types of confidants that may not fit the Petronio's (2002) categories of confidants when the agency of choice is removed from the confider. In any case when

disclosure occurs, there may or may not be rules created to manage the flow of private information to effectively coordinate chronic illness-related information.

### **Privacy Rule Coordination of the Disclosure of Chronic Illness-Related Information with a Friend**

In this section, to answer RQ4, I describe the experiences of participants in this present study as they implicitly or explicitly create rules surrounding the disclosure of their chronic illness-related information with their friend. During the interviews, I began with an open-ended question about boundary coordination: “Once you told your friend about your chronic illness, what, if anything, did you tell them about what they could and couldn’t do or say with this information?” After the participant responded, I further probed on either implicit boundary rule coordination (e.g., “What about the friendship made it seem like no discussion of how to handle this information was the correct decision?”) or explicit boundary rule coordination (e.g., “What about the friendship made it seem like a discussion of how to handle this information was the correction decision?”). In both cases, I asked, “How well did your friend follow these rules about what to do or say?” Whether rules were verbally stated or not, there was an overarching expectation of these participants that the information would be kept between the interactants. In this section, I discuss the findings concerning both (a) implicit boundary rule coordination and (b) explicit boundary rule coordination regarding sharing chronic illness-related information with a friend (see Table 5 and pages 37-40 for a discussion of privacy rule negotiation).

**Table 5: Negotiations of the Disclosure of Chronic Illness-Related Information with a Friend: Privacy Rules**

<b>Negotiations of the Disclosure of Chronic Illness-Related Information with a Friend: Privacy Rules</b>
<b>A. Implicit Boundary Coordination</b> (rules were not verbally given for the management of private information)
1. Related to the Relational History Criterion
2. Related to Privacy Orientation Criterion
<b>B. Explicit Boundary Coordination</b> (rules were verbally given for the management of private information)
1. Tension between Relational History and Larger Context

### **Implicit Boundary Coordination**

First, when considering implicit boundary coordination, Petronio (2002) explained that individuals will likely either hint at aspects of the private information for future disclosure or prompt a confidant to solicit a disclosure. However, I found neither of these strategies for coordinating implicit privacy rules regarding participants' disclosure of their chronic illness-related information with a friend. In my analysis of the participants' discourses, I instead found implicit boundaries due to the constituted friendship relationship. In this way, I again found the relational history contextual criterion (the characteristics of and past interactions with a friend) when I identified participants enacting implicit boundary rule coordination. For example, when asked about whether they told their friend what they could or could not do or say with the private information, Participant 13 responded:

Not really. I didn't tell her, "Don't tell people that I'm sick." She didn't. She understood that it was a sensitive thing, so didn't go around [saying it]. It was almost a similar experience of when I came out to people. I think it's analogous. I

don't tell people, "Don't say anything." It's implied that you don't go airing someone's business. I think for [my friend] especially...she's also a really private person. I think that she just got it. (13: 331-336)

Further, Participant 2 explained:

Participant 2: No. There were no restrictions on what he could do with it. I didn't have a problem...I didn't tell him that he couldn't tell other people or anything like that. I assume that he wouldn't tell other people, but if he did, I wasn't worried about it.

Interviewer: So, what was it about the friendship that seemed like there didn't need to be that discussion?

Participant 2: Like I said, I think it's just because he seems like a very private person by nature, I don't know. I think it's just implied in the relationship that he won't talk about things with other people. I don't generally blab about my other friendships or relationships with other people to my other friends in general.

Like...I don't generally blab about those things. The only person I guess I'd blab would be my significant other. So, I guess I should expect the same of him. That maybe he'll blab to his significant other, but I wasn't really worried about gossip.

So, I guess I just basically I trusted him, essentially. I trusted him not to. (2: 293-305)

In both of these exemplars, I heard implicit boundary coordination of participants' chronic illness-related information when the participant solely considered the relational history contextual criterion (the characteristics of and past interactions with a friend). They described how they had come to know their friends as private and trustworthy



confidants. In both cases, O found the implicit boundary coordination post-disclosure seemed counterintuitive on the surface level given that experiencing biographical disruption of chronic illness as an EA may be particularly risky to disclose with one's friend (Spencer et al., 2019). However, when considering the relational history contextual criterion, I found these participants perceived any explicit discussion of rules post-disclosure as unnecessary.

Additionally, I identified participants in the present study using their privacy orientations when deciding that implicit boundary rule coordination was the correct course of action post-disclosure. In the previous discussion of privacy orientation, some participants described themselves as more open in sharing their chronic illness-related information with others because they did not feel much stigma regarding their chronic illness. Here, Participant 8 further added:

[I] did not set any boundaries. I was like...I really don't care. Fortunately, because dysautonomia is not a stigmatized thing, really, it wasn't like, oh, I have AIDS or this STD, don't tell anyone. It's just a very kind of non-stigmatized issue.  
(8: 302-304)

Consequently, participants in this study citing a non-stigmatized chronic condition described what I understood as implicit boundary rule coordination to be appropriate in managing the private disclosure with their friend. Researchers would agree that more stigmatized information tends to have more clear and explicit boundaries while less stigmatized information tends to have more implicit boundaries (e.g., Venetis et al., 2012). Thus, it is perhaps unsurprising that those participants in this study I identified as having open privacy orientations based on perceptions of their chronic illness as non-

stigmatized would be more likely to create what I identified as implicit boundaries for the management of their private information.

With implicit boundary rule coordination, my analysis of the discourse of participants in this present study encouraged me to extend Petronio's (2002) conceptualization of how implicit boundaries could be created. While individuals may hint at aspects of a full disclosure or prompt a confidant to solicit private information as originally described by Petronio (2002), sometimes the criteria concerning the context of the relationship or one's privacy orientations regarding their private information can influence decision-making concerning boundary rule coordination. Yet, sometimes, even when individuals use relational history as a criterion for disclosure, I found that some participants found an explicit discussion of rules necessary post-disclosure.

### **Explicit Boundary Coordination**

Petronio (2002) described explicit boundary coordination through two strategies: disclosure warnings (e.g., "Don't tell...") and time parameters (e.g., "Wait until I do this first, then you can tell..."). When considering explicit boundary rule coordination, I heard participants using disclosure warnings as the main strategy for creating explicit rules. While those participants who I identified as creating implicit boundaries relied solely on the relational criterion to justify their decision, participants who I identified as creating explicit boundaries looked outside of the relationship when sharing their chronic illness-related information. For example, Participant 6 explained:

I did tell her not to let anyone know. Not because I was embarrassed to her, I just didn't want people to think I was weak. Because in science, especially compared to my experiences in community public health, things get taken away from you if

you're...even though it's not my fault this is happening, I didn't want my projects getting taken away. So, I asked her not to talk to anyone about it, especially supervisors and things like that. Basically, if I need help, I know when to ask. (6: 272-277)

Additionally, Participant 5 added:

I just ask them to keep it between us. Again, just because we... (school name), one, is this very small school, so things get around very quickly. I'm sure that there are people I haven't told that know. But for the most part, I like to have the authority and power to tell the people that I want to tell, and I really do believe my friends and professors and people I've worked with respect that. So yeah, I just asked him to keep it to himself. I think most of the people he would have told probably knew already anyways, but yeah, it's just...it's always something that I just ask to stay between me and that person. (5: 395-402)

In these examples, I heard both participants describing influences outside of the friendship led them to explicit boundary coordination using a disclosure warning (Petronio, 2002). Although these participants described what I considered to be inferential confidants (expected to receive private information disclosure), participants expressed a desire to ensure the flow of private information remained between the interactants. While both the implicit and explicit privacy coordination rules carried expectations of remaining within friendship relationship, those participants I identified as creating explicit privacy rules perceived their disclosures to be riskier in terms of potential consequences of broken privacy boundaries.

As such, my analysis of these present data demonstrated how private information that participants considered riskier would have more explicit—clear and strict—rules for the management of this information than information deemed less risky (Venetis et al., 2012). In this sense, I identified the participants’ responses as exemplary of constitutive communication, or the thread of self-other-relationship tied together by communication (Wilmot, 1995), at both the micro- and macro- levels of the relationship. Those participants I identified as creating implicit boundaries around their information enacted Wilmot’s (1995) constitutive knot as conceptualized given that the only influence on the disclosure of chronic illness-related information was the self-other-relationship, or what I call micro-constitutive communication. However, as we constitute, or create, our relationships through communication (Baxter, 2004), there is a need to consider one additional thread in our “constitutive knot” of the larger societal structures at play, or macro-constitutive communication. In this way, participants I identified as creating explicit boundaries brought in outside influences (e.g., work, school) that complicated how the conceptualization of the constitutive knot, acknowledging that their friendships did not exist in a vacuum. Through my analysis of these present data, I was able to show how relational constitutive knots exist with a larger societal context with real consequences of sharing private information with others. Because our friends may overlap in our school and work lives (in addition to other aspects of our lives), it is imperative that we continue to explore how not only communication constitutes our relationship, but the social/physical environment in which we communicate can further mold the expectations of that relationship.

## Summary and Conclusions

In Chapter 3, my goal was to answer RQs 1-4:

**RQ1:** What criteria do emerging adults with chronic illness use in determining an appropriate friend to whom to reveal private information about chronic illness?

**RQ2a:** What are the characteristics that emerging adults with chronic illness identify in friends they choose as confidants?

**RQ2b:** What changes, if any, in the friendship relationship do emerging adults with chronic illness describe with a confidant post-disclosure of chronic illness-related information?

**RQ2c:** What changes, if any, in illness management do emerging adults with chronic illness describe post-disclosure of chronic illness-related information to the confidant?

**RQ3:** How, if at all, did the type of confidant with whom emerging adults with chronic illness change future (non)disclosures of chronic illness-related information?

**RQ4:** What, privacy rules, if any, do emerging adults with chronic illness negotiate with a confidant when disclosing chronic illness-related information?

By using reflexive thematic analysis (Braun & Clarke, 2019a) guided by CPM (Petronio, 2002; Petronio & Durham, 2015; Petronio et al., 2022), I found four major themes based on my analysis of the participants' responses: (a) criteria for disclosure of chronic illness-related information with a friend, (b) consequences of the disclosure of chronic illness-related information with a friend, (c) types of confidants regarding the disclosure of chronic illness-related information with friends, and (d) privacy rule coordination of the

disclosure of chronic illness-related information with a friend. For the first theme, I discussed both (a) contextual criterion of abnormal circumstances and relational history and (b) privacy orientations based on medical need and stigmatization. With the second theme, I found both how individuals described (a) a more intimate relationship with their friend and (b) their friend's role in the management of the chronic illness. In the third theme, I identified three types of confidants based on my analysis of these present data: (a) inferential, (b) deliberate, and (c) consequential. With the final theme, I discussed both (a) implicit and (b) explicit boundaries around the disclosure of participants' chronic illness-related information with their friend. To follow, I briefly summarize the main ideas of these findings and discuss their implications. In particular, I focus on (a) criteria for disclosure, (b) consequences of disclosure, (c) types of confidants, and (d) privacy rule coordination.

### **Criteria for Disclosure**

In response to RQ1, which asked about criteria for disclosure, I identified both context and privacy orientations as the criteria for disclosure used by the participants in the present study. Since private information is thought of as protected and privacy is considered a right of ownership (Petronio, 2002), individuals often get to decide when and how to share their private information with others. Petronio (2002) explained that individuals decide to share or conceal information with others based on criteria such as context and privacy orientations. For these EAs deciding to share their private information with their friends, my analysis of these present data helped me to both affirm and extend the ideas considering the contextual criterion for disclosure. In the present study, I found how EAs shared their chronic illness-related information with a friend

considering either (a) abnormal circumstances or (b) the friendship relationship as enough of a context to reveal their chronic illness-related information.

First, my analyses of these present data exemplified Petronio's (2013; Petronio & Durham, 2015; Petronio et al., 2022) contextual criterion as a catalyst criterion through the participants' discourse on abnormal events. In tandem with the biographical disruption (Bury, 1982), or how chronic illness interferes with one's expected life trajectory, the participants in the present study sometimes shared their chronic illness-related information with a friend to inform them on unexpected events that occurred in their life (e.g., frequent medical appointments, COVID-19 pandemic). While researchers have argued that EAs may conceal their chronic illness from their peers to maintain a sense of normalcy (Spencer et al., 2019), I found in my analysis of these present data how participants described instances when they shared this information with their friend because they were experiencing abnormal circumstances from what may be expected regarding a "typical" experience of health and illness for an EA. Additionally, with the onset of the COVID-19 pandemic, I found that participants in the present study perceived a need to share their chronic illness-related information with their friend particularly if they were immunocompromised and at greater risk for contracting serious side effects from COVID-19. With the societal trauma that comes along with a pandemic, EAs with chronic illness may have found the pandemic to be a particularly traumatic event due to their vulnerability which could have prompted disclosure of their chronic illness-related information with their friend (Petronio, 2002). Although EAs described abnormal events as a contextual criterion for disclosure, they did not always describe the contextual criterion as catalytic.

I discovered how EAs in the present study relied on their relational history with their friend to provide them with enough context to share their chronic illness-related information with their friend. In line with previous literature (e.g., Venetis et al., 2018), I found in my analysis of these present data how EAs carefully considered with whom to share their private information when using relational history as a criterion for disclosure. My analysis of these present data showed how EAs described trusting their friend with their chronic illness-related information based on previous interactions with and observations of a friend. From my analysis, I found that participants in the present study perceived they could predict their friends' reactions to receiving the disclosure of their chronic illness-related information, making them viable candidates to become confidants of the private information (Petronio, 2002). From my analysis of these present data, I was unable to accurately identify the participants' reliance on relational history through Petronio's (2002; Petronio & Durham, 2015) conceptualization of contextual criterion as a catalyst criterion. Whereas Petronio (2013; 2018) described the contextual criterion as a type of a catalyst that prompts a disclosure (e.g., traumatic events), some participants in the present study considered the context of their relational history as more of a core, or stable, criterion for disclosure. I did not find the EAs' use of relational history to exemplify the other core criteria (i.e., culture, gender, privacy orientations), and I instead framed the relational history context as criterion of disclosure through which participants perceived their friend could receive the disclosure of the participants' chronic illness-related information.

When considering disclosure of chronic illness generally, I identified privacy orientations in my analysis of these data as a criterion for disclosure used by participants



to describe a sense of openness regarding their chronic illness-related information because of medical need or a perceived lack of stigmatization. I heard in the participants' discourse of the present study how some EAs shared their chronic illness-related information with a friend to potentially receive support in managing the participants' chronic condition. Additionally, I identified a perceived lack of severe stigmatization that could threaten an individual's identity from the responses of the participants with an open privacy orientation. In this sense, it is important to consider how different chronic illnesses may carry different aspects of stigma. While researchers using an umbrella term of "chronic illness" have described these conditions as stigmatized (e.g., Cardillo, 2010), individuals with chronic illnesses may carry different views of self-stigma. Researchers discussed self-stigma largely in terms of concealing "undesirable" aspects of one's identity (e.g., addiction, Earnshaw et al., 2019; mental health, Chan et al., 2019). However, I found through my analysis of these present data how EAs may instead be more prone to reveal chronic illness-related information when self-identifying as non-stigmatized. Thus, I described the privacy orientations of the participants in the present study considering their chronic illness-related information as more open when experiencing either a medical need for disclosing or a low amount of self-stigma.

### **Consequences of the Disclosure**

In answering RQ2b & 2c, about the changes in friendship and illness management post-disclosure, I found in my analysis of these data how participants reported an increase in intimacy with their friend while also desiring minimal or as-needed involvement in the management of chronic illness. First, it is perhaps unsurprising that I found when EAs in the present study revealed potentially risky information with their friend, they described

enhanced relational closeness with that friend (Rawlins, 2009). When considering relational history as a criterion for disclosure, I connected the EAs in this present study experience of increased relational intimacy with Rawlins' (2009) notion that friends socially construct what is acceptable and unacceptable disclosure with one another. I argued that participants in this present study considering the friendship relationship into consideration pre-disclosure may influence the outcome of that relationship during and post-disclosure. In this way, the DD-MM (Disclosure Decision-Making Model, Greene, 2009) could help researchers come to understand the cognitive process of decisions to disclose chronic illness-related information. Through the DD-MM, a key tenet of the model is that an individual considers how they expect their confidants to react to a disclosure before deciding to share one's information with that confidant. If we expect a confidant to react in a more affirming or positive manner, we would be more likely to share that information with them. As such, even if chronic illness-related information had not been part of the socially constructed acceptable topics for disclosure in the friendship, the confider's consideration of their relational history with their friend helped them to make the disclosure and thus increase the feelings of intimacy with their friend.

It is important to note that I found how most participants in the present study described satisfaction with their friend in their role regarding the management of chronic illness. Specifically, I described how the EAs in the present study mostly expected their friends to serve in an emotionally supportive role on a minimal or as-needed basis. Researchers have found EAs do expect and receive emotional social support from their friends generally (e.g., companionship, La Greca, 1992). When considering chronic illness, researchers found that support from friends does lead to better chronic illness-

related health outcomes (Kyngäs et al., 2002; Kyngäs & Rissanen, 2001, Sawyer & Aroni, 2005). Still, it is important to note that while different types of support may be desired or needed when experiencing chronic illness, receivers of social support want their desired form of social support to match the social support they receive (Merluzzi et al., 2016). The EAs in the present study mentioned that they were satisfied with their friends' role as emotionally supportive on an as-needed basis. In this way, the participants in the present study received their desired form of social support that they wanted from their friend.

### **Types of Confidants of Disclosure**

In answering RQ3, which asked about the types of confidants, I identified three types of confidants based on the participants' experiences in the present study: (a) inferential, (b) deliberate, and (c) consequential. While Petronio (2002) included both inferential and deliberate confidants in her original conceptualization of a confidant, from the discourse of one of the participants (and additional consideration of some participants' responses in Chapter Four) I am extending this conceptualization to add a category of *consequential disclosure*, which refers to those who receive private information as a result of a circumstance. As mentioned earlier in this chapter regarding inferential confidants, I was able to further affirm Petronio's (2002) conceptualization of the inferential confidant as I identified these confidants in the participants' discourse as EAs as a role inherently related to the relational context of friendship. Because I found the disclosure criterion of the relational history context to be inherent to an inferential confidant in my analysis of these data, I explained how the participants also expected their friend to be willing and able to receive their chronic illness-related information and

respond appropriately. In the present study, I found that EAs described their friends to what I interpreted as fulfilling this inferential confidant role in a positive and supportive manner.

Additionally, from my analysis of these data, I concluded that the friends described in this study also exemplified the deliberate confidant in soliciting the chronic illness-related information from participants (Petronio, 2002). This is perhaps unsurprising as researchers have associated the notion of the deliberate confidant with the idea of friendship (e.g., DiVerniero & Hosek, 2011). In the present study, I identified deliberate confidants in the participants' discourse when the friends wanted to offer more instrumental social support to the participant (Cutrona & Suhr, 1992). In this manner, I found the deliberate confidants solicited private information from the participants concerning using well-being checks and addressing dietary needs. In the case of well-being checks, the friends may have been prompted by witnessing symptoms of the EA's chronic illness (e.g., fatigue) (Petronio, 2002). When the deliberate confidant witnessed the participant experience a visible chronic illness symptom, the deliberate confidant decided to engage in a well-being check to see if the participant needed more instrumental support as opposed to emotional support. When concerning dietary needs related to the chronic illness, the deliberate confidant ensured inclusion of the participant in shared activities. Through soliciting the disclosure in asking about dietary needs, I found how these deliberate confidants enacted the equality dimension of friendship to minimize the differences between the interactants (Fehr, 1996), alleviating the inequality related to food consumption. In my analysis of the participants' discourse, I found the deliberate confidant's actions ensured the participant that the experiences associated with

chronic illness would not change the confidant's perspective of the individual in a negative manner. In both cases, the relationship of the friendship influenced the decision to solicit private information from the EA.

My particular addition regarding confidants to CPM theory is posing the consequential confidant; a type of confidant that did not fall within Petronio's (2002) previously conceptualized categories of confidants. While I already described inferential and deliberate confidants, the final category—reluctant confidants—did not fit either. In her original conceptualization, Petronio (2002) described the three categories of confidants fall within three dimensions: solicited vs. unsolicited; expected vs. unexpected; desired or undesired. However, the consequential confidant only satisfied two of those conditions: unsolicited and unexpected. For example, when Participant 13 described their friend who I identified as a consequential confidant, this participant did not make note of “desire.” However, they described how their friend became more accommodative and intimate post-disclosure, which was a similar outcome to both inferential and deliberate confidants in this present study. Over time, the consequential confidant in this study became more of a deliberate or inferential confidant in future interactions, also showing that confidant roles can be fluid. All-in-all, the EAs in this present study described feeling satisfied with how their friends enacted various roles as confidants of their disclosure of chronic illness-related information.

### **Privacy Rule Coordination**

In response to RQ4, which asked about privacy rule negotiation, I identified both implicit and explicit boundary rule coordination in the present study after participants shared their chronic illness-related information with their friend. In my analysis of these

data, I found that EAs in the present study further considered the relational history with their friend and their self-stigma regarding their chronic illness when coordinating implicit boundaries. For the EAs in present study, I found how they further demonstrated how friends socially construct what is acceptable and unacceptable to disclose (Rawlins, 2009), adding that the management of disclosed information is also socially constructed between friends. Through analyzing the participants' responses in the present study, I identified how EAs negotiated their expectations for management of the disclosure of their chronic illness-related information considering previous interactions and observations of their friend. Here, the participants in the present study knew what they could expect from the confidant once they decided to disclose (Greene, 2009). In other instances of implicit boundaries, my analysis of these data showed how EAs' open privacy orientation related to their perceptions of having a non-stigmatized chronic illness. These participants described how, because they did not perceive their illness to be stigmatized, they did not need further boundaries created around the disclosed information.

I found other participants in the present study who utilized what I understood to be explicit boundary coordination rules. While these participants described their friend as someone worthy of receiving the disclosure of their chronic illness-related information, I found the explicit rules were created due to factors external from the friendship relationship. Here, I found these participants in the present study to be more wary of stigmatizing behaviors that could result from others learning of their chronic illness-related information. Because the information was deemed riskier, EAs in the present study further protected their chronic illness-related information (Venetis et al., 2012). So,

while the self-other-relationship knot was tied together in a constitutive communication knot (Wilmot, 1995), the context of where that knot resided was deemed a macro-level factor regarding the expectations regarding the management of chronic illness-related information between friends. In Chapter 5, I further elaborate contributions to the theory and literature regarding the findings from Chapters 3 and 4.

## CHAPTER FOUR: RESULTS

### Overview of Chapter Four Results

In this chapter, I provide my findings to answer research question five: “How do emerging adults make sense of their decision to disclose and/or withhold their private, chronic illness-related information?” As I described in Chapter Two, prior to the interview I asked the participants to create a book cover that represented their experiences of sharing chronic illness-related information with a friend (the full text of the instructions can be found in Chapter Two). During the interview, I asked participants questions about their book covers. During this portion of the interview, the participant and I each had the book cover on our screens for reference. I asked questions such as, “I see that you called your book ‘ \_\_\_\_.’ Why did you decide to give your book this title,” “I see that you [drew, described] an image [or various images] on your cover. What is the significance of this/these images,” and, “How does this title/does this image(s) best capture the experience of sharing chronic illness-related information with a friend?” Through this process, during the interview the participants described the sensemaking of their experiences disclosing chronic illness-related information with their friends.

Throughout this chapter, I will describe my results that answer RQ5. “How do emerging adults make sense of their decision to disclose and/or withhold their private, chronic illness-related information?”, as related to the participants’ book covers and the interview data as the participants described their book covers and reflected on meanings in this discourse. As I analyzed these data, even though I did not ask participants to provide a metaphor for their experiences, every participant used metaphor as a tool for making sense of their experiences of disclosure of chronic illness with a friend. Much in



the way that Petronio (2002) rooted CPM in metaphor through using boundaries to explain the phenomenon of the disclosure and management of private information, I found that participants in the present study used metaphor as a sensemaking tool to explain their lived experiences. As participants described their book cover, I heard them demonstrate the key characteristic of metaphor as “understanding and experiencing one kind of thing in terms of another” (Lakoff & Johnson, 2003, p. 5). For example, Participant 1 called their book cover: “Explaining the Inexplicable,” describing how chronic illness “is not something that typically comes up in conversation between 18- to 25-year-olds...[so] there’s still that little part where unless they’re going through it, too, they’re never going to get it” (1: 664-666). Following along with Gerber and Myers Coffman’s (2018) description of using metaphor, my understanding of these data is that the participants in the present study used metaphor as a sensemaking tool, taking complex ideas and transforming them into understandable experiences and language. Thus, participants’ use of metaphors through their drawings and descriptions of their book covers leads the results in answering RQ5.

### **Overview of Metaphor**

Before I explain the results of Chapter Four, I highlight the use of *metaphor* as a main theme of this dissertation. Communication scholars are no stranger to discovering and using metaphor in their research, finding metaphor to be a useful tool for sensemaking through categorizing our experiences and understanding social interaction (Lakoff & Johnson, 2003). In this way, Lakoff and Johnson (2003) described how metaphor embodies how “we act according to the way we conceive of things” (p. 5). Communication scholars have noted that when communicatively making sense of

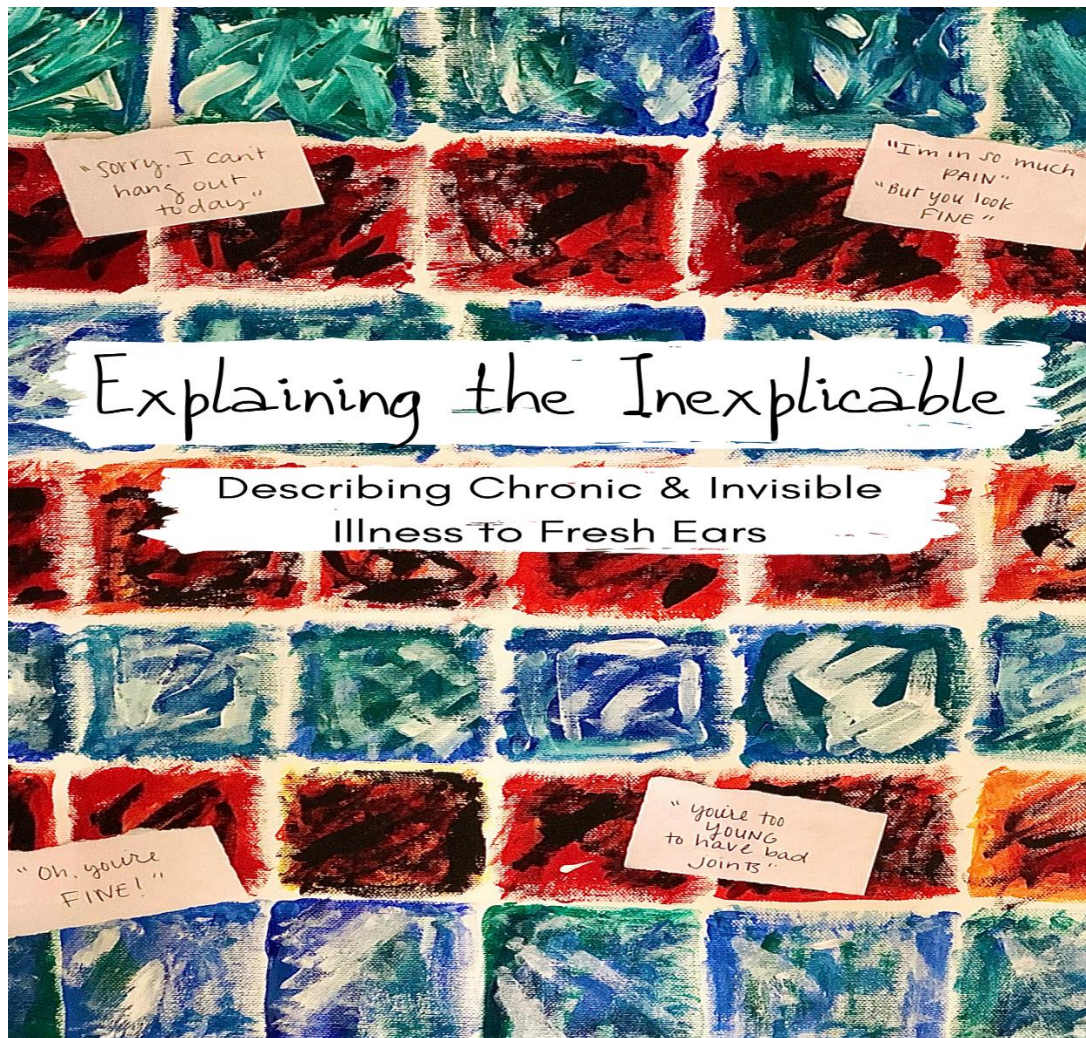
difficult circumstances surrounding health, individuals may invoke metaphor as a sensemaking device of how to respond to the issue at hand (Kranstuber Horstman et al., 2019). Thus, considering health, communication scholars have found that an individual's use of metaphor can enhance personal and relational well-being (e.g., cancer, Magaña, 2020; child loss, Willer 2019; infertility, Palmer-Wackerly & Krieger, 2015), showing that when faced with complex and difficult circumstances, an individual's use of metaphor can potentially alleviate negative personal and relational effects of these events. In this way, different types of metaphors may be used to make sense of one's social world.

To follow, I provide an overview for two types of metaphors that I heard from the participants discourse in this present study: (a) orientational metaphor and (b) ontological metaphor. In this section, I provide two participant book cover exemplars to illustrate how I conceptualized both orientational and ontological metaphors in the present study. In the sections following this section, I will describe the major themes of the book covers, demonstrating how the participants in this study used metaphor to make sense of their experience sharing chronic illness-related information with a friend. I start with an overview of the two types of metaphors that the participants in this study used, beginning with orientational metaphor.

First, Lakoff and Johnson (2003) defined an orientational metaphor as one that “organizes a whole system of concepts with respect to one another” (p. 14). First, in Participant 1's quotation above, they exemplified the orientational metaphor with their book title: “Explaining the Inexplicable” (Image 1). Through their experience of living with a chronic illness as an EA, this participant described how, because others cannot

fully understand their circumstance, making sense of their lived chronic illness experience can be difficult to communicate with others. Trying to explain can be difficult because experiencing a chronic illness as an EA is not a culturally dominant phenomenon for EAs, and this participant's use of "inexplicable" as a metaphor encapsulates the "typical" experience of healthy vs. unhealthy as a chronically ill EA.

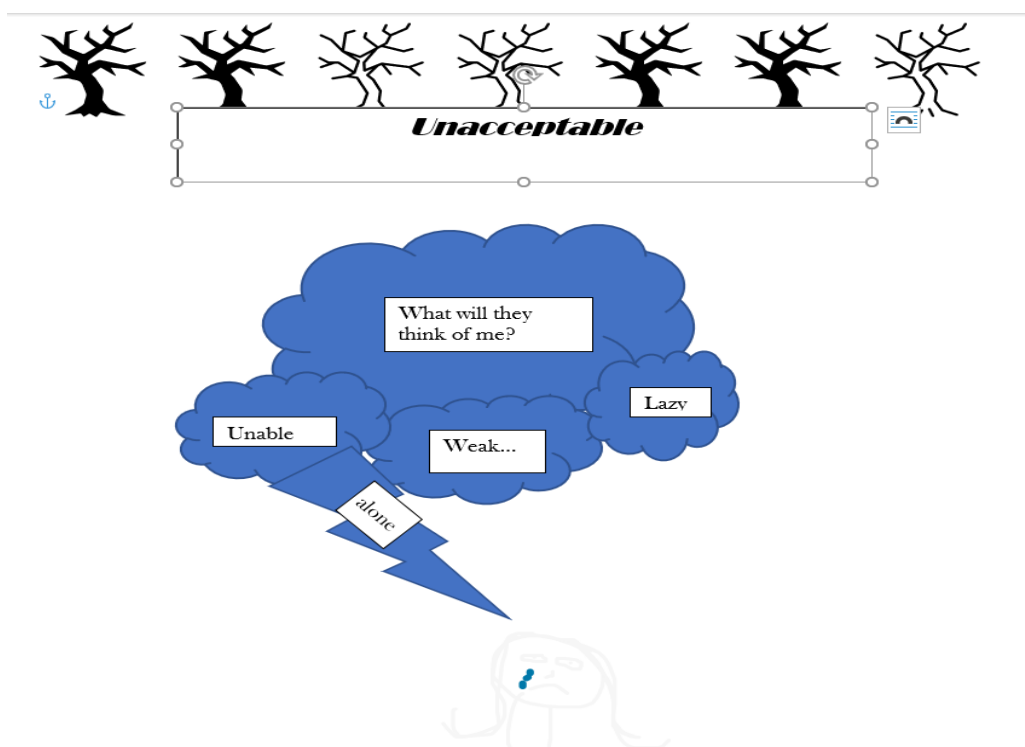
**Image 1:**



Second, participants in the present study also used ontological metaphors, or those that go beyond describing experience abstractly to tying their experience to objects (Lakoff & Johnson, 2003). Here, participants used metaphor to describe sharing chronic

illness-related information with their friend as an EA in terms of a physical object (see Table 6). Participants using ontological metaphors externalized their shared chronic illness information: while their chronic illness was something attached to them, they “disprove[d] the problem’s claims about their identity” (White, 2006, p. 33). For example, Participant 14 titled their book cover “Unacceptable” (Image 2), describing their chronic illness as a storm cloud of managing others’ perceptions of their chronic illness. They described how the different clouds in the storm carry different perceptions of inability, weakness, and laziness. Each of these clouds represented a part of their experiencing, demonstrating how they made sense of their chronic illness experience. By externalizing their shared chronic illness-related information with an ontological metaphor, participants in this study described how and why they exerted control over their chronic illness-related information.

**Image 2:**



Through the participants' use of orientational and ontological metaphors, in these present data I heard discursive constructions of two types of metaphors that I labeled: (a) privacy-related metaphors and (b) chronic illness management-related metaphors (see Table 6). As I describe my findings in this chapter, I will provide exemplar book covers and in vivo quotations to highlight the participants' sensemaking of their decisions regarding revealing and concealing information from a friend about their illness. I will also note which metaphors align with the results in terms of orientational and ontological metaphors. I will begin with the results regarding privacy-related metaphors.

### **Privacy-Related Metaphors**

Examining CPM literature, scholars would find that CPM theorists have not considered the use of metaphor as a sensemaking device in the disclosure process outside of the conceptualization of a boundary metaphor (Petronio, 2002; Petronio & Durham, 2015; Petronio et al., 2021). However, in answering RQ5, what I discovered in these present data is that participants used metaphor in the construction of their book covers and in their explanations of the covers they created as they highlighted their experiences of sharing their chronic illness-related information with a friend. Even so, because this present study was based in CPM, participants' use of metaphor allowed me to provide further insight in understanding a confider's sensemaking of disclosure through CPM—something I discuss more fully in Chapter Five (Discussion). In what follows, I will first describe the privacy-related concepts the highlighted in these data. After describing the privacy-related concept, I will provide participant book covers and narratives to show how they made sense of the privacy-related concept using metaphor. In this way, from

my analysis of these data I found privacy-related metaphors in terms of (a) the relational history contextual criterion and (b) testing boundary permeability.

**Table 6: Privacy-Related Metaphors**

<b>Privacy-Related Metaphors</b>
<b>A. Relational History Contextual Criterion</b>
1. Ontological Metaphor of the Relationship
<i>a. “The Chronic Illness Balloon”</i> —Negotiating control of private information
<i>b. “Support Me? Support Me Not?”</i> —Evaluating expected received support from a friend
<b>B. Testing Boundary Permeability</b>
2. Ontological Metaphor of the Private Information
<i>a. “Breadcrumbs of Disclosure”</i> —Sharing smaller pieces of information prior to major disclosure

### **Relational History Contextual Criterion**

The first privacy-related metaphor was that of the relational history criterion, described in Chapter Three as a type of contextual criterion describing how an individual considered their previous or observed interactions of their friend. Throughout several instances of the book covers, participants in the present study considered their relational history with their friend as a context they considered when deciding to share their chronic illness-related information with that friend. Through the relational history context criterion, participants described the *characteristics* of their friend rather than the *circumstances* surrounding the friendship as the criterion for disclosure. The characteristics of the friend came to light as the participants in this study discussed their book covers, as many participants re-emphasized the relational history context criterion as the focus for their book covers. For example, Participant 6 described the characteristic

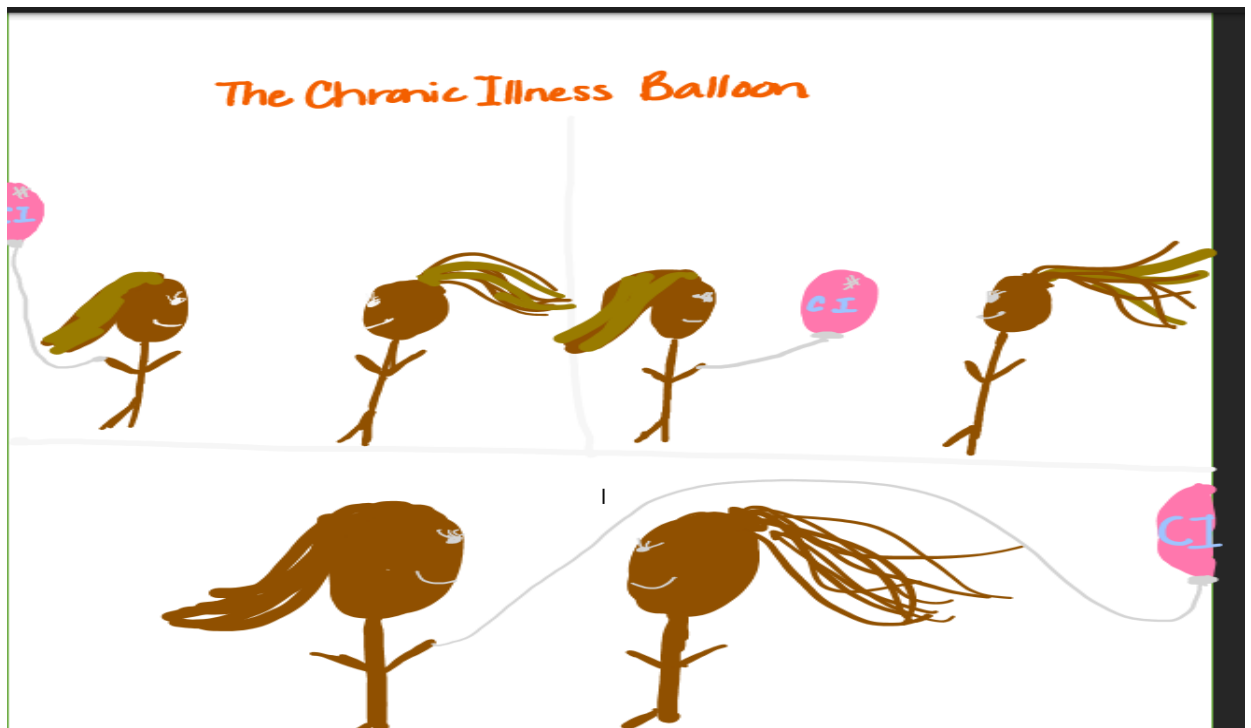
of their friend as trustworthy based on the participant's experience with their friend the past. When considering their relational history with their friend as a criterion for disclosure, participants in this study often used an ontological metaphor to describe their experience of sharing their chronic illness-related information with a friend.

**Ontological Metaphor of the Relationship.** When participants in the present study used their book covers to describe the relational contextual criterion, they often used ontological metaphors, or the use of an unrelated object to describe how they made sense of their experience, of how they negotiate the control of their chronic illness-related information with their friend. Often, the participants described more strict control of their chronic illness-related information in the beginning stages of the friendship. As the relationship progressed and the participants became more intimate with their friend, they allowed for their chronic illness-related information to be shared more freely. For example, as one participant discussed in their written interpretation of their book cover (see Image 3):

While some people may think of chronic illness as a weight or a barrier between friends, I think of it as a balloon. The balloon is always with me, regardless of whether I am talking about it or whether I look like I am holding a balloon. When I am in the beginning stages of friendship, my chronic illness balloon is barely visible. So invisible that most all people wouldn't notice it. But make no confusion, it is still there tied around my wrist. As my friendship progresses, I eventually put the balloon smack dab in the middle of me and my friend. It is at this point where I drop the balloon of chronic illness on the friend. It usually isn't some big event, or even due to some chronic illness situation. It is more that the

time has come for me to disclose about my chronic illness. Often the conversation is short and doesn't go into much depth. Then the next time we hang out, my chronic illness balloon goes back nearly out of sight. But again, it is still tied to my wrist. Typically for the remainder of our friendship, I never bring the chronic illness balloon back in the middle of us. It only is placed there when the friend pulls on the string to lower it into our view. When this happens, I am always shocked, but pleased that the friend remembered and cared enough to bring the balloon back. More often than not though, the balloon stays distant from our friendship but ever present around my wrist. The pull of the balloon on my wrist sometimes gets heavier or lighter, but rarely does it get so strong that I have to replace it in the middle of me and my friend. (7: 1-14)

**Image 3:**



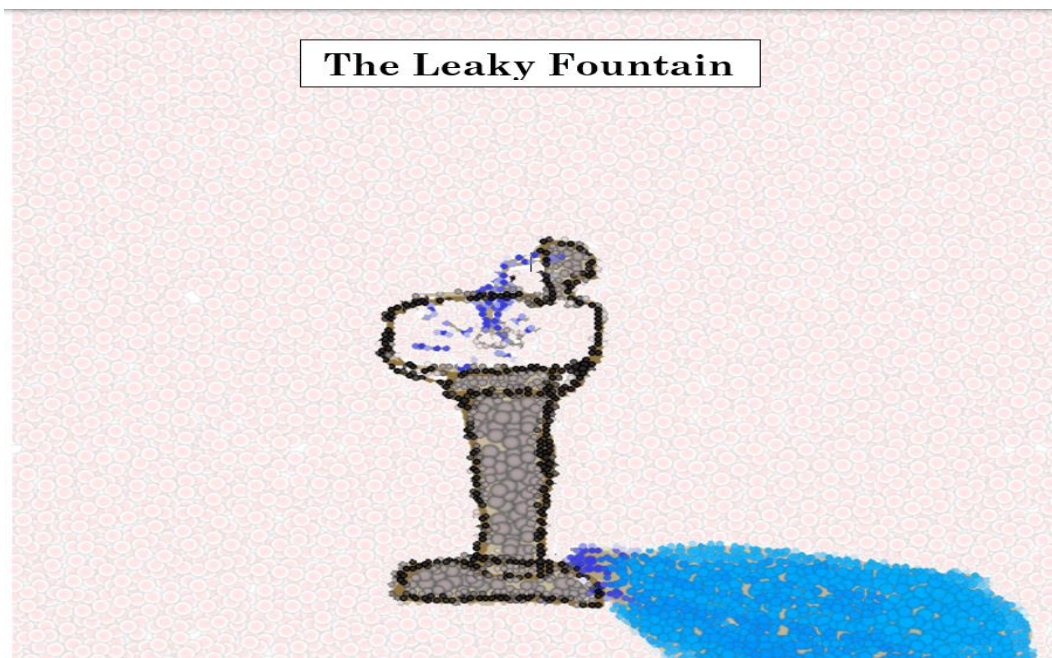


This participant's book cover and description of their book cover encapsulated how participants in the present study made sense of their relational history as a criterion for disclosure through using an ontological metaphor of a "balloon." This participant made specific mention that chronic illness was not something they consider a topic of disclosure at the beginning of a relationship, thus they hid their balloon. Rather, the participant described the process of getting to know their friend before allowing their chronic illness balloon to be visibly present in their interaction. In this way, the participant showed that even though their chronic illness is always present in the friendship—visible or otherwise—they considered their friend's attitude, demeanor, and past interactions prior to sharing their chronic illness balloon with them.

As this participant made sense of their experiences, they described how other chronic illness metaphors like "weight" and "barrier" did not capture their personal experience of the complex phenomenon of sharing chronic illness-related information with a friend as an EA. In using this ontological metaphor of a balloon, this participant demonstrated how an EA objectifies the sharing of their chronic illness in the form of a balloon to make sense of their personal experience (Image 3). This participant stressed in the interview that other, "heavier" metaphors, such as a "weight" or a "barrier" (7: 1), did not capture their experience. Instead, this participant emphasized the lightness of a balloon to separate the chronic illness-related information from their identity in the friendship. In this way, rather than something that felt burdensome or heavy, this participant showed a more fluid nature of sharing chronic illness-related information with their friend as the balloon (i.e., representing their experience of sharing chronic illness-related information) floated in and out of the relationship. In addition, Participant 15

made a similar point by referring to sharing their chronic illness-related information as a “The Leaky Fountain” (Image 4). They used this metaphor for externalizing their chronic illness-related information as water, something that comes out of them, but not their entire identity as an EA or the water fountain. In this sense of identity management, this participant found the private information to be something external and something they could manage as a part of their identity.

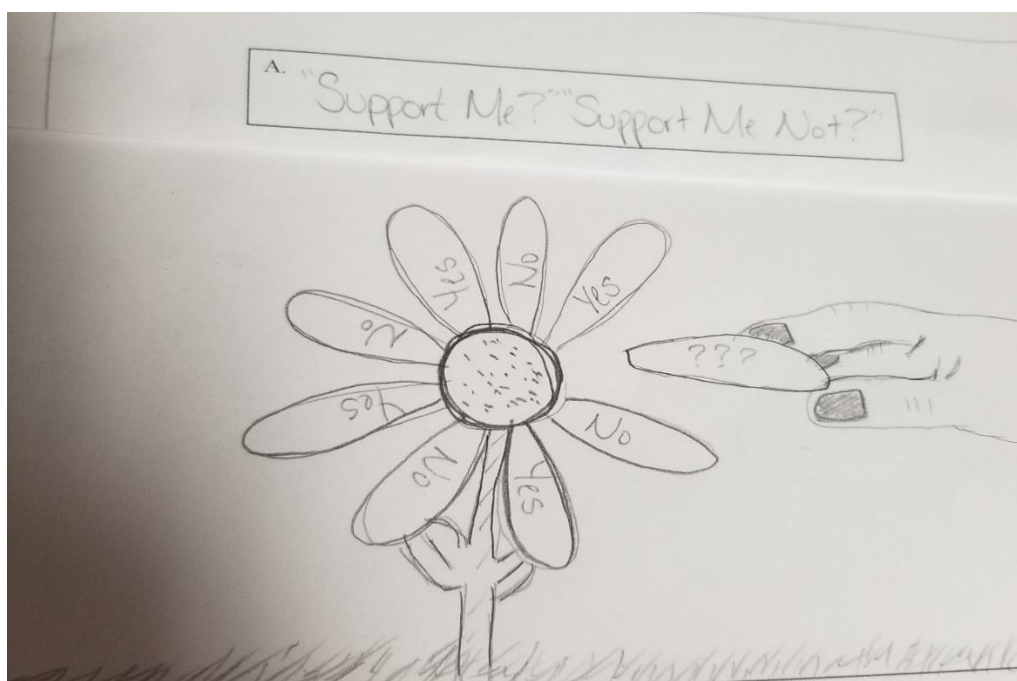
**Image 4:**



As I analyzed these data, I reflected on participants’ use of ontological metaphors in this present study as perhaps challenging a dominant perspective of biographic disruption for EAs with chronic illness (e.g., concealing to appear normal, Spencer et al., 2019) as the disclosure and management of the information post-disclosure did not appear as an obstacle in their friendship relationship. Rather, for example, Participant 7’s exemplar of a balloon metaphor showed how participants make sense of their disclosure of their chronic illness-related information as a carefully evaluated process in considering

the contextual criterion of relational history. In addition, Participant 12 made a similar point by referring to sharing their chronic illness-related information as a flower, using a twist on a cliché titling their book “Support Me? Support Me Not” (Image 5). In their description, Participant 12 described the careful decision-making in choosing a friend to receive their chronic illness-related information. Based on their past experiences with their friend, Participant 12 assessed whether their friend would be supportive of their disclosure of chronic illness-related information. In using a flower as a metaphor of social support, some petals said, “Yes,” while others said, “No.” The petal being plucked in the imaged is labeled, “???” and represents uncertainty experienced when an EA would not consider the relational history criterion. As such, I found the participants’ use of ontological metaphors helped them to make sense of their experience of sharing their chronic illness-related information with their friend based on the relational history criterion.

**Image 5:**



### **Testing Boundary Permeability**

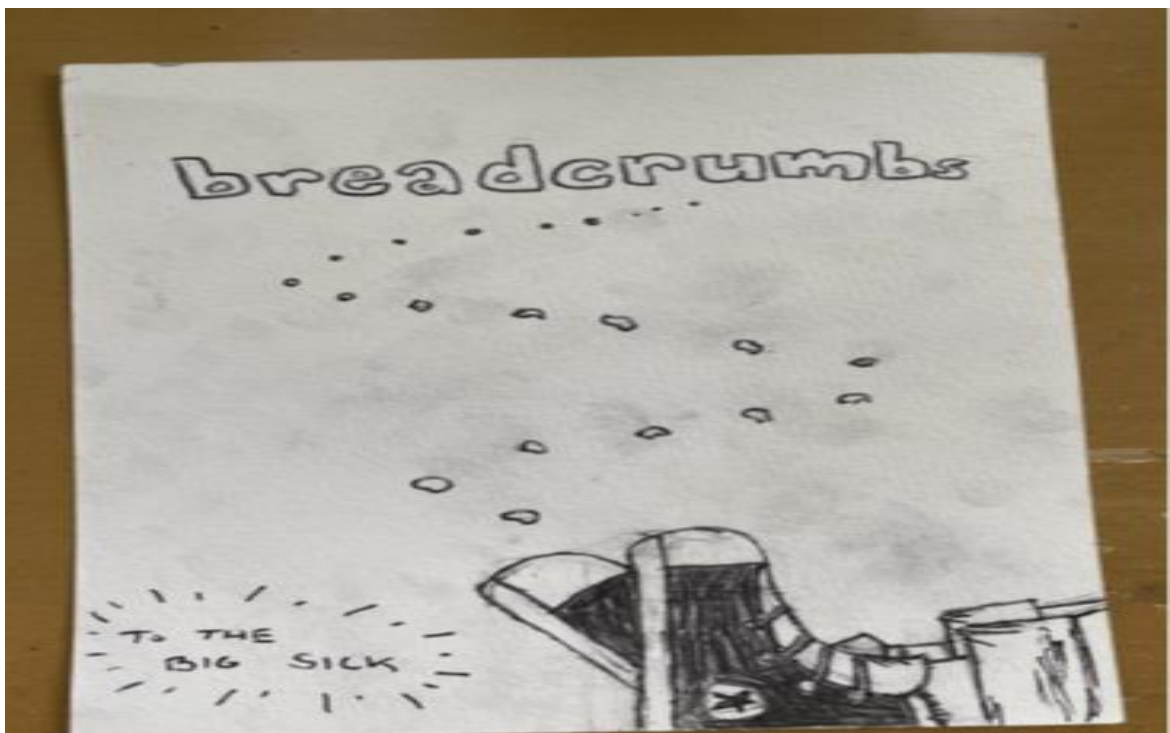
The second privacy-related metaphor participants in this present study used was hinting at chronic illness-related information. From my analysis of these data, I conceptualized hinting as subtle or tiny pieces of information regarding a larger piece of private information. For example, an individual may describe having headache while experiencing symptoms related to chronic illness before sharing their chronic condition to gauge the confidant's reaction. While some participants in this present study were more explicit in describing the friendship relationship as their criteria for disclosure, other participants in this study focused on how their process for choosing friends with whom to disclose. Petronio (2002) described hinting as strategy for creating implicitly stated rules regarding the management of private information. However, in using ontological metaphor, I found the participants in this present study made sense of hinting more in line with boundary permeability.

**Ontological Metaphor of Private Information.** Recalling from Chapter One, Petronio (2002) described how boundaries surrounding private information may range on a continuum from more permeable (information flows easily) or impregnable (information is restricted). In other words, boundary permeability is the degree to which an individual determines access to their private information. When considering sharing chronic illness-related information with their friends, I heard how participants in the present study sometimes made sense of their disclosure process by describing the hinting process. I identified hinting as a part of the participants' disclosure process in testing the participants' friend's reactions to smaller pieces of information before disclosing larger pieces of chronic illness-related information. For example, one participant evoked the

metaphor of “breadcrumbs” to describe their disclosure process, writing an interpretation of their book cover (Image 6):

I chose the name *breadcrumbs to the big sick* because I told my friends about my illness in tiny chunks, a bit at a time, almost like giving them a trail of breadcrumbs to follow, until eventually they understood my illness, which we all called “the big sick.” (13: 1-5)

**Image 6:**



In this book cover, the participant showed how they made sense of their decision to disclose their chronic illness-related information with their friend using what I interpreted as an ontological metaphor, or physically non-related object used for sensemaking, of “breadcrumbs.” From their written description of the book cover prior to the interview, the participant described how they shared tiny bits of information (e.g., “I have a headache, I cannot go out tonight.”) before fully disclosing their illness with their

friends. In this way, the EA gauged their friend's reaction to this smaller piece of information prior to revealing the full disclosure of a chronic condition. As such, they hinted at the information, but not with the purpose of creating implicit privacy rules as Petronio (2002) originally conceptualized. Rather, this participant, and others with similar experiences, shared "breadcrumbs" with their friend to assess a friend's reactions to the shared information. Once participants identified a shared understanding with their friend regarding smaller pieces of their chronic illness-related information, they decided to disclose their larger piece of private information (i.e., their chronic illness) with their friend.

Through their reflection, this participant demonstrated the sensemaking process of an abnormal life experience through the ontological metaphor of "breadcrumbs." In managing the biographical disruption of their chronic illness, the participant's understanding of their disclosure of chronic illness-related information with their friend aligned with previous research describing how chronically ill EAs may minimize their differences with their non-chronically ill friends (e.g., concealing symptoms of their chronic illness, Spencer et al., 2019). In this way, the participant preemptively managed how the communication could increase the perception of stigma they may have received from sharing their chronic illness-related information with their friend. Until the EA disclosed their chronic illness-related information, the EA's condition was not readily known or present in their interactions with their friend. as is the case with most invisible illnesses (Horan et al., 2009). In another example, Participant 2 described their chronic illness in terms of an energy metaphor, titling their book cover "I'm Just so F\*\*\*\*ing Tired" (Image 7). They described how, even though their energy resource may be

depleted, they sometimes experienced pressure to function as though they were fine. Participant 2 described how they tested others in terms of sharing smaller pieces of information in a similar fashion to Participant 13, but they sometimes experienced that they could not fully share their information with a friend because either the friend was dismissive, or the participant did not have the energy to explain their condition. Instead, they would hint at telling their friends, for example, that they were tired as a catch-all for any symptoms they experienced. Based on their friend's reactions, more information would either be shared or withheld. Thus, this participant, and others who matched their experience in the present study, made sense of their experience in terms of hinting at their chronic illness before fully sharing their information to maintain their ownership of the information. Thus, EAs in the present study incorporated ontological metaphors when considering both (a) relational history contextual criterion and (b) testing boundary permeability. I will next describe the metaphorical tools I found EAs used in making sense of their chronic illness management.

**Image 7:**



### Chronic Illness Management-Related Metaphors

The second major theme of the book covers involved metaphors of chronic illness management. Through much of this dissertation, I primarily discussed the social impacts of chronic illness EAs face. When EAs in the present study decided to share their chronic illness-related information with their friend, they made decisions considering a relational history criterion, privacy orientation criterion, and boundary coordination and the subsequent changes they experienced in their friendship and social support from their friends. In what follows, I consider how these social factors coincide with the lived experience of chronic illness. In this section, I describe how participants evoked ontological and orientational metaphor in terms of their chronic illness management post-disclosure—a prominent theme across many of the participant-generated book covers. The two main themes I will discuss are (a) experiencing chronic illness as a condition and (b) experiencing chronic illness symptoms (see Table 7).

#### Table 7: Chronic Illness Management-Related Metaphors



<b>Chronic Illness Management-Related Metaphors</b>
<b>A. Experiencing Chronic Illness as a Condition</b>
1. <b>Ontological Metaphor of Energy</b>
a. <i>“The Skeleton Crew”</i> —Considering the total amount of energy needed for a given day
b. <i>“Spoon Theory”</i> —Evaluating the amount of energy required for specific activities
<b>B. Experiencing Chronic Illness Symptoms</b>
1. <b>Oriental Metaphor of Energy</b>
a. <i>“Hiding during Role Reversal”</i> —Concealing information when revealing would necessitate social support

### **Experiencing Chronic Illness as a Condition**

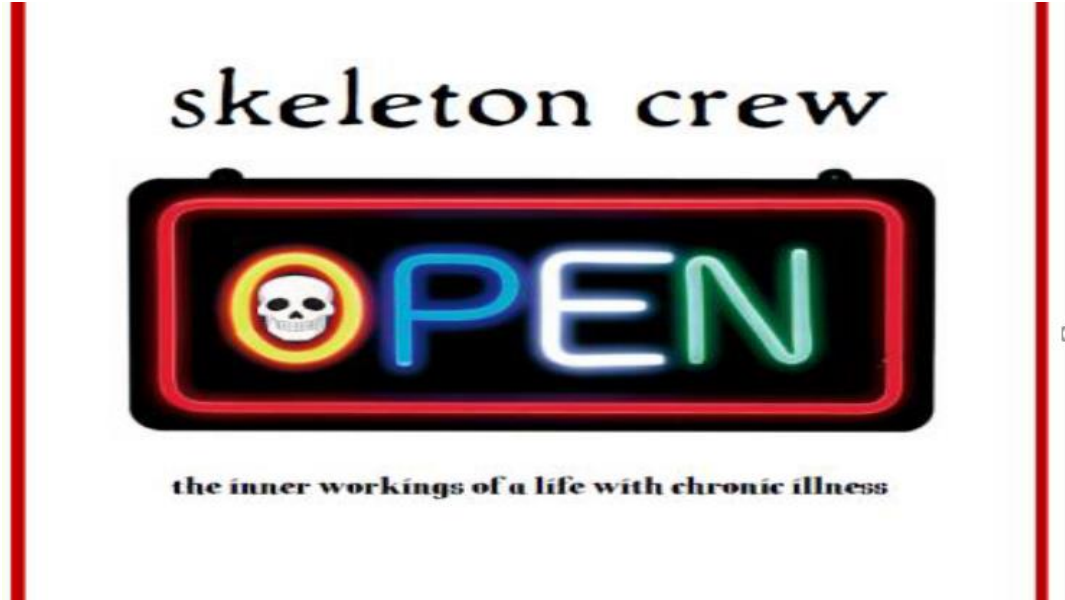
Each chronic illness described in the “Participants” section of Chapter Two: Methodology comes with its own set of symptoms. Most chronic conditions are characterized by slow development and gradual progression over an extended period (National Council on Aging, 2020), usually lasting one or more years (Centers for Disease Control and Prevention [CDC], 2021). Thus, individuals facing chronic illness may experience a variety of symptoms (e.g., fatigue, nausea, pain) at any given moment over time. Because consistent experience of symptoms can make an individual feel tired, participants in the present study often engaged energy as both (a) ontological and (b) orientational metaphors for their chronic illness experiences. I will first discuss how the participants in this study used energy as an ontological metaphor.

**Ontological Metaphor for Energy.** As previously discussed, individuals with chronic illness may experience consistent fatigue and pain depending on their condition(s). Because of these symptoms, individuals with chronic illness experience biographical disruption of what may be considered “normal” for “healthy-appearing” individuals (Bury, 1982). By definition, individuals with chronic illness experience a

social abnormality, meaning that they do not “fit in” with the expectations of being in a general state of good health. EAs with chronic illness may experience a greater sense of social abnormality due to the contextual age of chronic illness as more commonly present in older people (Kundrat & Nussbaum, 2002). When experiencing something abnormal, researchers found that individuals often used metaphor to communicate the lived experience of that social abnormality with others (Roystonn et al., 2021). In the present study, I identified in these present data how participants often used ontological metaphor, or replacing a concept with an unrelated object, to communicate how they made sense of living with their chronic illness. For example, one participant described the significance of the title of their book cover (Image 8):

So, I'm a sucker for sub-titles. In the non-fiction books, I love to read a lot, so that's kind of one of the first things that always pops into my mind. I would say Skeleton Crew is kind of a like a double-edged metaphor to it in the sense of like, obviously, my chronic illness in specific affects my skeleton and my joints and stuff like that. But then also, a skeleton crew is the minimum possible amount of people that is needed to accomplish a task. So, it kind of harkens back to running on empty as a person with a chronic illness. Or I don't know, are you familiar with the Spoon Theory?...So I was also kind of thinking of it that context. Like, okay, if we were to put into those terms, running constantly on the minimal possible number of spoons that you have left. So that's where I got the title of Skeleton Crew in particular. Then just kind of like, The Inner Workings of a Life with Chronic Illness, kind of like, the workings part almost harkens back to, okay, a skeleton crew accomplishing a job, etc. (10: 729-744)

Image 8:



In this example, the participant focused on their experience living with chronic illness, mentioning two ontological metaphors: (a) spoon theory and (b) skeleton crew. For context, Miserandino (2003) created spoon theory, using “spoons” as an ontological metaphor representing units of energy that one has available to use in a given day. As Miserandino described, “the difference in being sick and being healthy is having to consciously think about things when the rest of the world doesn’t have to” (p. 1). In this way, Miserandino noted how chronically ill young people must account for spending their limited amount of “spoons,” whereas those considered healthy do not have to count their “spoons.” The participant offered what I found to be an ontological metaphor of the skeleton crew to describe how they considered everything from their actual musculoskeletal chronic illness to completing daily tasks in how to spend their spoons. In this way, I found the participant’s use of two ontological metaphors (spoon theory, or units of energy to be used; skeleton crew, or the entirety of their energy to be used) to show how they made sense of their management of their chronic illness. In Participant

2's "I'm Just so F\*\*\*ing Tired" (Image 7), they also described Spoon Theory in terms of managing various daily stressors associated with chronic illness (e.g., answering questions about assistive devices, managing chronic illness symptoms). Yet, even when the skeleton crew is exhausted and there were no more spoons to give out, an EA with a chronic illness may experience having to "run on empty," an ontological metaphor that implies a battery or tank of gasoline, describing how one must continue expending an energy source to which they no longer have access.

Reflecting on my analysis of how participants used multiple metaphors when describing complex phenomenon, such as managing chronic illness as an EA, Lakoff & Johnson (2003) explained that individuals are likely to use multiple metaphorical devices to make sense of their experiences. In this way, I found how the participants' exemplars in this section and others in these data with similar experiences demonstrated the embodied experience of biographical disruption of their chronic illness as an EA through using multiple ontological metaphors.

### **Experiencing Chronic Illness Symptoms**

The second chronic illness-related metaphor I heard in these data involved participants' descriptions of circumstances of acute symptoms of their chronic illness. When experiencing an acute symptom of a chronic illness, an individual with a chronic illness may experience flare ups of fatigue, nausea, pain, or other symptom that the individual needs to address in the moment (CDC, 2021). Given individuals with chronic illness may view energy as a valuable resource, an individual with chronic illness would likely prioritize their physical needs over other needs for effective management of their resources. In present study, some participants used what I identified as an orientational

metaphor, or using an unrelated concept to describe their experience, to describe how they managed their acute symptoms of their chronic illness.

**Oriental Metaphor of Energy.** Perhaps because energy is a well-known concept that represents a resource to be expended, I found participants in the present study did not explicitly use energy as the orientation metaphor representing their acute symptoms of their chronic illness. Rather, I heard in these data how participants described the presence of a friend could increase the amount of energy needed when experiencing their acute chronic illness symptoms. Here, I identified issues participants described concerning providing social support for their friend rather than receiving social support from their friend and managing their symptoms. When a friend is reluctant to receive information or may receive information resulting from circumstance, they may feel ill-equipped to handle that information, which could result in a confidant privacy dilemma (Petronio, 2002).

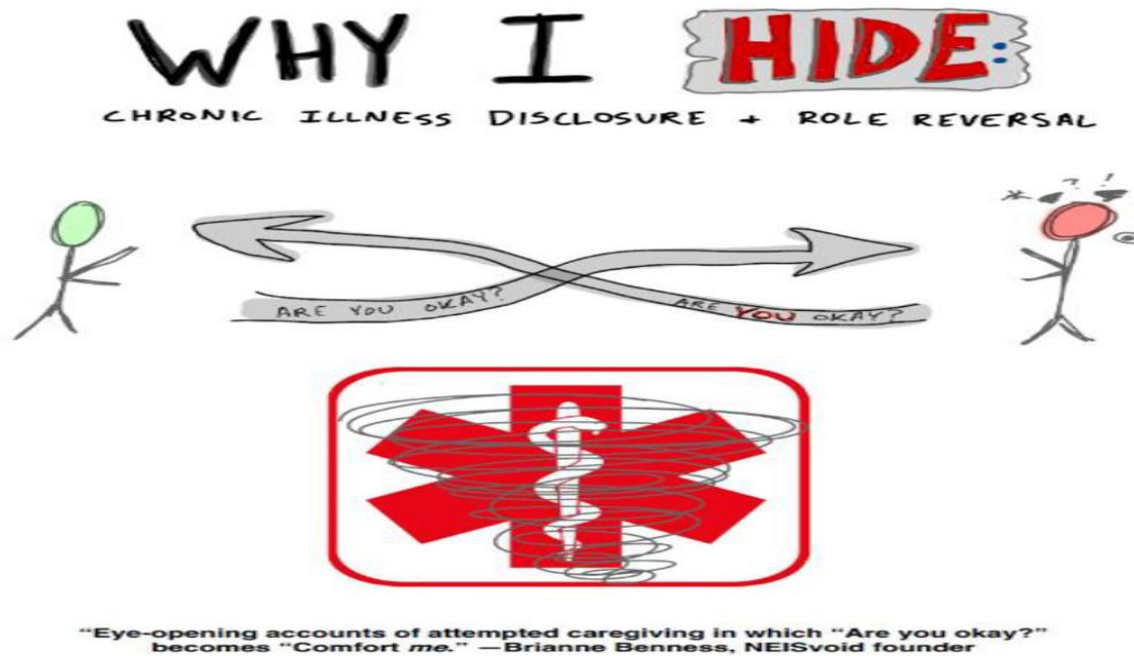
As I discussed in Chapter One, Petronio (2002) explained that there are three different confidants in CPM: deliberate, inferential, and reluctant. In Chapter Three, I identified an additional type of confidant from my analysis of these data called the consequential confidant, or those receiving the disclosure of chronic illness-related information based on unpredictable circumstances, such as the onset of chronic illness symptoms. With confidants, individuals sometimes encounter privacy dilemmas, such as handling sensitive private information that could pose a risk to the self or others, through which knowing that private information could cause personal or relational issues, such as breaking a privacy rule and sharing the private information with others resulting in boundary turbulence (Petronio, 2002). However, even when friends may be deemed

inferential confidants, or those expected to receive the private information, there may be unintended consequences in sharing private information with them. To make sense of how their friends reacted to receiving their information, some participants in the present study evoked what I identified as orientational metaphor.

For example, Participant 8 described unintended negative consequences of sharing their chronic illness-related information with a friend. Although they described positive examples in their interview, this participant also used “hiding” and “role reversal” as orientational metaphors, using an unrelated concept to describe a concept or experience, for energy management in their book cover. As this participant described their book cover:

It's very much like, I don't want people to know because what often happens in those situations is the role reversal part. Which is why I've got those arrows like, are you okay. Then it becomes, are you okay. Because if someone realizes what's happening, they will want to check on me or come with me. Then while I'm sitting there trying not to pass out, in the fetal position, they're like, how are you feeling, do you want me to call someone, what are you...what's going...I'm like, shut up. I have to tell people all the time, you do realize I live alone, I take care of myself. I really don't need or want your help in this scenario because then the roles get reversed and while I'm going through this awful thing, then I have to take care of someone else. Which is frustrating as all get out. So, while I'm good with disclosing generally speaking in a more abstract sense, in the moment of a health debacle, I immediately hide. Everything's fine. I'm just going to leave for a little bit. (8: 959-970)

Image 9:



From my analysis of this book cover, the participant's use of orientational metaphors highlighted an additional issue concerning energy. Rather than focusing on their chronic illness symptoms, this participant often described pressure to provide informational and emotional support for a friend that they perceive is often necessitated when they shared their acute chronic illness-related information with that friend. Because of this, they described an orientational metaphor of "role reversal" where, instead of receiving expected support from their friend amid acute chronic illness symptoms, the participant found themselves needing to provide support for their friend. In Chapter Three, I discussed how the participants in the present study were more satisfied with their friends when they received the desired type of social support from that friend. However, when experiencing acute symptoms of chronic illness, this participant demonstrated how expressing a desire for social support may be difficult to navigate with a friend. Due to this difficulty in managing physical needs and desired social needs, Participant 8

described the orientational metaphor of “hiding” to be an effective method of energy management allowing the participant to focus on their symptoms rather than the needs of their friend. In this way, this participant’s exemplar demonstrated to me how EAs with chronic illnesses may shift their focus from taking care of their acute chronic illness symptoms to their friend’s well-being should the chronic illness-related information be disclosed. In this mismatch of desired vs. enacted social support (Merluzzi et al., 2016), participants in this study expressed frustration with their friend. Participant 2’s “I’m Just so F\*\*\*ing Tired” (Image 7) echoed this sentiment by enlightening how sharing chronic illness-related information may be perceived as burdensome by their friend, especially when their friend may not be receptive to such information.

While disclosure theorists may describe withholding private information as concealment (Petronio, 2002), in this example the participant evoked what I interpreted as an orientational metaphor of “hiding.” The participant’s use of this word showed me the active disengagement with a friend when experiencing acute chronic illness symptoms. Thus, hiding is a type of concealment strategy. Whereas concealment is the act of withholding private information, hiding, as conceptualized by the participant, demonstrated how their confidant already knows of aspects of the participant’s private, chronic illness-related information. Yet, based on the interactions with their confidant, the confider may withhold future or more intimate information to prevent added stress of needing to deal with their friend’s need for support and the confider may conserve their own energy source. When I identified participants as enacting a hiding strategy, I found they heavily considered their confidant in terms of anticipated response. As such, the purpose of hiding was not just to keep information from their friend, but to protect



themselves and their chronic illness symptoms, focusing on their physical needs in that situation.

### **Summary and Conclusions**

In Chapter Four, my goal was to answer RQ5:

**RQ5:** How do emerging adults make sense of their decision to disclose and/or withhold their private, chronic illness-related information?

In analyzing the interview data and the book covers, I identified two major themes concerning the sense-making of EAs sharing their chronic illness-related information with their friends. based on the book covers and the participants' interviews: (a) privacy-related metaphors and (b) chronic illness management-related metaphors. For the first theme, I discussed how participants used ontological metaphors regarding (a) the relational history contextual criterion and (b) testing boundary permeability. For the second theme, I discovered how participants used ontological and orientational metaphors in making sense of their chronic illness management through (a) experiencing chronic illness as a condition and (b) experiencing chronic illness symptoms. To follow, I discuss conclusions from these findings and their implications. In Chapter Five, I further elaborate contributions to the theory and literature regarding findings from Chapters Three and Four.

#### **Privacy-Related Metaphors**

As part of the response to RQ5, the participants in the present study engaged metaphors to describe privacy-related concepts. While Petronio (2002) conceptualized CPM in terms of a boundary metaphor, the theory has not explicitly incorporated metaphor to further understand the process of disclosing private information with a

relational partner. First, my analysis of these data contributed to theorizing of disclosure through the addition of the relational history contextual criterion. In their book covers, the participants doubled down on this concept, further highlighting the importance of relational history when considering whether to share private information with their friend. As exemplified by the participants' book covers and description of their book covers, they showed a more complex and complete process of sharing their chronic illness-related information with their friend. With the retrospective nature of this data collection, the participants reflected on their experiences. For example, the "balloon" metaphor (Image 3) highlighted by one participant helped this participant to show their understanding of how their chronic illness-related information functioned in their relationship with their friend. They showed that, while this private information since the EA was diagnosed with the chronic illness, information about the chronic illness was not revealed until the participant considered their confidant worthy of receiving that information. Previous researchers support this notion as invisible illnesses are not made known until the affected individual shares that information with their relational partner (e.g., Horan et al., 2009). In this way, this participant's balloon metaphor, and others with similar experiences, helps us understand the broader set of personal experiences of sharing private information with a friend represented in these data.

Additionally, the participants' use of metaphor in this study showed me how CPM researchers could consider additional conceptualizations and understandings of privacy-related terms. For example, participant offering the "breadcrumbs" (Image 6) to describe the phenomenon of providing smaller disclosures prior to revealing their chronic illness in a larger disclosure. This participant challenges the way in which CPM theorists

described “hinting” as a phenomenon reserved for creating privacy rules (Petronio, 2002). Rather, this participant showed through their metaphorical sensemaking that hinting could be a useful tool for helping a chronically ill EA decide whether someone should be a confidant of their chronic illness-related information. Through making sense of their complex experiences due to biographical disruption (Bury, 1982), the participants in the present study exemplified how an ontological metaphor, using an unrelated object to make sense of a concept or experience (Lakoff & Johnson, 2003), helped them to more accurately describe their personal experiences. In this way, they described access to the information, or boundary permeability, as the main phenomenon through which an individual may use hints for revealing their private information.

### **Chronic Illness Management-Related Metaphors**

Via their discourse, I engaged the experiences of participants in the present study to be able to demonstrate the consequences of living with chronic illness as an EA. Here, participants evoked previously established ontological metaphors (e.g., spoon theory) to describe how living with a chronic condition as an emerging adult was biographically disruptive (Bury, 1982). In tandem with hiding, these participants described how the social factors of sharing a chronic illness with others was not just a decision based on the private information. Rather, experiencing the symptoms of chronic illness exacerbated these decisions when considering energy as an expendable resource when a person with a chronic illness finds themselves needing to take care of their friend who is struggling with the chronic illness revelation. In the examples of spoon theory and the skeleton crew (Image 7; Image 8), an individual may experience a feeling of running on empty, and thus were unable to provide further information to a friend when discussing their

experience of chronic illness symptoms. When considering the onset of chronic illness symptoms, a participant may withhold information from a friend to make sure that their own individual needs were met before bringing in their friend for social support.

While previous scholars explained that concealing chronic illness-related information is largely due to consequences of stigma (e.g., Defenbaugh, 2013; Hall & Miller-Ott, 2019), the participants in present study showed this was not the only case. Rather, withholding private information, much like revealing private information, was not necessarily a one-time event. Instead, based on their experiences of sharing chronic illness-related information with a friend in the past, chronically ill EAs may restrict future disclosures of their chronic illness-related information with a friend. In this way, the participants in this study showed that concealment can happen post-disclosure of private information. Their use of concealment may be explained by the disclosure decision-making model (DD-MM, Greene, 2009). Within the DD-MM, Greene (2009) explained how an individual takes many aspects, such as the anticipated response of their confidant, into consideration when deciding to reveal private health-related information. In this present study, participants sometimes decided to withhold their acute chronic illness symptoms from a friend because they anticipate their friend will elicit a need for informational and emotional support. Thus, if an EA's chronic illness flares up, they may decide to withhold that information to appear more "typical" to prevent "role reversal," both of which—revealing and concealing—could exacerbate symptoms of chronic conditions as evidenced by previous scholars (Defenbaugh, 2013; Earnshaw & Quinn, 2011; Moses, 2010; Spencer et al., 2019). Thus, the unique contribution of my work in this present study helps enlighten the nuances of metaphorical sensemaking in coming to

understand an EA's (non)disclosure of their chronic illness-related information with a friend. When utilizing metaphorical sensemaking, participants in this present study showed how they came to understand their experiences of sharing or withholding their information from a friend. In Chapter 5 Discussion, I will return to these important theoretical and practical implications.

## **CHAPTER FIVE: DISCUSSION**

### **Overview**

My central purpose for the present study was to understand how emerging adults interact and navigate the disclosure of chronic illness-related information with a friend. I centered my study around five research questions:

**RQ1:** What criteria do emerging adults with chronic illness use in determining an appropriate friend to whom to reveal private information about chronic illness?

**RQ2a:** What are the characteristics that emerging adults with chronic illness identify in friends they choose as confidants?

**RQ2b:** What changes, if any, in the friendship relationship do emerging adults with chronic illness describe with a confidant post-disclosure of chronic illness-related information?

**RQ2c:** What changes, if any, in illness management do emerging adults with chronic illness describe post-disclosure of chronic illness-related information to the confidant?

**RQ3:** How, if at all, does the type of confidant with whom emerging adults with chronic illness change future (non)disclosures of chronic illness-related information?

**RQ4:** How do emerging adults with chronic illness negotiate privacy rules with a confidant when disclosing chronic illness-related information?

**RQ5:** How do emerging adults make sense of their decision to disclose and/or withhold their private, chronic illness-related information?

In this final chapter, I discuss the various implications of my dissertation results to these research questions. First, I summarize the main contributions from the findings of Chapters Three and Four. Second, I discuss the implications and contributions from the findings. Third, I provide the theoretical implications of understanding how emerging adults interact and navigate the disclosure of chronic illness-related information with a friend. Fourth, I offer practical implications of these findings for emerging adults with chronic illness and their friends. Fifth, I conclude with the limitations and strengths of this dissertation and directions for future researchers and my own work.

### **Summary of Findings**

In Chapter Three, I addressed RQs 1-4. Centered in communication privacy management theory, my goal in this study was to understand how emerging adults manage and negotiate the (non)disclosure of their chronic illness-related information with a friend. While previous researchers examined individual aspects of EAs disclosing their

chronic illness-related information with a friend (e.g., disclosure of chronic conditions, Bute, 2009; disclosure and friendship in college students, McBride & Bergen, 2008; privacy rule management with relational others, Child & Petronio, 2011), scholars have not yet centered their work on what occurs when these phenomena overlap. Using CPM as a sensitizing theoretical framework for the present study (Bowen, 2006), I found four major themes regarding how the participants in this present study made decisions about and navigated sharing their chronic illness-related information with a friend in Chapter Three: (a) criteria for disclosure, (b) consequences of the disclosure, (c) types of confidants, and (d) negotiations of disclosure.

In Chapter Three, I first discussed the criteria for disclosure of EAs in this present study used when considering sharing their chronic illness-related information with their friend. The two main criteria I found from my analysis of these data were (a) the contextual criterion and (b) privacy orientations. I identified two types of contextual criterion participants used when deciding whether to share their chronic illness-related information with a friend: (a) abnormal circumstances and (b) relational history. I also discovered two categories of privacy orientations participants used when deciding whether to share their chronic illness-related information with a friend: (a) medical necessity and (b) non-disruptive conditions.

Second, in Chapter Three, I discussed the consequences of participants' disclosure of chronic illness-related information with a friend. In this theme, I described the changes and desired outcomes of EAs sharing chronic illness-related information with a friend. When considering the consequences of disclosure, I found participants described (a) the deepening of the friendship relationship and (b) minimal or as-needed involvement in the

management of their chronic illness. When describing their friend's role in the management of their chronic illness, the participants described (a) individual ownership of their chronic illness-related information and (b) only wanting emotional social support.

Third, in Chapter Three, I described the types of confidants I heard in the participants' discourse in the present study. I identified three types of confidants from my analysis of these data: (a) inferential confidants, those expected to receive private disclosure, (b) deliberate confidants, those seeking the private disclosure, and (c) consequential confidants, those receiving a disclosure based on non-planned circumstances. First, I explained how the participants I identified as having inferential confidants used the relational history contextual criterion, reaffirming Petronio's (2002) conceptualization of the inferential confidant as someone who is expected to receive the disclosure of private information. I identified two circumstances in which participants described deliberate confidants: (a) after the initial disclosure of a chronic condition and (b) regarding chronic illness-related information. Fourth, from my analysis of these present data, I added a new type of confidant based on the experiences of the participants: the consequential confidant, referring to how participants in this present study emphasized how their manifested symptoms of their chronic illness led to the disclosure of chronic illness-related information with a friend. I will discuss the implications of this addition to CPM theory later in this chapter.

Fifth in Chapter Three, I discussed the negotiations of the disclosure of chronic illness-related information with a friend regarding privacy rules. I found how participants in the present study coordinated both (a) implicit and (b) explicit boundary rules regarding their chronic illness-related information. When coordinating implicit



boundaries, I identified the participants considering the criteria of (a) the relational history context and (b) privacy orientations. From my analysis of these data, I also found instances when participants coordinated explicit boundaries when experiencing a tension between their relational history with a friend and some type of larger, external context (e.g., workplace).

In Chapter Four, I took a more emic approach (i.e., understanding the data from the participants' perspectives and sensemaking, Lindlof & Taylor, 2018) in the analysis of the book covers created by the participants in this present study to represent their experiences in disclosing health-related information to a friend. Through my analysis of these data, I identified metaphor to be the central theme of Chapter Four as every participant engaged metaphor as a sensemaking device in their book covers. Through my analyses of these data, I found two privacy-related metaphorical themes represented in the book covers: (a) relational history contextual criterion and (b) testing boundary permeability. Participants used two types of what I interpreted as ontological metaphors when considering the relational history contextual criterion, highlighting two key privacy-related concepts: (a) negotiating the control of private information and (b) evaluating expected support received from a friend. When participants in this present study described what I understood as testing boundary permeability, which refers to the flow of private information (Petronio, 2002), I found the participants used ontological metaphor to describe how they shared smaller bits of information prior to the major disclosure of their chronic condition to determine if a friend was able and willing to receive larger pieces of chronic illness-related information.

Second, in Chapter Four, I described how participants in this present study used metaphor to describe how they managed their chronic illness in two key ways: (a) experiencing chronic illness as a condition and (b) experiencing chronic illness symptoms. I identified both ontological and orientation metaphor in the participants' sensemaking process to describe energy when explaining their experience of chronic illness as a condition and chronic illness symptoms respectively. Now that I have summarized the main findings of this study, I will next describe how I am engaging the findings from this dissertation to further extend our understanding of the disclosure of private information based on the experiences shared by the participants in this present study.

### **Theoretical Implications**

In response to little theoretical attention that enlightened the process of revealing and concealing, Petronio (2002, 2004) created Communication Privacy Management theory as a rules-based management system in which people exercise a perceived right of ownership over their private information. Because of the perceived ownership of private information, individuals make decisions on whether to reveal or conceal their private information based on various criteria that Petronio (2013) conceptualized as core criteria that are more stable long term (e.g., privacy orientations, gender, and culture) and catalyst criteria that prompt or change an individual's privacy rules (e.g., motivation, context). Through navigating the revealing and concealing process, individuals may potentially shift roles from owner to co-owner of information, coordinate implicit or explicit privacy rules, and/or experience privacy dilemmas when sharing information with a confidant (Petronio, 2002). In her recent writings, Petronio (2018) described how the development

of CPM and its related concepts continue to evolve. As a scholar who has been working with this theory for several years (Hall, 2020a, 2020b, 2021; Petronio et al., 2022), my goal is to continue to contribute to the development of CPM theory. To that end, I offer four primary theoretical contributions of my work in the present study: (a) expanding the typology of confidants, (b) deconstructing the criteria for disclosure, (c) demonstrating dialectical tensions of private information disclosure, and (d) developing CPM concepts through metaphorical insights.

### **Expanding the Typology of Confidants**

My first primary contribution involves expanding the typology of confidants, in Chapter One, I discussed Petronio's (2002; Petronio & Durham, 2015; Petronio et al., 2022) original conceptualization of the confidant, or receiver of a private information disclosure, as three types: (a) deliberate (soliciting the disclosure), (b) inferential (expected to receive the disclosure), and (c) reluctant (not expected to or wanting to receive a disclosure). In this present study, I analyzed how participants engaged both (a) deliberate and (b) inferential confidants. While Petronio (2002) described deliberate confidants as, more often than not, therapists probing clients for information, participants in the present study described how their friend may enact a deliberate confidant role after the initial disclosure event, meaning that a friend may seek out more information to provide either social or tangible support for the EA. When offering emotional social support (e.g., checking in on general well-being) or tangible support (e.g., cooking meals) (see Cutrona & Suhr, 1992) to the participants in the present study, these conversations were prompted by confidant initiative, rather than requests of the person with the chronic illness. In this way, the confidant already knew about the confider's private information,

and the confidant sought out more information on their own accord. Other participants in the present study considered their friend an inferential confidant, expecting their friend to be able and willing to receive their chronic illness-related information. When describing their friend as an inferential confidant, the participants particularly reiterated the relational history contextual criterion. Through evaluating and experiencing a friend's interactions prior to the initial disclosure event, participants identified their friend as someone they perceived would be content with receiving their chronic illness-related information.

While I identified the different confidant types from Petronio's (2002) original typology in these present data (i.e., inferential and deliberate confidants), I also found that participants described an additional type of confidant that did not fit the previous categories of confidants conceptualized by Petronio (2002). In my analysis of these data provided in Chapter Three, I described how one participant's experience warranted the creation of a new type of confidant due to the forcefulness (Owen, 1984) of the participant's description (and I discuss checking this perception as a future research goal). In Chapter Four, I discussed how participants in the present study who used an orientational metaphor to describe their chronic illness symptoms also described how manifested chronic illness symptoms may lead to the disclosure of chronic illness-related information, further reinforcing Participant 13's description of their experience with their confidant. Within Petronio's (2002) typology of confidants, there is an assumption of choice in sharing one's private information with the confidant; an individual could refuse a solicited request from a deliberate confidant or decide to conceal private information from an inferential or reluctant confidant. However, Participant 13, and others through

their book covers in Chapter Four, noted they had not intended to share their chronic illness-related information with a friend, but rather were required to share their chronic illness-related information with their friend because of the physical expression of their chronic illness. What I observed in these data was that both Participant 13 and the participants using an orientational metaphor for their chronic illness symptoms described how their friend happened to witness the participants' chronic illness symptoms. As such, I conceptualized these participants' friends in the present study as what I conceptualized as consequential confidants. Here, these participants had very little, if any, agency in revealing their private information with their friend. Instead, the onset of chronic illness symptoms forced the participant to reveal their private information. Even though this participant experienced a positive outcome in personal and relational well-being with their friend, individuals experiencing chronic conditions may have unique circumstances when considering how and when to share their chronic illness-related information with others.

I conceptualized the additional category of a confidential confidant within the context invisible illness disclosure. For those with invisible conditions, information regarding their condition is not made known until the individual discloses that information to another person (Chang, 2021; Horan et al., 2009). However, those with visible conditions are often not afforded the same level of agency in controlling the flow of information regarding their condition due to the visibility of the symptoms of condition (Braithwaite, 1991; Romo, 2018). Thus, when an individual's invisible illness becomes visible, they likely lose some degree of agency and control in the information management of their condition. Through analyzing the data in the present study, I

conceptualized the consequential confidant to reflect the unintentional or unplanned disclosure of private information due to those situations in which the owner of the private information has little to no agency or control of their private information. In addition to the confidants of disclosure, I found how the participants in the present study continued to challenge preconceived notions of criteria for disclosure in CPM theorizing.

### **Deconstructing the Criteria for Disclosure**

My second primary theoretical contribution involves deconstructing the criteria for disclosure. I previously discussed in Chapter One how Petronio (2013; Petronio & Durham, 2015; Petronio et al., 2022) conceptualized the criteria for the disclosure of private information in terms of (a) core and (b) catalyst criteria. Petronio described core criteria are those that are more stable over time (e.g., gender, privacy orientations) while catalyst criteria are based on change/changing circumstances (e.g., context, motivations). However, I found that participants in this present study did not fit within either of these categorizations when they considered criteria for sharing their chronic illness-related information with their friend. Through my analyses of these data, I discovered that participants in this present study described (a) relational history contextual criterion as a confirming criterion and (b) privacy orientation as a catalyst criterion.

**Relational History Contextual Criterion.** When analyzing the data concerning relational history contextual criterion—evaluating and experiencing their friend’s interactions prior to the initial disclosure event with their friend—I found the participants did not focus on preconceived gendered expectations (e.g., women as more open and men as more closed, Petronio et al., 1984), cultural norms such as (e.g., the use of social networking sites, Choi, 2021), or their general orientation of how they conceptualized

their private information (e.g., Steuber & McLaren, 2015). Rather, the participants in this present study described the context of the friendship relationship (e.g., previous conversations with their friend) as the criterion for disclosure. While previous researchers have described the contextual criterion as both social and environmental, (e.g., perceptions of communication on social network sites, Choi, 2021; appropriateness of the topic, Hammonds, 2015; physical location, timing, Hosek & Thompson, 2009); these scholars continue to conceptualize the contextual criterion in terms of change or changing circumstances. When describing the social dimension of the contextual criterion (i.e., relational history contextual criterion), the participants experiencing chronic illnesses in this present study considered their observations and past experiences of their friend's attitudes, characteristics, and demeanor.

In this way, I found that the results from the present study further address McBride et al.'s (2020) call to consider a third category of disclosure criteria: confirming criteria. McBride et al. conceptualized confirming criteria as the criteria an individual may consider when sharing private information based on “experiences that reinforce routinized behaviors and beliefs” (p. 549). In other words, individuals may share their private information with a confidant based on their previous experiences with that confidant—including their immediate relationship and the environment within which the relationship exists. In a similar manner, I found that the participants in this present study sometimes found their evaluations and experiences of the relationship with their friend as their reason for their disclosure of their chronic illness-related information with their friend, rather than any changes in outside the environmental or social factors. Thus, I found the participants' use of the relational history contextual criterion to confirm their

observations and prior interactions with their friends as reason enough to share their chronic illness-related information with their friend.

**Privacy Orientation Criterion.** In contrast to the original focus of CPM that the privacy orientation criterion for disclosure is a core criterion (Petronio, 2013; Petronio & Durham, 2015, Petronio et al., 2022), I found the participants in this present study described privacy orientations more akin to a catalyst criterion, meaning that a change in how they viewed their private information influenced their decision to disclose or conceal their private information. For example, I discussed how Participant 2's privacy orientation changed over time as they became more comfortable with their chronic illness as part of their identity, but not their entire identity. While Petronio and colleagues (Petronio 2013; Petronio & Durham, 2015, Petronio et al., 2022) conceptualized core criteria as stable over time, an individual's identity, conceptualized in CPM as generally stable, could change. Because of the biographical disruption of the onset of a chronic condition, an individual is likely to change their perception of their identity (Bury, 1982; Spencer et al., 2019). Thus, their core, long-term criteria (e.g., privacy orientations) may also change. Because I found the participants in this present study complicated a dichotomy of core-catalyst criteria, perhaps scholars have prematurely established these criteria for disclosure in the distinct categories of core and catalyst criteria, as noted earlier in McBride et al.'s (2020) study in adding confirming criteria to CPM. Thus, what I would suggest to those working to continue to develop CPM is to further engage with how their participants describe their decisions to disclose their private information with others in an open-ended manner. As my work in the present study reinforces previous scholars' call to extend the typology of disclosure criteria, it is imperative that scholars



utilizing quantitative, interpretive, and critical methodology do not restrict themselves to preconceived theoretical categories of CPM or of any theory for that matter. In this way, scholars should continue to help refine and test aspects of their theoretical perspective just as I have discovered in the present study. In further understanding private information disclosure, I found that participants in this present study also demonstrated the dialectical nature of CPM.

### **Demonstrating Dialectical Tensions of Private Information Disclosure**

My third primary theoretical contribution involves elaborating on Petronio's (2002) description of CPM as an inherently dialectical theory that considers the tension between revealing and concealing private information. However, communication scholars often are focusing on other theoretical perspectives when discussing dialectical tensions, or opposing forces, in particular Relational Dialectic Theory (Baxter, 2011; Baxter & Montgomery, 1996). Yet, I found in these data from this present study the ability to showcase the dialectical contradiction of revealing-concealing, especially when I heard participants in this present study described boundary coordination, or rules that individuals create when moving information from individual ownership to collective co-ownership (Petronio, 2002). When considering the revealing-concealing dialectical continuum, Wilmot's (1995) constitutive perspective of communication highlights this privacy dialectic.

In Chapter One, I described my perspective of communication as constitutive via the lens of Wilmot (1995) through which the self-other-relationship are tied together in a knot via communication. Should the communication discontinue or change, the constitutive knot frays or changes. I will next describe how I engaged the with the data

from the participants in this present study to demonstrate either (a) micro-constitutive communication to reinforce or (b) macro-constitutive communication to challenge Wilmot's conceptualization of the constitutive knot through the revealing-concealing dialectic.

**Micro-Constitutive Communication.** When reinforcing Wilmot's (1995) constitutive knot, individuals enact what I describe as micro-constitutive communication. In micro-constitutive communication, the interactants are less constrained by the outside forces (e.g., cultural expectations, organizations) allowing them to enact the co-constructed relationship as Wilmot's (1995) self-other-relationship knot. In the present study, I found participants reinforced the constitutive knot through the creation of implicit boundary rules, or rules that were ambiguous or not clearly stated when private information is shared (Petronio, 2002). I discovered how the participants' use of the relational history contextual criterion shaped their perception of creating clear rules about how to handle their chronic illness-related information with their friend as unnecessary. In considering their self-other-relationship constitutive knot with implicit boundary coordination, I concluded that participants' disclosure their chronic illness-related information to be within the bounds of the constitutive knot, not requiring further refinement any of the three threads of the constitutive knot. Thus, the participants may have found it easier to reveal their chronic illness-related information with their friend because of the self-other-relationship triad created through the communication between the interactants. When considering micro-constitutive communication, individuals may be able to focus exclusively on their constitutive knot with their confidant to gauge whether they should reveal or conceal, and how much they should reveal or conceal, with

their confidant in a more implicit manner. However, some participants noted the presence of outside influences when considering whether to and how much to reveal or conceal with their friend.

**Macro-Constitutive Communication.** When challenging Wilmot's (1995) constitutive knot, individuals enact what I call macro-constitutive communication. In macro-constitutive communication, interactants experience more constraint, influence, or pressure from outside sources (e.g., cultural expectations, organizations), adding a fourth thread into Wilmot's (1995) constitutive knot of a *system*—any institution or relationship external from the dyadic relationship that influences the enactment of the dyadic relationship. In Chapter Three, I found that participants challenged enacted macro-constitutive communication when they created explicit boundary rules, or rules that were clearly stated (Petronio, 2002), regarding their chronic illness-related information. Specifically, participant 6 described that although they considered their friend trustworthy, outside influences (e.g., the workplace) influenced their decision to coordinate explicit boundary rules surrounding their chronic illness-related information. Because of factors external from the friendship, individuals may consider creating more explicit rules regarding their private information when the information is particularly risky (Caughlin et al., 2009). As such, the influence of the system of the constitutive knot further informs the revealing-concealing privacy dialectic as an individual considers how others' orientations towards private information, further considering whether to and how much to reveal or conceal with their friend.

From these data, I conceptualized the participants' experiences in this present study of enacting the revealing-concealing dialectic through (a) micro-constitutive and

(b) macro-constitutive. For micro-constitutive communication, or Wilmot's (1995) original constitutive knot of the self-other-relationship, EAs may be more likely to coordinate implicit boundaries regarding their private information. When considering the equality dimension of friendship (Rawlins, 2009), it is perhaps unsurprising that scholars often found individuals creating implicit boundary rules with friends when considering potentially risky health-related information (e.g., mental health, Hall, 2020). However, I described how participants in this present study sometimes considered external factors (e.g., school, workplace) as influencing the creation of explicit boundary rules, or macro-constitutive communication. In considering macro-constitutive communication, or a constitutive knot adding a thread of an outside force or system, I found how EAs in the present study also seemed to desire more explicit rules considering private information management. Even still, the participants in this study utilized various sense-making devices to describe their experiences of sharing their chronic illness-related information with their friend. In short, I include this contribution to the theory as important because I found it important for scholars, like myself, who view communication as constitutive to remember that our relationships do not exist in a vacuum. Although we constitute our relationships using communication, my analysis of these data provided further evidence of how external systemic factors (e.g., disclosing chronic illness-related information in one's workplace) likely influence how we use communication to constitute our relationships.

### **Developing CPM Concepts through Metaphorical Insights**

My fourth primary theoretical contribution involves how the use of metaphor allows for further development of CPM concepts. As mentioned in Chapters One and

Four, Petronio (2002) used a *boundary* metaphor when creating CPM to illustrate how interactants manage and negotiate the disclosure of private information. From its inception, Petronio (2002) used this ontological metaphor as a sensemaking device to illustrate complex concepts in more a more easily understood manner. Similarly, I found participants in the present study also used metaphor to describe their complex experiences of sharing chronic illness-related information with their friend. As I developed in Chapter Four, through their use of metaphor, I learned how participants sometimes challenged preconceived CPM-related concepts, such as hinting.

Petronio (2002) originally conceptualized hinting as a strategy to create implicit privacy rules surrounding private information. However, Participant 13 challenged Petronio's (2002) original conceptualization for the purpose of *hinting* in the disclosure process. In their book cover, Participant 13 evoked what I interpreted as an ontological metaphor of *breadcrumbs*. Through their use of *breadcrumbs*, I conceptualized this participant's metaphor as *hinting*, but rather as strategy for testing boundary permeability with a potential confidant of their private information. Thus, when considering one's lived experience of sharing private information with others, describing one's experience through sensemaking processes like metaphor can allow researchers to further develop and refine theoretical concepts and ideas. In the present study, I described in Chapter Four how the participants' use of metaphor informed CPM researchers' conceptualization of hinting and the relational context as a criterion for disclosure. In this way, engaging in sensemaking activities, such as arts-based methodology and metaphor creation, can allow individuals who experience complex phenomena, like an EA sharing chronic illness-

related information with a friend, to better explain and understand their lived experience (Leavy, 2018).

### **Practical Implications**

Scholars working with developing CPM theory have described it as a particularly practical theory (Petronio & Durham, 2015; Petronio et al., 2022). Petronio (2002) has stressed that she created CPM as a practical theory “designed to provide an explanation for communicative issues about privacy that individuals face in the everyday world” (p. xvii). Similarly, scholars continue to call for researchers to go beyond publishing their work in academic outlets and explicitly link one’s work with the well-being of the general public (Wethington et al., 2012). Thus, as the push for theoretical knowledge to become more focused on translational contributions continues to grow (Hecht & Miller-Day, 2017; Petronio, 2007; Suter, 2016). To this end, I provide two main practical implications of my findings in the present study when considering EAs sharing chronic illness-related information with a friend: (a) creating a resource for EAs with chronic illness to help understand their experiences and (b) offering a strategy for arts-based therapeutic practice for those working with EAs experiencing biographic disruption.

#### **Creating a Resource for EAs with Chronic Illness**

The first practical implication of my work in this dissertation is the creation of a resource for EAs with chronic illness. Because EAs with a chronic illness encounter unique experiences of biographical disruption (e.g., concealing to appear normal to friends, Spencer et al., 2019), being an EA with a chronic condition may exacerbate loneliness (Kaushansky et al., 2016). Throughout the interviews and book covers, participants in this present study described how their friends, unless they are also

chronically ill, would not be able to fully understand the lived experience of an EA with a chronic illness. Although they were largely satisfied with their friends' reactions, the participants in this present study still found moments when they needed and expressed a desire to be alone to manage their chronic illness symptoms. Thus, to ameliorate negative social effects of living with a chronic illness, EAs could learn strategies for effective management of chronic illness-related information and management of chronic illness symptomology.

In considering resources for EAs in the effective management of the social effects of their chronic illness, researchers described how EAs with chronic illness rely on their resources, specifically their social resources like friends and family (Luyckx et al., 2008; Seiffge-Krenke & Stemmler, 2003). For those EAs who experienced chronic conditions prior to emerging adulthood, they likely experienced some type of pediatric to adult healthcare transition healthcare service that may have included learning to manage the social effects of their chronic illness (Trivedi et al., 2021). However, those EAs who experienced the diagnosis or onset of a chronic condition during emerging adulthood may not have access to such a transitional resource, leaving them to make sense of their EA and chronically ill identity with little preparation for both transitions of chronic illness and emerging adult identities. Thus, EAs who experienced the onset of chronic illness during adulthood may not be as well-equipped to form these relationships due to the management of an ill-identity as a young person (Kundrat & Nussbaum, 2003) and learning how to effectively manage their chronic condition independent from their family (Rapley & Davidson, 2010).

Thinking about the applied possibilities of these findings, I believe the results from the present study can help me create a resource for those seeking experiences for how to share their chronic illness-related information with their friend. For example, when Participant 7 and I discussed the idea of an adult children's book, or a book that uses images and simplistic narratives, as a translational contribution from this dissertation. The participant mentioned that resources to help either the EA with chronic illness or their friend is scarce or likely to be a lengthy book on a chronic condition. To help connect the work of academics and the general public (Wethington & Dunifon, 2012), I brainstormed with Participant 7 on more effective methods for creating a resource for EAs and their friends. During this brainstorm, Participant 7 expressed that a collection of short, simple narratives they could relate to and/or show their friend to tell them of their experience would be a helpful tool for managing being an EA sharing chronic illness-related information with a friend. I asked each subsequent participant about the idea of creating an adult children's book, and each participant expressed interest in this type of resource.

In creating an adult children's book, I would combine genres of literature utilizing more adult-like themes—living as an EA with a chronic condition—with stylization of children's literature including pictures and short narratives. Researchers in the field of adult literacy use children's books often in their instruction (Bloem, 2022), describing how these books' general appeal and ability to break down complex topics into a digestible format can amplify adult learning (Brazee, 1992; Rief, 1992). Through using the EAs' book covers and stories of their social experiences regarding chronic illness in this study, creating an adult children's book from the participants' experiences would



allow me to fill a gap in desired resources for EAs with chronic illness in the learning how other EAs manage the social effects of their chronic illness.

### **Creating a Strategy for Arts-Based Therapeutic Intervention**

The second practical implication of my work in this dissertation is the addition of an arts-based methodology in therapeutic practice that could assist EAs with chronic illnesses in making sense of their complex circumstances. Researchers have long noted that arts-based approaches to research are particularly well-equipped for allowing participants to express their lived experiences (Shemer & Shahar, 2022). For example, young adults with a stigmatized identity may experience less isolation or stigmatizing behaviors when engaging with others through photovoice (Cosgrove et al., 2022). In their systematic review of arts-based interventions with EAs, Smriti et al. (2022) found that EAs using engaging in various forms art therapy (e.g., drawing, poetry, drama, music) contributed to better mental health outcomes for the EAs. Researchers have also shown that the use of arts-based group interventions, like podcasting and drawing, can help increase the quality of life for an EA with chronic illness through forming a more positive social identity and experiencing less feelings of social isolation because they have the opportunity to engage and make sense of similar experiences with other chronically ill EAs (Dingle et al., 2019). Yet, because the researchers in these studies focused on group-based interventions, their results and interventions may not be accessible to all EAs experiencing a chronic condition.

Given the dyadic nature of this study, those seeking to provide therapeutic support for EAs with a chronic condition may find my use of an arts-based intervention particularly useful. As evidenced in this present study, the participants drew upon their

lived experiences to make sense of and create a representation for their social experiences of chronic illness. Through the creation of their book covers, the participants in the present study experienced a sense of what therapist White (2007) described as externalizing conversations. In his book, White (2007) described externalizing conversations as those that “employ practices of objectification of the problem against cultural practices of objectification of people” (p. 9). Through externalizing conversations, people may be able to separate their personhood from the problem(s) they experience. When engaging in externalizing conversations, White (2007) noted that people often evoked metaphor to make sense of their life and identity. Through this sensemaking process, individuals engaging with externalizing conversations and metaphor may become better equipped to solve their problems and shape their life in a desired fashion (White, 2007).

From the book covers in this present study, I discovered that participants evoked metaphorical language and visual representations of their social experiences as an EA with a chronic illness. Upon analyzing these data, I found that using this arts-based methodology may equip practitioners and other researchers with a translational skill to improve chronically ill EAs overall well-being (Wethington et al., 2012). In using the arts-based methodology of the book cover creation, I found my participants providing novel findings regarding the concept of *energy* as a key term for living as an EA with a chronic condition. While it is well-known that lower energy is associated with chronic conditions (CDC, 2021), I found through arts-based methodology how the participants in this present study experienced energy in terms of an interpersonal relationship. Specifically, the EAs in this present study described energy as a precious resource in

limited supply. When thinking of their chronic illness as an energy supply, the participants in this present study effectively communicated the social experiences of living with a chronic illness. Externalizing their chronic illness as an energy supply allowed them to focus on fixing the problem rather than experiencing a need to fix one's identity (White, 2007). Thus, for EAs with chronic illness experiencing the complex phenomenon of intersecting (and sometimes culturally opposing) identities of youth and illness, providers (e.g., therapists) may consider instructing their patient to create a book cover that encapsulates their experience of living as an EA with a chronic illness. Later in that meeting or at a subsequent meeting, the provider could then discuss patient's externalization of the problem(s) associated with their experiences with their chronic illness.

### **Strengths, Limitations, and Directions for Future Research**

In reflecting on this dissertation, it is imperative to consider and understand the (a) strengths, (b) limitations, and (c) directions for future research of this dissertation.

#### **Strengths**

First, in considering the findings of this present study, I identified three specific strengths of the study: (a) the innovation of combining traditional interpretive methodology with an arts-based methodology, (b) shedding light on an understudied population, and (c) understanding chronic illness from the communication and privacy perspectives.

#### **Combining Traditional Interpretive Methodology with Arts-Based**

**Methodology.** The first strength of this study is showing how combining multiple methodologies can lead to innovative discoveries in the results. When initially creating

the study, I was going to construct the arts-based product with the participant in-person. However, with the COVID-19 pandemic complicating this procedure, I decided that I would offer my participants a prompt to create a book cover based on their experiences of sharing chronic illness-related information with a friend. In this way, participants were less influenced by my presence in the creation of their book cover. Their independent book cover creation perhaps allowed the participants to better reflect their lived experience without the social presence of the researcher during its creation (Lindlof & Taylor, 2018). Taking this into consideration, utilizing both interviewing and an arts-based methodology provided a more wholistic story of the participants' experiences—a key goal of the reflexive thematic analysis used in this present study (Braun & Clarke, 2019a).

**Shedding Light on an Understudied Population.** Second, this study provided the opportunity for me to shed light on an understudied population concerning chronic illness: the emerging adult. Researchers have given a lot of deserved attention to mental conditions of EAs, particularly college students (e.g., Venetis et al., 2018). However, when concerning chronic conditions, EAs have not had the same attention, evidenced by the lack of resources for those who experience the onset of a chronic condition during emerging adulthood discussed in the practical implications of Chapter Five. Yet, in knowing that friends are pivotal relationship for social support for emerging adults (Arnett, 2015), I sought to understand how EAs share their chronic illness-related information with their friends. In further examining the role of the friend as a confidant of private information disclosure, I began to show how chronic illness and friendship interact when considering the disclosure of private information. A common theme

through research on sharing private health-related information is the concept of stigma. Researchers have noted that information perceived as particularly risky and more stigmatized is less likely to be disclosed with others (Caughlin et al., 2009; Defenbaugh, 2013). Some researchers have emphasized that one's perceived ability to share their condition with a friend can mediate the perceived risk of the information and the relational relation closeness (Venetis et al., 2018). In other words, if an individual feels they are well-equipped to share their information with a friend, stigma and the closeness of the relationship are not as heavily weighted. However, rather than considering their ability to share their chronic illness-related information with their friend, the participants in this present study more so focused on the relationship as the key factor for deciding to share or withhold their chronic health-related information with their friend. As such, this present study shows that scholars should continue to centrality of the relationship as it relates to the communication of potentially risky health-related information.

### **Understanding Chronic Illness from a Communication and Privacy**

**Perspective.** Third, this study provided me the opportunity to further illustrate chronic illness in terms of communication and privacy. First, many aspects of chronic illness are invisible, making them likely unknown to a relational other until information regarding the chronic illness is revealed (Horan et al., 2009). When chronic illness symptoms become visible in the presence of a relational, however, the agency and control of sharing information regarding one's chronic illness are diminished. In other words, either the revelation of information or manifestation of symptoms make a chronic illness visible. Researchers have examined the careful and planned disclosure of chronic and mental health-related information (e.g., Horan et al., 2009; Spencer et al., 2019; Venetis et al.,

2018), but, as the participants in this study expressed, the management of the visibility of chronic conditions is not as well-known. From my analysis of this study, I found how participants sometimes desired being left alone or were unsure of how to manage a relationship when a chronic illness becomes visible. While witnessing a friend experiencing chronic illness symptoms, it may be intuitive to want to offer support for that friend or act in their best interest. However, in noting the potentially involuntary disclosure of private, chronic health-related information, I provide further consideration of the appropriateness of communicative behaviors with an interpersonal other who has a chronic illness.

### **Limitations**

First, in considering the limitations of the present study, the participants in the present study largely represent white, female individuals, and the participants in this present study needed to speak English. This is an important limitation of the present study because researchers have well-documented that non-white people experience greater health disparities compared to white people (Clayton et al., 2014; Yoo et al., 2015). Additionally, those who do not speak English or have limited English proficiency in the United States, where this study was done, often experience more disparities within the United States' healthcare system such as less access to preventative healthcare and cancer screenings (Diamond et al., 2019). While I recognize this limitation and did think about it during the data collection of the study, I was limited in my ability to effectively recruit and interview participants in the study as my data collection fell during the height of the COVID-19 pandemic in 2021. I was restricted to online recruitment strategies and

interviewing via technology and while both my co-PI (advisor) and I engaged in an active push for research participants, it was extraordinarily difficult to find people to take part in the interviews. In addition, Asher-Schapiro and Sherfinski (2021) noted that the persons of color, and especially persons of color in rural areas, are much more affected by the digital divide than white people. Thus, because of the constraints of the COVID-19 pandemic, my ability to access participants, and especially participants from minoritized populations, was inhibited. What I intend to do to address this issue is to re-open my data collection following this dissertation and use that as an opportunity to fill out and further test my findings and to expand both the overall number and the diversity of my population. What I would suggest for future researchers not affected by a pandemic is to avoid such issues is to work with local libraries and public spaces with free-to-use technology to be able to accommodate to those participants who may want to participate but are unable to do so given to various circumstances.

Second, I did not separate participants who experienced chronic illness prior to emerging adulthood and those who experienced chronic illness only upon reaching adulthood. As discussed earlier in Chapter Five, EAs who had a chronic illness prior to emerging adulthood were more likely to have had access to resources assisting with transitioning from adolescence into EA (Butalia et al., 2021). Thus, although I offer initial inquiry into how EAs manage and negotiate the (non)disclosure of chronic illness-related information with a friend through my work in the present study, analysis of EAs diagnosed both before and after reaching emerging adulthood merits further consideration.

### **Directions for Future Research**

I will discuss two future directions for researchers and for my own work: (a) dyadic interviews and (b) chronic illness stigma.

First, I believe that undertaking this study with both the EA and their friend may produce fruitful results. Although dyadic interviews have their risks, such as issues in confidentiality and conflict of interest (Forbat & Henderson, 2003), interviewing both the EA and their friend may allow for what Koenig Kellas (2018) described as “interactional storytelling,” or how interactants collaboratively tell a story (p. 66). With this heuristic, researchers could examine how the interactants engaging in turn-taking, perspective-taking, and sense-making. In this way, approaching the study from an interactional storytelling lens allows a researcher to ask the participants to share the story of when they shared/received chronic illness-related information with/from their friend. While I focused on the individual retrospective interviewing method in the present study (Lindlof & Taylor, 2018), researchers could approach this study with a dyadic retrospective interviewing method to further understand how EAs and their friends enact and receive social support and make sense of the disclosure of chronic illness-related information. Researchers could have the interactants create individual book covers to see how each participant makes sense of the experience individually and/or create a book cover collaboratively to further illustrate the sensemaking processes of sharing chronic illness-related information. In future studies, I aim to engage with both the confider and confidant in friendship relationships to further discover their shared understanding of sharing chronic illness-related information. Although asking an individual to identify and invite a friend with whom they shared their chronic illness-related information may pose risks to the friends (e.g., engaging in past conflicts and maintaining confidentiality,



Forbat & Henderson, 2003), I believe this will be an important future inquiry for me to capture a more holistic picture of the process of disclosing chronic illness-related information.

Second, researchers should further consider the findings regarding privacy orientations from this study. Some of the participants described their chronic condition as having perceptually little to no stigma, while other participants described having perceptually high stigma. Given that more stigmatized identities carry more risk in revealing them to others (Caughlin et al., 2009; Defenbaugh, 2013), it is important to consider potential differences in disclosure behaviors given the perceived levels of stigma of an EA's chronic condition. While more information may be readily available and understood by the public regarding certain chronic conditions (e.g., asthma), other conditions (e.g., fibromyalgia) may not have such luxury and could complicate the disclosure process. Thus, in future studies, I intend to further explore how individuals' perceptions of the stigmatization of their chronic illness relates to their orientation of their chronic illness-related information.

In the present study, I looked at how EAs decided to share their chronic illness-related information with a friend. Through this dissertation, I believe I made important conceptual, theoretical, and practical contributions in both understanding and managing the phenomenon under inquiry. I am hopeful that this dissertation extends my journey in understanding how EAs manage and negotiate sharing chronic illness-related information in their interpersonal relationships. Moving forward my goal my research and applications are to continue to share the stories of those whose voices have either not been heard or been hidden from view and to help people with chronic illness and those in

their relational orbits to effectively understand and make decisions regarding sharing their private information with close relational others. Because of this dissertation, I believe I have further amplified the voices of EAs experiencing chronic conditions, and how they decide to share that information with a friend.

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## Appendix A: Interview Protocol

[Turn on tape recorder] Before we begin with the open-ended questions, I would like to learn a bit about you

- 1) Demographic Information:
  - a. What is your age?
  - b. What is your gender?
  - c. What is your race?
  - d. What is your sexual orientation?
  - e. What is your religious affiliation?
  - f. What is your highest level of education?
  - g. With what chronic illness or illnesses are you diagnosed?
    - i. Follow-up: For how long have you been diagnosed?

Now that I know a bit more about you, I'm going to ask you some questions about a friend who we will discuss throughout the interview. Prior to this interview, I asked you to reflect on your relationship with one particular friend who you discussed your chronic illness with no less than 6 months ago. I would like to know a little bit more about your relationship with them.

- 1) Friendship Information:
  - a. What name should I call this friend?
  - b. When and where did you meet \_\_\_\_?
  - c. How long have you been friends with this person?
  - d. To the best of your knowledge, what \_\_\_\_ 's...
    - i. Age?
    - ii. Gender?
    - iii. Race?
    - iv. Sexual orientation?
    - v. Religious affiliation?
    - vi. Highest level of education?
  - e. What health condition or conditions did you tell \_\_\_\_ that you have?
  - f. Approximately when do you recall telling \_\_\_\_ about your chronic illness for the first time?
    - i. Clarification, if needed: This can be month, year, and/or season. I'm basically trying to get an idea of how long it has been since you shared this information.
  - g. How close would you say you are/were with \_\_\_\_ at the time you first told them this information about your chronic illness?
    - i. How close would you say you are with \_\_\_\_ today?
- 2) Tell me the story about when you first told \_\_\_\_ about your chronic illness. Describe, as best as you can recall, what you and \_\_\_\_ did and said in this situation.

- a. Probe on disclosure:
  - i. What is it about \_\_\_\_ that influenced your decision of telling them about your chronic illness?
  - ii. What circumstances led to the decision to tell your \_\_\_\_ about your chronic illness?
  - iii. How did you tell \_\_\_\_ about your chronic illness? For example, was it in person, over the phone, texting, etc.?
  - iv. How did your friend react to receiving this information? What did they do or say?
    1. How satisfied were you with \_\_\_\_ 's reaction?
    2. How did you feel about \_\_\_\_ 's reaction after you told them about your chronic illness?
  - v. How did you feel about sharing this information from your friend?
    1. What emotions did you experience?
  - vi. In many situations, we choose to disclose information to another person Thus,
    1. How much choice did you believe you had when you told your friend about your chronic illness?
    2. What, if anything, do you wish had been different about this interaction with \_\_\_\_?
- b. What motivated you to disclose your chronic illness to \_\_\_\_?
- c. Probe on information management:
  1. Once you told \_\_\_\_ about your chronic illness, what, if anything, did you tell them about what they could and couldn't do/say with the information you gave them?
    - a. Probe on specific information sharing strategies:
      - i. Who did you say \_\_\_\_ could or could not tell about your chronic illness, if anyone?
      - ii. What aspect of the information about your chronic illness did you say \_\_\_\_ could or could not tell, if anything?
    - b. Probe on friend's boundaries:
      - i. What, if anything, did \_\_\_\_ say about how to handle the information?
    - c. Probe on no boundaries:
      - i. What about the friendship made it seem like you didn't need to tell \_\_\_\_ how to handle your information?
        - Would you be able to provide an example?
      - ii. What about your chronic illness seem like you didn't need to tell \_\_\_\_ how to handle your information?

- Would you be able to provide an example?
- d. Probe on implicit boundaries:
  - i. What about \_\_\_\_'s behavior in the past led to little or no discussion about handling this information?
    - Would you be able to provide an example?
  - ii. What about your experiences of chronic illness led to little or no discussion about handling this information?
    - Would you be able to provide an example?
  - iii. How well did \_\_\_\_ follow these rules about what to do or say?
    - Would you mind providing me an example of when not following rules occurred?
    - Who, if anyone, did they discuss information about your chronic illness that you know of?
    - Why do you think they decided to tell this person(s)?
- e. Probe on explicitness:
  - i. What about the friendship made it seem like you needed to tell \_\_\_\_ how to handle your information?
    - What about your friend's behavior in the past made it seem like a discussion was needed on how to handle this information?
      - i. Would you be able to provide an example?
  - ii. What about your experiences with chronic illness made it seem like you needed to tell \_\_\_\_ how to handle your information?
    - i. Would you be able to provide an example?
  - iii. How well did \_\_\_\_ follow these rules about what to do or say?

- Would you be able to provide an example?
  - Who, if anyone, did \_\_\_\_ discuss information about your chronic illness that you know of?
  - Why do you think \_\_\_\_ decided to tell this person(s)?
- f. Probe on information management overall:
- i. How satisfied do you feel about your experience of disclosing this information to \_\_\_\_ overall?
    - Please explain.
  - ii. How do you sharing think this information with \_\_\_\_ changed your friendship, if at all?
    - Please explain.
- 3) How have you and \_\_\_\_ discussed this information about your chronic illness condition since the first time you revealed your condition to them?
- a. How often do you talk about your chronic illness?
  - b. What have you discussed about your chronic illness?
  - c. Why have you two discussed your chronic illness?
  - d. How, if at all, have any of the expectations changed about what you want \_\_\_\_ to say or do with information about your chronic illness?
    - i. If changes occurred, why?
    - ii. If not, why?
  - e. What personal, health-related information has \_\_\_\_ told you about their health, if anything?
    - 1. Who discussed their health information first, and why?
    - 2. What do you think motivated \_\_\_\_ to talk with you about their health condition?
    - 3. How do you believe \_\_\_\_'s sharing of their health information with you changed your friendship, if at all?
- 4) After telling your friend about your chronic illness, how did you feel about your chronic illness?
- a. How involved, if at all, would you say is \_\_\_\_ in helping you manage your symptoms?
    - i. What does \_\_\_\_ do or say to help you in your management of chronic illness?
    - ii. How responsive is \_\_\_\_ to your concerns about your chronic illness?
    - iii. How understanding is your friend about your concerns regarding your chronic illness?

- iv. How satisfied are you with \_\_\_\_'s role in your chronic illness care? Please explain.
- b. How involved, if at all, would you say are your parent(s)/guardian(s) in helping you manage your symptoms?
  - i. What do your parent(s)/guardian(s) do to help you in your management of chronic illness?
  - ii. How responsive are your parent(s)/guardian(s) to your concerns about your chronic illness?
  - iii. How understanding are your parent(s)/guardian(s) about your concerns regarding your chronic illness?
  - iv. How satisfied are you with your parent(s)/guardian(s)'s role in your chronic illness care? Please explain.
- c. How, if at all, has your personal care of your chronic illness changed since sharing this information with your friend?
  - i. If there are changes:
    - 1. Why do you think these changes occurred?
    - 2. Do you believe these changes are for the better? Why or why not?
  - ii. If there are no changes:
    - 1. Why do you think nothing changed?

Now that I'm aware of a few of you/r experiences regarding your friendship and chronic illness, I'd like to ask you a few final questions on this topic.

- 1) How does a friendship differ from talking with family members or a partner when the topic is chronic illness-related information?
- 2) What advice, if any, would you give to another person if they are thinking about talking with a friend about their chronic information?
  - a. Probe:
    - i. Why (if needed)?
- 3) What advice, if any, would you give to another person receiving chronic information from a friend?
  - a. Probe:
    - i. Why (if needed)?

Let's turn to your book cover as I'd like to ask you some questions about your book cover:

### **Book Cover Design**

Prior to our interview, I had asked you to design a book cover that would capture your experience of sharing chronic illness-related information with a friend. In doing so, I asked you to give your book a title and draw, describe, or in some other manner create

the cover for the book. I then asked you to send me this information, and we will now look at this together, and I will ask you some questions about your book cover. Keep in mind that if you wish to change or edit anything about your book cover throughout the interview, you are welcome to describe these changes. What questions do you have before we begin?

To begin, let us both take out our copies of your book cover.

(At this point, pull up the email from the participant, and let the participant know they did a phenomenal job in creating their book cover).

I really enjoyed reviewing your book cover prior to our interview, and I'd like to ask you a few questions about it.

1) Title:

- a. I see that you called your book “\_\_\_\_\_.” Why did you decide to give your book this title?
  1. Probe:
    - a. How does this title best capture the experience of sharing chronic illness-related information with a friend as an emerging adult?
    - b. What kind of audience was in mind when you made this title? Why?
    - c. Of all of the words in this title, what would you say is the most important? Why?
    - d. What do you hope this title tells people who may be interested in reading what's inside?

2) Design:

- a. I see that you [drew, described, other representation] an image [or various images] on your cover. What is the significance of this/these image(s)?
  1. Probe:
    - a. How does this/these image(s) best capture the experience of sharing chronic illness-related information with a friend as an emerging adult?
    - b. What kind of audience was in mind when you [drew, described, other representation] this/these image(s)?
    - c. If multiple images:
      - Of all of these images on the cover, what would you say is the most important? Why?
    - d. If one image:
      - Of all of the aspects of this image on the cover, what would you say is the most important? Why?
    - e. What do you hope this/these image(s) tell people who may be interested in reading what's inside?

3) Format:



- a. I'd like to ask you just a few more questions about the idea of getting this information out to the public.
  1. What are your thoughts on getting information to others who may be experiencing similar things as you through a book?
    - a. If not a good method:
      - What would you recommend as an effective way to get this information to others like you, and why?
    - b. If a good method:
      - What makes this a good way to get this information to others like you?
  2. What are your thoughts on getting this information to others who may be receiving information, like your friend in this study, through a book?
    - a. If not a good method:
      - What would be a good way to get this information to others like your friend?
    - b. If a good method:
      - What makes this a good way to get this information to others like your friend?
  3. What would the contents of this book need to address in order to best assist those in situations similar that of you?
    - a. Please describe.
  4. What would the contents of this book need to address in order to best assist those in situations similar to that of your friend?
    - a. Please describe

4) Wrap-up:

- a. Those are all of the questions I have about your book cover. At this point in the research, I will analyze all book covers and all responses to the interview questions about them. After this analysis, I will create a book cover that best captures the experience of sharing chronic illness-related information to a friend as an emerging adult. After creating this, I will send out an email with this attached along with a brief description of my findings from the first part of my interview to all of the participants in a blind carbon-copy email who agreed to such communication. If you agree to this, all that I ask is that you look over both documents (the book cover and the preliminary finds) and send your thoughts. I will explicate this again in that email, but I am basically going to ask, "Did I get this right?" To which you are welcome to agree and/or disagree on all of the results, part of the results, or none of the results. Would you be okay with participating in this in the future? Please note that this is still voluntary,

and you may withdraw from this at any time, and you are not obligated to respond to the email when I send that out either.

- b. (Mark yes or no on the participant's informed consent)

Thank you again for agreeing to participate in my study. The experiences you provided me with today will help shed light on the process of friends receiving information about various chronic and/or mental health issues. What other information would you like to add that I didn't address today would you like to add before we end?

Thank you again for agreeing to participate in this study.

**Appendix B**

**Book Cover Template:**

B.

A.

C.

Instructions:

*You are not limited to this template. Feel free to use anything that helps you create a book cover based on your experiences of sharing your chronic illness-related information with a friend.*

1. In Box “A,” type/write your title based on your experiences of sharing your chronic illness-related information with a friend. Feel free to use any font and/or design and/or to move this anywhere on the cover. Take notes about your decisions for words, font, design, and placement.
2. In Box “B,” design your cover based on your experiences of sharing your chronic illness-related information with a friend. Feel free to use any images, words, or other medium to create what you envision on this cover. Remember: you do not have to be a creative mastermind to do this. I am not looking for a masterpiece as I am looking for what you envision best represents you and your experience(s). If you would like to simply describe what you envision on the cover, please move to Box “B” description below.
3. Consider Box “C” a placeholder for the author’s name(s). On the cover of most books is the name or names of the author(s) of the book. This is included for you to remember this information is also on the cover. You are welcome edit the font and/or design and/or to move this anywhere on the cover. Please do not put your own name here to maintain your confidentiality throughout the research process.
4. Once you are finished creating your book cover, save this file and send it to me via email at [robert.hall@huskers.unl.edu](mailto:robert.hall@huskers.unl.edu). (If you are not using this template, you may fax,

[Write as much as you would like to best describe what you envision to be on the cover of your book in this space.]

send a picture, or send a document with your cover to me via email at [robert.hall@huskers.unl.edu](mailto:robert.hall@huskers.unl.edu)).

Box "B" Description: