

THESIS

“POTS EQUALS UNCERTAINTY”: EXPLORING UNCERTAINTY AND PRIVACY MANAGEMENT
OF PEOPLE WITH POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME (POTS)

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ABSTRACT

“POTS EQUALS UNCERTAINTY”: EXPLORING UNCERTAINTY AND PRIVACY MANAGEMENT OF PEOPLE WITH POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME (POTS)

Postural Orthostatic Tachycardia Syndrome (POTS) is a rare, incurable, and invisible disability. POTS is an understudied illness in the medical field and even more so in academia. The importance of studying the experiences of people with POTS is to improve the way these individuals, and others with invisible disabilities, negotiate privacy and uncertainty. Privacy and uncertainty are particularly worthy of investigation in studying POTS because people with POTS have to negotiate large amounts of uncertainty and disclosures. This study sought to use the lens of uncertainty and privacy management along with emergent themes. Twenty-four in-depth interviews were conducted. Participants hailed from North America and Europe. Findings of this study revealed complex and dynamic negotiations of privacy and the management of uncertainty. Participants explained they attempt to disclose only vague explanations of their illness to most people because people do not understand. There was deep and profound uncertainty surrounding pre-diagnosis, prognosis, treatment options, and symptoms. Participants also had a hard time deciding when and how to disclose their POTS. Uncertainty about reactions and understandings to disclosure played a role in complicating decisions on whether and how to disclose. Invisible disabilities pose distinct and specific challenges that can build theory to include unconsidered voices and experiences that complicate previous scholarship. This study revealed more avenues to be explored going forward.

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Introduction

When asked what she wished more people knew about postural orthostatic tachycardia syndrome (POTS), Elise stated, “I wish people would know, especially people that have illnesses that aren't easy to diagnose... You're not crazy, keep driving, keep going, and go to doctors that will listen” (Slattery, 2017, p. 1). POTS is a form of autonomic dysfunction categorized by a spike in heart rate and a drop in blood pressure upon standing. The nervous system in people with POTS malfunctions and sends the wrong signals to the heart and brain (Fedorowski, 2019). POTS is a debilitating chronic condition that can be classified as an invisible disability (“Postural Tachycardia Syndrome Information,” 2018). POTS is an understudied illness in the medical field and even more so in academia. To date, scholars from multiple disciplines have done little to account for the unique challenges and personal struggles that are faced by individuals living with POTS. There is scarce, if any, qualitative data on the experiences of people with POTS, and the handful of quantitative medical studies that do exist are largely inaccessible to a general audience.

POTS is a rare, incurable, and invisible disability; therefore, until an individual with POTS discloses their diagnosis, others will be unaware of the challenges the individual is experiencing. Along with disclosure challenges, People with POTS are also faced with a great deal of uncertainty about symptoms, and how their symptoms will affect their social relationships and personal lives. A person with POTS may have uncertainty being involved in social events due to debilitating chronic symptoms (e.g., passing out, puking, etc.) and they must decide whether and how to disclose their POTS diagnosis to the people interacting with them. The importance of studying the experiences of people with POTS is

to improve the way these individuals, and others with invisible disabilities, can negotiate privacy and uncertainty in a society that doubts the validity of their disability. Privacy and uncertainty are particularly worthy of investigation in studying POTS because people with POTS have to negotiate large amount of uncertainty and disclosures. POTS has invisible invisibility, both in awareness and in symptoms, people with POTS have to disclose to inform someone they are disabled and most likely those people will not know what POTS is. There is uncertainty when disclosing, but also just from living with POTS whether that be medical, personal, or social.

POTS as an understudied invisible disability gives scholars an opportunity to expand knowledge on the uncertainty and privacy management of illness from a nuanced perspective. Studying POTS specifically opens opportunities for insight into how people with other invisible disabilities negotiate uncertainty and privacy management because POTS has such a broad spectrum of symptoms that would overlap with the symptoms of other invisible disabilities. These symptoms include: fatigue, headaches, dizziness, small nerve neuropathy, lightheadedness, heart palpitations, exercise intolerance, nausea, lack of concentration, shaking, syncope (fainting), coldness or pain in the extremities, chest pain, and shortness of breath (Anderson, 2014). These symptoms often lead to a diminished quality of life that researchers have compared to “patients on dialysis for kidney failure” (Fedorowski, 2019). POTS’ wide spread symptoms and incurability overlap with the experiences of others with illnesses such as: fibromyalgia, ehlers danlos, multiple sclerosis, cystic fibrosis, traumatic brain injury, and epilepsy, to name a few (Agarwal et al., 2007). These symptoms can be the catalyst of uncertainty for people with invisible disabilities. For all these disabilities, including POTS, there can be uncertainty about how and whether to

disclose their illness, how to manage symptoms, how to pay for medical bills, and how renegotiate of personal and social roles (Brashers, 2001). The qualitative findings of this study can be applicable to how people with other invisible disabilities navigate uncertainty and privacy management.

The incurability of POTS and these other invisible disabilities call for more work to be done on the experiences that people with rare, incurable and invisible disabilities face surrounded by uncertainty. The experiences of people with POTS and these other invisible disabilities are distinctly different from what is known from literature on terminal illness and disability (Anderson, 2014). This is in part because of the invisibility of invisible disabilities. Unlike seeing someone using a cane or a wheelchair, there are no obvious cues that communicate disability to the onlooker. This fact poses challenges in daily life. For example, those with invisible disabilities may be yelled at for parking in a handicap spot because of their “normal” appearance. Those who have invisible disabilities are an important part of the disabled population and they have their own unique communication challenges when it comes to relating to others (Allen, 2004; Garland-Thomson 2010). Overall, POTS is an appropriate case study for the study of communication as the experiences of those who have POTS may be generalizable to others suffering from rare, incurable, invisible, and disabling illnesses.

Communication Privacy Management Theory (CPM; Petronio, 2002) can serve as a lens to better understand the privacy negotiation experiences that accompany having an invisible disability. When a person has an invisible disability, they must make frequent decisions about concealing and revealing their disability. Braithwaite (1991) using CPM found that people with physical disabilities feel pressure to disclose their disability for the

comfort of the able-bodied. People with invisible disabilities are often faced with disbelief when revealing their status because their claims do not match their outward appearance (Brown, 2002). This study seeks to understand how people with POTS decide whether and how to disclose information about their invisible disability using Petronio's CPM framework. This involved examining how people with POTS view their private information, manage their privacy boundaries, navigate control and ownership, form their own privacy rules, and how they conduct privacy management dialectics. By using CPM as a guide I have analyzed what factors participants take into account when deciding whether and how to disclose and also how POTS affects their privacy rule formation.

Not only are people with POTS potentially bombarded with decisions on privacy management, they also must manage large amounts of uncertainty, which suggests Uncertainty Management Theory (UMT; Brashers, 2001) is an appropriate second driving theory. To explain, doctors often do not have treatment programs for people with POTS and even the leading expert neurologists for POTS are unsure on the prognosis for people with POTS (Dysautonomia International, 2012). POTS is also often misdiagnosed and patients are turned away because of doctors' lack of knowledge and the lack of awareness of POTS. Patients are often told that their illness might be just all in their head, leading to depression and anxiety causing greater uncertainty (Dysautonomia International, 2012). All of this leads to uncertainty for the patient and this specific uncertainty is unstudied and requires further analysis to understand. Using Brashers (2001) framework on uncertainty management in illness, this study identifies and furthers our understanding of how people with POTS manage and are affected by uncertainty in various contexts while being ill. Specifically, I analyze what issues characterize participants' medical, personal, and social

uncertainty and also what strategies are enacted to manage uncertainties. The overall goal of this study is to expand knowledge on how people with POTS, and broadly people with invisible disabilities, manage uncertainty and privacy.

In this thesis, I first give more background and information on the nature of POTS. Subsequently, I begin my review of literature starting with Communication Privacy Management Theory and moving into Uncertainty Management Theory, posing research questions driven by each theory. Next, I explore the interconnectedness of CPM and UMT, leading to my final research question on how uncertainty may affect privacy negotiation and rule formation. These questions then lead to my description of the methods that were employed in the study. Following this, I present my findings and my discussion of the theoretical and practical implications of these findings.

The third research question of this study asks: *what strategies do people with POTS use to manage uncertainty about illness, personally and socially?* The interviews revealed that many participants felt that they were not in control of the management of their uncertainties, and this made it much harder for participants to employ strategies. Though strategies were limited, two clear strategies emerged. The first strategy found was acceptance of the uncertainty surrounding POTS. The second strategy was honest communication and this strategy functioned both personally and socially to manage uncertainty.

Literature Review

This study uses two theoretical frameworks as its: Communication Privacy Management Theory (CPM; Petronio, 2002) and Uncertainty Management Theory (UMT; Brashers et al., 2002). In this chapter, I first present the theoretical framework of CPM and its tenets. Then, I review how CPM has been used to analyze the communication challenges of people with invisible disabilities, like POTS. After my discussion on CPM, I present my first research question. I then move into how Uncertainty Management Theory can be used as a lens to study the uncertainties faced by people with POTS. Gaps still exist in our understanding of the function of uncertainty and there effects on people with invisible disability. Following this review of UMT and communication literature, I present my second and third research questions. Finally, I explore the interconnectedness of CPM and UMT, so I can present my fourth and final research question on how uncertainty may affect privacy negotiation and privacy rule formation. Before exploring these theoretical frameworks, I begin by defining and explaining POTS.

Postural Orthostatic Tachycardia Syndrome (POTS)

POTS is a dysfunction of the autonomic nervous system (ANS). The ANS is part of the peripheral nervous system, “which controls all unconscious bodily functions, including heart rate, blood pressure, digestion, bladder function, pupil constriction, body temperature and stress response” (Busmer, 2011, p. 19). In addition to symptoms involving the malfunctioning of the ANS, POTS patients also describe trouble with concentration, distraction, and functional memory that disturb personal and work life (Anderson et al., 2014). The nervous system is split into the sympathetic and parasympathetic systems. The sympathetic controls the expenditure of energy. The parasympathetic controls rest and

recovery. The body needs this to maintain homeostasis. However, when it comes to POTS patients, their nervous system does not fire correctly (Fedorowski, 2019). Recurrent episodes of syncope (passing out) can lead to mental distress and psychosocial dysfunction, seriously interfering with quality of life and potentially increasing the incidence of mood or anxiety disorders (Anderson et al., 2014).

POTS is a chronic illness that is often poorly recognized by medical professionals and also poorly understood. At the onset of POTS, a patient's symptoms are often misconstrued as an anxiety disorder, and so the patient faces further mental distress, as they cannot receive an accurate diagnosis (Dysautonomia International). Without diagnosis, patients often feel hopeless (Slattery, 2017). There is a general feeling of relief when a diagnosis is finally received even though the prognosis is not good (Paturel, 2015) as "there is no cure for POTS but symptoms can be managed to improve quality of life" (Busmer, 2011, p. 21).

There are many unknowns when it comes to living with POTS. For example, misdiagnosis and lack of knowledge have led POTS patients to be asked by doctors, "Are you on drugs? Are you sure you this isn't just in your head? And, are you just depressed?" (Slattery, 2017, p. 15). On top of lack of knowledge that impedes diagnosis, doctors also do not have treatment programs and attempt to help with the symptoms of POTS by administering cardiac and opioid drugs (Agarwal et al., 2007). However, these drugs will not cure POTS and each drug comes with additional side effects such as vomiting, fainting, confusion, and driving restriction, to name a few (Dysautonomia International, 2012). In short, living with POTS can be living in uncertainty. Because POTS patients have to handle higher levels of uncertainty, it can affect them interpersonally and intrapersonally

(Agarwal et al., 2007). Part of that uncertainty stems from an unclear prognosis as the leading expert neurologists for POTS are vague on the prognosis for POTS patients (Fedorowski, 2019). Experts tentatively believe that if a person has POTS for over five years, they may not go into remission and will face a lifelong battle with the disease (“Postural Tachycardia Syndrome Information,” 2018). It is also stated that developing POTS before the age of eighteen gives the potential to grow out of it (Dysautonomia International, 2012). However, there is no official consensus on this prognosis (Fedorowski, 2019).

Having discussed the broad range of symptoms faced by people with POTS, it is important to reiterate that these often-severe symptoms do not present with obvious disability cues to an onlooker. POTS is often classified as an “invisible illness” in medical literature, but it is important to remember that POTS is a disability and therefore invisible disability is more applicable (Anderson et al., 2014). This is an important distinction because illness may have the connotation of being acute or short-term, whereas disability communicates the chronic, long-term, implications of having POTS. The Invisible Disabilities Association, in 2019, estimates that 10% of Americans have an invisible disability, however exact prevalence is difficult to acquire because of the terminology differences used in literature (Invisible Disabilities Association, 2019; Matthews & Harrington, 2000). The terms ‘hidden’ and ‘non-visible’ indicate that a person’s disability could become visible if someone looks carefully (Matthews & Harrington, 2000). However, invisible implies that the disability cannot be seen at all (Matthews & Harrington 2000). Dealing with symptoms on a daily basis with no end in sight poses challenges in daily life.

Those with invisible disabilities face their own unique communication challenges when it comes to disclosure and relating to others (Allen, 2004; Garland-Thomson 2010).

Communication Privacy Management Theory (CPM)

Communication Privacy Management Theory (CPM; Petronio, 2002) is the first guiding theory of this study. CPM is an important theory for explaining how people view their private information, manage privacy boundaries, navigate control and ownership, form privacy rules, and how people conduct privacy management dialectics. Petronio has been working on the development of CPM for more than 30 years with the aim of solving everyday problems through the application of theory. CPM's applications make it an ideal fit for studying the communication challenges faced by people with POTS. The goal of this study is to improve the way that people with POTS and, in turn, other invisible disabilities, negotiate privacy in a society that doubts their validity.

Five suppositions of CPM. Petronio's (2002) theory of CPM is grounded in five specific suppositions about the exchange of private information. These five suppositions include: private information, privacy boundaries, control and ownership, rule-based management, and privacy management dialectics. Petronio's five suppositions allow scholars to use the theory for practical application and gain an understanding of systems of privacy management (Petronio 2007).

The first supposition of CPM states there is a unique interplay of intimacy and privacy within human communication and relationships, because intimacy and privacy are separate yet fundamentally related to disclosure. Petronio (2002) explains scholars can better explore the relationship of privacy and intimacy as separate but related by making privacy information the subject of disclosure. As self-disclosure and intimacy are

fundamentally related, the goal of self-disclosure is often intimacy because implicitly this is how people seek to advance their relationships (Petronio, 2002). According to Petronio (2002), intimacy is a conglomeration of “affection, expressiveness, compatibility, cohesion, sexuality, conflict resolution, autonomy, and identity.” (p. 143). Intimacy covers a vast array of aspects of close relationships. However, in the disclosure of disability, such as POTS, this is not always the circumstance. In this case, disclosure may result in embarrassment, discrediting, or shame. Though this consequence may occur in the able bodied, the negative behaviors are specifically tied to the ability of the person with a disability. If a person with POTS faints or pukes at their job, co-workers are shocked or confused by these symptoms especially if they are continual (Agarwal et al., 2007). This can leave the person with POTS feeling like they do not have a choice in disclosing their private information (Braithwaite, 1991).

Subsequently, supposition two contends that privacy boundaries are integral to whether a person chooses to disclose or not disclose. Petronio introduced the notion that people, personally and/or collectively, believe that they own the rights to their individual private information. Privacy boundaries are the lines of ownership that mark out people’s private information. The individual manages personal boundaries, but two or more people manage collective boundaries. The management of a collective boundary can range from just two people, to a family, to a community, and even a society. Petronio (2002) argues that once an individual decides to disclose private information with another person or people, the recipients of said information become co-owners of the information with the discloser. For example, if a person with POTS discloses their diagnosis to a friend, then that friend is also an owner of that information. Boundary turbulence will occur if the person

with POTS does not agree with how this friend discloses this private information. For example, if the person with POTS makes an explicit request that the friend not share this information with anyone else, and, if the friend does not follow this rule, there will be boundary turbulence. This example illustrates the collective boundary of two people with the private information of disability and illness. A study done on private health information and family communication found that coordination of collective boundaries was essential in the family to avoid stigma, obtain social support, and receive the proper medical care and treatment (Ebersole & Hernandez, 2016).

Information can be shared to form collective boundaries, but the question remains as to who is in charge of this information. Petronio's (2002) third supposition states that private information is something that an individual can own. This perceived ownership gives individuals the power to choose to disclose or not disclose private information. There are three levels of control represented by the spectrum of thick to thin boundaries, including: High control (secrets), moderate control, and low control (openness) (Petronio, 2002). For example, literature suggests there is usually thick boundary around the private information of being infertile to avoid uncomfortable conversations, pity, and stigma (Steuber & Solomon, 2012; Ebersole & Hernandez, 2016). The higher the level of control, the more selective an individual may be on disclosing. Disclosing invisible disability may have a high control boundary because of stigma, discrediting, or shame, but this information may have to be disclosed for the sake of safety or comfort of the able-bodied. For example, 80% of POTS patients experience syncope (fainting), and disclosing this to individuals such as co-workers may be important for the patient's safety at work and for

the comfort of bystanders (Petronio & Kovach, 1997). This forfeits the privacy of the individual for the collective (Petronio & Kovach, 1997).

It is important to this study to explain why this stigma is prevalent in relation to disability because disability has been stigmatized for thousands of years and this stigma may affect disclosure. Much stigma around disability stems from the Western world's focus on the medical model approach to disability (Linton, 1998). Linton (1998) argues that the modernization of medicine and the increased diagnosis of the disabled led to an altered perception of people with disabilities by able-bodied individuals (Iwakuma & Nussbaum, 2000). The medical model of disability makes disability the sum of the individual, a problem that is medical and needs to be corrected or cured, meaning if medicine could eradicate disability then it should. The medical model ignores social structures, cultural implications, and marginalization (Allen, 2004). Structurally, It is evident in the lack of thoughtful design of most everyday buildings and events (Bricher, 2000). The medical model influences the structure of educational systems, medical practices, social policies, and our laws (Bricher, 2000). When disability is spoken about, people are first to notice what is different about a body or mind. There is an implicit demand to bring disability closer to an idealized "normal" (Bricher, 2000). Western cultures have a commonly held belief that disability is a disqualifying factor for full participation in society and daily life (Garland-Thomson, 2012; Linton, 1998). This view is grounded in "eugenic logic, which tells us that our world would be a better place if disability could be eliminated" (Garland-Thomson, 2012, p. 341). The model is situated in an "ideology of normality" which has strict views on what is deviant and therefore cannot be normal (Allen, 2004). This perspective has dominated policymaking, for example the Americans with Disabilities Act

was not enacted until 1990. The focus is on curing the disabled and not on improving the civil rights for people with disabilities (Allen, 2004). It is important to acknowledge the social construction of disability and stigma because this greatly affects the risks of disclosing disability.

Stigma affects ownership of private information, but it can also affect how people create rules for disclosure. This is explained in supposition four, rule-based management system (Petronio, 2002). This management system explains how private information is regulated through the different levels of disclosure. When someone receives a disclosure, they become a responsible party of managing the discloser's private information. As a result, information co-owners must engage in boundary coordination. Boundary coordination means accepting the management of both personal and collective boundaries, as individuals must not only coordinate their private information but they also become guardians over the information shared with them (Petronio, 2002). Within the context of health discourses, the individual that discloses often perceives that it is implicitly known that the co-owner(s) should not share their information. Because of this, the discloser and recipient often do not set explicit boundaries around this private health information, because people believe that they still solely owned their health information (Smith & Brunner, 2016). Culturally, health information is implicitly private to many people, so the disclosure may believe there is implicit understanding when there is not (Smith & Brunner, 2016). The implications are that there is a greater chance of boundary turbulence when boundaries are only implicitly set, and therefore if health information usually have implicit boundaries then health disclosures may be fraught with more turbulence (Petronio, 2002; Smith & Brunner, 2016).

Following rule-based management, Petronio's (2002) final supposition is privacy management dialectics. "Dialectics" are the assumption that people experiences a tension of oppositions and contradictions in their social life (Petronio, 2002, p. 12). Petronio uses this supposition to highlight the interplay of dialectics and regulation of private information, suggesting, "the theory is grounded in the unity of dialectics including disclosure-privacy, public-private, openness-closedness, and autonomy-connectedness" (Petronio, 2002, p. 12). Dialectics in this context refer to the extent to which people experience social tensions between contradictions and opposites (Petronio, 2002). CPM focuses on the open-closed dialectic because it highlights the tension people feel between revealing private information and concealing information to maintain privacy (Petronio, 2002).

In addition to the five suppositions of CPM, it is important to highlight privacy is an intimate possession that is a part of who we are as humans. According to Petronio and Kovach (1997), "Privacy accords a sense of individualism and control over one's life" (p. 116). Control is meaningful because as Petronio (2004) details people believe they have they right to own their information, to forfeit that is a loss of rights. This is complicated by disability. Often privacy is stripped in the name of safety, essentially degrading the individual's sense of autonomy (Petronio & Kovach, 1997). Petronio & Kovach (1997) studied a nursing home in Scotland to analyze how declining health affects privacy. They found that, "Elders often have to give up the privacy of their bodies to accommodate health conditions" (Petronio & Kovach, 1997, p. 115). People with POTS also have to forfeit their privacy to accommodate the able bodied. For example, a person may have to forfeit privacy in school to receive accommodations such as ice packs, laying on the floor, and leaving the

room. Petronio & Kovach (1997) argue, “the balance of privacy and caring becomes an ambitious undertaking” (p. 116). There is great uncertainty on how to manage privacy connected to the balance of safety and comfort of the able-bodied. Invisible disability may be another factor that complicates this balance even more because it has to be disclosed to be known (Mishel, 1990).

While navigating this tension between disclosing health conditions for accommodation and concealing because of privacy, there are a host of issues that can arise. For example, even pre-diagnosis when people with POTS disclose symptoms to doctors they are often discredited based on the doctors’ lack of knowledge (Paturel, 2015). Feeling discredited by a trusted health professional could potentially lead to a greater control on boundary security because embarrassment, shame, and anger may be risks they do not want to face again. The tension here is that the people with POTS must continue to go to the doctor and disclose even when they are not believed in order keep fighting for diagnosis. Indeed, the average wait time from onset of symptoms to diagnosis of POTS is 5-7 years (Dysautonomia International, 2014), thus making privacy negotiation inherent and frequent when living with this invisible disability. This 5-7 year average means that people with POTS are in and out of the doctor’s office and trying to negotiate much needed accommodation with no documentation of diagnosis.

Three management processes of rule development. Petronio’s five suppositions add understanding of systems of privacy management, but in order to understand the complete system, CPM includes explanations of the management processes of rule development. CPM is based on the assumption that rule management processes regulate the degree to which an individual will reveal or conceal private information (Petronio,

2002). People create and learn rules regarding to whom they should disclose and how much or how little to disclose to them. These rules shape social interactions around disclosure (Petronio, 2002). The three rule management processes of CPM include: "(a) foundations of rules ranging from the way they are developed to the elements that make up their attributes, (b) boundary coordination, and (c) their turbulent nature" (Petronio, 2002, p. 23).

The first management process is privacy rule formation. This process is twofold: development and attributes, meaning that a person's development and attributes will affect how they create privacy rule (Petronio, 2002). Exploring how development and attributes affect the formation of privacy rules helps to understand why individuals reveal and conceal the way they do. As CPM theory grew from its debut, reviewers had questions about how people come to exist within the context of Petronio's suppositions. To address this, Petronio expanded the theory with five criteria for rule development. "The best framework seemed to consider the criteria on which people judge whether to reveal or conceal" (Petronio, 2004, p. 203). Culture, gender, motivations, contextual restraints, and risk-benefit ratio are fundamental to the origin of these rules (Petronio, 2004). Studies have shown that women are more likely to disclose to other women and/or same-sex partners than to men (Petronio, 2004). This means that most people's privacy rules are geared to disclose more to women than men regardless of their own gender. Risk-benefit ratio is also integral to POTS because of the stigma of invisible disability. "Risks and costs include: embarrassment, unwanted sympathy, being misunderstood, or making the self or other uncomfortable" (Braithwaite, 1991, p. 256). This is important because all four of

these risks, can seriously inhibit disclosure. These risks may weigh heavily when being balanced with benefits because they are strong negatives.

Boundary coordination is the next process of management of rule development. The foundation of this process is that private information has both personal and collective boundaries (Petronio, 2002). The establishment of rules is very important with not only our individual private information, but also with others. People coordinate these rules to relieve the tension of revealing and concealing. When individuals become privy to private information they become co-owners of that information thus creating a collective boundary (Petronio, 2002). This addition is important because it explain that more than just coordination happens, but that people have to manage these boundaries and craft their own rules to negotiate them.

Co-owners regulate their boundary management through boundary linkage, boundary ownership, and boundary permeability (Petronio, 2002). Boundary linkage occurs when others become privy to private information. The discloser and the co-owner become linked on the boundary around the information. This also includes if a third party becomes aware of someone else's private information. This linkage may be based on attraction, gender, and interpersonal relationships and is used as way to connect with others (Petronio, 2002). Boundary ownership signifies the rights and privileges that the co-owner perceives as theirs with another's private information. Rules are set to manage the co-owner, but if these rules are implicit or ignored, the co-owner may violate the rules causing tension (Petronio, 2004).

The third and final management process is boundary turbulence. Turbulence occurs when collective boundaries are disturbed (Petronio, 2002). This happens when a co-owner

violates management rules. Boundary negotiation is complex and dynamic. This means that when turbulence occurs, renegotiation of the rules is vital, and this does include self-correction (Petronio, 2004). CPM gives us a theory to analyze how people with invisible disabilities, such as POTS, make judgments over revealing and concealing private information (Petronio, 2002).

CPM & invisible disability. There is minimal research on how people with invisible disabilities manage privacy, but there are a handful of scholars that have made a distinct effort to expand understanding. Matthews (1997) sought to address this gap by investigating shame among people with invisible disabilities. She found that people with invisible disabilities do not disclose except for “practical” reasons. Practical reason might include accommodations, making an able-bodied person feel more comfortable, or explaining a behavior such as fainting (Matthews, 1997). This study revealed that people with invisible disabilities “felt disclosure would elicit unwanted sympathy, invite judgment, and damage existing relations with people who might not understand their disability, and most significantly, might not find them believable” (p. 409). Hayden (1993) found similar results in her study of disclosure among people with chronic illness. She found that disclosure is mainly based in practicality for the individual, and that individuals only disclosed when they felt they would not be judged or pitied and that they would be believed. At the heart of these disclosures was a need to manage the risks of disclosing the “deviance” of their illness or disability (Hayden, 1993). This means that disability disclosure as risks attached, Hayden conceptualizes this as deviance, but this could also be considered the risk of being stigmatized.

In addition to observing the myriad of reasons why people with disabilities do not disclose diagnoses, research has analyzed the differences in privacy management between the able and the disabled. There is a large gap in understanding of meanings of disability between people with disabilities and the able-bodied (Hayden, 1993). The root of this was that those chronically ill have a “different language” to explain their experience which the able-bodied cannot understand without the real life experience of living with something like chronic pain (Hayden, 1993). In one study, participants consistently reported feeling more understood by those with similar life experiences (Turner & Kelly, 2000). This barrier creates inherent boundary turbulence because meanings of disability do not match up. To combat this, Hayden (1993) suggested imagination as a strategy, allowing the ill to help the well visualize their struggle

Disclosure of a disability is based on upon perceived practicality (Blockmans, 2015). CPM declares that disclosure is primarily based on the goal of greater intimacy, but Blockmans (2015) concluded that people with disabilities have to disclose primarily out of whether it is practical or not. For example, a person with a disability may feel compelled to disclose to their teachers because of a need for accommodation. This is an important finding, because it is distinctly different from Petronio’s assumption that people disclose for deeper intimacy. If people with disabilities are not disclosing for deeper intimacy this could affect their relational maintenance and overall well-being. The emotional energy to disclose could affect how people with disabilities use or do not use disclosure to further deeper intimacy.

While Blockmans’ (2015) approached disclosing disability from a hybrid framework of CPM and psychology, Braithwaite (1991) sought to address this gap through the use of

CPM solely. In her study, Braithwaite (1991) focused specifically on how visible disability and privacy management function. Specifically, Braithwaite (1991) sought to understand the privacy management that a visible disability poses, for example how a person with a disability responds when a nosy person asks how much their wheelchair costs. People with disabilities strive to establish themselves as individuals before disclosing their disability or illness because they are worried about being categorized as only disabled (Braithwaite, 1991). Furthermore, people with physical disabilities do not disclose at random; disclosure is calculated based on the context and risk-benefit ratio (Braithwaite, 1991). While Braithwaite's study revealed how much management someone with *visible* disabilities has to do, it does not discuss the uncertainty of managing these boundaries and the extreme pressure to disclose, especially when the disability is invisible. It is helpful to understand people with physical disabilities do not disclose at random because it gives reference to study invisible disability disclosure.

There is a gap in our knowledge on how invisible disability presents specific privacy management challenges. Invisible and visible disabilities both have privacy challenges, but it is important to note that individuals with invisible disabilities reveal and conceal more often and more private information because their ability is not readily visible (Matthews & Harrington, 2000). People with invisible disabilities are also less likely to be believed when it comes to disclosing disability than those with visible disabilities, which complicates disclosure (Matthews & Harrington, 2000). This is important to explore because people with invisible disabilities deserve to have a voice in these foundational privacy rules and management. People with invisible disabilities may have different challenges when it comes to rule formation and disclosure that have not been considered in current research.

This study seeks to analyze how individuals with POTS, an invisible disability, perceive and struggle with the management of their privacy. Thus, the following research question:

RQ1: How do POTS patients decide whether and how to disclose information about their invisible disability in everyday life?

Uncertainty and Communication

Having discussed the relevant literature on CPM, I will now move on to my second theoretical framework, Uncertainty Management Theory (UMT; Brasher 2001). Uncertainty has been conceptualized and theorized in various fields using both quantitative and qualitative methods because it is an innate part of our human communication (Berger & Calabrese, 1975). High uncertainty and serious illness are conjointly related, and the more complex the illness, the more complex the uncertainty management (Brashers et al., 2003). In the following sections, I discuss how uncertainty reduction and illness uncertainty evolved into Brashers' work on Uncertainty Management Theory. I then explain the structure of UMT and the theory's contributions in the field of communication studies. This evolution has begun to extend into health communication and serious illness specifically. Through my review of literature, I identify the gaps that still exist in our understanding of the function of uncertainty and their effects on people with invisible disabilities. Following this review of uncertainty and communication literature, I present my second and third research questions.

Uncertainty Management. Early theories on uncertainty focused on the need to reduce uncertainty, but based on criticism the study of uncertainty shifted to how uncertainty is managed (Sunnafrank, 1986; Kellerman & Reynolds, 1990; Knobloch & Miller, 2008). Many theories represent this movement towards management instead of

reduction including Problematic Integration Theory (Babrow, 2000), Uncertainty Management Theory (Brashers, 2001; Brashers et al., 2002), and Knobloch and Solomon's (2002) concept of relational uncertainty. The individual details of these newer theories vary, but at their core they all assume that uncertainty is not always negative, does not always need to be reduced, and people manage uncertainty in different ways. This means that people not only consider what behavior is likely or unlikely, but also whether the behavior may be helpful/harmful (Brashers, 2001; Brashers et al., 2002). If person with an invisible disability believes someone will have a positive and helpful response to something such as helping them walk, then they are more likely to disclose that they need assistance. However, people may lack the information in order to clearly evaluate responses and also may have difficulty integrating these two elements. This shift still reinforces that communication is the essential component to managing uncertainty (Brashers, 2001; Brashers et al., 2002).

Taking this concept that uncertainty does not always need to be reduced, Babrow (2001) and Mishel (1990) explored the management of uncertainty specifically in a health communication context. People with serious illness experience various forms of uncertainty and its management throughout the trajectory of their illness (Babrow, 2011). Uncertainty about illness arises from how people relate to their illness, whether this is based on how complicated their symptoms are, complex information from doctors, thoughts on prognosis, or how to integrate this new health knowledge into their daily life (Babrow et al., 2000). Indeed, uncertainty is a critical variable that influences a broad range of a patient's experience. This could include uncertainty about their doctor's ability, prognosis, medicine effectiveness, treatment plans, and so on (Mishel, 1990). Uncertainty

occurs “in the form of vagueness, ambiguity, unpredictably, and lack of information” in health contexts (Mishel, 1990, p. 258).

Both Babrow (2001) and Mishel (1990) define uncertainty as the inability to decode illness contexts. The conceptions of uncertainty and illness by Babrow (2002) and Mishel (1990) while practical, only focus on how illness uncertainty affects people in health contexts. Uncertainty about illness, however, does not exist in a vacuum separate from social and personal lives.

Uncertainty Management Theory. Drawing on Babrow and Mishel’s work, Brashers sought to deepen our understanding of how individuals respond to uncertainty.” Like Babrow, Brashers believed that uncertainty was much more complex than other models suggested. Mishel’s (2003) work with HIV patients also added to his conviction to add to our knowledge on uncertainty. With both Babrow and Mishel as inspiration, Brashers developed UMT.

UMT primary contribution is that it emphasizes how uncertainty makes people respond both communicatively and psychologically. Brashers defines uncertainty as existing “when people feel insecure in their own state of knowledge or the state of knowledge in general about a topic” (Brashers, 2001, p. 478). The assumption of uncertainty as positive or negative is based on the person’s emotions toward the uncertainties. For Brashers (2001), uncertainty is not inherently positive or negative, and it is not also something to be reduced but instead uncertainty can be managed, increased, or decreased based upon the person’s feelings toward the uncertainty. Although these conceptions can be applied in other context, Brashers has a clear emphasis on health decisions. For Brashers, the core of uncertainty for people with serious illness is that

uncertainty does not always need to be reduced. To illustrate, when it comes to prognosis, uncertainty can serve to foster hope and therefore individuals may want to preserve the uncertainty. For instance, because doctors know so little about when a person with POTS could go into remission, uncertainty can foster hope that remission could occur at any time rather than the hopelessness of the belief it may never go away. Brashers argued that we must shift the understanding of uncertainty in order to recognize how people cope with it. Brashers argues if uncertainty is inherently anxiety-producing and needs to be reduced then there is no way to understand how people like a POTS patient can perceive uncertainty as hope (Brasher 2001).

UMT assumes that all emotional responses are about the perception of the individual and not the uncertainty itself. Brashers (2001) argued that negative responses to uncertainty happen when that uncertainty is perceived as dangerous state meaning that that knowing the information by lead to harm. Positive responses occur when the uncertainty is seen as preferred state meaning that “not knowing is better than knowing that harm is inevitable” (p. 262). Neutral responses occur when the person perceives the uncertainty as not relevant that they know more about the issue. Brashers (2001) also argues you can experience negative and positive emotions to the same uncertainty; for example one might feel both excited and worried when engaging in activities like sky diving.

Also with these previous stated assumptions, UMT argues that uncertainty management should be viewed through three lenses (multilayered, interconnected, and temporality), which are labeled as the tripartite model (Brashers et al., 2003). First, uncertainty should be considered to be multilayered. People are embedded in layers of

contexts that make up their whole situation whether the contexts are positive or negative. For example, someone with POTS is not just worrying about the effects of their symptoms, but there could also be uncertainty about their doctor's skill, the effect of their illness on their relationship with a partner, and how society may view them. Brashers (2001) argues that uncertainty can be about the self, others, relationships, and other features of contexts. Uncertainty about self and others includes beliefs, behaviors, abilities, and values that the self or others hold. Uncertainty about relationships is questioning the durability and quality of specific relationships. Brashers (2001) articulates that other contexts include social norms, rules, and conventional procedures. In the context of POTS, the severe symptoms can affect all aspects of life, from not being able to go out with friends, to not being able to do favorite activities, and renegotiating relationships.

Not only are uncertainties multilayered, but they are also interconnected with one another (Brashers et al., 2002). This means that one uncertainty about health can snowball from one layer (self, others, relationships, and contexts) into others. For example, uncertainty about the severity of symptoms can lead into uncertainty about lack of information on POTS into concerns about financial stability (Brashers et al., 2002). Specifically, a POTS patient may be uncertain if a symptoms flare result in needing to stay the hospital for a few days, which in turn leads to uncertainty regarding how to pay the medical bill. Each uncertainty is like a chain connecting one focal dilemma to the next.

Temporal dimensions are the third part to Brashers et al. (2002) tripartite model. Brashers (2001) asserts that uncertainties can be short-term and long-term. Uncertainty can be transformed over time as one problem reaches resolution and another takes its place. This is important in the study of invisible disability, specifically with POTS, because

symptoms vary over time. Short-term uncertainty for someone with POTS could be a situation such as, “Will I make it up the stairs without passing out?” or “Will my friend be mad if I cancel plans because I feel too sick?”(Brashers et al., 2002). While long-term uncertainty might include wondering if remission will ever occur.

The three parts of Brashers’ (2001) theory serve as a strong guiding framework to study uncertainty when it comes to invisible disability. The three considerations of uncertainty being multilayered, interconnected, and temporal allow for a holistic view into the life of someone living with an invisible disability like POTS because they have unique communication challenges. The layers in Brashers’ (2001) theory suggest that uncertainty is experienced through several sources at once. One uncertainty can increase or decrease other uncertainties around living with POTS. And lastly, experiences of uncertainty are in flux and change through time.

Brashers (et al., 2003) using these foundations assumptions tested the theory in health contexts and found that people with serious illness experience uncertainty medically, personally, and socially. Each of these types of uncertainty (medically, personally, and socially) are assumed as multilayered, interconnected, and temporal. This expanded Mishel’s (1990) and Babrow’s (2001) conceptualization of the interplay of illness and uncertainty outside just the context of medical uncertainty. These sources of uncertainty were identified and reaffirmed in studies on HIV (Brashers et al., 2002), type 2 diabetes (Middleton et al., 2012) dementia (Stone & Jones, 2009), and organ transplantation (Martin et al., 2010).

These three sources of uncertainty (medical, personal, and social) pervade the life of a person living with serious illness. According to Brashers et al. (2003), medical

uncertainty occurs as people attempt to understand their diagnosis and symptoms. In past studies, medical uncertainty has presented as uncertainty surrounding symptoms, treatment options, prognosis and diagnoses (Martin et al., 2010). Brashers et al. (2003) states that personal uncertainty occurs when people attempt to understand the implications of their health on their identities, roles both personal and professional, financial stability. Previous studies have found personal uncertainty on disability status, treatment costs, employment obligations, and insurance procedures (Brashers et al., 2003; Martin et al., 2010). Social uncertainty happens when people are unsure how to navigate social situations, interpersonal interactions and relationships, and the affect of their health on others (Martin et al., 2010). Going out and being social with friends and family was a part of relational maintenance and after developing POTS social outing abilities were greatly affected causing uncertainty.

Brashers' (2001) theory serves as a strong guiding framework to study uncertainty when it comes to invisible disability. Brashers (et al., 2003) found that people with serious illness experience uncertainty medically, personally, and socially, and the uncertainties within these categories are multilayered, interconnected, and temporal. I believe this nuanced model can help gain understanding of the specific issues that face people with POTS, medically, personally, and socially. These assumptions lead me to consider the following research questions:

RQ2: A) What issues characterize medical uncertainty in people with POTS? B) What issues characterize personal uncertainty in people with POTS? C) What issues characterize social uncertainty in people with POTS?

RQ3: What strategies do people with POTS use to manage uncertainty about illness, medically, personally and socially?

CPM & Illness Uncertainty

When researching the experiences of people with POTS negotiating privacy and uncertainty, it was important to explore not all how privacy and uncertainty affect participants separately but how they affect and inform each framework. There is scant literature that attempts to bring CPM and UMT into conversation with one another, but therein lies a gap for fruitful research. This study is an opportunity to expand knowledge on uncertainty and disclosing invisible disability from a nuanced perspective. The importance of this endeavor is to make uncertainty and privacy management narratives available and applicable to others with invisible disabilities that are potentially also bombarded with uncertainties and disclosure decisions.

This study seeks to examine how illness uncertainty affects a person's management of privacy. Babrow (2001), Mishel (1980) and Brashers (et al., 2003) made great strides to gain understanding on how uncertainty functions for people with illness. However, there are still important areas of illness uncertainty left to be discovered. Petronio (2010) touches on this dilemma in the context of illness when someone discloses illness and the uncertainty may be too much for recipient to handle. By combining these two theoretical frameworks, there is opportunity to learn and better understand the experiences people with invisible disabilities through the study of POTS.

Uncertainty may be a barrier to making privacy management rules and to negotiating when to disclose. For example, the relational turbulence theory contends that relational uncertainty disrupts the ability to make sense of situations because of the lack of

information (Solomon, Knobloch, Theiss, & McLaren, 2016). This has implications for the combination of CPM (Petronio, 2002) and UMT (Brashers, 2001). For example, too much uncertainty because of illness could disrupt the ability to create privacy rules. It could be possible, like in the relational turbulence model that uncertainty may cause trouble coding and decoding messages that could contribute to how one might reveal and conceal private information. This uncertainty about self-beliefs, other's beliefs, relationships, and other contexts may overwhelm decisions to self disclose (Petronio, 2002).

Uncertainty can create reactivity and turmoil that is unaccounted for in CPM. Reactivity means perceiving situations as more negative or harmful to their relationship (Knobloch, 2010). This is an interesting implication of how Brashers' (2002) conception of uncertainty will affect people with invisible disabilities. Reactivity and turmoil would affect how a person would negotiate collective boundaries and self-disclosure (Petronio, 2002). If people are experiencing a range of negative emotions this may influence how they influence the cost and benefits of disclosure and/or how open or closed their boundaries for disclosure may be.

Disability highlights the unpredictability and instability of living in the human body. As Braithwaite found in her 1991 study of disclosure and disability, people with disabilities must balance the risks and costs of disclosing disability. Risks included specifically, "embarrassment, unwanted sympathy, being misunderstood, or making the self or other uncomfortable" (Braithwaite, 1991, p. 256). Similarly, people consider what behavior is likely or unlikely, and whether the behavior may be helpful/harmful when managing uncertainty (Brashers, 2001). At the heart of disclosing diagnosis is a need to manage the risks of disclosing the "deviance" of disability (Matthews, 1997; Hayden, 1993).

Management of uncertainty on how people may react could directly affect privacy management. Scholars have acknowledged the balancing of risks and benefits when deciding to disclose (Hayden, 1993; Matthews, 1997; Braithwaite, 2000; & Petronio, 2002), however they do not explore the effect of uncertainty management in weighing out these, hence I ask:

RQ4: How does the management of uncertainty affect how POTS patients share private information surrounding their illness?

Method

To understand the experiences that people with POTS face, I conducted a qualitative investigation of how people with POTS negotiate privacy and manage uncertainty and how their uncertainty affects their privacy management. This study sought to use the lens of uncertainty and privacy management along with emergent themes to get to the heart of the lived experiences of people with POTS. I was not trying to generalize their experiences, instead I analyzed what they have in common. This endeavor contributes not only to information for people with POTS, but also others with invisible disabilities.

In this section, I provide an explanation of myself as the researcher, an overview of the participants of this study, the techniques of my data collection, and the procedures to be employed in analyzing that data. Before conducting interviews, I obtained Institutional Review Board (IRB) approval.

Role of the Researcher

The researcher is an instrument in collecting and analyzing data in a qualitative study. As a researcher, my experiences are important to this study. As a person with POTS, I have an innate connection to my participants. I was a collegiate athlete when I developed POTS. Before the onset of symptoms and diagnosis, my body was in peak physical condition. I could run multiple miles and play soccer for over 50 hours a week. Within just a month, however, my world changed. I could barely get up a flight of stairs without passing out. I could not shower without passing out. I could not even go to the bathroom by myself. POTS was a drastic and life changing event for me. I had to fight to get out of bed. I had to fight to even dress myself. My journey with POTS has been long-lasting, and I have dealt

with the ramifications of this disability for five years. Therefore, I have a strong grasp on what POTS is and the community that is affected by it.

I lived at Mayo Clinic in a POTS and pain rehabilitation program for a month and a half. During the course of my stay, I was confronted by the many lived experiences faced by my peers with POTS. It lit a fire within me to move academic research to a place where people with POTS, and all people with invisible disabilities have a voice for their unique struggles. The importance of studying the experiences of people with POTS is to improve the way these individual, and others with invisible disabilities can negotiate privacy and uncertainty in a society that doubts the validity of their disability.

My experience living with POTS gave me a strong ability to effectively guide my participants through semi-structured interviews. As an interviewer, it is my job to help my participants articulate their meanings through my comments and questions (Charmaz, 2006). During the interview process, I was able to ask for clarifying details to accurately describe my participants' experiences (Charmaz, 2006). My positionality as someone with the same invisible disability gave me the ability to relate and more accurately portray my participants' lived experiences.

Participants

Twenty-four in-depth interviews were conducted in order to obtain data saturation. To qualify for this study, participants had to be diagnosed with POTS and be at least 18 years old and speak English. The twenty-four participants interviewed ranged in age from 18 to 60 ($M = 32.7$, $SD = 12.3$). 80% of participants identified as female, 12% of participants identified as male and 8% identified as non-binary. This distribution is consistent with the average of women versus male identifying and non-binary with POTS

(Fedorowski, 2019). The length between onset of participants' symptoms to POTS diagnosis ranged from one year to 20 years (M= 8.7) and they saw between 2 to 18 doctors before receiving a POTS diagnosis. Participants hailed from North America and Europe. Specific locations of participants will not be included in this study to protect the anonymity of participants because they could be the only person with POTS in that location and could be easily identified. Participants pseudonym and ages are included Table 1.

Table 1. Participant Information			
Participant	Age	Length of Interview	Pages of Transcript
Jacob	21	59:19	17
Eryn	23	29:41	12
Robin	57	33:22	14
Jane	28	59:22	32
Audrey	32	51:22	23
Raza	23	46:27	17
Ruth	60	58:25	24
Dianna Prince	50	48:02	18
Hannah	24	43:05	18
Mallory	28	56:52	17
Alex	26	34:15	14
Lara	30	40:26	15
Kristen	32	33:03	18
Darien	28	44:36	16
Kate	26	48:41	17
Clarke	31	27:37	14

Eve	27	36:00	16
Lexa	52	58:02	21
Hannah F.	29	29:18	12
Sarah	49	1:07:08	38
Jay	47	1:02:45	37
Ash	18	46:29	18
Hallie	24	43:42	18
Mitch	22	28:59	13

Recruitment. Snowball sampling (Lindlof & Taylor, 2011) was used to grow the sample size of known participants to data saturation. According to Bourgeault et al. (2010), snowball sampling is the most efficient way to reach populations that are hard to access or hidden. Recruitment began with known participants, and a few more participants were gathered through snowball. Dysautonomia International’s president and medical research board allowed for this study to recruit on their social media and list servers. The response was immense, and is promising for the future study of POTS. The IRB recruitment text can be found in Appendix A.

Procedure

Data collection. Qualitative interviews were used to examine the participants’ negotiation of privacy and uncertainty management when it comes to their invisible disability. Interviews are vital to create rich data from the lived experiences of the participants. The average of the interview lengths was about 45 minutes and the standard deviation was twelve. All interviews were transcribed in whole. With only quantitative

studies done on people with POTS, it was important to use interviewing to capture their stories and experiences through their own words and perspectives. All interviews were audio recorded with participants' permission. An informed consent form can be found in Appendix B. Interviews took place over Skype or the phone according to participants' preferences. The participants were recruited internationally, but had to speak English because of the limitations of the researcher.

Interview protocol. To explain the interview protocol, I present a review of all four of this study's research questions and what interview questions will be employed to answer them. The interview protocol can be found in the Appendix C. In order to answer RQ1 (How do POTS patients decide whether and how to disclose information about their illness in everyday life?), the questions were modeled with Communication Privacy Management Theory in mind. These questions inquired with whom and when participants choose to disclose their POTS diagnosis to better understand their specific privacy management rules. These questions investigated the privacy boundaries and rule formations surrounding this of this health information. Additionally, questions allowed participants to articulate the effects of disclosure surrounding invisible disability.

In pursuance of RQ2 (RQ2 a) what issues characterize medical uncertainty? b) what issues characterize personal uncertainty? c) what issues characterize social uncertainty?) and RQ3 (What strategies do people with POTS use to manage uncertainty about illness, personally and socially?), interview questions were grounded in Brashers (2002) Uncertainty Management Theory. Interview questions were used to target the different levels of uncertainty that participants deal with daily have. The goal was to uncover

management strategies by questioning the uncertainty around personal and social relationships.

Finally, in order to answer RQ4 (How does the management of uncertainty affect how POTS patients share private information surrounding their illness?), a hybrid of UMT and CPM was used to investigate the intersection of these theories applicability to the experience of having an invisible disability. The goal was see if participants' uncertainties about POTS (illness specific, personal, and social) could overwhelm their privacy management process.

Data analysis. CPM and UMT are the guiding communication lenses for this data analysis. These theories along with an iterative approach allowed themes to emerge by looking at how the data and theory interact (Tracy, 2013). The research questions and subsequent analysis are vital to revealing the lived experiences of participants in relation to theoretical frame works.

An iterative approach was used to analyze the data collected from my participant's interviews (Tracy, 2013). The focus of this study is the experience of living with POTS—an invisible disability. This methodology allows me to oscillate between emergent themes and my two guiding communication theories. According to Tracy (2013), “an iterative approach also encourages reflection upon the active interests, current literature, granted priorities, and various theories the researcher brings to the data” (p.184). This was a reflexive process in which I visited and revisited the data, theoretical insights, and themes.

As I approach the data, I had the research questions in mind. Analysis began with open coding, which is examination of small sections of the text made up of pertinent words, phrases, and sentences (Strauss & Corbin, 1998). Strauss and Corbin (1998) state that, “the

purpose of open coding is to help the analyst gain new insights into the data by breaking through standard ways of thinking about (interpreting) phenomena reflected in the data” (p. 423). With the iterative approach, the coding process was a reflexive process of visiting and revisiting theory, data, and current research. Axial coding followed open coding.

Axial coding is the process of identifying the relationships of sub-categories to their categories. This process led to further development and cultivation of my codes and categories (Strauss & Corbin, 1998). Codes and categories were compared and contrasted until saturation was reached (Creswell, 2007). For example my axial code of disbelief included open codes such as: can’t understand, refuses to understand, didn’t believe me, questions my explanations, thinks I am making up, won’t believe me, no matter how I explain, and credibility questioned. I followed Charmaz (2006) suggested guidelines for axial coding. Charmaz (2006) suggests to initial code data, create inductive categories, revise these categories, make memos about your codes, continually compare and contrast the data to the broader literature, crafting categories, and being aware of where the data does not fit into categories. This approach allowed me to be thoroughly immersed in the data and make more dynamic categories. The words of my participants guided the development of numerous codes and categories, which were cultivated into 16 axial codes. From these categories, I present my final themes.

Results

The twenty-four semi-structured interviews that I conducted produced a complex data set that further develops Uncertainty Management Theory and Communication Privacy Management Theory, as well as furthers understanding of the lived negotiations of privacy and uncertainty for people with invisible disabilities, specifically POTS. The purpose of this study is to expand research on invisible disability, through the analysis of POTS, and to bring greater understanding to how people with invisible disabilities negotiate disclosure and uncertainty. The following section provides an overview of the results in concurrence with the previously stated research questions. In order to capture the lived experiences of the participants, I present interview data to support the findings. Seven of the participants have asked explicitly that their real names be used in conjunction with their experiences, and the other seventeen participants will have pseudonyms to protect their identities.

Privacy Rules for Disclosure

Interviews revealed that deciding whether and how to disclose was an ongoing “calculus” for participants. The first research question asked: *How do POTS patients decide whether and how to disclose information about their illness in everyday life?* Participants explained they attempt to disclose only vague explanations of their illness to most people because people do not understand. Deciding whether to disclose or not centered around two tenets: *a) is it a necessity to disclose, and b) will I be believed.* Even with these two tenets at the forefront, participants felt at many times unsure whether to disclose.

Necessity. Participants, whose symptoms caused them to faint, felt that they must disclose to the people around them whether that be at work, with friends, or with family.

This was based on the importance for everyone in the vicinity to know that the situation (passing out) was not an immediate emergency and that this was the participant's typical experience. For example, Kate shared that she must disclose her POTS right off the bat, "Because I never know if I'm going to pass out." Other participants' disclosures were similarly motivated by their bodies' symptoms. For example, Zach stated:

I'll say I have POTS whenever I feel like it's appropriate. Like if I feel like someone was going to be confused as to why I'm acting weird, if I'm out of breath from just walking by the stairs or something. Whenever I feel it gives insight or I trust the person just enough to just let them know.

While participants were mostly unanimous about disclosing for explanation of their symptoms, the degree of disclosure varied from being open to fully explain their POTS versus giving a little information as possible.

Generally, participants found that it was hard for the people who had been told about POTS in depth to understand what POTS is and participants struggled to have individuals believe them with full disclosure of their POTS and, so instead participants opted for ambiguity. Jay illustrates this by saying:

If I'm talking to a doctor or a healthcare person, the explanation is different than if some fellow mom, one of my kids' friends' moms, and I just want to give them a really short, vague explanation that, yeah, that I don't want to give too much information.

Only a couple participants felt open to explaining at depth to co-workers or strangers for the sake of awareness, but the rest of the participants erred on being vague, if possible. Jane conveys this clearly by saying:

There are times when I feel pressured to disclose, but most of the time, I offer it as an explanation, because I will be doing something weird, or I'll be like, "I need to go now," or "I can't do that." God, it is like the never-ending calculus of figuring people out. It's a lot less strange to be like, "My blood pressure is too low, I must sit," you know? People are much more likely to be accommodating if they have a reason, no matter how vague.

The aspect of ambiguity is present in almost every interview I conducted, but there were two exceptions. Jay, however, stated that she was vague about disclosures until her kids became diagnosed with POTS. Jay stated:

Then it's definitely a different story. Because my kids have it, because they have more symptoms as they've gotten older these past couple of years and gone through puberty and changes. My older two are 15 and 17 at this point, so they've had more symptoms the last two years. I find myself being more descriptive when I describe it to people now because I'm not just telling my story; I feel like I'm preparing everyone to hear my kids' story.

Like Jay, Mallory also found herself using more descriptive explanations of her POTS and symptoms for the sake of awareness. Mallory acknowledged that explaining POTS in depth posed her as an "outsider", but she still did it because it might help others struggling with disclosing by trying to educate people about POTS. Mallory stated:

I'm very open about it [disclosing POTS]... But I've always been okay with being a little on the outside. And so, especially since I've been walking with a cane, or I've needing to sit down, I've been pretty open about it... And if people are curious, I will absolutely talk to them about it because; to me ... There have also been other health

issues in my family, as everybody's. But I find that it's so much better if you talk about it if you are able to and if you have the strength to. So, I'm very open about it because to me, my effects are out in the world. It may be different if it didn't affect me when I went out, if it was a very private thing and it related to private. But people see there's something different. And so, I'm like, "Okay. Yeah, I'll tell you why I have a cane, even though I look healthy," and all that kind of stuff.

Jay and Mallory juxtaposed the majority that opted for more vague explanations. However, Jay acknowledged she stated out vague and shifted to open when her kids were diagnosed. Mallory postulates that there is a strength needed to disclose openly and that it can be isolating in her experience. It is possible that being vague versus open may be less taxing on the participant.

Belief. The need for vague explanations as a default for necessary disclosures stems from the calculus of if a participant thinks they will be believed if they disclose their POTS diagnosis. Hannah stated:

You kind of weighed the pros and cons. Like if I tell this person what I have and they go from looking at me like a normal person to, "Oh my gosh, like you have an illness." It's definitely tough cause some people do react in a kind of like an extreme way and you know the commenting of like you look normal, so how is this real?

Vague explanations typically went better for disclosure of symptoms than trying to explain POTS because participants perceived people were more likely to believe vague explanations than the full explanation of POTS.

POTS is not a straightforward illness to explain because it affects the entire autonomic nervous and symptoms can be extensive because of this. These symptoms are

invisible to the onlooker. This can result in a lengthy explanation that can take much emotional labor on the part of the participants. Participants described that people that they disclosed to often prefer a vague explanation, and they were not met with disbelief when they offered vague explanations. However, when trying to fully explain, participants were often met with disbelief. One participant was told directly, “Oh, that’s a junk diagnosis” which in turn caused her to be more secretive with her information (Kate). Halle explained:

I spend 75% of my time trying to pretend it [POTS] doesn’t completely affect me and the other 25% trying to explain that it does exist to a bunch of people who don’t believe me

Halle’s quote highlights the disparity of lived experiences from the person with POTS to the people they disclose to. Communicatively it is hard to connect when two people’s experiences are very different. The able-bodied person may reject the disclosure of the participant, thus participants felt safer just giving vague explanations.

These constant messages of disbelief also routinely occurred when disclosing to doctors. There was emotional turmoil tied to doctors being unable to understand and correctly interpret the messages patients are communicating about their symptoms. Candy stated, “What planet am I on? You know? Because it had been, at this point, six years since that original doctor had noticed the symptoms.” Candy’s experience highlights how disorienting it can be receiving untrue messages and blame from the medical community. Candy had been trying to communicate her symptoms in order to be diagnosed, but without knowledge on the practitioner’s part, the communication could not be effective. It can take years for a person to find a doctor that can properly diagnosis them. Jay concurred with this same sentiment saying, “the more times you hear, ‘we don’t see anything that’s

wrong with you,' or 'We've run our tests and nothing shows that you're sick,' you really question your sanity after a while." There is a sense of desperation in the retelling of participants' experiences of trying to get diagnosed. Again in Jay's quote, there is emotional turmoil from lack of belief and he even questions his sanity.

Several participants believed that their gender played a part in the disbelief of doctors. Many felt that being female discredited many of their symptoms in the eyes of doctors. Jane described this as:

The constant, never-ending messages. This is your fault. Your weight is your fault; you're not trying hard enough. You need to diet and exercise. Four times a week of running isn't enough. You're anxious. You're tired. You're depressed. You're a girl.

Communicating their very real symptoms, participants were shut down and discredited by their disclosure. The medical communities lack of knowledge seemed to lead to stereotyping. The doctor could not figure out the diagnosis, and so the blame was laid on the participant. Likewise, Sarah felt gender was a huge variable in getting diagnosed faster. In addition to having POTS herself, Sarah has two children who have POTS. She saw gender at play when doctors believed her son and diagnosed him faster than her daughter, who had the same symptoms. Echoing the claims that gender is at play with diagnosis, Clarke stated, "I knew something was wrong, very, very wrong with me and it seemed like none of these [doctors] would listen, and they all seemed to be male, male doctors." She believes the doctors told her nothing was wrong and her symptoms were a result of stress because she is a woman.

Many participants recounted extremely negative reactions of disbelief following disclosure from co-workers, strangers, medical professionals, friends, and even family. Kristen recounted, "I would explain to coworkers and then, you get a lot of strange looks. I just don't even try to explain it in public most of the time anymore." Hannah articulated this saying people don't believe her, "until they actually witness like me unconscious or me in the hospital. Then I find a lot of the time people really question or really are in disbelief." No matter how participants attempted to communicate the validity and seriousness of their POTS, some people still did not believe them.

Uncertainty Management: Medical, Personal, & Social

Communication is central to the foundation of uncertainty management and its investigation (Brashers, 2001). Communication behaviors are important to appraising the information seeking and information avoidance that people may use to reduce, maintain, or even increase their uncertainty (Brashers, 2001). Brashers found that uncertainty during illness took the form of three specific sources: medical, personal, and social. These sources of uncertainty were identified and reaffirmed in studies on HIV (Brashers et al., 2002), type 2 diabetes (Middleton et al., 2012) dementia (Stone & Jones, 2009), and organ transplantation (Martin et al., 2010). POTS, unlike these illnesses, has dual invisibility because there is a lack of awareness and knowledge about POTS and symptoms are invisible to an onlooker. This study's second research question asked: *what issues characterize a) medical uncertainty, b) personal uncertainty, and c) social uncertainty?*

Medical uncertainty. According to Brashers et al. (2003), medical uncertainty occurs as people attempt to understand their diagnosis and symptoms. In past studies, medical uncertainty has been presented as uncertainty surrounding symptoms, treatment

options, prognosis and diagnosis. The goal of this study in was to uncover the issues that characterize medical uncertainty for people with POTS (RQ2a). For participants, there was deep and profound uncertainty surrounding *pre-diagnosis, prognosis, treatment options, and symptoms*.

Pre-diagnosis. Unlike previous studies, all of the participants experienced pre-diagnosis uncertainty not just from their symptoms, but also from the medical world's reaction to them (Brashers et al., 2002; Donovan et al., 2015). Medical professionals told all, but one participant that there was nothing wrong with them. Participants of this study started presenting symptoms such as loss of consciousness, memory problems, seizures, heart palpitations, vomiting, slow/frozen digestive track, shaking extremities, flushing, tachycardia, low blood pressure (as low as 30/80 compared to normal blood pressure which is 120/80), migraines, and heat intolerance. It is possible there were other symptoms that were experienced, but not disclosed in the interview. I present the findings of these symptoms not as a list of problems that the participants deal with, which is certainly clear and abundant, but as a testament to the reaction of doctors to these specific symptoms. Participants were told by medical doctors while presenting these symptoms that they were on drugs (3 participants), that they were alcoholics (2 participants), that they were just stressed (8 participants), that they were faking it (5 participants) that it was just hormones (2 participants), and that they were just seeking attention (4 participants). This medical uncertainty caused participants to feel uncertain about the ability of medical professionals and about their own ability to understand validity of their symptoms.

One exemplar of the struggles of the participants during pre-diagnosis can be seen through Hannah's story. Hannah was just 15 when she went to the doctor for what she described as 'debilitating' symptoms:

I went into the ER, after being there all day, the doctor came in after running tests and sat next to me, looked me right in the eye and said 'I think this is just stress from being a teenager and the cure is yoga.'

Following this admission, Hannah laughed that the notion that her POTS was said to be just stress and that she only needed yoga, but she admitted this hard to shake off going forward trying to find relief for her symptoms. She was feeling very real symptoms from her POTS, but with no answers from the medical world, she said she became uncertain about how she was even feeling.

Many participants described the emotional struggle having to continue to go to doctors when medical professionals still were disbelieving participants. Eve stated, "I told my parents that I didn't want to go to the doctors anymore. I didn't want to hear the same thing over and over again [that nothing was wrong]." Continuing to go to the doctor was creating more uncertainty than the symptoms alone. Alex also articulated this tension of doctors not knowing, but also needing doctors to help. Alex stated, "I've kind of gotten a thick skin to doctors and what they say. You know what I mean? I take everything with a grain of salt, literally." Alex become numb and/or avoidant to the negative messages in order to find some resolution to navigate the high levels of uncertainty.

Diagnosis. The length between onsets of symptoms to diagnosis ranged from one year to twenty years within the group of participants. Participants saw between two to eighteen doctors before diagnosis. All participants felt validated when finally receiving a

diagnosis of POTS after fighting through messages of disbelief and misinformation. POTS incurability and treatability is what caused uncertainty in diagnosis for participants. The range of knowledge and information among the doctors of participants varied greatly.

The validation of receiving a diagnosis was a turning point experience for participants in dealing with their medical uncertainty. As the pre-diagnosis findings suggest, the participants of this study were subjected to disbelief and discrediting from the medical community before arriving at a diagnosis. Finally having a name for what doctors had told participants was nothing, was validating for participants across the board.

When asked how receiving a correct diagnosis felt, Eve stated:

Completely justified, like I wasn't really crazy. I also was told that multiple times, that I should go talk to somebody. I was doing it for attention, and that there was nothing wrong with me, and that it was strictly in my head. It just really made me feel like I'm really not crazy. There's really something going on. I'm not just doing this myself.

This quote highlights the validation and temporary reduction of uncertainty received from finally receiving a diagnosis. Another participant, Lexa, said, "It was like another stamp of approval. Like, yes, she is not like a drunk person or a dramatic person or making something up to get out of work." Many participants had begun to internalize these messages from doctors that maybe nothing was wrong. A diagnosis seemed to quell some of that internal dissonance between real symptoms and messages from medical professionals that it was nothing. Ash stated he knew something was wrong, but he knew he would have to wait and be persistent to find doctors who would help after having

already experienced fighting for a diagnosis of another incurable chronic condition. Clarke conveyed this as well:

I may not have been in medical school, but I'm not an idiot and I just couldn't stand that. And so when a Dr. X, who's my new doctor, she told me and my husband that this is what it was [POTS], we were both just like so happy to know that someone else understood and could prove that what was happening was real.

The validation received from a diagnosis was a positive shift in uncertainty, because participants felt authenticated in their experience with their own symptoms. The next stage of medical uncertainty came when discussing what this diagnosis of POTS means when it comes to prognosis and treatment options.

Prognosis. There is no standard prognosis agreed upon in the medical community for people with POTS. That fact alone caused uncertainty for participants. This uncertainty meant both hope and hopelessness when it came to prognoses for participants. The mixed prognoses of participants highlight the inconsistency of knowledge about POTS in the medical field. Some participants were told that they would grow out of their POTS (none have), others were told to push salt and fluids and you'll have a normal life (that was not the case in their lived experience), and some were told that they would be wheelchair bound and unable to work (which was true for some, and not the case for others). Ruth explained that receiving her prognosis "only felt like a rollercoaster." In the following quote Alex articulates the uncertainty at play:

I was told from when I started passing out, when I was 10, that I was going to grow out of it. I was told that for a long time... it's just going to go away. And then,

obviously, I'm like, Okay, well, I'm 24 and I just had another syncope episode. I'm not growing out of this.

The incurability of the syndrome sparked uncertainty in participants of their long-term quality of life. A few participants spoke of suicidal ideation during the initial diagnosis and prognosis period as they thought about living with and managing their symptoms long-term. Participants felt deep validation in knowing the name of their illness, but many described being ready to take on and 'fix' their POTS after knowing what it was. However, this is not the case with a POTS diagnosis as there are some makeshift treatment plans and trial and error medications, but no cure.

One area that participants voiced particular concern about their prognosis was parenthood. Specifically, participants were concerned that their POTS could affect pregnancy, childbirth, and parenthood. Conversations about parenthood and disability arose during interviewing, specifically about how ability could affect childbirth and parenthood. Doctors who tried to communicate this specific medical uncertainty varied in effectiveness. Three of the participants were told by their doctors frankly that they should not have children because of their POTS diagnosis and prognosis. Of the participants in this study with children, 4 out of 5 of them also had children with POTS. The medical community has not substantiated POTS to be hereditary. Alex stated

One doctor, he literally told me that I was going to be wheelchair bound and told me that I should never have children. And as a 25 year old at that point, sitting in his office that was the last thing I wanted to hear.

Clarke was also told not to have children and to adopt if she ever wanted kids. For Clarke the doctor was only concerned about the affect of pregnancy and childbirth. For Alex, the

doctor also expressed concern about her ability to succeed in parenthood because of her POTS.

The varied opinions of medical professionals led to medical uncertainty about prognosis, leading participants to turn to social media for answers. Many participants connected online through support groups and Facebook pages to find that there were a wide variety of outcomes for living with POTS both better and worse than what they had been told by their doctors. Most participants said the initial statement of prognosis was unsettlingly, but for some learning more from the community gave them hope of a better prognosis in the uncertainty of it. Several of these participants felt devastated, only to find more information from the community that this medical advice is not necessarily true for all patients. Yet another participant felt that it validated her feelings of her own capabilities, and was glad the doctor was direct and honest with her and her husband. For example, Clarke stated:

[The doctor] told me point blank that I should not have children. And actually I was so relieved to hear that, um, because I had all these other doctors who sort of hemmed and hawed about it. She was the first one to say, you know, you don't feel good, you're sick; you have too much going on... That was very validating in terms of someone just making a clear recommendation.

Two male participants expressed concern about passing on their genes to biological children. Though there is not enough evidence to prove POTS is indeed hereditary, both participants expressed that even the chance was worrisome. Jacob stated:

I don't want to have kids just because of medically, everything I've gone through, um, I would never want to inflict that on another person... I have spent a lot of time

thinking about it... but my mom's over there aching to have grandkids and, uh, she was definitely expecting some from me, and unfortunately I ruined her life long dream.

Though the male participants did not have the same concerns of struggling with pregnancy and childbirth, there was still great concerns about how genetically passing POTS to a child would affect their children's lives. There was too much uncertainty of POTS being hereditary, for both male participants to feel comfortable to take the chance.

Overall, prognoses for people with POTS is uncertain just on paper alone, the quality of life and ability vary wildly, but this is not the only medical uncertainty at play with prognosis. Medical professionals are giving people with the same illness and symptoms vastly different prognosis, and this in turn causes even more uncertainty on what the prognosis could be for their lives and about the medical community.

Treatment options. Similar to the prognoses given above, the advised treatment plans for people with POTS varied greatly. Following diagnosis and prognosis, all participants were told the similar statements that there is no specific treatment plan for people with POTS. Five of the participants were diagnosed by doctors and then told that they had to find a different doctor to help with their treatment plans. The only universal tie is POTS patients were told that they should drink lots of water and salt, to combat their low blood pressure and blood volume, but this only addresses one symptom. All other symptoms need treatment plans to be tailored to them specifically and vary based on the person's comorbidities.

Participants' express this struggle of uncertain treatment plans. For example, Kristen stated:

It was hard at first. It just, you know, not having a specific treatment plan of, 'Hey, this is what we're going to do and this is going to be all-better.' It was frustrating for it to be kind of, hey, we're going to throw some stuff at it and we'll see if it works.

Dave echoes this frustration at a lack of plan to combat symptoms, saying:

Just the kind of trial and error of it was frustrating because, you know, after six years, I just wanted it somebody to say, 'Hey, this is what you need to do and it's going to be better.' Not, it could be, you know, a year or two before we finally get something, a plan that might work.

It is natural that when people are feeling extremely unwell, they want a cure or at least a plan to help them feel better. This is a hard reality for participants. A few participants stated they were sent home with a treatment that did not work and no one followed up with them or helped them to correct it. Erin when asked how she felt about her treatment options stated:

Like they sucked. They did well because the cardiologist at first told me that what we needed to do is just properly hydrate and exercise correctly and it would go away. And I'm like, no, I don't think you understand. I'm bedridden.

The validation of diagnosis seemed to get lost in the next hunt for some type of plan to help with their POTS. Ash explained the experience of lacking a treatment plan by saying:

One of the most difficult things about POTS is the balance. I'm like suppose to rest, but not decondition. I'm supposed to push myself, not over do it. But then no one can tell me what is too much, or what is too little. I'm just supposed to figure it out. But what makes it even harder, is that it changes every day.

They had to discover what would work on their own with doctors telling them there is nothing we can do, you have to live with it.

Symptoms. Participants also faced significant medical uncertainty from their symptoms on top of uncertainty about treatment plans and prognosis. People with POTS experience multiple symptoms daily, and these symptoms were described as unpredictable in nature and severity. The majority participants when asked if their symptoms were predictable said “yes and no.” Participants felt that there were some factors in their control when it come to not exacerbating symptoms, but on the other hand articulated that they never knew if a flare of symptoms would hit out of nowhere. Raza stated:

Yes, but not always. Sometimes they [symptoms] sneak up on me and I'll be like, wait, what did I just do something to exacerbate my symptoms and maybe sometimes I'll be able to figure it out, but also I know for a fact if I'd run up two flights of stairs, I'm going to be pretty miserable. So like in that sense, yes, it depends on whether it's like a, a conscious decision knowing this is going to exacerbate me or realizing immediately after. But other times it's something that's outside of my control and I'm not able to predict it.

Many participants, like Raza, verbalized that yes they could control actions that might worsen symptoms, but are unable to truly predict the symptoms themselves and their severity.

Participants described days where they could not get out of bed or walk around due to symptoms that seemed to happen without warning. For example Robin stated:

Even though my legs weren't down more than three hours, I was stuck in bed for three days. I couldn't even sit up for like 24 hours. So, I definitely don't feel like I can really completely predict it.

Even avoiding triggers for participants did not guarantee that they would not have a flare of symptoms. Hannah also states this clearly saying, "there's a lot of variables when it comes to POTS. If I avoid this or don't do that, then maybe it will be okay. But in reality there just isn't any control." There is a lack of control that exists in predicting specific symptoms, when they might occur, and how severe they might be.

Comorbidities. On top of the medical uncertainty of POTS symptoms, participants also had other chronic illnesses along with their POTS that cause other symptoms and/or exacerbate their POTS. Twenty of my twenty-four participants also had Ehlers-Danlos and Twenty-two of the twenty-four had mast cell activation syndrome. These both have strong correlation to POTS. Other comorbidities included, cancer, gastroparesis, mitochondrial disease, type-one diabetes, epilepsy, pulmonary atrial hypertension, and small nerve neuropathy. I have included the addition of these comorbidities for two reasons. One, to illustrate that participants are united by their POTS and had to have POTS for this study, but are also experience other medical uncertainties from other symptoms not explored in this study. And secondly, because participants articulated that these comorbidities were also a part of their identities along with their POTS.

Personal uncertainty. According to Brashers et al. (2003), personal uncertainty occurs when people attempt to understand the implications of their health on their identities, roles both personal and professional, financial stability. Previous studies have focused on personal uncertainty with regards disability status, treatment costs,

employment obligations, and insurance procedures (Brashers et al., 2003; Martin et al., 2010).

Identity reformation. Participants all experienced uncertainty about their identities after living with POTS and their other comorbidities. This uncertainty about what their new identities would look like sparked a transformational process of introspection. There were three distinct feelings from participants about this identity reformation: loss, the dichotomy of participant's present identity and past identity, and reformation. The loss of participants' past identities was a process. Participants did not reach acceptance of their reformed identities over night; it took time. As Mitch stated, "It's getting hard because I'm still grieving. A part of me is still angry that I have POTS. Another part of me is sad about it. But I'm mostly in denial of it." Participants that were more recently diagnosed related more to loss and the dichotomy rather than reformation, but this does not predict if they would or would not reach reformation of identity.

There was a dichotomy of the participants' past and present identities. Participants struggled with a wide range of debilitating symptoms and often reflected on their lives before POTS. Ash illustrated this by saying, "It's so soul crushing to even remember what being normal was." There was pain in the changes between past and present realities. There was also uncertainty how to navigate feeling caught between these two identities of healthy and sick. This dichotomy was an ongoing process.

After developing POTS, many participants were unable to continue their passions. The majority of participants described their work as their passion, and seventeen participants reported that POTS caused them to be unable to work at their jobs. These

participants felt that their work was foundational to their identity and this caused personal uncertainty of their identity. Audrey stated:

Oh my gosh, it's terrible. My sense of purpose had been completely wrapped up in being a nurse, and the work I did, and helping people. I've always been the sort of person that enjoyed helping other people since I was little.

Similar to Audrey, Dianna was also unable to work due to her POTS and experienced the loss of work as her passion. Dianna articulated this saying; "I had to close my practice, which was heartbreaking because it's one of the things I was most passionate about in life." Ruth said that POTS has robbed her of her own identity and it [POTS] became the only identity. All three of these examples highlight the overall feeling of loss recounted by participants as they began living with POTS. With this loss of work, hobbies, and other passions participants recounted that they felt as if they had lost their own sense of purpose. Some participants felt stuck in this phase of medical uncertainty, but others went on to explain their process of negotiating the dichotomy of their present and past identities.

The majority of participants expressed not only a sense of loss but also a process of reconciling their previous sense of identity with their new lived experiences with POTS. They verbalized that they did not want to have their identities be totally consumed by being ill, but they felt had to battle against feeling like it was because it is such a big part of their lives. When asked how POTS has impacted her identity, Clarke said:

I am a disabled person and I've never felt that way prior to really getting bad... So now I feel like my identity, my POTS and my EDS [Ehlers-Danlos] and all of that together, it, it's who I am now in addition to all the other things. That's a major part of me now because it takes up so much from my life and my family's life.

Reaching this new identity entailed intrapersonal communication, but also communication with others in the POTS community. Jay articulates this saying:

I mean that was part of the acceptance phase, I think, that took me years. It was kind of reexamining my worth and redefining it, because I had to completely redefine, for sure, and just my own perception of talking to other POTS patients or seeing other people with POTS. I think a lot of people who are bedridden at home and, I don't think they see the capability or the capacity, or the drive, or whatever it is to really push through that acceptance portion. I think that really holds a lot of people back because they don't see the value and they don't see their worth yet, and it's hard to see that, it's a process.

Participants described their POTS as consuming their lives and it inevitably sparked resentment for the loss of past their identity Acceptance came from participants acknowledging that they have changed in some ways because of their POTS and that was okay.

All participants felt that living with so much uncertainty (medically, personally, and socially) did in some way change what they valued in life. These value changes included appreciating the “little things” and self-care. These value changes to their identities stemmed from living with POTS everyday. Participants stated that living with POTS caused them to value the “little things” in life more. This meant a greater appreciation of what they could do on a given day versus what they could not do. Before POTS, they described appreciating these little things a such as being able to get out of bed, going outside, and taking a walk, to name a few. These little things were attached to a change in ability, but

this ability changes cause some participants to be grateful for what they still could do. Alex explains this by stating:

I value everything more. So much more. Just the little things. And honestly, just enjoying things that you would normally think, 'Oh, this is just an everyday thing.' I find gratitude in those things because I'm able to do it. At one point, when I was on my beta blocker ... So, I couldn't get out of my bed for almost three weeks. So, now when I'm sitting by the pool, I'm like, 'I'm at the pool and this is the greatest thing ever.'

Being able to do activities or actions that were taken for granted without a disability, took on new light and importance to participants. Mallory echoes this sentiment stating:

Absolutely, just the simple things, being able to ... My parents came this weekend. Just being able to sit on the back porch with them here, and talk, and be outside, it was a huge accomplishment for me. Even my dad made the comment that 'it's so nice feel to sit outside with you and talk.' I'm like, it *is* nice to be able to sit outside and not have to be in the house all day.

"Everyday" tasks that could seem inevitable can take tremendous energy for a person with POTS, such as going outside or walking up the stairs. This change in value is important to acknowledge because disability does not just cause seemingly negative consequence to a person's identity, and often research tends to focus on these negatives instead of the positive changes too (Rosemarie-Garland, 2012). This means that though overall there is chronic uncertainty, uncertainty does lead to positive outcomes occasionally.

Participants also expressed that they valued self-care more since living with POTS. The majority of participants described themselves as type-A personalities and very self-

motivated before getting diagnosed with POTS. Other medical studies have also found that participants were “go-getters”, type-A, and highly motivated before developing POTS (Agarwal et al., 2007; Fedorowski, 2019). Eve conveys this saying:

I am really learning to put my needs first. And like honoring the boundaries and finding the boundaries of my health and my stress because I really did not value those before. I would look at those and the rear view mirror as I was keeping on going as the type-A personality, um, and take a lot of pride in that behavior. Oh, I was up for a 50 hours, look at me. I was up for 50 hours. No problem. Now, they're not as far in the rear view mirror... pausing there and making a different decision for my health

Participants, like Eve, described that self-care was not a priority before they had POTS, and that they would often sacrifice their bodies to get more work done. POTS for many participants caused them to reevaluate their body's needs and take time for self-care.

Roles. While identity is how participants think and communicate about themselves, roles are prescribed or predicted behaviors associated with specific positions, socially or professionally (Martin et al., 2010). POTS greatly affected the roles that participants occupied and occupy. In many cases professional roles could not be continued because of an inability to work from having POTS. This alone financially affected participants, because it meant going from a dual income home to a single income, changing careers, or going on disability. Ability alone changed the way participants thought about their own roles and how their roles had changed.

Several participants felt like a burden particularly to their partners and family because they could not perform the same tasks they once did. Housework came up in

almost every single interview, because by nature cleaning and cooking can be extremely difficult activities for someone with POTS. Participants felt guilt for not being able to contribute to their partnership in a way they perceived as “50/50” (Jane, Alex, & Halle). The shift in what the roles of a partner “should” look like financially, domestically, and romantically caused participants to not only feel guilt but they were uncertain that they could find purpose in life. This led participants to feel uncertainty on how their partners and family would adjust to this shift and uncertainty about their life’s purpose. For example, Sarah explained, “when I got sick enough that I had to stop working, the change in my perception of my utility, my role in my family, and my expectations for myself was one of the most devastating parts of this.” These roles seemed to hold innate value to participants, and because POTS shifted what their roles look like, the results were hard. Participants had to renegotiate where their self-value came from. Many described their roles at work, or in the community, or as a parent or child identified them and gave them value. A guilt and embarrassment came from not being able to perform their roles in the same way. Some participants though articulated that while at first this shift in goals unsettling, once they renegotiated how their roles would work for them now, their sense of purpose was “restored in a sense”(Alex).

The role of being a parent was something that came up in almost every interview, whether it was negotiating how to be a parent and have POTS or deciding not to have children because of POTS. As stated earlier, many doctors adamantly advised some participants not to have children. Parents with POTS often felt it was hard to renegotiate being a parent and being disabled. Others never thought they would assume the role of a stay at home parent, but POTS forced the role upon them. Some participants also felt that

they would take on the role of being parents and then were told that they should not.

Audrey captures this sentiment, saying:

Another big thing for me is my husband and I decided not to have kids, which I've always wanted to have kids. But, I can barely function for myself... It's not even the physical, not just the carrying of the child but even adoption. Unless something changes or they figure out a better medication, we're just not capable of doing that.

Roles for these participants were fraught with uncertainty. In many cases, participants did not know if they could ever fill the same roles they once did, and more importantly there was great uncertainty about how loss of roles affected their perceived sense of worth.

Social uncertainty. Social uncertainty happens when people are unsure how to navigate social situations, interpersonal interactions and relationships, and the effect of their health on others. All participants acknowledged in some capacity a loss of friends stemming from having POTS. Going out and being social with friends and family had been a part of relational maintenance and after developing POTS social outing abilities were greatly affected causing uncertainty.

Friendships. Participants all had some uncertainty about interpersonal relationships with friends. All participants stated that they had lost friends because of having POTS. Eryn stated, "I have definitely lost friends over it [POTS] because they don't, they think I am making it up or I'm just bailing on them because I'm a flake." This loss of friendship was attributed mainly to a lack or unwillingness to understand their change in social ability. Jay stated:

The friends that I had were real active and the friends I was running with, and the friends that I was doing with Pilates with on a weekly basis, when I didn't have that physical activity connection with them, then we didn't have anything, really.

All participants experienced a change in their ability to go out and be social. Because of POTS symptoms, participants described that it was difficult to go to social outings like that they had before such as parties, traveling, going out to eat, and other events. There is much energy and planning taken into account before participants could go out to be social. For example, Eve explains how POTS affects her social life:

[POTS] definitely makes it hard to do things with people, especially when it's hot or if it's anything outside. I always have to take extra precautions...It makes you feel very isolated. Most people don't want to just sit in the couch and play cards or whatever inside.

This caused uncertainty in the ability of the participants to engage in relational maintenance through social activities. Two participants stated, "If they're not understanding, then they just disappear" and "I lost all of my friends, um, because that's what happens when you're sick" (Alex; Lexa). Friends that believe and are willing to try to understand are the friends that stayed in the participants' lives. Another key uncertainty socially, was participants often had to cancel on friends and family because of their unpredictable symptoms. This caused guilt in some participants because they could not do what they said they would. They physically could not go out, but they did not want to be perceived as not wanting to engage relationally. Participants felt judged by some friends and family members negatively for this unpredictability. For example, Eryn stated:

My really good friends understand. They don't get upset about it anymore, but I have definitely lost friends over it because they don't, they think I am making it up or I'm just bailing on them because I'm a flake.

Participants struggled with how to effectively manage their relationships while being seriously ill and at the same time perceived that they were often judged or not believed.

Family. Loss of friends was universal among participants, but the majority of participants also experienced a loss of family as well. Participants felt that managing familial relationships was a juggling act, and that they lost relationships with family members because of disbelief. However, when family members did believe the participants, the relationships became deeper and stronger. For some participants this meant their extended family did not believe them, but their immediate family did. For others, most of their extended and immediate family had disbelief, but at least someone in the family or a partner believed and understood. Eve stated, "Honestly, some of my family members don't believe me. When I got the diagnosis, not my close family, but my aunts, uncles, cousins, everything, they think that my family and I just overreact type of thing." Eve did have the support of her immediate family, but was faced with disbelief by the other parts of her family. This lack of belief leading to the loss of relationships among friends and family created social uncertainty and this inevitability changed the way participants communicated. This led to less communication about having POTS, and less of a motivation to continue the relationship because of the person's lack of acknowledgement of their disability. For example, Jenee explains:

My family, because my mom has autonomic dysfunction and she felt really ashamed of that and she feels shame around being sick at all, she has a very hard time talking

to me about it, so she and I basically don't talk about it. That's painful and difficult in and of itself. My family isn't receptive to really hearing about it.

This disbelief led to a loss of communication or less frequent communication, and avoidance of talking about their POTS.

Uncertainty Management Strategies

The third research question of this study asks: *what strategies do people with POTS use to manage uncertainty about illness, personally and socially?* The interviews revealed that many participants felt that they were not in control of the management of their uncertainties, and this made it much harder for participants to employ strategies. Though strategies were limited, two clear strategies emerged. The first strategy found was acceptance of the uncertainty surrounding POTS. The second strategy was honest communication and this strategy functioned both personally and socially to manage uncertainty.

Participants felt that their symptoms could be wildly unpredictable and so that medical uncertainty could not be managed per se, but some participants articulated that accepting that they could not have full control of their bodies helped them to deal with that uncertainty broadly. Kate stated:

I think that's the biggest thing that I learned from having POTS and just, yeah, having chronic illnesses is that life is unpredictable. You don't know what's going to happen and you should not worry about those things that are not in your control because you are losing time ... I can sit here and worry what if things ever gets so bad for me... Well there is no point in worrying about that because if it comes to that, I'll deal with it.

With the unpredictability of symptoms and quality of life always being in flux, the one strategy to combat this overwhelming uncertainty was to accept it so as to not be overwhelmed by it. Zach reiterates this sentiment of the other participants saying, “with my condition all of a sudden I go from passing as a functional human to being bedridden and those sorts of things. It's something I try not to think about too much or it's consuming.” The strategy of acceptance seemed to take place at a very introspective level, which makes sense based on the sheer amount of uncertainty experienced.

Participants expressed using open communication and honesty as a strategy for uncertainty management for personal and social relationships. These strategies however were only used with those closest to the participant in their social system, and were not used for people that they were not close to, for example co-workers, strangers, and extended family. Participants communicating clearly and honestly with their support system helped to manage uncertainty about relationships and roles. Granted this strategy was only used with trusted close friends and family, so this did not apply to the management of uncertainty with friends and family members with whom they were not as close. Participants said that being honest with their partners and other close friends or family, helped to cause less misunderstanding about the abilities of a given day. Because POTS symptoms are unpredicted communicating clearly with their trusted support systems, helped to manage uncertainty about the level of understanding with loved ones.

Strategies for managing social uncertainty beyond those who are close friends or family had limited findings in this study. Participants were often at a loss on how to articulate managing more broad social and personal uncertainty. As Eve expressed:

Everything is uncertain. On a daily basis, I don't know how I'm going to feel the next day. Some days I wake up and I feel fantastic. It's a constant battle back and forth between what I can and can't do on a daily basis. It's constant.

There was so much uncertainty it seemed that most of the uncertainty could not be managed. Participants did not feel in control of the uncertainty in general that they were experiencing. Participants had to use a lot of emotional energy to deal with so much uncertainty. This expenditure of emotional energy left little energy to focus on strategies of uncertainty that was outside their body and closest interpersonal circle.

Uncertainty & Privacy Management

My final research question inquired: *How does uncertainty affect how people with POTS disclose private information surrounding their illness?* Participants had a hard time deciding when and how to disclose their POTS, as was reflected in the section above. The findings show that uncertainty about reactions and understandings to disclosure played a role in complicating decisions on whether and how to disclose.

Participants expressed that they were unsure broadly of what reactions would occur from their disclosure of having POTS. Candy stated:

I usually was able to hide it from people but every once in awhile it would show and when that happened I would lose friends, you know? They couldn't bear it. They couldn't bear to see it. So, I've always kind of kept it on the DL [down low].

The inability to predict, or the uncertainty surrounding someone's reaction to disclosure caused most participants to limit their disclosure. Reactions of the people being disclosed could vary from disbelief, judgment, sympathy, understanding, and support based on the response of participants. Participants also expressed people believed them more when they

looked more traditionally ill (i.e. In a wheelchair, a hospital mask, cane, pale, etc.) and did not believe them if they looked too healthy. Alex expresses this saying:

It's really hard because they do not understand and they judge you, because one day you can do something totally fine, and the next day you're sick. I lost a best friend of over a decade because of my POTS.

Participants were apprehensive to disclose even if the reaction to the disclosure could be more positive because they felt they could not trust their predictions of the other person's reaction. Participants also assumed when disclosing that people did not know what POTS is based upon past experiences. Hannah stated:

People react in many different ways. I feel like it was frustrating because it almost felt like a punishment for something that I didn't choose to have happened. I didn't choose to be unwell but yet I was being punished for being different.

Uncertainty seemed to limit the openness of disclosure. Some participants report being very open when first diagnosed, and then becoming more closed off because of negative reactions.

The dual invisibility of POTS, both in awareness and presentation of symptoms, placed participants in liminal space when it come to communicating through disclosure. On one hand participants are faced with debilitating symptoms and on the other hand there is a general population that thinks they do not look sick or disabled enough to be believed. This is compounded by the fact that not only do participants have the appearance of health, but also there is very limited awareness on what POTS is. Participants are trying to communicate that they are indeed sick and disabled, but because of these two elements are unsure there is a large disconnect in communication.

Participants through this uncertainty could not find a universal way to communicate their POTS and disability across these differences. There are too many factors to negotiate for a participant to even feel confident in their ability to predict outcomes of disclosure and to form their own privacy rules. Thus participants default to “I will be as vague with my explanation unless I have to explain to explain it deeper,” because these negotiation take some much emotional labor to even decide to disclose (Jay).

Discussion

This thesis began by citing relevant research on POTS, Uncertainty Management Theory, and Communication Privacy management Theory. Communication theory research had yet to examine the experiences of people with invisible disability in regards to disclosure and uncertainty. This thesis addressed these gaps in communication scholarship. Twenty-four interviews were conducted with participants of varying ages, backgrounds, geographic locations, and lengths of diagnosis with POTS. This thesis explored the following questions: (RQ1) How do POTS patients decide whether and how to disclose information about their illness in everyday life? (RQ2a, b, c) What issues characterize medical, personal, and social uncertainty? (RQ3) What strategies do people with POTS use to manage uncertainty about illness, personally and socially? And, (RQ4) how does uncertainty affect how people with POTS disclose private information surrounding their illness?

Findings of this study revealed complex and dynamic negotiations of privacy and the management of uncertainty. This discussion section is organized as follows. First, I will explain the theoretical contributions to both Communication Privacy Management Theory and Uncertainty Management Theory, as well as the theoretical contributions we gain by combining the two theories. Second, I will discuss the practical contributions of this study. Finally, I will conclude this study by acknowledging the limitations and proposing future directions to explore.

Contributions to Communication Privacy Management Theory

My findings broaden CPM's assumptions on rule formation criterion by showing that disability may be a contextual restraint but rule formation changes from one rule

management system to the other because there may be a continual disruption of rule negotiation. In CPM, Petronio explains five criteria for rule development. These five criteria (culture, gender, motivations, contextual restraints, and risk-benefit ratio) are meant to help consider why a person would decide to reveal or conceal (Petronio, 2004, p. 203). Petronio (2002) defines contextual criteria as people experience life-altering events that change their privacy rule. When it comes to disability, Petronio (2004) states people with disabilities receive more requests to explain their disability, but outside of people inquiring, people with disabilities use the other four criteria to make decisions on disclosure (Braithwaite, 1999; Petronio, 2004). This study contributes to our understanding of contextual factors for those navigating invisible disability by highlighting two specific rule changes that come from participants' contextual factors: (a) Is disclosure a necessity? and (b) Will I be believed when I disclose?

Necessity. Necessity operated as a foundational privacy rule for the participants in this study. That is participants felt pressure to disclose because they thought it was necessary. Participants stated at many points in each interview that they disclose as little as possible unless they have no other choice. In these circumstances, the traditional rules identified by Petronio were not as salient—it did not matter what their culture background was (my participants' backgrounds varied significantly), they felt robbed of their own motivations to disclose or not to, context varied significantly, and the risk-benefit ratio seemed strained for participants. Participants felt that they *had* to explain some of their behaviors related to POTS for the comfort of others. For example, if they pass out or vomit frequently then they felt they had to explain to the onlooker. Many participants articulated that they had to give an example for their “weird” behaviors.

When disclosure was not deemed a necessity, participants would only give vague explanations because they felt unable to gauge a person's reaction to their diagnosis. Sometimes, participants disclosed to people who they thought were going to be very receptive and then those individuals were not; conversely, they sometimes disclosed to people whom they thought would judge them harshly, but those individuals were very receptive. The varied experiences made it hard for participants to feel uncertain in their predictions of the reaction they would get to their disclosure. To underscore this, loss of friends after disclosure was universal for participants and it was a good example of how often the people that participants thought would be very receptive were not.

Departing from previous literature, this study suggests that people with physical disabilities are strategic with their disclosure and anticipate the questions they may be asked (Braithwaite, 1991). The findings in this study indicate is more difficult for those with invisible disabilities to be strategic with their disclosures as it is difficult to predict the questions that will follow. As Sarah stated, "I try not to disclose unless I'm forced to," is much different then strategically waiting to disclose until the relationship is more developed. There is a sense that disclosure of POTS on a day-to-day basis is withheld until the person with POTS has no option in their privacy management except to disclose.

In addition to this uncertainty around reactions, disclosure on the part of the participant also involved the participant serving as an educator and this is not something explored in CPM (2004). Disclosure for people with disabilities centered on answering questions about what caused their disability and inappropriate questions on how the disability affected them (Braithwaite, 1999; Petronio, 2004). Petronio's examples only focused on physical disabilities and the questions answered by the individuals with

disabilities were along the lines of: “How did you end up in a wheelchair?” In the case of POTS, people with disabilities actually have to educate and explain their disabilities. For example, disclosure of POTS for participants was much more than stating, “Hi, I’m [blank] and I have POTS.” Most people, including medical professionals, do not know what POTS is. Therefore, participants disclosing that they have POTS means that they will have to explain it to people for the first time. Furthermore, they will be expected to explain it in a way that others can understand. This can be a long and emotionally draining process, as my participants described. Participants felt that people just needed an easier answer to explain their behavior than the whole truth.

Belief. This study contributes to the theory by expanding what could be considered a “risk” when deciding to disclose. Participants identified uncertainty around whether the person they are disclosing to believes them as a risk associated with disclosure—this is not a risk that has been considered by interpersonal scholars in previous literature on disability (Braithwaite, 1999; Petronio, 2002; Petronio, 2004). Petronio (2002) claimed that “high-risk” disclosure might cause “shame, threat, or severe embarrassment” (p. 67). The risk for those with POTS does not lie in the disclosure itself, the risk lies in whether the person disclosed to will believe the participant’s explanation of POTS. Participants have concrete evidence that they have POTS, and that it causes disability symptoms, but people can choose to not believe them. There is relational risk of people not believing participants with POTS. As one example of this, participants expressed a loss of friendships after being diagnosed with POTS.

In addition to disbelief among friends, participants also expressed concerns with disclosing in the workplace. Disclosing POTS at work could have potentially horrific

consequences (i.e., being discriminated against or harassed) for participants, and most participants feared asking employers for accommodations and telling them their POTS diagnosis because of this. Articulating needs to an employer can be hard especially when newly diagnosed, and can it be met with disbelief and distrust, according to participants. Some participants felt that they would be discriminated against if they did disclose their POTS. The dual invisibility of POTS also causes a problem for disclosure in the workplace. As Eve's quote articulates, employers may be disclosed to, but they do not believe the person with POTS, until they see it.

Contributions to Uncertainty Management Theory

This study adds to the scholarship that affirms Brashers et al. (2003) conceptualization of uncertainty as innately multifaceted, but there are specific aspects of having POTS that have distinct nuances within medical, personal, and social uncertainty compared to other disabilities. Like individuals with diabetes, cancer, dementia, and HIV/AIDS, people with POTS experience uncertainty that can be categorized as medical, personal, and/or social (Brashers et al., 2003). This finding suggests that some broad categories of uncertainty are consistent across disabilities/chronic illness.

The nuances of uncertainty for participants medically, personally, and socially, came from the dual invisibility of POTS having low awareness, medically and publically, and symptoms that do not present physically. From a medical perspective, patient and provider communication was often reported to be ineffective because of a lack of provider knowledge about POTS and the provider's tendency to dismiss. Patient and provider communication was also fraught with uncertainty when it came to lack of knowledge on prognosis and treatment plans. Participants reported that personally they were caught

between their past and present identities. Socially, participants struggled to effectively communicate diagnosis to people they disclosed to, possibly because most people disclosed to did not have similar experiences with invisible disability, and they lacked knowledge.

Medical uncertainty. People with POTS experience a great deal of medical uncertainty before getting diagnosed. They face this uncertainty for a longer period of time than other physical or well-known illness because of medical professionals' lack of knowledge about POTS (Fedorowski, 2109). Medical professional's not believing them or disregarding their symptoms, likely a result of the lack of knowledge that medical professionals have about POTS, compounded uncertainty. This study revealed that people with POTS are bombarded with messages that they are fine, faking it, an alcoholic, on drugs, or simply seeking attention while they are experiencing real and debilitating symptoms. While participants felt uncertain about the ability of medical professionals and how to make sense of their symptoms, after diagnosis, uncertainty still existed around prognoses and treatment plans.

Participants had extremely complex bouts of medical uncertainty from doctors not being able to diagnosis them properly to receiving vastly varied messages on prognosis to having no concrete treatment plans. The level of participants' medical uncertainties were distinctly more complex than previous studies because of the degree of medical uncertainty that occurred while doctors could not identify that the participant had POTS. This was not the case with studies that focused on people with cancer, people with HIV, people with diabetes, or people having organ transplants (Brashers, 2002; Martin, Stone, Scott, & Brashers, 2010; Middleton, LaVoie, & Brown, 2012; Donavon et al., 2014). Participants are met with unknowledgeable doctors and an illness that has limited research on it medically.

People with POTS have to fight to be believed by doctors that cannot pinpoint their symptoms as POTS. And even after participants received the diagnosis, doctors' explanations of POTS prognosis varied vastly. Trying to find a course of treatments that helped a participant's life sometimes took years. The nervous system is very complex and the dysfunction of it in turn causes complex symptoms.

Personal uncertainty. Personal uncertainty caused much turmoil for participants and lead to identity reformation. Donovan et al. (2014) also found young adults with cancer had uncertainty of identity, but this stemmed from being at a transitional point of their lives and being sensitive to rejection. For participants in this study, uncertainty of identity stemmed from the loss of ability to do the things they once did. POTS caused all participants, in some way, to lose of one of their passions. For many participants, their job was their greatest passion. When their symptoms stopped them from doing said job, participants were left wondering who they really were without their passions. This loss of participants' sense of passions demands further research into the negotiation of this uncertainty about identity and how people communicate this.

Negotiation of roles was also found to cause personal uncertainty in this study. Participants felt like they were a burden, particularly to their partners and family because they could not perform the same tasks they once did. For participants, uncertainty stemmed from a belief that worth was connected to productivity. Reformation of identity caused participants to come to see that their worth is not measured by their productivity. The reformation of identity is important for future study because not only have little been done on invisible disability identities, but also this reformation is distinct from other conditions because communicating this identity is complicated by the invisibility of POTS.

Social uncertainty. These participants all experienced loss of friends and most experienced at least some loss of communication with family. This loss adds to the testament of resilience of the participants, and it introduces an important endeavor to work towards more effective communication surrounding invisible disability. Similar to other studies on illness and uncertainty management (Donovan et al., 2015; Brashers et al., 2002), participants experienced uncertainty regarding their ability to sustain interpersonal relationships. Participants were experiencing great personal struggles in dealing with symptoms themselves with medical uncertainty which were interconnected and multilayered with interpersonal uncertainty. Interpersonal relationships are foundational to coping with hardships. However, unlike the findings of those studies, these individuals with POTS reported uncertainty in their relationships due to lack of knowledge about the disease itself. Unlike other invisible disabilities (Diabetes, Multiple Sclerosis, ALS, etc.), which are recognized by the larger population, POTS is a relatively unknown condition. Participants were not only worried about maintaining relationships because of their disability, there was also uncertainty as to if their family and friends even believed that they were ill. As POTS has dual invisibility, awareness of POTS—and invisible disability in general—is key in helping to improve these challenges with social uncertainty for patients and understanding among the general population.

The findings of this study suggest that the element of (in)visibility needs to be considered when using Uncertainty Management Theory. Participants undoubtedly experienced uncertainty on medical, personal, and social level but the specific causes of uncertainty were different than uncertainty management exploration on terminal or conditions with much more awareness, such as type-one diabetes. The dual invisibility of

POTS caused the uncertainty that participants experienced different than those faced by terminal illness or more well known conditions. Participants had battled to be believed in medical, personal, and social settings. This demands further consideration when exploring uncertainty management in those with invisible disabilities.

Uncertainty management strategies. Unlike previous studies in which uncertainty managements were clearly articulated by participants (e.g., Brashear's 2003 study of people with HIV), participants in this study had a hard time identifying strategies they use manage their uncertainty. Participants felt that the uncertainty was ultimately unmanageable, but had two strategies for dealing with medical and social uncertainty. This may be due in part to the amount of uncertainty and the various types of uncertainty faced by participants. There may be a level of uncertainty that interrupts people's abilities to create strategies in Uncertainty Management Theory. The two strategies that were identified in the findings are acceptance of uncertainty and honest communication. Strategies were hard to identify for participants and they articulated that uncertainty was in flux and their lives were unpredictable--this made it harder to have strategies for a broad range of scenarios. According to participants, accepting uncertainty for both the good and the bad made participants feel less overwhelmed by the different types and amounts of uncertainty they faced. Honest communication, meaning being truthful about symptoms and feelings as a strategy, was only used with participants' closest supporters. From participants' stories, it seems that there is so much energy spent on managing symptom uncertainty and their closest relationships, that more broad social uncertainty strategies could not be developed.

Acceptance as a strategy points to the overall chaos of participants' experiences. They cannot control their symptoms for the most part, treatment plans are limited, and people choose not to believe them when they have a very real illness. There was definite avoidance as well illustrated by participants, but overall acceptance was more global for participants. The one sense of control was their own attitudes about their situations. Participants articulated that if you stay stuck in the mindset where you have uncertainties stopping you from trying to live your life, that is no way to live. Acceptance of uncertainty exists in a large way in their lives and empowered the participants to keep going.

Honest communication as a strategy for uncertainty was only used with the very closest people in participants' support systems. This honest communication helped participants feel on the same page as their loved ones. In this way, the participant's support system knew exact how the participant was feeling physically and emotionally. Because there is so much medical uncertainty, being very open and honest about goals and symptoms helped relationally with their loved ones. This way there was no miscommunications or hurt feelings about roles or abilities for a given day. Participants stressed the importance of open communication also because symptoms can vary wildly day-to-day and even hour-to-hour, but this was only with their very closest confidants not with everyone.

The amount of uncertainty faced by participants was high and there was even uncertainty on how to manage the uncertainty. The emotional energy that accompanied dealing with high amounts of uncertainty was great. This chronic expenditure of emotional energy was similar to chronic depletion described in the theory of resilience and relational load (Afifi, Merrill, & Davis, 2016; TRRL). The TRRL examines how the communal

orientation and maintenance of our relationships on a daily basis influence communication during stressful moments, as well as how stress is appraised (Afifi, Merrill, & Davis, 2016). The challenges of participants struggling to maintain personal relationships could be attributed to relation load and should be explored (Afifi, Merrill, & Davis, 2016). Further inquiry into this how emotional energy component to the management of uncertainty would be a fruitful addition to theory especially in the case of invisible disabilities where you have uncertainty so compounded. This could explain why these two specific strategies for uncertainty management were most salient for participants of this study. Participants may not have had the emotional energy to have more strategies socially for people outside of their closest social circle.

Uncertainty and Privacy Rule Management

The findings indicated that uncertainty complicated how participants negotiated privacy rules on whether and how to disclose. Participants felt that they could not accurately predict the reactions of people to whom they disclosed. There was great uncertainty on whether a person disclosed to would believe the participant. Limited scholarship has attempted to combine Uncertainty Management Theory and Communication Privacy Management Theory. The important conclusion is that uncertainty did indeed complicate privacy management and changed the way participants disclosed, specifically when it came to participants developing privacy rules in two ways. The first effect of uncertainty on CPM was that the contextual criteria for rule development was complicated by uncertainty, and the second was that participants felt that they could not balance a cost benefit ratio for disclosure because of uncertainty.

A key finding of this study was that the contextual criteria of CPM did not conform to the experiences of my participants and were heavily influenced by uncertainty. Petronio's (2002) contextual criteria included traumatic events, therapeutic events, and life circumstances as three large groups of situations where context affects the way privacy rules change and are established. Traumatic and life circumstances as criteria directly related to my participants. Traumatic events were defined as situations where people have to deal with "disruptive events that may change their lives forever" (Petronio, 2002, p. 57). According to Petronio, a person experiences a traumatic event which causes tremendous stress, so they change their privacy rules about disclosure to talk about the trauma then they get relief and achieve homeostasis. Life circumstances were described as stressful events, but not the same level of traumatic events (Petronio, 2002). Petronio's examples of life circumstances were divorce and people with disabilities. Petronio (2002) states the conversation of disability as a life circumstance is with the understanding that the person with a disability "has worked past the trauma of learning they have a disability" (p. 64). The participants of this study, experiencing trauma with disability did not just disclose to people about living with a disability and reach homeostasis. And my participants, who would fit Petronio's conceptualization of "working past" the trauma of disability, did still experience moments of trauma. Experiences of trauma came in intervals and could be long lasting, and were not resolved through disclosure.

The context of POTS effect on privacy management rules was interconnected, multilayered, and temporal. This was much like Brashers explanation of how uncertainty functions (Brashers, 2001). Uncertainty within context, made participants felt as if they had no control over the development of their privacy rules. Participants did not just reconfigure

their privacy rules and experience the homeostasis they had before they were diagnosed; Participants did not know to navigate forming “effective” privacy rules. And privacy rules that could be helpful may not be possible because of how much low awareness affects conversations around disclosing POTS. Context had a more dynamic effect on how participants attempted to navigate disclosure. For example, even having been diagnosed with POTS for multiple years some participants expressed that did not know how or when to disclosure because of the nature of their POTS being an invisible disability. Overall, the experience of uncertainty is complex in living with POTS, and one-directional privacy rule development did not adequately explain the participants’ experiences.

Participants also could not develop privacy rules based on risk-benefit ratio criteria because participants felt they could not effectively predict the reactions of the people. Uncertainty itself can be seen as a risk, but uncertainty was also at play when trying to measure the risk-benefit ratio. This study also found that a risk a disclosure might not be the actual disclosure itself, but whether the disclosure is believed. Participants experienced great amounts of social uncertainty, and reported a loss connection with family and friends in part because of not being believed.

The combination of Uncertainty Management Theory and Communication Privacy Management Theory is fruitful for this research because uncertainty can have an effect on disclosure via privacy rules and there can be complications with disclosure which can cause more uncertainty. Uncertainty and privacy were mixed together in the experiences of people with POTS, and it is important to not just look at them as two different phenomena, but rather to examine how privacy rule development is disrupted by the uncertainty. The combination of Uncertainty Management Theory and Communication Privacy Management

Theory allows for a more dynamic lens to understand how people with POTS and other invisible disabilities navigate disclosure. People with chronic, invisible, and incurable conditions face life changes that are not just turning points, but complete and utter reorganizations of their entire lives. These changes are intricate and multilayered and privacy rule development as a one directional processes cannot adequately explain this without Uncertainty Management Theory.

Practical Implications

Practical considerations for improving disclosure must consider the dual invisibility of POTS. More public education is needed on invisible disability, and it would be beneficial for a study to be done to identify and test what message would be effective in educating the public. Additionally, a campaign for spreading awareness of POTS would be greatly beneficial to participants, both publicly and in the medical community. Perhaps through a coordinated effort between communication scholars and Dysautonomia International, information booklets could be provided hospitals and providers' offices to instruct them on identifying the symptoms of POTS. People with POTS often have their first interaction with their POTS symptoms with an emergency room teams, and so it will be important that these units can identify specific symptoms and refer them as necessary. Dysautonomia International's website also has a list-server of all neurologist that specialize in POTS, which could be distributed to doctors for referrals if patients have the qualifying symptoms.

For practical solutions for disclosure on a daily basis, doctors and an educational campaign could direct patients to Dysautonomia International's website. On this website patients can find medical cards that explain POTS and their behaviors that help to explain

what POTS is and can be given to questioning individuals without putting all of the responsibility to effectively communicate on the person with POTS. The medical cards link back to the website for explanations and statistics on POTS, so the burden of education is not completely on the person with POTS, but rather on the person to whom they disclosed. Dysautonomia International also provides brochures to give to friends and family members and an educational video that not only explains POTS, but also talks about invisible disability. Many people have to find this information on their own, and it would be helpful for patients to be directly connected to this resource via their doctors. The next step would be educating people how to use these tools with disclosure, because the resources are available but rarely used. From the findings of study, participants struggled to how much to disclose to people because most people do not know what POTS is and may not believe them. This would direct people disclosed to credible and accurate information on Dysautonomia International's website. Explaining POTS to people also takes a great deal of energy and guiding people to the appropriate resources could be potentially helpful for managing personal and social uncertainty.

Medical uncertainty will also have to be combatted with an awareness campaign of POTS for doctors in general, but also helping patients get connected to others with POTS quicker after diagnosis. Doctors could be advised to make an initial suggestion that the patient should find POTS support group online. As seen with identity, prognosis, and treatment plans, the best wealth of knowledge comes from the people also living with POTS. This could help with social support and answering questions to which doctors do not know or are unsure of the answer. As seen in the findings, doctors were making assumptions about prognosis and quality of life that are only informed by their limited

experience, so it could be beneficial for them explain to the patient that there is limited data on POTS to make definitive assumptions about prognosis and also suggest that the patient ask others with POTS. These campaigns could be a good start helping people with POTS negotiate uncertainty and disclosure.

Limitations

Though this study advances invisible disability studies and two theoretical frameworks, there are notable limitations to this research study. Though the study reached saturation with these twenty-four participants' experiences, everyone's story and experiences are different. Therefore, it is possible that these themes may not be found in others with invisible disabilities, as POTS is a unique disease.

The theories used in this study limited the analytical lens. For example, throughout the interviews, participants' answers were stories of resilience and many themes surrounding resilience emerged. Participants found ways to continuing persevering against the adversity of their bodies, at times their own friends, the bulk of the medical field, and disbelieving families, to find answers for themselves and to try to create a life where they can continue. This process was challenging, scary, and nothing like they had faced before, but participants pressed forward and learned how to manage. In future studies, approaching the data with a different theoretical lens may help us learn more about the varied experiences of people with POTS.

Experiences of researcher

It is important to explain how my position as a researcher and a person with POTS affected this study. Throughout my study, I continually noticed how my experiences and

the experiences of my participants converged and diverged. This section highlights my experiences as a researcher with this specific population of people, of which I am a part, and also gives suggestions to future researchers.

As a person with POTS myself, I felt a strong kinship with the participants. Their struggles and their journeys emotionally affected me. Participants were eager to help contribute their stories in the hopes their stories could help others. There was a need to connect and to help others to find connections. I was overwhelmed with the honesty and vulnerability of participants. Participants were adamant that the only people that could truly understand their experience were other people with POTS. I would not have been as effective of an interviewer without that experiential knowledge. While I related very strongly to the experiences of participants, I was surprised that our experiences with communication and disclosure were distinctly different. I personally am open to always explaining in depth my behaviors instead of using ambiguity, so the hesitation to disclose was not a theme I was expecting because my own communication has been so different. Based on my experiences collecting data with this population, one strategy I would suggest for future researchers would be to be honest and open about life experiences that are foreign to you as researcher with participants. Participants already have to try so hard to be believed, it is very important to acknowledge and validate people's experiences. I owe the participants of this study my deepest gratitude and respect for their insights, experiences, and disclosures.

Future researchers should give this population, and individuals with other invisible disabilities, a platform to have their voices heard. Participants have lived with disbelief from many people, and validating these participants through the interview process is

powerful. If you have not lived with POTS, you can acknowledge the fact you cannot imagine perhaps the stories heard, but refrain from comparing your experiences. People with POTS are desperate to have their voices heard; and the process of researchers listening to these stories is critical to raising awareness on POTS and those living with invisible symptoms.

Directions of future research

The response to the recruitment of this study was overwhelming. People with POTS are willing to share their stories in order to spread awareness of POTS and living with invisible disability. This study revealed more avenues to be explored going forward. These avenues included improving awareness of POTS and other invisible disabilities (both medically and socially), resilience and relational load, and the intersection of Uncertainty Management Theory and Communication Privacy Management Theory.

Lack of knowledge came up again and again in this study, medically and socially. Doctors dismissed participants with very real and debilitating symptoms. How could patient-provider communication be improved for people struggling with invisible disabilities? Or should doctors be more attuned to identifying how people describe invisible symptoms? The answer is perhaps both, and needs more exploration for practical applications, such as physician training. Socially, more research needs to be conducted on how people communicate across ability when there are great differences in experience and knowledge. Many people to whom participants disclosed did not believe the participant in this study. How does this belief or disbelief complicate disclosure?

Participants' stories are also filled with accounts of resilience. Further analysis of this data is warranted to analyze how participants utilize discourse and other materials to

create a new normal for their lives. Studying the specific experiences and communication of participants with invisible disabilities could add more nuances to the study of resilience.

In interpersonal communication, this study is a start to trying to understand uncertainty from the perspective of invisible disability and the exploration of what role that disbelief plays in depleting relational load for people with invisible disabilities. This relational load depletion could perhaps better explain the loss of friendships because of the chronic depletion from non-close. This needs to be further explored as interpersonal relationships are important to people's overall well-being and are especially important during times of illness. Participants appear to still show great resilience, but this type of depletion from ongoing uncertainty surrounding participants' diagnosis should be further studied in conjunction with the effect of disbelief on relational load and resilience.

Participants were bombarded with messages of uncertainty, and their stories and the stories of others with invisible disabilities deserve a voice in communication scholarship.

The intersection of Uncertainty Management Theory and Communication Privacy Management Theory needs further research. This study indicates that there be a connection uncertainty and rule formation. A study focus solely on this endeavor moving forward would advance theory. The goal of that being to practically help people dealing with great amounts of uncertainty feel safe about disclosure through better strategies.

Conclusion

This project's objective was to illuminate the connections of theory and the lived experiences of people with POTS. Invisible disabilities pose important unconsidered nuances to disclosure and uncertainty. This theoretical approach has shown invisible disabilities pose distinct challenges; these specific and distinct challenges can build theory

to make scholarship more nuanced to include unconsidered voices and experiences that complicated previous scholarship.

POTS as a rare and understudied invisible disability gives scholars an opportunity to expand knowledge on the uncertainty and privacy management of illness from a nuanced perspective. Studying POTS specifically opens opportunities for insight into other invisible disabilities on uncertainty and privacy management because POTS has such a broad spectrum of symptoms that overlap with the symptoms of other invisible disabilities, thus giving insight into other invisible disabilities. POTS' wide spread symptoms and incurability overlap with the experiences of others with illnesses such as: fibromyalgia, ehlers danlos, multiple sclerosis, cystic fibrosis, traumatic brain injury, and epilepsy to name a few (Agarwal et al., 2007). These symptoms can be the catalyst of uncertainty for people with invisible disabilities. For all these disabilities, including POTS, there can be uncertainty about how to manage symptoms, how to pay for medical bills, and these illnesses demand a renegotiation of roles (Brashers, 2001). The qualitative findings of this study can be applicable to how people with other invisible disabilities navigate uncertainty and privacy management.

Like many of participants, I was told that I would not be able to work as I could before POTS. Doctors and acquaintances told me that I would not be able to handle a graduate program, and this thesis is my testament to the POTS community. POTS is devastating, triumphant, and life altering; similar to many other invisible disabilities. Scholarship and also awareness of experiences of people with POTS can help with the believability of disclosure and privacy of invisible disabilities.

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