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## Chronic Care: Illness Narratives of Parents Caring for Teens with POTS

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Chronic Care: Illness Narratives of Parents Caring for Teens with POTS

by

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Under the Direction of Cassandra White PhD

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## ABSTRACT

Parents who care for teens with POTS (Postural Orthostatic Tachycardia Syndrome) engage in a variety of activities to guide, support, and advocate for their child. This study expands the illness narrative framework to look at the invisible and often untapped knowledge of the parent caregiver. POTS is a lesser-known disorder that can lead to disability in some cases. Due to its varied presentation, many youths can experience a delayed diagnosis and treatment, navigate multiple doctors, and deal with social and interpersonal systems that can disrupt their planned life path. Through language development and expectation alignment, the parent caregiver becomes a critical and necessary bridge builder to the medical system and social institutions that cannot fully address the complex wellbeing of teens with chronic illnesses.

**INDEX WORDS:** Parent caregiver, Motherhood, Chronic illness, POTS, Cultural anthropology, Medical anthropology, Ethnography

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## **DEDICATION**

For my daughter.

I am forever inspired by your ability to advocate for possibility and lean into joy.

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## TABLE OF CONTENTS

<b>ACKNOWLEDGEMENTS</b> .....		<b>V</b>
<b>LIST OF FIGURES</b> .....		<b>X</b>
<b>LIST OF ABBREVIATIONS</b> .....		<b>XI</b>
<b>1 INTRODUCTION</b> .....		<b>1</b>
<b>2 CHRONIC ILLNESS AND PARENT CAREGIVERS</b> .....		<b>14</b>
<b>2.1 Chronic Illness and Parent Caregivers</b> .....		<b>14</b>
<b>2.2 Adolescence / Young Adulthood</b> .....		<b>16</b>
<b>2.3 Parent Roles</b> .....		<b>21</b>
<b>2.4 Parents and Caregiving</b> .....		<b>23</b>
<b>2.5 Motherhood</b> .....		<b>28</b>
<b>2.6 Motherhood and The Self</b> .....		<b>31</b>
<b>2.7 Extended Parenting</b> .....		<b>38</b>
<b>2.8 Reflection</b> .....		<b>41</b>
<b>3 CHRONIC ILLNESS AND NARRATIVES</b> .....		<b>42</b>
<b>3.1 Historical Look at POTS</b> .....		<b>42</b>
<b>3.2 Scientific Explanatory Model of POTS</b> .....		<b>48</b>
<b>3.3 Frameworks</b> .....		<b>51</b>
<b>3.3.1 <i>Illness Narratives</i></b> .....		<b>51</b>
<b>3.3.2 <i>Structural Violence</i></b> .....		<b>60</b>

3.4	Reflection .....	66
4	METHODS .....	67
4.1	Managing the Autoethnography .....	67
4.2	Informal and Semi-Structured Interviews.....	72
4.3	Recruitment and Participants.....	74
4.4	Participant Observation, Podcasts, Medical Memoirs, and Online Support Groups.....	76
4.4.1	<i>Dysautonomia International Conference</i> .....	79
4.5	Organizing the Data.....	81
4.6	Reflection .....	83
5	EXPERIENCES WITH POTS AND FINDINGS .....	84
5.1	My Illness Narratives.....	84
5.1.1	<i>She Looks Great</i> .....	84
5.1.2	<i>Too Much Missed School</i> .....	85
5.1.3	<i>Emergency Room as a Last Resort</i> .....	86
5.2	Findings.....	88
5.2.1	<i>Gaps in the Medical System</i> .....	88
5.2.2	<i>Gaps Beyond the Medical System</i> .....	103
5.2.3	<i>Gaps in the Medical Adjacent</i> .....	113
5.3	Reflection .....	114

<b>6</b>	<b>DISCUSSION .....</b>	<b>115</b>
6.1	<b>The Environment .....</b>	<b>115</b>
6.2	<b>Finding Words.....</b>	<b>118</b>
6.3	<b>Parents: Problems and Possibilities.....</b>	<b>121</b>
6.4	<b>Advocacy and Activism .....</b>	<b>126</b>
6.5	<b>Reflection .....</b>	<b>128</b>
<b>7</b>	<b>CONCLUSION .....</b>	<b>129</b>
7.1	<b>Why Study POTS and Parents .....</b>	<b>133</b>
7.2	<b>Recommendations .....</b>	<b>134</b>
7.3	<b>Reflection .....</b>	<b>137</b>
	<b>APPENDICES.....</b>	<b>140</b>
	<b>Appendix A .....</b>	<b>140</b>
	<b>REFERENCES.....</b>	<b>141</b>

**LIST OF FIGURES**

Figure 3.1 Learning how to place an NG tube hospital bedside ..... 71

**LIST OF ABBREVIATIONS**

AARP American Association of Retired Persons

AMAB Assigned Male at Birth

CDC Centers for Disease Control and Prevention

ED Emergency Department

EMA European Medicines Agency

ER Emergency Room

FDA United States Food and Drug Administration

FDIA Factitious Disorder Imposed on Another

HIPAA Health Insurance Portability and Accountability Act

MCA Medical Child Abuse

MHRA Medicines and Healthcare products Regulatory Agency

NAC National Alliance for Caregivers

NG Nasogastric

NJ Nasojejunal

OI Orthostatic Intolerance

POTS Postural Orthostatic Tachycardia Syndrome

## 1 INTRODUCTION

The transition between the ER and the hospital room felt chaotic, but it also offered a sigh of relief. This was the first time in five emergency department visits that the doctor knew what POTS (Postural Orthostatic Tachycardia Syndrome) was and more importantly had a plan of care, so I had this passing thought that maybe getting admitted would help my daughter. We were nine months into her diagnosis, but we were not connecting these episodes with POTS. In this moment she was unable to hold herself up, was experiencing dizziness, chest pains, and when she spoke her words were distracted and not coherent.

As I stood in her hospital room doorway, gripping a plastic bag full of her street clothes, watching the nurses shift her to a bed and hook her up to loud beeping machines, I overheard a woman's voice at the nurse's station behind me say, "this looks like a bad POTS flare, my son gets them." At the time I did not realize how important having a healthcare professional with lived experience was when looking for help. All I could think was, flare? This is a flare! And this is bad!

If we could name it, I hoped we could fix it. But it was not that easy. Discovering what helped stabilize and manage her inpatient care meant that I would take on a lot of the nursing and tech work once we were back in the home, albeit without the benefit of a shift change. Some of these activities required me to wake up every two and half hours to manage the fluids that were being delivered through her nose and into her stomach via a nasogastric (NG) tube and continuous pump. This activity quickly became unsustainable to my own long-term health, but workable solutions to the prescribed protocols were hard to come by. Asking for help meant trying to answer questions about why she needed the tube and why she was unable to manage the feeds herself. Early on that was a struggle because we were still trying to understand it ourselves.

While there were multiple follow up doctor appointments, there was little time to explain her ongoing symptoms let alone the struggles with the day to day (night to night) management of her care. Gratefully, but with some push back from her medical team, support toward a more sustainable management of her protocols came from searching the internet and asking questions of other moms managing similar situations. It was through online groups and forums that I found language and ideas that helped with the trial-and-error approach common in chronic illness care.

My experience here highlights how caregiving, comforting, and coping support are all overlapping themes in chronic illness parenting and advocacy. The very acts of caregiving and providing comfort support the ability to cope with the challenges of a complex illness. These activities are often situated beyond the scope of medical teams and make advocacy both an act of care and a pathway to meaning-making for the parent caregiver. While it is not my intention to suggest a monolithic parenting care model, this project highlights that such care exists and that there is a need for awareness and support that current categories of care distinguished by developmental age or degree of disability do not fully capture. In asking how parents (often mothers) of chronically ill teens with POTS experience the role of caregiver in the contemporary United States, I explore how parents make meaning of their teen's illness as their role of caregiver evolves and expectations of parental involvement change.

I chose POTS as a focus for this study because of my familiarity with it as a parent caregiver and mom of a teen affected by POTS; my autoethnography is a key feature. I also chose POTS because it is an invisible illness that challenges many of the self-reliance narratives promoted in American child rearing and society at large.<sup>1</sup> A teen requiring support may conflict

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<sup>1</sup> Invisible illness is used to describe an illness without visual cues, such as in mental health. In recent years Chronic Illness sufferers have used it to also describe their invisibility within the systems that are meant to treat them. It is not a new term; according to the Invisible Disability Project it was first used in the UK and the US when describing the issues men experienced when returning home from World War I (2017).

with the detachment process from their parents but can also use a more intensive level of care to achieve effective interdependence within their own timeline. Disability policy researcher Laura Davy explains that “autonomy cannot be enabled without care, and care cannot be enabling without respect for autonomy.” (Davy 2019, 102). Here, the parent is required to both hold and push against institutional, social, interpersonal and culturally age-defined developmental boundaries and make visible the teen in need of care. For the parent this not only means taking on or maintaining a higher level of involvement with their teen, but also taking on some of the behind the scenes work not typically associated with parental care in this age group in the United States to support their autonomy. This level of intensive parenting that came of age in the 1990s (Hays 1996; O’Reilly 2020, 24) takes on a different meaning when viewed from the perspective of chronic care and the varying needs of the adolescent.

Beyond managing direct care which includes learning about the illness and its treatments, parent caregivers also operate within three other categories of responsibilities as outlined in family researcher and nurse Susan Sullivan-Bolyai’s work on the role of parent as caregiver. These include being able to identify, access, and coordinate resources; maintain the daily operation of family duties; as well as maintain the self (Sullivan-Bolyai et al. 2004). It is this last category of maintaining the self that is of significance for this study; the Sullivan-Bolyai article outlines it to mean the daily activities parents do to maintain their health, like getting enough sleep and eating well, as well as nurturing relationships, their career, and their personal goals, as well as having agency over their stress management and capacity in the caregiving role (II 2004). I see maintaining the self as more than acts of self-care framed by having access to physical, mental, and spiritual support (Sullivan-Bolyai et al. 2004), it is also enmeshed into the meaning making and communication activities performed by the parents while operating within the

constraints of an illness that has various presentations and degrees of disability that can fluctuate on any given day. From my conversations with parents, it seems to be the awareness and acceptance that comes with the journey for answers that allows for self-care and maintenance to be integrated into their lives, but it also depends on access to various levels of support and the challenges of the illness.

An illness like POTS can be debilitating long before there is a diagnosis. It can cause devastating and transformative consequences to the quality of life of those impacted (Seeley et al. 2023; Flack et al. 2018), yet POTS is not well known. In rooms where I have presented this work, fewer than half of the audience raise their hands when asked if they have heard of POTS. Unfortunately, this lack of awareness tracks into medical appointments and emergency departments which has resulted in people waiting years and seeing multiple doctors before receiving a proper diagnosis (Shaw et al. 2019). Further delays in treatment are exacerbated by high levels of misdiagnoses and symptom dismissal (Boris, 2018). This can be exhausting for the teen and parent looking for answers, while they also feel the pressure of a shorter transition timeline from pediatrics to adult medicine. Here parents are co-creating systems of care with their child, medical teams, and social supports in hopes it will transition with their child. To do this, parents are using new pathways of care and approaches and finding crowd-sourced guidance when traditional medical pathways do not always lead to answers.

Generally, the profile of a teen diagnosed with POTS favors those assigned female at birth with an onset of symptoms averaging around age 13-14 (Boris 2018; Boris et al. 2024; Bourne et al. 2021; Raj 2013). Female predominance in POTS and their experience of more symptoms over male patients is not well understood. Studies tend to focus on biological explanations such as sex hormones (Fu et al. 2010) or the differences in autonomic function

(Christou et al. 2005) but have been limited in their evaluation of gender identities (Bourne et al. 2021) Interestingly, there has been a noted correlation to teens who are high academic performing athletes, but this observation may also show the bias of who has access to care and how highly engaged parental sport behaviors can transfer to medical ones (Farchtchi 2020). In this study all the parents I spoke with have daughters with POTS and generally fit the high academic and athlete profile. Typically, it was the impact of symptoms on their sport that lead to those first doctor appointments. As the illness progressed there was a notable shift in focus from getting back on the “field” to getting back a quality of life. This too highlights the challenges of finding care in one’s neighborhood or state. While more doctors are becoming familiar with POTS, many patients are still traveling for treatment. More than half of the people I spoke with for this study have travelled more than an hour from their home for care. In one conversation with a mom, she noted that they “traveled all over the country” to find the specialized care her daughter needed.

While I will go into more detail in the following chapters a brief introduction to POTS identifies it as a form of dysautonomia, meaning it is a dysfunction of the autonomic nervous system. The name itself comes from one of its most noticeable symptoms—a dramatic and sustained increase in heart rate of 30 points (40 points in teens) above a resting rate, usually caused by a change to an upright position (Agarwal et al.; Boris 2018; Raj 2013). Additionally, symptoms can be present in any of the body’s systems the autonomic nervous system controls and can require a large management team of specialists that focus on their respective areas of the body. While these symptoms can present on a spectrum from a mild impact to being bed bound, there is not usually one doctor managing the overall impacts of the illness. Even when the patient has access to a specialist clinic, they are often referred to their hometown doctors for protocol

maintenance. This can be a challenge when it was a lack of medical awareness that sent the patient to the specialist clinic in the first place. While the assumption with children and adolescents is that the pediatrician acts as a medical liaison, the reality is the medical management role often falls to a parent, meaning the parent is the bridge between multiple doctors (who are not in communication with each other). I have personal awareness of medical advocates or account managers that can support this gap, but none of the parents I spoke with in this study used such a service. When parents take on this level of medical management it represents an expansion of their role as parent caregiver and can be in conflict with the ideal version of parenting.

For this reason, I centered the study on the parents, mostly moms, who take on the role of medical manager and parent caregiver. Here, I want to note that there is difficulty in describing an experience that is not entirely your own. It is not enough to explain it by proxy. While the parent perspective is often captured to legitimize what the teen has shared about their illness experience with the doctor (Kleinman 1988, 16), parents are also experiencing their own narrative, impact, and sense of self within their role. While caregiving is a good way to conceptualize the work parents do, it is worth noting that the parent story exists for them only because it exists for the child. The child will continue to have the illness experience with or without the parent. In this way the parent perspective can also be denied and dismissed within certain medical and social settings. Here I use Foucault's introduction of "subjugated knowledge", knowledge that has been disqualified and is lower on the hierarchy of science (Foucault and Gordon 1980, 82). I argue that it is the actions of the patients and the parents who "emancipate" this knowledge and work to gather and share it as a collective which makes it "capable of opposition" (Foucault and Gordon 1980, 85). If advocacy, activism, and in some

cases knowledge production become the work of the parent caregiver, then honoring the construction of the parent caregiver narrative makes visible both the work and the body of knowledge being collected.

I have used the term “parent caregiver” throughout this work to identify the additional labor load a parent of a teen with chronic illness takes on. To explore this experience, I use Arthur Kleinman’s illness narrative and explanatory model approaches (Kleinman 1988). Elaborating on the work of child psychiatrist Leon Eisenberg, Kleinman’s early work focused on the distinction between disease and illness, where disease sits within the language of medical professionals and the term illness encompasses the patient and their extended social world and all those affected by the patient’s condition (Eisenberg 1977; 1988). Eisenberg did acknowledge the interchangeableness of illness and disease in contemporary English usage (1977, 11), but I wonder about the cultural impact of this use of language when exploring the diagnosis and treatment of POTS considering medicine calls it a syndrome and not a disease. Situating it in the concept of illness puts all the responsibility on the patient. They are experiencing existing in illness, and its effects on their lives and those of their caregivers, and they are actively researching and looking for answers. For this reason Kleinman’s later work blurs these lines of distinction, noting how access to a wide array of medical information has impacted how people talk about and experience illness (2019, 97), an idea proposed earlier by Lila Abu-Lughod when she discussed welcoming the “dilemmas” associated with anthropological work in a world where the “unintended reader” and those being written about have access to the research being done on them (1991, 159-160). Here the parent bridges the gaps and turns to community and the internet to learn about the illness, engaging with and then adding to the available pool of knowledge.

Using the idea of illness narrative with the caregiver showcases the work parents do to honor the child's lived experience of the disease and the impact the illness has on everyone in the family within this changing landscape of information access. Parents not only have access to the research, but they also search it out and, in some cases, become financial investors in these studies. In some ways I feel parents have become the anthropologists Kleinman wished the doctors to become. Kleinman had envisioned the doctor as a connector where they take on the role of the anthropologist doing an ethnography (Kleinman 2019, 96), not just a member of a care team with only fifteen minutes to spend with a patient. In these appointments it is often the parents who are observing and participating and pulling together emic and etic perspectives in the hopes of identifying patterns and finding answers for their child, and for themselves. A recent study on a contested diagnosis highlights that the search for knowledge and effective care that parents do supports them in giving meaning to their experience of the illness. When this knowledge is respected by medical teams' parents feel trusted and when it is not, they can feel "a lack of trust towards professionals" (Ringer and Schön 2024). Additionally, the parent's work is not confined to the illness itself, but to the schools and social structures their child needs to navigate. It is reasonable to think that this experience of feeling trusted or lacking trust in the system extends to all structures parents navigate. Collectively, this parental knowledge is finding its way to online support groups and podcasts that are often run by and for mothers and shared among those on a diagnosis and treatment journey.

Within this environment of care there is also an entanglement with concepts of harm which begins in the diagnostic journey, if not before. For this reason, a large portion of my interviews focused on the experience towards a diagnosis. Many aspects of medical trauma emerge during this time, and I was curious how it sets the tone for future encounters. Between

dismissal of symptoms to ongoing testing, and the trial and error of treatment protocols, parents bear witness to the experience and often need to advocate for testing and treatments that they have researched themselves. As an archetype this is seen as problematic parenting, a possible over-reach of their role and a questionable investment in misleading or misunderstood medical information (Schaffer et al. 2009). In some cases, it is even considered medical child abuse for parents to advocate for medical tests or treatments (Eichner 2016). However, it is also the role parents are expected to take in caring for their child. It is only when this behavior pushes against an established expectation that the gap widens and creates a need for a collective space. Online research and parent-led communities become archives of data, a collection of information curated and available to those in a similar situation. This is often a protected space; it would not be incorrect to say that there are gatekeepers that create and maintain boundaries around these participants and their experiences within the forum. This protection is both a form of care and a way to maintain integrity. It is a community of parents who found their way to online forums looking for answers because other parents were willing to share what they learned along the way, but this can also become protected knowledge hidden behind a private virtual wall. Entry is connected to having an awareness of a possible diagnosis or an actual diagnosis and finding a corresponding online community or parent-led website to engage with, often at various levels of anonymity. In this way it was important that those sharing their stories were protected from identification.

Remaining anonymous is an interesting aspect of being a parent and telling your story while also being an advocate. There are details that while important to the story must remain unsaid because of the possible harm it could cause the child, now or in the future because of the longevity of records in the digital age. Additionally, as the teen becomes an adult, they have

agency over their narrative and that must be respected. In this way the parent's story becomes constrained by the same ethics important to anthropological research, but also by public systems of stigma and taboo. Creating a space to discuss and honor these conundrums was an important part of my research design. It came from a particular place of personal experience that threads throughout this work and was driven by a desire first to share that this behind-the-scenes work is happening even as parents question the language they use to explain it, and second, to highlight that some of this work is caused by inadequate systems and structures held up by neoliberal rhetoric that does not play well in the lived experience of illness and further challenges the agency of the parent.

Extrapolating from the experience of POTS, the current environment chronic illness presents in has a history of symptom dismissal, especially for illnesses on a gender distribution that favors those assigned female at birth and displaying an onset of symptoms in the teen years. Gender bias studies are limited in pediatrics; however, a recent study suggests bias in medicine mirrors those in society. For example, there is an expectation for girls to take more control of their health than there is for boys, resulting in children presenting with the same symptoms being evaluated differently depending on if they were seen as a girl or a boy (Carrilero et al. 2023). In the following chapters I will look at how parent caregiving and chronic illness converges to create a dynamic set of care activities that sits on a sliding scale and manipulates normative transition to adulthood models and challenges the idealized or normalized role of parent. Along with sharing my own family's autoethnographic experience, I completed two semi-structured interviews with moms of teens with POTS, as well as fifteen to twenty casual un-structured conversations with parents of chronically ill teens. Additionally, I have observed hundreds of interactions in online forums created for parents managing a child with POTS. I focused

primarily on the diagnosis and management journey and this work was informed by the ongoing search for language to describe the experience and feelings of making informed decisions in an environment where the illness is not well known.

The reality of needing to fight for medical care in the United States highlights inadequacies within the system that have roots in neoliberal policy, but certainly threads throughout the treatment of those that sit in the margins of what can be biologically explained. Research on the social and cultural experience of POTS can be extrapolated for general use in a variety of healthcare disciplines with respect to a population managing chronic illness. While a surge in long Covid cases has generated increased awareness of POTS, there is still a long way to go. There should not be a gap so large in the medical system that it needs a global pandemic to increase funding and support for an illness that causes disability in 25% of those diagnosed (Benrud-Larson et al. 2002, 533; Raj et al. 2018). In the following chapter, I pull from multiple disciplines to highlight chronic illness care at the intersection of parenting, and I bring forth that caring for an adolescent with POTS can further highlight the challenges and impossibility of modern motherhood. Here I introduce the idea of “extended parenting” to explain the work that sits in the gap between parenting and caregiving. As such, this study explores how this very personal experience is enmeshed in the relationship between parents and teens and highlights important ethical considerations as parents search for support outside medical systems protected by privacy and the 1996 passing of Health Insurance Portability and Accountability Act (HIPAA). Next, I include a brief biomedical explanatory model of POTS and explore the use of illness narratives and structural violence in the parent experience.

The methods chapter details how this research evolved to look at the parent experience beyond the medical encounter. Initially, I used the foundation of previous research into illness

narratives and the use of physical therapy to bridge the illness experience gap between patients and their doctors (Ross 2022). However, in meeting with a few parents I found a commonality that focused on the lack of language in describing the behind the scenes work that supported the look and behavior of a thriving child. That is not to say that the child is not thriving, it is to say that the work it takes to meet normative developmental markers looks different and often involves extra steps and support from the parent. To honor this invisible reproductive labor, I focused on parents of adolescents and this time of growing independence. Following methods is a findings chapter that includes a few illness narrative vignettes that mirror some of the challenges discussed with parents.

The ethnographic findings are organized into two sections, “gaps in the medical system” and “gaps outside of the medical systems.” Here, there is an understanding that it is the parent’s—often one parent and most often the parent identified as “mom” whose job it is to create independent self-reliant adults, but there is little discussion about the environment in which this job is performed. POTS offers an opportunity to explore parenting through a web of non-existent resources, and the social structures that butt up against the lived experience of an illness that renders many of those suffering (and their families) to what Arthur Kleinman calls the margins, people going against the grain of the center (1995, 2).

The discussion chapter pulls together the threads of the parent caregiver and how they are crafting both narrative and meaning as they advocate for their child and for themselves. Exploring the greater environment and noting that acquiring the language of illness and treatments tracks with the experience gained as the reality of chronic care becomes normalized within the home and parent child relationship. I also highlight that as medical language is

acquired, there is a risk of losing the personal narrative back to one that has been created by medicine and therefore can become a medicalized one (Frank 1995, 5).

In the conclusion, I focus on the parent caregiver and the lived experience of what I refer to as “extended parenting.” Engaging in the work necessary to support milestone achievements means a level of support that can be seen as not age appropriate from an external gaze, and sometimes an internal one. With a large percentage of POTS patients experiencing disability and periods of symptom flares it is reasonable to look at the need for supportive care long after the age of majority, and ask, how does this activity impact the parent child relationship? And if the child cannot separate or launch, how does that impact our understanding of the rites of passage and liminal spaces during this transitional time?

## **2 CHRONIC ILLNESS AND PARENT CAREGIVERS**

Exploring the experience of the parent as a caregiver in the context of POTS in teens meant looking at the intersections of the medical system and healthcare providers, parent caregivers, chronic illness, adolescence, and parenthood, but especially motherhood. When I visualize this intersection, I see a dynamic gap across which multiple lines crisscross at different intervals and spectrums on a moving continuum in a 3D space. When I described this visual to a parent, they reminded me that adding the aspect of time really makes this a 4D experience, meaning that new knowledge can change the perceptions of the past and possibilities for the future. Maybe that is why it is so hard to explain. Time creates space for acquiring knowledge and then changes the language used to describe the experience as well as the narrative. This further shifts the size of the gaps parents cover, shortening some while widening others. These gaps become the space parents are required to bridge and all together they become the environments I have aimed to share.

### **2.1 Chronic Illness and Parent Caregivers**

The numbers for chronic illness in the United States are startling. The Centers for Disease Control and Prevention's (CDC) 2022 report lists six out of ten adults in the United States as having a chronic disease, and four out of ten having two or more (CDC 2022: online). The CDC's website further identifies chronic illness as a condition(s) that has lasted at least a year, that requires ongoing medical treatment, and/or limits daily activities (2022). This punctuates that in the United States, treating chronic illnesses makes up 90% of the \$4.1 trillion in annual health care costs (National Alliance for Caregiving 2020: online). This project identifies that what supports the for-profit medical system in the United States are unpaid caregivers who

manage a variety of the behind-the-scenes acts of care and comfort required to maintain a quality of life for the person with the illness.

Caregiving, however, is too broad a topic to cover for the present research, in this thesis I focus on a subset of the family caregiver that I call the parent caregiver. Generally, family caregivers fill an essential and often invisible role within the health care system. While distinctions are made between the professional caregiver and the family caregiver along the lines of pay and credentials, a 2020 report by the National Alliance for Caregiving (NAC) stated that 53 million Americans are providing unpaid care to family members due to aging, illness, or disability (NAC 2020: online) Note, this number does not include a category for the parent caregiver of a child under the age of eighteen. An AARP report from 2021 approximates that family caregivers invested \$600 billion in unpaid care by averaging 18 hours a week in care duties during the year (AARP 2023: online), the report further points out that current family caregivers are often sandwiched between caring for an older relative while also having children in the home. This level of care often comes with a large impact on the employability and life path of those living with chronic illness and by extension their family caregiver (Beatty, 2012; Committee on Family Caregiving for Older Adults 2016, 149).

Family caregiving research tends to focus on elder and aging care (NAC 2020). For clarity in this study, I use the term parent caregiver to define a parent engaged in the medical and social support activities for their chronically ill teenager, a key distinction from a caregiver who provides care for a parent. I also want to identify the parents in this study from parents caring for a child born with their illness, or one whose illness emerged in early childhood, often noted as a special needs parent. While parents can most certainly be caregivers for a child(ren) of any age, in this study I highlight two distinct characteristics of parent caregivers of chronically ill

teenagers: 1) the limited time available to learn how to support their children before they become legal adults, and 2) parents of teens with POTS are dealing with recent and less certain care demands that may lean into long term care planning and support. POTS is an illness of uncertainty and fluctuates in the degree of impact to daily living and in the level of care needs. Because POTS is an illness that often presents during the mid-teen years (Shaw et al 2019), teens and families managing a new diagnosis may also be dealing with major life changes while experiencing a shorter runway to adulthood in which to find pediatric healthcare and support requiring additional investment on behalf of the parent. This is especially noteworthy for teen patients without an established relationship with a doctor. In short, the parent caregiver is a role that exists as an identity because someone defines themselves by performing this role (Gómez-Zúñiga et al. 2021). Language and defining the role of caregiver falls within overlapping structures of needs and responsibility and the parent caregiver to the adolescent has a distinct presence here.

## **2.2 Adolescence / Young Adulthood**

Conceptualizing the roles and expectations of teenagers is an exercise that requires attention to cultural differences and the constraints of expectations. This was foundational in Margaret Mead's work which stressed not all cultures look at adolescence as a period meant to be difficult and that in Samoa the transition to adulthood was done without harm to future instability as it is noted to be in American adolescence (1928, 206). Turning to specific cultural differences such as early exposure to ideas of sex and death and engaging in levels of adult work at an early age, Mead points out it is cultural constructions that highlighted the differences between Samoa and American transitions from adolescence to adulthood (1928, 201). Today, social structures offer a keen awareness of the all too difficult aspects of adolescence (Chen and

Farruggia 2002). Entire bookshelves are dedicated to selling parenting books filled with advice and guidance on how to create self-sufficient and independent adults. Of note here is how Western and American culture emphasize independence, a trait which is not universal and can be juxtaposed with cultures valuing interdependence (Markus and Kitayama 1991). In American parenting, the highly valued aspects of individualism include independence, which sits on a spectrum and “can exist on many levels simultaneously” (Kusserow 2004, 24). In this way it feels too convenient to view adolescence as an invisible waystation on the way to adulthood. As an age group and developmental period, adolescence is in flux and the definition of how this stage of life is understood is subject to wider societal and historical forces.

A 1904 psychological manual identified adolescence as being between the ages of 14 and 24 (Hall 1904, xix). Today, in the United States, adolescence often equates to the teen years. According to the World Health Organization (WHO) adolescence is considered to range from age 10 to 19 (WHO 2024: online) while the American Academy of Pediatrics uses a range from age 12-21 (Hardin et al. 2017). These shifts may align with both biological changes such as earlier menstruation in girls and cultural shifts with an increase in the high school population throughout the 20<sup>th</sup> century (Arnett 2000). This also opens a distinction for terms such as “emerging adult” to mark the period between late teens and the early 20s (Arnett 2000). While developmental psychologist Jeffrey Arnett’s initial paper spawned a whole discipline of study into emerging adulthood, critiques say its use in place of late adolescence and the idea of “early adulthood” disrupts the nuances between development stages, the transition to adulthood, and accumulates in a myth that does not pay attention to class structures or cultures outside of America ideologies (Côté 2014). Parents may look at these overlapping grey areas that mark adolescence, but youth became structured in America by using the age of 18 as the benchmark

for legal adulthood with the change of voting laws in the 1970s. What followed was further regulation of behaviors such as identifying the drinking age as 21 (Cole 2016). Even the American Academy of Pediatrics (AAP) notes that the limit of age 21 in pediatric care is arbitrary as more research asks for age allowances in the need for specialized health care for the special needs of “adult” patients with issues that started in childhood (Hardin et al. 2017). The focus on a hard line for adulthood when there is so much grey area can be a challenge for the parent caregiver to navigate and offer support when their child is not ready to take over the entire breath of caregiving responsibilities for themselves.

Here I find myself questioning the ideas of liminality in our current environment to describe the whole of adolescence when there is little to identify its beginning or end (Chen and Farruggia 2002). While I agree with the description of the adolescent age group as becoming and in transition, it also seems that when it is used as a blanket “condition” of a group that spans the years of adolescence (Turner 1967, 93), it adds to the ambiguity and lack of understanding of a period of development explicitly framed by cultural maturation constraints and leans into evolutionary theory using adult status as the point of high achievement. For example, the focus on raising independent and self-reliant children in American society has intensified the landscape of parenting, while not fully considering the social and economic environments in which children are raised and their place in it. I see the “betwixt and between” Victor Turner describes in his theory of liminality as an actual place of existence for the chronically ill teen, further distinguished by its invisibility to a society willing not to see the “novice” adult (Turner 1967, 95). While the process through the liminal means moving into a third and “stable state” that recognizes the completed transition and comes with a set of cultural expectations as describe by Van Gennep, it is one that not all who become ill can travel.

In her book, *Illness as Metaphor*, Susan Sontag speaks of two kingdoms, one of the well and one of the sick that “sooner or later each of us is obliged” to be part of (1979, 3). Using this framing, journalist Suleika Jaouad describes in the autobiography of her illness journey the grey space in which she lives between these two kingdoms (2022, 199). Finding a way to live within the grey becomes an act of choice, one Jaouad took as a physical trip, a self-mediated rite of passage to find out what was on the other side and to learn how she could be independent from being “only a cancer patient” (Jaouad 2022, 220). Situating both adolescence and chronic illness in the framework of a liminal portal creates a broken chain that can appear fixed by external means (turning 18, completing treatment) but in behavior and need for support can create a cycle of perpetual liminality.

Without discernible or purposeful rites of passage into the next stage, the idea of a perpetual liminality becomes a reality simply because cultural expectations both marginalize and lack resources for those that do not or cannot comply. For adolescents and adults living with POTS, the uncertainty of flares and access to accommodations highlights the in-between. To look beyond this perpetual liminality, I share Homi K. Bhabha’s idea of the “third space”, a place of hybridity “that carries the burden of the meaning of culture” (1994, 38). It is here that “strategies of selfhood” create new identities and collaborations “in the act of defining the idea of society itself” (1-2), furthering this idea, Bhabha describes a “partial culture”, which explores “the contaminated yet connective tissue between cultures” and identifies that there are always blurred lines between cultures (Bhabha 1996, 54). I see this as a way to let go of trying to identify clean edges of stages in the process of development and instead see the overlapping and messy nature of growth. This third space is one of possibility, here, occupied by both the ill teen and their parent caregiver who can be supportive as they identify their active narrative being

built together. This is not just a story framed by the constraints pushed onto them, but one with the awareness of age, development, and a mindfulness towards the transition to adulthood when health is a factor. This is a family living within the observable contradictions of teaching independence, needing support, and experiencing adolescence differently than what was expected.

In 2011, a review of literature on adolescence noted that while there is historical research on childhood, there is very little on adolescence, and where it exists, it seems to focus on negative medical or psychological issues, more so than on well-being (Schlegel and Hewlett 2011). A report to develop a definition of adolescent well-being outlines that five domains can be categorized: good health, connectedness, safety, education, and agency (Ross et al. 2020). Since each of these categories are challenged by illness, this study highlights the experience of parenting and caring for a teen when the very basics of wellness are not met and fighting for a quality of life pushes the role of parenting past the age of 18 simply because it rubs up against the social idea of a normative path to adulthood.

Adolescence as a development period is not really discussed as a stage of life. It is framed by the idea of becoming in a way no other age group is, and in the United States there are overlapping and multiple stages of possible rites of passages into adulthood that not everyone participates in, meaning there is not one culture path or activity that identifies the transition into adulthood other than waking up on your 18<sup>th</sup> birthday. While it signals the ability to vote, it is not bathed in new affordances. The new legal adult is not free to drink alcohol until age 21 and is unable to rent a car until 25. 18 is a legal adult that is still given training wheels. The shift to adulthood at 18 may be most felt by the parent of a chronically ill child. Minutes after midnight on the morning of my child's 18<sup>th</sup> birthday I was notified that I no longer had access to my

child's medical charts. We knew this would happen. The transition itself was not difficult; it was just another frustrating process that we could not manage until her birthday, and on that day, we experienced multiple technology challenges that we were told were normal because this process was never smooth. In other words, the law says she is a full adult with the right to privacy, but the systems that manage that privacy do not always get it right. The My Chart system, an online patient portal software developed by Epic that many healthcare providers in the U.S. use (Heath 2024), kicked my daughter out of her account and elevated me, something we had to fix in person. If you have one doctor this may not be an issue but when you have multiple doctors across multiple platforms it becomes another headache on an already long to do list of medical management for the parent and the teen that all comes down to a change in age and factors nothing else into the transition. While this challenge with technology is relatively minor, Faye Ginsburg and Rayna Rapp point out that this transition “can create a profound existential gap between normative ideas of American adulthood and the uncharted realities faced by disabled young adults and their families” (2024, 129). This further highlights how parents take on and evolve within the parent caregiver role.

### **2.3 Parent Roles**

In asking how American parents guide chronically ill teens into adulthood, I was struck by how little information was published on this relationship dynamic. Research on the teen population offered clinical explanations for “deviance” and expectations for “good behavior” but reports on the lived experience is lacking (Schlegel and Hewlett 2011). Where the parent child relationship is included, there is also an expectation of behavior on the part of the parent that does not seem to have been fully explored beyond social expectations. A study that focused on connections between parent behavior variables (such as catastrophizing about the impact of the

illness) and the level of disability children with orthostatic intolerance (a dysautonomia similar to POTS) and chronic fatigue, reported a correlation between the level of parent worry and the level of child disability (Kluck et al. 2017). This led to reports citing this research as a finding of causation, where higher levels of parent (mother) worry made the child report higher levels of disability. However, a return to the initial study outlined a paragraph that noted the study was not designed to interpret levels of causation between the parent's behavior and the child's experience of illness. That this correlation could also be interpreted as the level of child's disability causing the parents to have high levels of catastrophizing behavior (Kluck et al. 2017). Yet the level of ongoing negative hypotheses into the role of parents in medical settings, and beyond, continues to frame the experience of medical teams which is felt by the parents. There seems to be an anticipation and warning that leans toward a problematic parent as inferred from the articles that continue to cite this study and frame parents as such. When anthropologist Mara Buchbinder studied a pain clinic in California, she looked at both the "backstage" and "onstage" areas of the clinical space (2015, 32) and observed how the doctors said one thing in the meetings with parents and child, but pathologized the parent's behavior in the staff only meetings.

Buchbinder shared how backstage conversations lead to discussions of how the parents themselves are a constraint to the recovery process but are also needed as a supportive resource (2015, 115). Highlighting the impossible positions parents navigate further informs the experience of the teen patient and their parent when it is recreated in medical appointments. I have experienced this myself when told that my concerns were meddling into my daughter's care. This is subjective to the doctor, as I have also been commended for the way I create space for my daughter to speak in her doctor appointments. There are lots of ways parents influence their children, medical systems included, but this gap in experience was key to organizing the

literature review. Parents are considered problematic while being relied upon to encourage and implement the proscribed protocol.

Parents have no choice but to engage in these environments. The gap created by the chronic illness is an undefined grey area being managed by the parent asking for help. Somewhere between sickness and health, inpatient and outpatient, dependence and independence are the spaces where the chronically ill experience fractures off a normative path and may never quite make it back. In a lot of ways, it is simply the comparison to the unfulfilled trajectory that creates this gap. This is not just because there is a lack of acceptance of the illness, but because the level of care required is also compared against this unfulfilled trajectory. To say this another way is to believe that there is an idealized way in which the teens of America are expected to navigate these years, and by extension, there is an ideal way in which parents should guide them. These expectations or rules are implicitly and explicitly threaded through social and cultural structures creating an impact on behavior that often amounts to “playing the game,” a term that comes up in conversations with parents. Overall, this is encouraging the chronically ill community to question the relationship between how the game is set up and the power within it (Foucault 1997, 296). Here the status quo exists to measure the disability, reducing and recreating the dependency/autonomy binary instead of allowing for “dependency to be lived” (Davy 2019). It is the spectrum of the gap, the distance from the normative trajectory that ends up defining ability, and by extension the need of the parent to provide additional care during a time when traditionally they may be expected to offer less.

#### **2.4 Parents and Caregiving**

Giving care sits at the intersection of a variety of needs. It is often about holding space for the personhood of the ill or infirmed. This is no different for parents taking on this role. Myra

Bluebond-Langner explored the impact on families managing cystic fibrosis in the 1990s. Her study looked at the boundaries that families set around their “normal life” and the various phases entered as they made it through the disease's progression. Cystic fibrosis is a different illness today than when the study was performed in the early 90s, with those impacted living into adulthood and managing established treatment protocols. However, specific to POTS I found alignment with Bluebond-Langner’s discussion on community building and advocacy work, and then a pulling away from those activities when the illness is well managed (1996, 13). Many parents get involved in fundraising activities and activism, as noted with the passing of the ICD-10 code for POTS and those that gather to ask congress for additional research funding (Dysautonomia Advocacy Day: online). I was also struck at how often family members interviewed by Bluebond-Langner discussed the film, *Alex: The Life of a Child*, and wondered how popular media plays a role in public understanding of disease. The made-for-television movie was based on the book Alex’s father, sportswriter Frank Deford wrote about his daughter’s life and their families experience with cystic fibrosis (1997). Since, caregivers are rarely seen as “authoritative sources,” Deford’s celebrity status may have helped add a layer of trustworthiness (Briggs and Hallin 2016) and elevated the narrative. As I reflect on it now, I consider it a parent caregiver illness narrative that may have helped bring the illness into public life. For an illness like POTS where both the public and medical professional awareness is lacking, sharing awareness becomes a form of advocacy. This can come early in the medical journey, sometimes even before a diagnosis. Parents are researching, asking questions, and studying the illness while managing their worry and struggles (Coffey 2006). Advocacy work then creates a bridge to community and the outside world in what could otherwise be a very isolating time.

Caregiving as advocacy opens a space for it to become a form of self-care. Parents of chronically ill children are often reminded to take care of themselves, but many forms of self-care can feel inaccessible. I am encouraged by the work of the *Caffeinated Caregivers* and their framing of how the work parents are already doing in challenging medical and social systems builds advocacy skills and can add an additional sense of purpose that is situated in ideas of self-care (Stearns and Nutile 2024). Engaging in fundraising efforts as discussed by Bluebond-Langner (1996) is one way, but some parents are creating educational non-profits that raise funds for research. Standing Up to POTS is such a group. As a website, podcast, and community they share information and resources for people and caregivers managing POTS. They were founded by Cathy Pederson, a professor of biology who was able to use her scientific knowledge to help herself and others after her daughter was diagnosis with POTS (Meet Our Board of Directors: online). Key in this space is that fundraising can be directed to a specific doctor and purpose. In this way, relationships are being developed with specific doctors or researchers that become allies, and it is these groups of patients and parents that are leading the efforts for change.

Beyond the need for information and awareness, support for the parent caregiver is becoming present in the literature as well. A 2022 study suggests that nurses are in key positions to improve maternal resilience by understanding how the families construct strategies so they can support positive outlooks (Bristow et al. 2022; Coughlin and Sethares 2017). Here, medical teams can support partnerships by bringing in nurses to interface with patients and the parents between follow up appointments. In my personal experience and in conversations with parents having access to the nurse or a nurse practitioner has been extremely supportive. In contrast a recent study on the parent caregiver of cancer patients highlighted the ambiguous expectations of care requirements between hospital and home, and suggested clear expectations from the hospital

of what is expected of parents could ease overall anxiety (Roug et al. 2023). To support caregivers dealing with financial strain a study looked to restructuring Medicaid in a way that enables parents to focus on caregiving activities without the worry of financial repercussions from missed work (Feliciano 2022). Each state has different laws that impact parents' access to resources. For example, the state of Georgia offers a tax-free financial stipend, with coaching and guidance, for those becoming family caregivers, but it has heavy stipulations, including the caveat that this must be the caregiver's only job. Caregivers would not, for instance, be permitted to operate an online store to bring in additional income (Medicaid Structured Family Caregiving (SFC): online). Noting that the well-being of the parent supports the well-being of the child, it seems important to address that parent caregivers are vulnerable to not only financial, but physical and psychosocial strain as well (Koch and Jones 2018). The medical care teams of the teen must consider the parent's illness narrative in order to understand and support the whole family and help them support the patient. Additionally, I argue that providing space for parents to communicate their expectations, experience, and environments would go a long way in supporting partnerships between families and medical providers.

**The Parent Caregiver Role** is not new; a study on how parents use love to overcome the fear associated with raising a child with a rare illness identified a variety of frameworks to analyze the experience of this level of parenting and care (Gómez-Zúñiga et al. 2021). The four care responsibilities from the 2003 Sullivan-Bolvai report listed in the introduction, “managing the illness, identifying and accessing community resources, maintaining the family unit, and maintaining the self (Sullivan-Bolvai et al, part 1 2003, 458 cited in Gómez- Zúñiga et al. 2021, 2), organizes the themes around daily care activities. While a 2015 report identified six categories of supportive care needs that parents offer their child and are organized as emotional,

practical, physical, psychological, informational, and social (Pelentsov et al. 2015 cited in Gómez- Zúñiga et al. 2021, 3), which leads to a third model that organizes around the process and burden of caregiving and includes, background and context, child characteristics, caregiver strain, intrapsychic factors, coping and supportive factors and health outcomes of the parent caregiver (Raina et al. 2004, cited in Gómez- Zúñiga et al. 2021, 3). Gómez-Zúñiga using these models, points out that within the experience the parent role itself may become overly “merged” or “engulfed” by the role of caregiver when the parent role extends beyond what is considered “normal” and can cause conflicts and possible identity crisis (2021). Put together we see models that touch on the role of the parent caregiver that give frameworks for research and highlight a need for the illness narrative and explanatory models of parents to be understood from the context of their family and the community in which the family lives. One key aspect that gets rolled into themes but is often not discussed within these frameworks is the work involved for one person to take on the responsibility of educating and informing others within the family (Fradin 2023, 65). Someone in the family is becoming the point person, the manager, and the head caregiver.

With a full spectrum of care needs, parent caregivers of teens with POTS sit in a wide range of disability and possibility. However, there is a knowledge gap between what is shared with the parent when the child is diagnosed and the expectations around ongoing care responsibilities because they are considered part of the parent’s role (Sullivan-Bolyai et al, part 1 2003, 459). Securing adolescent compliance of protocols, for example, is a task meant for the parent to figure out. The reality is parents need support here. Even when the child is compliant, parents need to navigate social systems such as public and private schools to seek accommodations that will support or at least not complicate compliance. From a greater

perspective we can question the value, or the lack of value seen in a role that crosses the lines of responsibility and reaches into other domains, such as the classroom, to assert itself. This level of invisible reproductive labor making itself seen is a topic that threads throughout this work and leans directly into the studies of motherhood.

## **2.5 Motherhood**

“We know more about the air we breathe, the seas we travel, than about the nature and meaning of motherhood” – Adrienne Rich (1986, 11)

In her book on the neurological changes experienced in pregnancy, Chelsa Conaboy shares that motherhood is something we look at “sideways” and study it through a lens of being transformed in the moment of having a child (2022, xi). Becoming a mother is an experience touted as natural and based in maternal instinct but is really a major event effecting hormones and behavior which is not often acknowledged (Conaboy 2022, 22)—a perceived happy event where the reality of distress in the process of becoming that is reported by many new mothers can be stigmatized instead of recognized as a major event requiring many lifestyle changes and ongoing adaptations (Copeland and Harbaugh 2019). Additionally, the distinction of this role can be made invisible and generalized when the term parent is used when it is mothers doing most of the parenting (Frye 2012, cited in Ennis 2020, 274). For example, in a literature review of 29 studies that looked at the supportive needs of parents who had children with rare diseases, participants were identified as couples, yet the large majority were mothers (Pelentsov et al. 2015). This highlights that in America there is still an expectation that parents identifying as mothers are the ones doing most of the care work.

Expectations of gender roles may be a key to how both parents take on the extra care work in different ways. A systematic review of the father’s role in chronic illness care,

highlighted that involvement indicated improved family functioning when the father was engaged in care, but that this level of care also increased the father's anxiety, distress, and need for support (Spurr et al. 2023). How this is different than the mother's experience was not detailed, nor did the study look at a cross section of families raising children without chronic illness, but the conversation opens room for research on how fathers participate and what can be done to support the whole family. Additionally, this also leads to the acknowledgement of trans dads, trans moms who were assigned male at birth (AMAB), and nonbinary people who do not identify with the term mom but engage in what is understood as mothering practices. Also, parents in same sex relationships where either no one or one or more people are in the role of "mom" should be considered. Motherhood has been framed as "something inextricable from women with uteruses" and this language is alienating when someone is doing the work but not fitting this model (Ratchford 2021). While these identities were not part of my sample population thinking through the acts of care assigned to the role does highlight how motherhood is constructed within families. And how in the United States mothers are the default caregivers regardless of the level of impact.

There is a general understanding of how disruptive chronic illness is to families. A study exploring families managing hydrocephalus highlighted how uncertainty and vigilance dominates their daily lives (Smith et al. 2013), and a look at mothers in Brazil whose children were living with cystic fibrosis felt vigilance redefined their level of care, causing changes in how the whole family operated (Tavares et al. 2010). Here it is important to note that focusing all the work of care on the mother is stressful and can lead to levels of burnout. In a study of caregiver burden, the level of medication management, number of trips to the hospital or doctors' appointments, along with lower levels of self-efficacy in the child, can increase the level of

burden on the mother (Javalkar et al. 2017). Without understanding the environment, who does what in the home, and the inadequate social and interpersonal structures of support there is a perpetuation of stress that is carried by the parents and most often the mother as they navigate the needs of the day.

While parents do worry about the future, in conversations, they seemed more focused on what their child might need or is missing out on in the present. Medical teams worry about this too, but sometimes to a fault, often recommending that the teen be in school despite their symptoms (Kluck et al. 2017), however, this insistence does not consider the school environment, or the work parents engage in, nor the structure of the family needed to make this possible. Engaging with the direct impact of POTS symptoms on caregivers' lives can offer a more nuanced look at the experiences of invisibility, isolation, and interdependency of the young adult (Farchtchi 2020). This is foundational to the recognition needed to highlight the increase in parental involvement and caregiving into adulthood which is a known reality in the POTS world (Boris 2018), and to understand how it impacts the life path of the caregiver. In a recent study, parents of children diagnosed with a rare inherited metabolic disease discuss feeling like they have become healthcare workers (Rogalski 2023). The article further outlines how parents (mothers) learn treatments and acquire knowledge to a level doctors will not with a particular experiential lens. This understanding creates space for parents to be engaged in the process of training medical students (Rogalski 2023, 7). While this study is situated in Poland it highlights and honors parental knowledge and helps turn their experience into avenues for wider support. This also involves a deeper discussion on what aspects of caregiving go beyond the expectations and obligations of motherhood, for how long, and how this work impacts the ideas of the self.

## 2.6 Motherhood and The Self

In my research the most primary parent caregiver of teens with POTS are the ones who identify as “mom”. They are the parents overwhelming in attendance at conferences, online support forums, and support meetings. At large, mothers are recognized as playing a crucial part in the transmission of culture and the reproduction of society, often through everyday activities (Barlow and Chapin 2010). Caring for a child with chronic illness can shatter and shift the everyday habitus by changing the internalized culture and expectations of the family and their resources (Bourdieu 1990 quoted in Tomanović 2004), but it also reproduces the internalized habitus of women and mothers as the default caregiver. Regardless of the personal desire of the mom, there is an expectation of the role. Chronic illness then creates additional constraints and challenges that shine a light on the already impossible role and identity of mom.

I did not intend to create an informal label in the use of “mom”, but it is the word most often used when mothers described themselves during interactions for this study. Colloquially the mother seems to be described as the person who has given birth or has taken on the responsibility of a child as an adoptive parent, and mom is the word often used to describe a person who is doing the work of raising and providing caregiving for the child. Generally, they seem interchangeable. When looking into these labels, I found Mielle Chandler advocates in her studies of motherhood for the role of mother or mom to be considered a verb (1998, 273), that it is the maternal practice of mothering that creates the mother, “an identity formed through a repetition of practice which constitute one as so profoundly interconnected that one is not one, *but is simultaneously more and less than one*” (1998, 274). For further discussions on maternal theory, I looked to Adrienne Rich’s distinctions of motherhood and mothering, which identify

“motherhood as institution and ideology, and mothering as experience and identity” (O’Reilly 2020, 19). All of which are situated in the gendered role of the primary family caregiver.

Both the ideology and the identity of motherhood seem to always be in a state of self-discipline because in contemporary Western culture, ideally moms are always laboring, if not for the sake of the child, then for the critical gaze and expectations of social groups and the greater society. Thus, mothers are operating inside an invisible panopticon (a self-governing prison design that is meant to be observed by one person without the prisoners ever knowing if they are being watched, but self-monitoring just in case they are) (Foucault 1995, 206). Here, mothers are held up to a standard of existence only to ensure the recreation of the very structures that judge her because moms are both an interdependent person, experiencing the self as a socially active role within the family, and an independent person, experiencing the self as an individual (Kusserow 2004, 19). Moms are enculturating their children, doing so in a way that is unique to their personal experience but also influenced by the social structure at large. Examples of this can be seen at a nice restaurant if a child is unable to sit through a two-hour meal. When a child cannot behave “like an adult” society expects the mom or perceived mother figure to manage their child or leave the restaurant. Here, moms are both the disciplined and the disciplinarian.

When faced with a complex and chronic illness, moms can be treated like they are in a restaurant with an unruly child. Here, they often need to push back and reframe normative and able body social models, not just for their family, but for social systems and the society at large. In doing so, they expand their reach in reproductive acts beyond their family unit and become advocates and activists in the process. This is a very active process of making the invisible, visible, which can feel problematic to the society at large. It equates to letting the child run around the restaurant and turning on those doing the judging and calling them out for their

intolerance. Additionally, if the mother were to beat her child into submission at the restaurant to meet the wants of the public, it would be too much for the public. They want compliance but do not want to bear witness to the process. There is an unwritten social contract, an expectation, a lane she is expected to stay in; there is also an explicit legal one. In medical settings these positions overlap, there is an expectation for the mom to go along with testing and treatment regardless of harm—and also not to be too eager to instigate testing and treatments, because both can be considered medical child abuse (Eichner 2016). In the greater gaze, this is not just about disrupting the restaurant or the medical office but touted as the need to raise a child properly so they will grow into a proper adult. The future casting put on the child and the parent makes invisible the entire process of development for both parties. For example, I have seen a common reply in any online forum about young adults that is generally something to the effect that “they will need to figure it out as they will not always have their parents to do it for them,” whatever “it” is, is the fault of the parents. In many ways, chronic illness offers a sharp criticism to this gaze by forcing the invisible to become public in the here and now, particularly in the context of the parent caregiver engaging with these institutions as they care for a child that is not meeting the expectations of society or the “ideals of independence” (Davy 2019).

Chronic illness highlights the additional reproductive work performed to support their child and the present awareness required by moms to be in the now, and by further planning and (co)-constructing a new trajectory for their child (Giddens 1991, 71). Often parents are “imagining and designing” a new possibility without the help of “positive models or pathways” (Ginsburg and Rapp 2024, 129). Taking care of all the pieces so the here and now can be a space of presence and memory-making is the ongoing struggle parents face when the trajectory changes and their work takes on new dimensions. As a mom and researcher, Danilyn Rutherford

looks to open the ways parents can envision a new family life with a permanently disabled child (2020, 1454). Against the backdrop of an ableist society that further diminishes a person with disabilities and by proximity their caregiving parent, Rutherford explores how parents tell “the evolving story of their lives,” first accepting society's viewpoint of the disabled and “diminished person” before seeing the “gift” their child gives them (2020, 1455). Aided by the perspective of raising her own child who does not have the ability to respond to or with love in a normative way, Rutherford’s work is a radical act that touches on expanding the concepts of the parent-child relationship and why it is important to their sense of self and role as parent to do so (2020, 1458). Making decisions within the context of their own parental value systems allows them to envision a new trajectory for their lives while experiencing a new kind of reciprocity as well (2020, 1465,1474,1478). This mindful push back can put them in the margins, but in a way that creates possibilities for new spaces.

Similarly, studies that look at the self-formation of mothers supporting a transgender adult child in Israel identify the need to be a “good mother” through a commitment and responsibility to the well-being of their child (Amrami 2022, 16), which further aligns with Foucault’s subjectivation and need for a critical and reflective look at the self (Amrami 2022, 16). These moms are active in learning the “gender literacy” required to understand their adult child’s position in the world and by doing so recreate their mom role as an active supporter and advocate past the “launch” phase of parenting and sometimes for other people’s children as well (Amrami 2022, 4). In contrast, parents trying to manage the care of an adult child with borderline personality disorder show that the challenges and constraints to the parent-adult child relationship due to the illness thwarts the role of mom and can lead to a moral breakdown with no real pathway for resolution (O’Dougherty 2022, 501). In this context, parents are often

isolated from support systems and lack resources from both a familial and social source that could help mediate the care their child needs which can cut them off from a community to connect with. Threading these experiences through a moral lens of care highlights that the acts of mothering are ones of choice and desire, an attempt to build a third space of possibility of what parenting can be.

The general desire to reduce a child's suffering may play a pivotal point in the journey of motherhood to a new imagined future, one that requires them to change or take on new characteristics and ways of being (Amrani 2022, 205). In each of the previous examples there are external forces engaging with the internal agency of motherhood; this call to action can inspire transformative work within the moral identity of motherhood even when the mother/parent is unable to help their child. However, this transformation can have devastating consequences for those stuck in a loop of crisis.

The irony of a push for a self-reliant nation is a mother who takes on the care needs of a child past the age of maturity because there are no other systems of care available to support her child or her own independence. This gap in care is reinforced by the national narrative of individualism that not only sets the bar of motherhood, but it also fails to acknowledge the work that holds together the very fabric that allows that bar to exist in the first place. All the behind-the-scenes work is invisible to a critical gaze that judges from a point of view far from the center of the family and looks to honor a normative myth that cannot hold up to the lived experience. In a neoliberal context there is a lean toward intensive parenting which rose from the politics of the late 80s and early 90s (O'Reilly 2020, 24). Intensive or even helicopter parenting is often noted by the "time, energy, and material resources" expended on the child as Sharon Hays identified when highlighting the assumption society has that it is the mom that should drop everything to be

by the side of her sick child (1996, 8). It is the negative view of this level of parenting that fails to recognize the “demands made on mothers today are unparalleled in history” (O’Reilly 2020, 25), this tension between being expected to be highly engaged parents, and also being shamed for it underline the impossible aspects of modern motherhood.

In her book that discusses the internalization of parenting challenges with school snack time foods that come into conflict with the personal values of the parent, socio-cultural anthropologist Jennifer Patino highlights the intensive levels of parent involvement (often by the mother) during early years of education. Initially the intensity of the mother is identified by her engagement levels and physical presence when volunteering in the classroom as well as by the category of healthy or unhealthy snack she brings and her response to the food contribution of other parents. This entire activity is judged on the food and the personal value attached to it, but also the self-guarding to not be one of those helicopter parents, all of which is measured against a parent who has “checked out” and is not a participant in the activity (Patino 2020 177-188). Here Patino highlights the impossibility of attaining the ideal—it is important not to be “checked out” but also just as important not be a “helicopter”, and so there is a level of self-monitoring that is happening all the time while also offering a critique of others for being too far one side or the other.

While this high level of parent in the classroom involvement often wanes by 8<sup>th</sup> grade (Patino 2020 177-182), there remains a certain level of involvement required by parents for the school and the student to achieve success. One thought for understanding the intensive mother is that this level of being a busy mom mirrors a day at work in the office. The intensive mother is not interested in invisible and devalued work and these public activities, such as in the classroom at snack time, can be seen as productive (O’Reilly 2020, 25).

In another view that considers the rise of social media, the home has become a place of production, where the labor of both sharing media and reacting to it take place in the realm of the economy (Ross and Craig 2022). While the level of work involved on behalf of the audience can be debated, for the parent caregiver it is the invisible work of being the audience is both research and community building. When traditional appointments with the doctor do not result in answers, mothers become an active audience, participating in care work to find answers for themselves and their child based on what has been shared on the internet from other moms facing a similar situation. This level of intensive investment is a way to cover a gap for both the media creator and the audience but is also mediated by a level of social disciplining of a mothering style. There is a self-awareness to it in much the same way we see in the mothers in the classroom during snack time.

The awareness of the construction of self in the role of mom is based on external factors that parents move through as transitional and informal states without clear distinctions or rites of passage (Giddens 1991, 74). Even the act of birthing, which could be argued as a rite of passage, is bounded by the social idea that a woman's body knows what to do, in birth and in child rearing. Motherhood however is not a "natural or biological function... it is fundamentally a cultural practice that is continuously redesigned in response to changing economic and societal factors" (O'Reilly 2020, 20). The self as mom is being recreated within the context of their constraints. The idea that the mother is only crafted around the child, opens the role to criticism that can lead to pathologizing acts of care and comfort. The role has a purpose, to reproduce culture, but how moms reproduce it is subjected to Foucauldian themes of control including the basics of care. Where ideas like co-dependency are discussed out of context and used to push back on the acts of care for a child society wants to see learning how to care for themselves but

also wants to hold parents responsible. Here, mothers may look for understanding by forming relationships with other moms experiencing similar illnesses with their children (Carey, Block, and Scotch 2020, 38). These acts of resiliency become advocacy, as these collectives are safe spaces, both in person and online, to share some of the personal narratives carefully constructed around parenting (Giddens 1991, 76). Mothering, in this way, is not just embodied acts but the judgements and internalized thinking we have about being mom. While ideals can be formed from a shared history and activity, it is not the space for true self-actualization (Giddens 1991, 78), especially if actions constrained by outside pressures do not always mirror how the mother thinks about parenting or how their role needs to change in order to support their child.

## **2.7 Extended Parenting**

A key feature of this study is the active role of parenting juxtaposed against social expectations. The parenting role can extend beyond what is expected during adolescent years by focusing on present needs and allowing the future to be reimaged. While this can be true in parenting even when there is no illness to contend with; in this study I use illness management to show that the parent caregiver role can extend beyond the age of majority. This major shift in personhood and state recognition for the teen might go unnoticed if it were not for the bureaucracy attached to it. A legal adult in the United States at age 18 is not afforded a blank check into adulthood; there is a bit of an apprenticeship toward becoming a fully recognized adult that can legally drink or rent a car. These guard rails are meant to support both the young adult and society, but there is little in the way of guard rails to support the chronically ill or their caregivers that does not involve extra work on the part of each party. I identify this extension of care labor beyond the societal expectations of 18 years as “extended parenting.” While these expectations are somewhat of a myth and many parents extend care to their child throughout

their lives, viewing this work through the lens of POTS and chronic illness highlights this practice which can offer new pathway of possibilities for both the child and caregiver.

The hope is the new adult will take over their own care. However key factors highlight this transition that differ than a normative model. The number of doctors, specialist, medications, and accommodation requests means the work involved in transferring specialist care and finding doctors and rebuilding a care team is significantly increased. By extension this may increase the need for support and guidance when making medical decisions. This position can triangulate the parent and the child with the medical provider to create a more realistic view of care. For example, in popular discourse, it may be common to hear of a spouse, an adult child, or a friend attending a doctor's appointment. In some cases, it is advised, so they can take notes and be a second set of ears (Levine 2023). Yet this type of social support breaks down during the period that marks the shift to adulthood. It is this period where the focus on breaking the bonds of the parent child relationship uniquely make this extra attention and support seem "out of place" and too intensive from an American parenting perspective. Any care activity for an older relative is seen as normative, but the same activity done for a teen or young adult seems overbearing, overprotective, and disruptive to their self-sufficient path to adulthood. My project identifies that this work is happening and is resisting the push to conform to social and interpersonal expectations of what parenting should look like. By doing so the parents place boundaries around their families to recreate what is possible in the relationship during this time. They move through the power imbalances of the parent child relationship to balance obligation and dependency with commitment and trust and possibilities of a deeper relationship (Giddens 1991, 92-97). In action extended parenting holds space for a longer launch window that build resilience in both the child and the parent.

Extended parenting is not a new concept. It is discussed in the archeological record noting when births come too early for the offspring to care for themselves, parenting care ensures survival of the species. This biological need opens pathways for culture and framing of how the young are raised and how they develop (Uomini et al. 2020). While extended parenting in humans follows this early survival pattern, I use it here to describe the need for support beyond what may be seen as normative development models in adolescence and the shift to adulthood—if not for survival, then for an improved quality of life. This is not unseen in the general population. Economic issues over the last few decades have caused huge cultural shifts in marriage ages, home ownership, and how long young adults live with their parents (Trussell 2023). For illness, extended parenting can look supportive as well as intensive. It involves all the markers of time, attention, and resources of intensive parenting (Hays 1996), but it is work that creates the possibility of new narratives and redefines what parenting can be.

In general parenting seems to be broken into these stages, birth, parenting, and empty nester, with a variety of categories scattered in-between noted by the child's age or activity involvement. The parent who leaves the hospital after their child is born is not the same parent who send them off into adulthood. While we do not tend to afford development periods to parents, raising a child is not the same as giving birth to one. And it would be difficult to say a parent should immediately know what to do when their teen becomes ill and the trajectory of their life path completely changes. My initial thought was that chronic illness created an extended adolescence that fit the models of emerging adulthood (Arnett 2000). But the more I spoke with moms the more I heard framing that suggested the work they were doing was so their child could live into adolescent norms, and I shifted to see this work more as extended parenting. These moms felt challenged by the actions they needed to perform or the support they needed to

offer not because of the work itself but because the work was considered not to be age appropriate. However, moms could frame it as being “an expert” on their child and knowing what their child needed, regardless of the child’s age. In some cases, this puts strain on friends and even relationships within the family when they prioritized the needs of their grown child. In some ways this seems like it could be part of the role of parent, but there is also a societal push back that sees this work as damaging to the independence of the child. This thinking not only reinforces the ideas that make illnesses invisible, but it also has the effect of making the child invisible as well. In this way extended parenting creates the possibility for support as the child learns to advocate for themselves on their own timeline and within their own life structure.

## **2.8 Reflection**

When Clifford Geertz “believ[ed] with Max Weber” in the “webs of significance,” he was speaking on the threads of interactions, symbols and myths that not only make up a particular worldview but are used to interpret meaning (1973, 5). It is this web of connective tissue that parent caregivers find themselves navigating and trying to make meaning in. They are not just learning about the illness, though that is extremely important, they are interacting with it, interpreting patterns, and looking for partners (medical and beyond) to help find answers. Parents can be challenged by the impossibility of modern guidance. They can find themselves stuck between providing intensive support and being challenged for offering it. In some cases, parent caregivers are redefining the way illness challenges the status quo. By using extending parenting, they can build new spaces and protect a way of being in that space. In the next chapter I explore how illness narratives can validate the parent’s work and experience as well as help support the family in the chronic illness journey.

### 3 CHRONIC ILLNESS AND NARRATIVES

#### 3.1 Historical Look at POTS

The importance of sharing a historical and biomedical explanatory model of POTS in this study highlights two things. One, sharing this information spreads awareness of this illness and further underlines that disordered bodies are at a disadvantage in the American medical system. The gaps identified in the experience of illness seem freely discussed in popular culture but are often relegated to foot notes in academic literature if mentioned at all. This invalidation of the lived experience against what is considered a valid biomedical model is what Foucault considers “games of truth” or a set of rules in which parents (and patients) need to be acquired to communicate effectively within the respective environments (Foucault 1997, 297-298). Second, it sets the stage for understanding historical implications of the medicalization of illness and the balance parents and advocates try to achieve when supporting the need for research that hopes to offer clinical proof of the lived experience. For example, studies into bacterial agents responsible for the presentation of illnesses initially misdiagnosed as schizophrenia started in the anecdotal. They were pushed forward into popular culture media and further advocated by a journalist who was afflicted by such an illness (Cahalan 2012). Additionally biomedical explanations are more readily accepted by patients when they resemble the lived experience (White 2005), highlighting the need for an understanding of the lived experience from the patients’ and families’ points of view. Similarly, the need for biomedical proof often informs the diagnostic journey of invisible illnesses such as POTS and the experience is threaded throughout the history of the illness and the systems that reproduce unhelpful opinions and behavior within medical and social settings.

It has been generally agreed that contemporary awareness of POTS dates to 1993 when the illness was named by researchers at the Mayo Clinic (Schondorf and Low 1993; Agarwal, et

al. 2007). Labeled a syndrome, POTS is a collection of symptoms that are often grouped together and range in severity (Grubb 2008). To test what was happening with the increase in heartrate (tachycardia) during position changes with early patients, researchers used tilt tables. They strapped patients to a table that gave the doctors the ability to move the patient to an upright position but prevented the patient from falling to the floor if they experienced a partial or full syncope or fainting episode (Schondorf and Low 1993). While the table test is said not to be harmful, it is very uncomfortable for the patient. In a presentation shared at the Dysautonomia International conference in 2024, Dr. Blair Grubb discussed how someone without POTS would not feel the effects of the table test so to understand what their patients were experiencing they developed a depressurization unit that pulled blood to their lower extremities. Dr. Grubb reported that it was the worse he ever felt and honored those in the audience that live with this experience on a regular basis (field notes July 2024). The tilt table has remained a standard diagnostic tool until recent years.

1993, however, was not the first time the grouping of dizziness, fatigue, and brain fog symptoms were recognized as an illness. In 1871 an “irritable heart” condition called DaCosta Syndrome first noted these symptoms in military populations. In 1919 Dr. Lewis described an “effort syndrome” that would be called Soldiers Heart during the First World War (Wooley 1976; Agarwal, AK et al. 2007; Boris 2024). In the second half of the 20<sup>th</sup> century researchers Cohen and White identified the illness as two syndromes: one they considered mild, naming it neurocirculatory asthenia, but the other was more severe, and they labelled it a manic-depressive disease (Wooley 1976). This is a significant addition to the history thread given that in recent years over 75% of people diagnosed are either suggested to have or are misdiagnosed with and treated for mental health issues before receiving proper care for POTS (Shaw et al 2019; Boris et

al. 2024). Specific implications for persons with POTS notes that anxiety tests often include the experience of somatic symptoms in their questionnaire. For example, someone reporting high levels of pain, breathlessness, and increased heartrate would score high on an anxiety questionnaire, yet these are all symptoms of POTS. This makes the standard tests for anxiety unreliable for patients with POTS. Interestingly, when an Anxiety Sensitivity Index is used in patients with POTS the results tend to show they have less anxiety than the general population (Raj 2006). The unfortunate continuation of the prevalence of this misdiagnosis and mistreatment of POTS patients highlights the lack of consistency and awareness across diagnosis and treatment pathways.

More than 150 years have passed since these illnesses were observed and there is still not an FDA approved therapy for POTS (Miller et al. 2018); treatment is based on a best practice, trial-and-error model, which takes a lot of time for each patient and their team to work out. This counters the often-quoted Mayo Clinic report that teens will grow out of POTS (Torborg 2017). A closer look at the data in the report reveals the headline does not match what the numbers identified. Reporting on this study combined two data points to show that 86% of the people surveyed had their symptoms resolved within five years, when the actual number was 19% (Bhatia et al. 2016). What the report really seemed to show was that it took up to five years for 86% of those surveyed to find a protocol that help them manage their symptoms. The reality is teens are not growing out of their illness. During the Dysautonomia International conference in 2024, Dr Boris shared data on a systematic review across multiple countries that has found no statistical evidence pointing to teens growing out of POTS (field notes July 2024; Boris et al. 2024). This is significant because this myth is currently being perpetuated in doctors' offices, and unfortunately in internet search engines. I have had doctors quote it back to us and have had

to pull up the actual data in the report that shows how misleading the title is. One point that gets missed in these debates is that this messaging seems to say that it is okay for teenagers to suffer through these years because they will be fine later—obviously missing any context on what makes someone “fine” in their teens or in their early 20s. What is truly telling is not having FDA-approved protocols, which means that patients, parents, and advocates need to push back against outdated and unreliable reporting of data while also fighting insurance companies for access to care. As a federal governing body, the FDA cannot approve treatments until testing is done to prove their efficacy. While this gap has financial considerations for families in America, it highlights issues with access to care across the developed world.

The FDA and its equivalents in Europe (EMA), Canada (Health Canada), and the United Kingdom (MHRA) follow a similar model of diagnostic trends, with a sustained increase in standing heart rate of 30 points (40 points for teens) from a supine position as the indicator for POTS (Raj 2006; Agarwal et al. 2007). However, there is no true standard test across countries or even physicians used for diagnosis. For example, MHRA promotes using the NASA Lean Test over tilt table tests to help with diagnosis, this is something that has just started to be promoted in America. The NASA Lean Test has the patient rest for 15-20 minutes lying down in a relaxed position. Then they stand up against a wall with only their shoulder blades touching while their heels remain six inches from the wall. Heart rate and blood pressure measurements are taken every minute for ten minutes, but this test also observes the skin and extremities for color and temperature changes, and it also assesses cognition (Lee et al. 2020). This test is said to be less uncomfortable than the tilt table, but still means to invoke an increase in heart rate with the position change and therefore relies on the patient’s experience during testing.

As far as treatments, there are two basic protocols to follow for POTS, one which includes non-pharmacological interventions such as an increase in salt and fluids and another that includes pharmacological interventions such as beta blockers and medications to control blood pressure (Raj 2006). Often a mixture of both protocols is used, however MHRA tends to support medication control options (after a brief trial of non-pharmacological interventions), over the increase in fluids and salts which tends to be encouraged in the United States for children and adolescents (Living with POTS 2024; Nicholson 2020). Another slight difference is how the acronym is displayed. In the United States “POTS” is used, and, in the UK, “PoTS” is used. While this seems like a small point it can still create confusion. For example, “potts” is short for spinal tuberculosis or tuberculous spondylitis, an illness my daughter does not have but one that was added to her medical chart when a doctor did not know what POTS was. With all these differences it is important to point out that the consensus within the community is that while there are recommended protocols in place, more research is needed, and this speaks to the uncertainties associated with this illness from a biomedical perspective. Not all doctors agree on an approach, and not all doctors within a team agree on a protocol. For example, while one doctor might advocate for IV fluids, another might argue against it, which puts the responsibility back on the parent when looking to support a teen during a flare. Overall awareness of POTS has increased, and diagnosis times have decreased due in a large part to the post viral complication of long covid reported in patients early in the pandemic (Mallick et al. 2023). All of this has further highlighted the need for research and treatment guidelines as well as public awareness.

A recent win for the POTS community was the acceptance of an International Classification of Diseases (ICD) code. In its 10<sup>th</sup> revision, the ICD-10 code for POTS is G90.A (An Advocacy Victory 2022). The code was proposed and advocated for by Dysautonomia

International (DI), a non-profit educational and advocate group started by Laura Stiles, a POTS patient who began writing a blog in 2012 to share information with others about her diagnosis. A community grew and with the help of patients and parents and now a medical board, DI has grown into an education and research funding platform. Before their work on the code which went live in October 2022, persons entering the ER with POTS would be coded by their symptoms. For example, my daughter was coded as “dizzy and giddy” when presenting in the ER with a POTS flare that resulted in a fourteen-day hospital stay. This step by the international community improves communication and awareness, and the chance of treatments being approved by insurance simply because they can be accurately coded, identified, and essentially tracked. This also becomes a point of advocacy on part of the parents in which many take on the responsibility of now communicating the existence of the ICD-10 code to doctors within their care teams.

These small steps forward are promoted and advocated by the POTS community. There is a considerable push from the POTS community asking for more research funding and FDA support. Protocols are just suggestions until the FDA recognizes them as standard, and for that to happen much more research and testing needs to be focused on this community. In the meantime, the scientific uncertainty around POTS complicates the experience for patients, parents, and caregivers. While a diagnosis is helpful for community-building, there are few distinctions between uncontrolled POTS symptoms and the flare experience from a biomedical perspective. Without a clear and consistent explanatory model of POTS symptoms, diagnosis, and treatment, parents of teens can be caught in the middle of multiple systems and healthcare teams trying to manage an illness like they are an account manager. While the assumption is this labor will transfer to the teen as they become an adult, the reality is that a longer timeline of support is

needed (Boris and Moak 2022). This further highlights assumptions on the side of the medical team in teen management of symptoms, parental responsibility, and concepts of providing care that will be explored in further chapters.

### **3.2 Scientific Explanatory Model of POTS**

I have attended three Dysautonomia International conferences, all three as a parent of a teen with POTS and the last two also as a researcher deep in the field. The doctors here speak to like-minded colleagues and still advocate strongly for the patient to be listened to and believed. It is enough to make you feel the bubble will follow you back home. POTS is not rare, but it can feel that way because for a long time it was rare and difficult to obtain a diagnosis and receive treatment. POTS is still an often misunderstood and misdiagnosed illness. A 2019 report taken from an ongoing online community survey shows that the average diagnostic delay was over five years, with female presenting patients showing a longer diagnosis delay of two to three years over male presenting. With women being primarily affected by POTS, this could indicate a significant gender bias I will expand on in the structural violence section. 75% said they were misdiagnosed prior to their POTS diagnosis, with 77% told they had psychological issues before being diagnosed with POTS. And an important note for this study, 34% were diagnosed with POTS as a teen and many who were diagnosed later in life reported their onset of symptoms during their teen years (Shaw et al 2019). While the severity of the illness sits on a spectrum, getting a diagnosis in the teen years speaks to the level of involvement needed on behalf of the parents, not just in getting a diagnosis but in finding treatment and care.

POTS or postural orthostatic tachycardia syndrome is a form of dysautonomia, or a dysfunction of the autonomic nervous system. I note this again because while it is named for an increase in heart rate, POTS is not a heart condition. Many people are diagnosed by a

cardiologist because to receive a POTS diagnosis, cardiologists must rule out any other possible issues with the heart (Raj 2013). While POTS is an issue of the autonomic nervous system and would fall under the discipline of neurology, cardiologists are the leading doctor in diagnosis and follow up care, followed by neurology (Shaw et al 2019). It can be confusing for a patient to know where to turn when experiencing a variety of symptoms associated with the nervous system which controls automatic functions all over the body that are often not thought about until a notable dysfunction.

The autonomic nervous system is a part of the peripheral nervous system which regulates a lot of the body's processes that are largely involuntary such as the heart rate, blood pressure, and digestion. The autonomic nervous system contains three distinct divisions in the body: sympathetic, parasympathetic, and enteric. A body experiencing dysfunction can present with symptoms that are impacted by these processes. The sympathetic nervous system is responsible for activating the body; this is often known as the "fight-or-flight" response. The parasympathetic nervous system works with the sympathetic system; it is often called "rest and digest" (Hirsch 2022). These interactions can have an impact on the enteric or GI system which can result in a list of symptoms such as pain, slow motility, and nausea that make it seem like a completely different issue than POTS but are part of the long list of symptoms patients need to manage (Tufvesson et al. 2024).

GI issues have a significant impact on diagnosis because a lot of POTS patients have issues that are misdiagnosed as anxiety or filed under "functional" when no structural issues in the GI tract can be found (Shaw et al 2019). Functional is a term discussed a lot in medical offices. It is not necessarily a catch-all term but fills a role when a direct cause cannot be pinpointed. Here I found an interesting distinction or resistance in the use of this language in online

forums. Where a doctor might use functional to describe a misfiring of the nerves in the stomach causing pain, parents and patients in online discussion forums tend toward calling it neuropathy. While not explicitly shared, it seems the term functional is received in the online community about as well as being told “It is all in your head” and they are finding and using language that better describes their experience.

Working bodies can feel the experience of POTS when standing up too quickly and the body adjusts to manage the blood flow. When we stand up, multiple actions happen within the body all at once. The vessels in the neck constrict so gravity will not pull all the blood from the head to the feet. There might be a slight drop in blood pressure which then instigates a spike in adrenaline, which is a hormone that sends a signal to the heart to increase the heart rate and keep the blood flowing north, and all of this is happening automatically to optimize a return to homeostasis. Among many things this activity in the body is an adaptation to gravity. But the heart can only pump the blood that is available. If a body is fighting to keep blood in the head, and the blood is draining, that body will experience dizziness, and sometimes pass out. The increased heart rate is sustained much longer, possibly hours, mimicking the effects of a panic attack. Blood pooling in the extremities can cause discolorations on the skin. The chest might become tight and feel sore (Agarwal et al. 2007; Boris 2018; Boris and Moak 2022; Kelly 2016; Miller et al. 2020; Raj 2013). There might also be gasping for air known as air hunger and levels of breathlessness (Reilly et al. 2019). When symptoms hit a crisis, the body may go into what is known as an acute “flare,” where brain fog, fatigue, and weakness become a serious issue and can have extreme impact on the quality of life (Boris 2018; Raj 2013).

The main protocol for treatment is to increase blood volume to help the circulatory system with an increase in fluids and salt, generally two-three liters of non-caffeinated fluid and

over five grams a salt a day (Raj 2013). Many people use electrolyte formulas like Pedialyte and sport drinks such as Gatorade, and new brands have come on the market to support electrolyte replenishment that are marketed directly to the POTS community. Additional non-pharmaceutical treatments include exercise and compression stockings, while pharmaceutical treatments to manage the symptoms include medications to support blood pressure, heart rates, fluid retention, and fatigue. Many of these are considered off-label uses, meaning they are used to manage a symptom (Raj 2013). None of these are a treatment for POTS the illness, POTS currently has no known cure, they are protocols meant to make the symptoms of POTS manageable. This highlights that for teenagers and their parent caregivers, POTS is an illness that needs active and ongoing participation to understand the symptoms and find a treatment that helps with their lived experience.

### **3.3 Frameworks**

#### ***3.3.1 Illness Narratives***

Foundational to this study is the parent caregiver story. This includes not just the physical care labor, and how it affects their lives, but how they are making sense of the experience. Key to framing these ideas was Arthur Kleinman's *The Illness Narratives* in which he outlines how listening to the patient center themselves in the narrative of their illness could assist the care team in supporting protocols and treatments (1988). Here I underline that the experience of chronic illness is enmeshed into the life course and that in the "development of a particular life... illness becomes inseparable from the history" (Kleinman 1988, 8). Similarly, the parent caregiver experiences an impact to their life course as well, as they join their child into the uncertainty of illness care.

Applying the idea of illness narrative to the parent caregiver experience creates a broader understanding of the illness and speaks to the choices made when crafting the narrative of care. To use Arthur Frank's language, the parent caregiver's story falls into the category of quest narrative; it is the journey of accepting the illness and using it to move forward (1995, 115). Frank further organized the quest narratives into "memoir, manifesto, and automythology" (Frank 1995, 119). Where the memoir reports the illness experience alongside life events without a claimed insight, the manifesto comes with an agenda for social change identifying that "society has added to the physical problems that disease entails, and it calls for change, based on solidarity of the afflicted". The automythology then becomes less political and affords a new personal existence for the afflicted to live into (Frank 1995, 120-123). This last organization aligns with Bhabha's discussion of the third space (Bhabha 1998, 30), that can be a space of new possibilities. While not explicitly meant for the caregiver these facets of the quest experience fit the parent's experience in this evolving role of caregiving, care guiding, and independence supporting. The meaning they are making of the experience is both an intertwined and separate phenomenon. It is informing their particular life but also reflexive and speaking for the care of another. While both the teen and the parent may have similar goals of wellness, the trajectory of both are impacted differently and understanding both narratives may offer a fuller picture of the environment and agency (or lack thereof) in which the illness sits.

Further, medical anthropology includes narrative (story) as one component of the Experience-Near or Experiential Approach to the study of illness. The experience (feeling) and meaning (how it is connected to moral questions) rounding out this framework are typically used to show the connections between illness and issues in social systems (Brown and Closser 2016, 21). In this work, the narratives speak to the challenges in accessing a diagnosis and receiving care, as well as challenges experienced within social systems and interpersonal relations. The

meanings of illness impact the construction of self when lives are disrupted and there is a direct impact to the body's experience (Mattingly et al 2000, 28). When both the teen and the parent have been disrupted, the parent does not often have a voice for self in this space. The parent's job here is often to validate what the child has said but does not necessarily explore the family experience or perspective.

The illness narrative comes from a specific form of data collection done with the intent of understanding the experience of illness within the context of the person's everyday life, cultural background, identity, and economic situation (Kleinman 1988, 28-31). From Kleinman's perspective this meant changing the way patients' medical histories were being jotted down and shifting to methods such as "ethnography, biography, history, and psychotherapy", to create knowledge that shares what it is like to be living and suffering with an illness (Kleinman 1988, 28-29). The clinical strategy Kleinman employed was the explanatory model which focused on questions that asked the patient what they thought caused their problem, what they think the sickness does to them, the illnesses severity, and the kind of treatment they should receive (Kleinman et al. 1978). By expanding beyond the symptoms and medical history a new understanding is created, which Kleinman calls a third sense of illness meaning (Kleinman 1983, 31), and further aligns with Bhabha's third space (Bhabha 1998, 30). The meaning the sick person transfers to the illness experience from their life with it. This is notably different than the cultural meanings of illness that may become significant to the sick person as they weigh in with their own experience (Kleinman 1983, 31). Understanding this distinction by employing narrative skills helps students of medicine improve listening, observation, and reflection skills from a place of empathy (Charon 2006, x). The shift from the theory and methods of illness narratives to competency training and clinical use is referred to as narrative medicine.

Narrative medicine arrives in the early 2000s with most programs focusing on a read-reflect-respond pedagogy (Milota et al. 2019). In order to train medical personal, Rita Charon developed a degree program in Narrative Medicine at Columbia University in 2009 (Program of Narrative Medicine: online). Centering both the patient and caregiver, Charon's focus is supporting narrative competence for medical personnel and improving the relationship between practitioner and patient (2006). Charon identifies the divides between patient and care teams with four threads: the relation to mortality, the context of illness, beliefs about disease causality, and emotions of shame, blame, and fear. For Charon, Narrative Medicine bridges these divides (2006, xi). Which further creates a more positive and connected experience for the patient, and their families. For parents these four threads are experienced through constraints of parenting and the enculturation of intensive responsibility. While more research is needed in this area to see how this is reflected in patient outcomes (Milota et al. 2019), there are opposing views to the work involved in capturing the illness narrative and the nature of the narrative self as a universal skillset armed with storytelling abilities (Woods 2012).

One key issue with implementing illness narrative into the clinical setting is that most doctors do not have the time to employ it. In her memoir *The Invisible Kingdom*, Meghan O'Rourke outlines the issues with a siloed medical system that offers fifteen-minute appointments and is unable to communicate across disciplines to connect the dots for those suffering with chronic and complex illness (2022). This can be further hindered by the expectation of a sick person within the doctor's office and beyond. While sociologist Talcott Parson's now criticized theory of the "sick role" is no longer used, it does offer a historical backdrop to how illness, explicitly illness that can be treated, sat in a matrix of how being sick equated to "social deviant" when unable to contribute to society, yet unable to contribute was

one of the criteria for the illness distinction. Other criteria outlined by Parson's included not being able to get well through sheer will or by pulling themselves together, that they felt an obligation to "get well", and they sought the help of a physician and cooperated with them (Parson 1951, 436-438). In this model the "sick" are required to fulfill certain obligations in the effort towards wellness and to reject any tendencies to dwell in sickness and the care it affords, or what Parson called "secondary gain" (Parson 1951, 437). Parsons never considered the relationship between the patient and the doctor to be equal, giving more weight to the technical knowledge of the physician (Williams 2005), which highlights a certain level of control needed to manage the role of illness. Basically, if too many people were deemed sick, society would not function well (Parson 1951, 430) so who gets to be sick must be controlled, and with that comes levels of stigma monitored by society at large. One key criticism of the sick role model was that it did not make room for the ongoing need for support that someone with a chronic illness may require (Williams 2005). But observing chronic illness through these obligations may identify why it remains a challenging experience for both the patient and the physician today.

While theories may have shifted, the medical system is still geared to handling issues with neat beginnings, middles, and ends; think the ringing of the bell that marks the end of chemotherapy treatment for a cancer patient. It is an image that does not fully encompass the road back to health or the after-chemo care required to get there. The medical system is simply not set up for long meetings to discuss multiple bodily symptoms requiring a trial-and-error approach to care and a documentation review of what is working and what is not. Unfortunately, for the chronically ill this level of work might be where some of the answers are, so it is forced into the patient and parent's hands. While individual responsibility is a foundation of the neoliberal approach to wellbeing (Viens 2019), medicine as a commodity causes challenges for

the chronically ill looking for services that fit their needs and allow space for their narrative to guide their personal care.

During an earlier research project, I looked at ways doctors could further bridge the lack of time for narrative collection by using resources already established within the care team, such as physical therapists (Ross 2022). There was a precedent here as Cheryl Mattingly used patient exchanges with physical therapists to explore the narrative structure of the illness experience as it unfolded over multiple visits. Mattingly shared that certain narratives are helpful for exploring these experiences specifically highlighting the event-centered, experience-centered, and created-for-audience experiences (1998, 8). Narratives that are event-centered are focused on human action and interaction. Narratives that are experience-centered, describe not only what they are doing in the world, but what the world is doing to them. Narratives that create an experience for the audience “offer meaning through evocation, image, and the mystery of the unsaid”; they are meant to evoke a wonder-what-happens-next for the listener (Mattingly 1998, 8). This investment in the story is something marketing researcher Anne Hamby calls transportation, identifying that when stories shift from a normative experience and the listener becomes invested there tends to be a higher level of motivation to make meaning of it (Hamby et al. 2017). For the patient and parent trying to find answers having an invested listener can help guide what are important narrative points as they continue the healing journey. Medical team members such as the physical therapist who meets regularly with patients may be in the position to not only capture such narratives but also offer a bigger picture over a timeline of hours versus the minutes given for a follow-up appointment.

Challenges to the narrative model remind us that there may be alternative ways to find meaning in illness. Listing seven concerns with the focus on the narrative, such as trusting what

is shared, mindfulness of harm, overinflating forms of self-expression under the narrative umbrella, collapsing forms and contexts, missing the functions of story types, cultural overlooks, and, considering narrative to be the only form self-expression, Angela Woods encourages the expansion of tools to understand the meaning-making in illness (Woods 2011). Here, as digital technology changes, we see parents engaging in images and short form story as they post or share on social media. They not only make meaning of the illness but also investigate and comment on their role in it. Maybe it is not enough to challenge the universality of storytelling skills; what is needed is to identify the skills parents and patients need to tell the story of illness in a way that is both meaningful and effective and inspires investment from the medicine team.

Where the uses of illness narrative as a framework are implemented, additional challenges are noted. A study in Brazil shows that community health workers were trained in narrative medicine to create alliances and improve cooperation with their patients. However, this model needed more organizational support to achieve connection and compliance (Pinto et al. 2021). Compliance is a point of reflection in chronic care. It was one of Kleinman's biggest challenges with his patients and became a foundation for his concept of the explanatory model. Chronically ill patients are often labeled as "difficult" and "non-compliant" in the biomedical world, making their care automatically tagged as challenging. Kleiman goes so far as to explain that the cycling of symptoms is simply exhausting for the doctor (Kleinman 1988, 225). But this too is part of the illness narrative. The patient and the family are aware of the challenges because they are experiencing them as well as feeling the dismissal when their voices are not heard.

Narrative then becomes a way to track the progress of the journey and the systems the families find themselves navigating. Pamela Schaff shares, in *Pediatrics and Narrative Medicine*, that narrative medicine does more than support care, it creates health justice

advocates. Children can find their voice and be stewards of their care (2022). Children and teens with illnesses are often put into situations in which they need to stand up and advocate for themselves as they ask questions and become aware of the illness they have. In personal experiences and interviews with parents, moments were identified when teens were able to push back and advocate for their needs. Taking an active and “adult” role in their own care. While this is a step towards self-management, the lived realities share additional supportive narratives. In a webinar of six adult POTS patients sharing advice on how they transitioned into managing their own medical care, they all reported still getting assistance from their mothers. Moms were supporting health journeys in various ways by attending appointments, working in the background to set up and confirm appointments, picking up and manage medications, as well as reminding their child to stay up to date on certain aspects of their care such as fluids and salt intake (Flores 2023). Olympic swimmer Katie Ledecky shared in an interview about her memoir that her mom looks out for her and helps her stay on top of her fluids and salt intake that manages her POTS (Kuzma 2024, SELF online). While this could be normalized as parenting behavior, it sits in the narrative as a behind the scenes shoutout of the work it takes to support the management of illness and that few should have to do this alone.

In some ways connecting the perspectives of healthcare professionals, caregivers, and patients supports building language that helps put people on the same page in both the clinical setting as well as in the research labs. Integrating narrative knowledge then becomes an interesting aspect of medical practice. How does learning medical language or the medicalized version of an illness impact how the teen or parent experiences the illness? Ronald Schleifer tackled some of these issues when discussing narrative knowledge and the multiple ways we use language to describe being unhealthy, detailing how it is easier to describe unhealthiness or

perceived unhealthiness than the elusive ideas of what it is to have health (2013). For POTS this means there are a variety of terms that could describe the sickness, but how do you describe a good day? These descriptions will impact the use and re-creation of meaning. Finding the balance between the biomedical world and the experienced world takes shape when identifying the meanings of words like syndrome. It does not signify the experience or severity of the illness. AIDS, for example, is a syndrome. This simply means that there are so many symptoms that illness can present in any number of ways. The use of syndrome then sits in a narrative that helps explain its meaning, and therefore should not live only in the patient, or only in biomedicine, a challenge seen when certain symptoms such as fatigue become medicalized in a way that disrupts and stigmatizes patient care.

Distinctions in meaning are further highlighted by the care experience revisited by Kleinman after his wife was diagnosed with Alzheimer's. Expanding on his narrative framework and the work of others that came after, *The Soul of Care*, added a moral lens to the act of care (2019). Here Kleinman is explicit that the goal of his explanatory model was meant to be used to connect the patient and understand family views of the illness but was frustrated that this had become just another checklist of data collection without deeper engagement (Kleinman 2019, 95).

Illness narrative taken in a clinical setting can co-create knowledge that integrates the biomedical knowledge and the psych-biomedical knowledge with the lived experience. By including the caregiver and the family in the illness narrative a fuller picture can be assessed with questions designed to get beyond the body's symptoms and disease history and explore meaning making through cultural background, identity, and economic situations. When we look at the experience of teens, I see the parent caregiver as that bridge and feel there are avenues available

to support their narrative competence. They are both the listener and the storyteller, they are the on-going, ever-present caregiver in a role that requires them to learn and perform new ways of caring and comforting. For the parent caregiver however, the work of making meaning of the illness in their life is pushed outside the doctor's office and into the realm of self-care, friends, and therapists who may and may not have the narrative training to support or validate the lived experience. While the parent caregiver has a perspective of the illness, their role is often tied to advocating for their child in the doctor's office and theorizing outside of it. Illness narratives then could bridge this gap and help form partnerships.

### ***3.3.2 Structural Violence***

Beyond the illness narrative framework, this study looks to themes of structural violence often discussed by medical anthropologist Dr. Paul Farmer through the lens of medicine and social justice. The discussion on western biomedicine's inability or lack of willingness to treat the whole person (1999) and instead perpetuate a Cartesian dualism that insists the mind and body are separate (Eisenberg 1977; Mehta 2011), align with a siloed system of medicine that creates further challenges in accessing whole body care. Structural violence points to social structures that impede societies (Farmer et al. 2006). In 2004, Farmer replied to a comment by Nancy Scheper-Hughes who was advocating for broader concepts of structural violence, by adding that structural violence also includes levels of symbolic violence (2004). This nod to Pierre Bourdieu and habitus was not new to Farmer's work, but it can be addressed in this study by the invisible nature of POTS, the power differences between doctors and patients, and the growing use of the word "gaslighting" to describe a doctor's dismissal of symptoms, where an anthropological term may be symbolic violence. While it may not be completely unconscious, the doctor's dismissing does not come from a place of having created the experience in which the

symptom exists but likely comes from the bias built into medical and social structures, medical training, and social understandings of illness.

The term gaslighting comes from the 1944 Ingrid Bergman film *Gaslight* and was based on a 1938 play titled *Gas Light* by Patrick Hamilton, in which a husband purposefully reduces the gas to make the lights flicker and when asked about it by his wife, denies that he sees them flickering. He does this to convince her she is descending into mental illness and cannot trust or take care of herself, with the plan of stealing her money (Cukor 1944). While the term gaslighting is used in psychology to note a form of psychological abuse, to define it as medical gaslighting means having symptoms downplayed and dismissed with a silencing of the patient (Ruíz 2020). This could be a doctor who is dismissive because they have no frame of reference for a symptom with no apparent cause, or they may also have racial, class, and gender biases that challenge their interactions with patients and caregivers. While I am not excusing the behavior, looking at the structures medical systems operate in does offer a cultural lens versus a malicious one seen in the film. Regardless of the intent, however, for some patients the dismissal of symptoms highlights that the balance of power lies with the doctors and that their ability to rewrite symptoms through a misdiagnosis, or a dismissal can be both harmful and violent. Medical anthropologist Leah M. Ashe's autoethnography of a ten-month hospital stay that began with a colonoscopy request and ended with her disabled (and led to her death), was a medical experience she had to literally escape from and which stemmed from symptoms being rewritten by medical staff as an eating disorder, allowing the hospital to take full control of her body and keep her admitted over her own objections (2021). Invoking Ivan Illich's use of iatrogenic, meaning doctor-made, harm (1976), Ashe shows that what start as harmful "system-bound indignities" arise from the "de-personalizing effects of institutionalization" and lead to

intentional and destructive violence on the patient (2021). Popularizing the use of terms such as medical gaslighting around these experiences then creates the opportunity for a collective to develop and advocate for change while pushing back against this harmful behavior and also addressing the structural issues that cause and reinforce it (Foucault and Gordon 1980, 85).

Black feminist anthropologist of medicine, public health, and race Chelsey Carter's ethnography of two daughter caregivers seeking care for their mother whose health had been failing for over a year notes the medical gaslighting their mother experienced. Symptoms brushed off as aging meant it took over 10 ER visits and a month long stay in the hospital to receive an ALS diagnosis. Their mother died from ALS one month after the diagnosis (2022). A possible key to the symptom dismissal is awareness. Carter's research reports on aspects of medical gaslighting that sit deep in the system and identifies how there are researchers and clinicians within the ALS community that do not believe Black people can have ALS (2022).

Furthering the gender and racial biases that framed the ALS experience highlight that it is a man's world when it comes to the medical data that sits as the foundation of biomedicine. It has only been since 1993 that Congress put into Federal law the requirement for women and minorities to be included in clinical research if it is to be funded by the National Institute of Health (NIH) (History of Women's Participation in Clinical Research: online). Still, women do not often make up a large enough segment of participants in medical studies even though they are 50% or more of the afflicted population. For example, in The Global South up to 55% of women are HIV positive, yet they only make up "19.2% of participants in antiretroviral studies, 38.1% in vaccination studies, and 11.1% in studies to find a cure" (Perez 2019, 200). Additionally, medication can cause different reactions in biological sex cells of cisgender men and women, if only male cells are tested in early trials and the medication is shown not to work,

females could be missing out on medications that could work for them but will not be studied further simply because female sex cells were not part of the early trials (Perez 2019, 204). This is further underscored by the varying degrees in which adverse reactions to medications are measured in cisgender men and women. An FDA report in 2014 showed data on the differences but offered little on why ciswomen are comparatively experiencing higher levels of adverse reactions (Keating and Millman 2014). Simon de Beauvoir's quote from *Second Sex* seems fitting here: "Representation of the world, like the world itself, is the work of men; they describe it from their own point of view, which they confuse with the absolute truth" (Beauvoir 2011, 162 in Perez 2019).

Examples of language used in research reports can further perpetuate racial and gender biases. In an article published in 2022 about pediatric POTS, a take-home point listed under diagnostic criteria states that, "POTS affects predominantly white females in the United States" (Boris and Moak 2022). While it is true that mostly white women have high rates of being diagnosed with POTS, it is certainly not a diagnostic criterion to be white nor is race noted as a statistical difference in diagnostic trends (Shaw et al. 2019). This point, if necessary, could have been made without being listed under diagnostic criteria, since its inclusion there could have unintended consequences for non-white cis females presenting with POTS symptoms. In and of itself this is a point worthy of further study and is one Boris himself clarifies when discussing his research in person (DI Conference field note 2024). While I could not find data on the experience of non-white teens exhibiting the same symptoms and being dismissed because of skin color, to highlight the impact of the use of such language I looked to a medical precedent during the AIDS epidemic because it was initially called GIRDS, gay-related immune deficiency. Because of this, many people were put at risk and contracted HIV because they did not identify as gay. This also invites conversation about the lack of care I highlight as the

structural violence inherent in a medical system set up as a commodity that is not meant for everyone to access. Who gets access and how long it takes are important features of the ongoing narrative of the family dealing with a chronic illness.

Interesting to note here is that while women are more likely to have POTS than men, men are diagnosed two to three years earlier than women. This strongly suggests a bias against women and the symptoms they present on their way to a POTS diagnosis (Shaw et al. 2019). In this way parents of teenage girls are needed to fight medical systems and have their child heard and believed to access treatment because there seems to be a bias against them. It is this labor that shifts the paradigm because parents are refusing to accept an “all in your head” verdict when internet searches can provide some level of validation and the collective points to medical gaslighting.

The impact biomedical articles have on the diagnostic journey intersects with the need for parental intervention, something Boris discusses in the same article by noting the challenges parents can cause medical teams during treatment (Boris and Moak 2022). While often based on small case studies or single experiences, a medical teams introduction to potential harm caused by parents is part of the lens through which medical teams view parental behavior because they are trained to look for abuse in complex cases, when the actual case studies of medical abuse have not been well researched (Eichner 2016, 228-236). Medical anthropology is in the position to explore how structural violence not only impacts the diagnosis of POTS and chronic illness but how it can unintentionally reproduce stigma in research papers and feed into the structural assumptions of medical abuse by the parents when the vast majority are in need of support.

An additional justice thread in this study is Farmer's discussions on “bearing witness” and finding compassion and solidarity useful to get beyond how willing we are to look away from

“the causes and effects of structural violence” (2003, 16). Bourdieu would add here that bringing “light to contradictions” does not resolve them (1993, 944), as translated by Farmer (2003, 224). Here, I explore how parents are “bearing witness” and acting as both advocates for their children, and activists for the children of others. Parents are bringing light to assumptions and enacting change. In this way the study does not only look at the various themes of denial of experience but situates them within the context of medical and social systems meant to support the wellbeing of those it serves, but instead relies on the parent to advance the cause. This also brings in the boundaries parents create to protect their families (Bluebond-Langner 1996, 13), often deciding how far down the advocacy rabbit hole they will travel. In waiting room conversations with parents, the idea of enjoying what they can, while they can, come up around discussions of how far they are willing to fight for acknowledgement of what they are observing. There is a paradox here that warrants a deeper look: not quite a cruel optimism from the perspective of the parent but a witness to it as they observe their child thwarted by the system that is meant to help them and instead guides the co-creation of a third space the medical teams are welcome to join as they are vetted.

Important to note in the long arc of systemic change is that as children grow into adults there are narratives they may want to protect. A key aspect of this dynamic relationship is the development stage in which it happens. Where there is the responsibility of care there is also the potential for harm. Parents are holding the story and the memory of illness and care, building a history of what works and what has not worked and all the trials along the way. As adolescents turn the corner to adulthood, they take on the responsibility of their story. The potential for harm is a present reminder of attachment to the future for the parent caregiver. What is shared now can

follow the adolescent via their medical chart as well as social media spaces and highlight the distinct challenges in telling a story that is deeply woven into the agency of another person.

### **3.4 Reflection**

POTS is an illness that is challenging on many fronts. It has been historically difficult to receive a diagnosis, and many teens and parents have experienced various degrees of medical gaslighting. Once diagnosed POTS needs a trial-and-error approach to find a protocol and treatment that will work. This individualized treatment sits in an illness narrative that encompasses the caregiver and the family but that the parent has to push to be heard. As a tool, illness narratives can be challenging in a system constrained by time and the structural issues of a neoliberal system that wants the ill person to take responsibility for their care but also submit and do what they are told. Understanding the narrative can create awareness of where the illness lives and how it impacts the family and lessen the experience of medical gaslighting while finding ways to enhance the partnerships between families and medical teams. In the next chapter I will share the methods used to capture these narratives.

## 4 METHODS

This project has approval from Georgia State University IRB under number H23575 and represents over two years of field work. To structure what felt like the ongoing nature of this research I organized my methods into stages. While they overlap, they note distinct changes in how I refocused or reframed this work. Specifically, I want to highlight two modes of interviews, informal conversations that happened by virtue of my positionality as a mother of an adolescent with POTS who is in and out of medical offices and hospitals multiple times a year, and the semi-structured interviews that were scheduled sit downs done virtually. I conducted participant observation in person and in online forums as the chronic illness community and their caregivers are a population with no defined physical location. I followed multiple citation threads during the document analysis phase that offered windows into how researchers may be thinking about stakeholders and identified that parents themselves were engaged in this work as well. To start, I want to identify that my autoethnography has become a key feature and guide of this research.

### 4.1 Managing the Autoethnography

I have thought a lot about what it means to be “native” as per Kirin Narayan (1993) in this space because the reality is that the parent caregiver is also dropped into this situation and experiences the need to learn their way into being an “insider”—not just for the illness, but the medical and social systems as well. So, while I have a particular point of view of the medical system through this experience, it differs from my daughter’s because my experience is from the point of view of an able-bodied mother and caregiver who through my role as parent is enmeshed into her story. Her story exists without me witnessing it and she provided consent for me to share some parts of it. My story as a parent caregiver does not exist without her, but the witnessing and

my autoethnography were instrumental in organizing the information I was collecting from interviews and participant observation.

I initially started conversations with other parents of chronically ill youth to better understand what I was experiencing. As a methodology, the autoethnography is not just a retelling of our experiences, it is a rigorous look at the literature and a reflexive look on an illness narrative within a particular space and time (Parker 2021) and from a particular point of view (Abu-Lughod 1991, 141). As a parent guiding a teen with complex illnesses, I often felt unsure of myself and my parenting. In the beginning we were tackling issues in the order they had been diagnosed, but it soon became apparent that POTS was about to take center stage. These early conversations helped me find a community of parents looking for some of the same things I was, answers and support. I also found that parents are not just searching and venting, they are analyzing and reanalyzing experiences through new lenses of knowledge in hopes of finding answers for their children. My journal notes started to look more like field notes early in my exploration as deeper questions emerged through reflections that encouraged me to circle back to parents and clarify thoughts and ideas. My experience became mediated through these distinct spaces that overlapped and, in some ways, required different ways of being and different uses of language. As my experience grew, I could speak with doctors about presyncope (pronounced pre-sink-o-pee) but use more descriptive language such as “extreme dizziness” or “almost passed out” with family and friends. This level of awareness has shaped the research, and my experience is shared here in the form of autoethnography because it informs the work and my relatedness to those who participated.

Writing from the point of view of an autoethnographer or a self-reflective ethnographer has not been without controversy. There is a fine line between telling someone’s story and

becoming the story. Ruth Behar shares in an interview with Rita Elena Melian-Zamora that she received massive push back for a chapter in *Translated Woman* that shared her personal reflection, struggles, and growth within the experience of her work. She explained that while the book was still assigned to students, the professors would tell them not to read the “narcissistic” chapter (Melian-Zamora 2020, 576). However, if “every view is a view from somewhere” (Abu-Lughod 1991, 141) and ethnography is both a tool for collecting and for sharing research, then a framed perspective offers a figural and literal place for the author to make creative decisions from, even when those decisions have not been popular. A shift toward reflexivity involved a critical look at the researchers’ own biases and was a welcomed tool in confronting ideas steeped in colonialism (Jacobs-Huey 2002, 791); it also put a spotlight on the researchers’ positions within their work. In a discipline focused on identifying power structures this focus forced a critical look at the anthropologist’s role and their methods.

I have worried and reflected on how close I am to this project, and from a praxis model how passionate I am about sharing the parent caregiver perspective. It was important to offer space for the voice of parents, not just from a perspective of sharing their point of view of what their child was experiencing, but a point of view of what they were experiencing as the parent. I have also struggled to find balance. I have been in those conversations of knowing where words fail but catching the eye of another parent conveys so much more. The greater society does not seem ready to see what is playing out in real time for us. But this is not my autobiographical account of the last four years. It is a deeply reflective and researched. The framework of the autoethnography has afforded me “insider” access to people, places and conversations I may not have gained otherwise. It has helped me craft questions and focus on specific parts of this experience. Still, part of the process was about understanding my identity as a mother and as an

anthropologist through a “multiplex identity” and “situated knowledges” (Narayan 1993). While my field is the United States with a generalized focus on the southeast and the state of Georgia, I grew up in Canada and have experience with a different way of doing medicine. As such, I needed to radically accept, observe, and participate in the experience of being an American and learn how medicine works here to be an effective guide for my daughter. The parts of me that were a dance mom and spent years fighting for my daughter to get back to the stage needed to shift gears to find a way to preserve some kind of quality of life for her. This experience was met with a deep understanding in many of the conversations I had with moms in the illness community, but not so much anywhere else.

In some ways I see this writing as resistance. While I am grateful that a part of me has learned the skills to question knowledge and its reproduction through anthropology skills, I also see other parents taking on these skills in their journeys. I was not just listening to issues; I was hearing and reading in online forum about what the collective was doing to enact change. It was what cultural anthropologist, Katheryn Kozaitis would call a study in “center-outer reform” (2013, 140). The voices of the parents who shared their experience, their fight, their reflections are inspiring. Because this is not just happening for people with POTS. This is the experience of the American Medical System. It is the experience of pain itself, where “to be in pain is to have certainty, to hear someone else’s pain is to experience doubt” (Scarry 1985, 7). This is to say that parents live in the gaps between the margins of care and the structures that butt up against it reminding you that they know more than you, insisting that what is happening to you and your experience of it is secondary. To explore this nuance and properly frame my insights, I pulled together years of medical records, jottings, journal entries and fieldnotes to compile the autoethnography. Exploring my own experience through narrative was an interesting way to

articulate the gaps I was experiencing in the medical system, but there was also a feeling of overwhelm when deciding where to start and how much to include. To further process my illness narrative, I had a colleague use my list of questions and interview me. The interview was recorded, transcribed, and coded and I was immediately aware of a story I return to in various forms, the management of my daughter's feeding tube. From the learning curve to the behind-the-scenes care required, this one aspect of the experience has highlighted many gaps in multiple systems that I have had to cover. My daughter uses it to support her fluid requirements and it was originally placed during a nine-day hospital stay caused by a flare in May of 2022. With a single training session instigated by a nurse that I am so grateful for to this day, my daughter and I left the hospital believing it would help her fluid management but with little knowledge on how to care for or manage the tube itself. For that we leaned on the knowledge of others.



Figure 3.1 Learning how to place an NG tube hospital bedside

## 4.2 Informal and Semi-Structured Interviews

To understand my topic focus, I initially had informal conversations with parents of chronically ill children and teens in both the United States and Canada. These conversations happened in person, virtually, and via email and text messages. Some were convenient, in that they happened fortuitously, for example sitting next to parents at conferences and in doctors' offices, but others were planned with connections made through other parents when sharing my research themes. These informal conversations focused on the experience of guiding teens with illness and ended with a question that asked what the parents would like to have or what they felt they needed when they were starting this illness journey with their child. I found connections between themes of frustration with the medical system, acknowledgment of the amount of work involved in supporting their teens, and beautiful messages of hope. One conversation stood out when a parent suggested a need for language that describes the behind-the-scenes work parents are engaged in. I nodded in agreement and started thinking about how integrated into our lives the illness becomes. On the surface, language can highlight the fundamental gaps with support structures in the United States; from an anthropological lens it reaches deep into the cultural threads of power and knowledge and notes who gets seen and why large portions of our citizens are invisible. Language also identifies how meaning is developed and makes narratives an important bridge for context when navigating a biomedical world. To explore further I turn to Arthur Kleinman's work.

Illness narratives is the term used in Kleinman's discussion of how to collect an "explanatory model" (EM) of illness. He outlines eight specific questions meant to help him understand how his patients saw and experienced their illness (Kleinman et al. 1978). Many researchers have expanded on these questions for use in specific medical and therapeutic

explorations. For example, McGill University developed the McGill illness narrative interview (MINI) which was later incorporated into the Cultural Formulation Interview called the DSM-5-CFI that looks to support cultural identity, social stresses, and care expectations within the illness explanation (Kirmayer et al. 2023, 243-248). Narrative therapy is used to identify pathogenic narratives so they can be replaced with stories of well-being. Narrative also informs medical family therapy and is used to support a family managing chronic illness and symptoms often categorized as medically unexplained and that would generally be considered an invisible illness (Kirmayer et al. 2023, 243-248). Medicine narrative models are considered tools, where therapy narrative models are considered interventions. They can support a shift in how medicine manages chronic illness. Biomedical models look to create direct links between an underlying pathophysiology and a symptom, while the illness narrative situates itself between this process and encourages a broader look for meaning and includes all the spaces in which narratives are mediated such as interpersonal interactions, health care settings, community, and society as well as media at large (Kirmayer et al. 2023, 243-248). In my interviews I looked to the illness narrative and explanatory model to explore how parents were making sense of their child's illness through the work they were doing to support their child's health and social lives.

Most of the parents I initially spoke with identified as mothers, except for two fathers, one of whom shared his experiences but referred me to his wife, describing her as the one I would really want to talk to. Collectively these early conversations represented illnesses such as diabetes with onset during teen years, hydrocephalus, and cancer, with the majority being POTS or a similar dysautonomia like orthostatic intolerance as well as comorbidities like Ehlers Danlos—a connective tissue disorder common in people with dysautonomia. While these informal conversations continued throughout the fieldwork, it was the early group that helped me shape this study. In the beginning I asked questions to understand how parents felt navigating

medical systems and what their personal needs were. This was something I was trying to understand for myself as well. However, what I discovered is that parents were also learning how to navigate systems beyond healthcare such as public education and the legal rights of those with disabilities. Additionally, these conversations were connected by the challenge in talking about the experience. I would hear the phrases like, “there are no words to describe it” or not feeling understood when trying to explain it. While said as a passing comment, possibly in a literal context, I have come to see it as figurative as well. Learning how to describe something that we initially have no framework for has highlighted many gaps in care paradigms that parents are filling. When explicit, the comment points directly to the behind-the-scenes labor needed to manage daily care and maintain some level of normalcy, but also to the confusion of feelings felt in this space. It was a phrase that would show up in additional data exploration such as podcast interviews with parents of children with POTS (Brook 2023) and interviews with authors sharing their illness and care narratives in memoir form (Hermann 2022; MacNicol 2018).

Armed with information from the informal conversations with parents, podcast interviews, and a review of questions and concerns voiced in online support groups, I developed a set of questions designed to collect an illness narrative that focused on the diagnosis journey, leaning into how parents research information and support the protocols and treatments offered to their child as they continue to access supportive care.

### **4.3 Recruitment and Participants**

The criteria of the ethnographic interviews looked for parents of a teen who had been diagnosed with POTS by a physician or medical team member for at least a year and that the child was considered a teen at the time of diagnoses, but their child did not currently need to be a teen at the time of the parent interview. I used the widest age range by merging the WHO and the

APA adolescent ranges, which together define the ages of 10-21 as relevant. I believe having the diagnosis for a year gives parents time to both learn about the illness and develop a narrative to make sense of the constraints the illness has brought into their lived experience. I initially worked within my local network of informal interviews which proved both rewarding and challenging. While having a quick conversation to catch up and hear about new developments in the medical journey was straightforward, the recorded interviews were more difficult to schedule. Ongoing text message exchanges were had, but it was difficult to formally connect with mothers still managing the care of their child. Many interviews were cancelled, including some by me when flares, last minute doctor appointments, and emergent health concerns took precedence. What I found interesting for this study was that this was also happening with parents with children now in their 20s, it was not surprising to me that a parent would be this engaged; emergent and life disrupting flares were still happening years after diagnosis. A key theme within these cancellation conversations was a shared gratitude for understanding without judgement. Even without the interview this activity represents important experiences about the lives of parent caregivers. The ability to move within the uncertainty of the illness and pivot, when necessary, highlights the ongoing precarity to the daily schedule and further identifies some of the isolation that can happen when not feeling understood or validated by this ongoing reality within friend groups and family.

Looking to expand outside my network I turned to online communities and was encouraged when Dysautonomia International posted my IRB-approved recruitment flyer to their social media profiles within the United States, which was then reposted by the local chapter here in the State of Georgia. In the end however the semi-structured interviews came from a mixture of both my network and the larger POTS community, with parents selected through network

sampling or chain-referral sampling, reflecting that the community is scattered across the country and not located in one physical space (Bernard 2018, 149). The interviews were done online via Zoom sans video with the audio recorded and later transcribed. Other than notating times when running themes were discussed, I held taking notes until the end of the session.

The two parents with whom I conducted semi-structured interviews are American and identify as white with a middle to upper middle economic status. Both actively participate[d] in finding answers for their child's illness and interestingly, they both have a history of being involved in social work. Amanda is a married mother of two in her early 40s. Both of her teenagers have chronic conditions; her daughter was diagnosed with POTS in 2022. To support her daughter's current needs, Amanda has taken a leave from work. She is fun and feisty and a fierce advocate for her daughter. Sharon is married and their only child is living on her own now. Sharon is open and reflective of her experience over the last decade and her supportive nature was evident throughout our conversation as she asked questions of my own experience as well as offered timely advice. I will not be able to speak on the demographics of those participating in convenience sampling or in online forums.

#### **4.4 Participant Observation, Podcasts, Medical Memoirs, and Online Support Groups**

In some ways I switch between mom and being in-the-field many times during an appointment or a hospital stay, but often I find when I am "in the field" I am thinking through the experience with a different lens, one that does not filter through the ongoing needs of my daughter. There is awareness and a shift when speaking about the greater community that I am still finding language for; parents do this as well. In our conversations there is the particular about their child and then an awareness of the collective struggle, an important observation that became key to this work. Where is the ability to step away and gain perspective? I became

aware of this challenge when reading Dorinne Kondo discuss her fragmenting and collapsing of self that resulted in her almost not recognizing her reflection during research in Japan (1990, 16). Unlike Kondo I could not initiate a distancing process, but instead tried to create a fusion that emphasized the “various aspects of identity” (Kondo 1990, 17) for myself as a parent and mother, caregiver, guide, advocate, and activist.

Key to understanding how these aspects were integrating and modifying parental actions was seeing the themes thread through other media spaces. Moms replying to interview questions on podcasts about not having the words to explain the emotional load the experience takes on them (Brook 2023), along with medical memoirs highlighting the gaps between what they were being told they should experience and what they were experiencing with an illness, were conversations that added to the recreation of isolation and invisibility of illness (O’Rourke 2022). This all served to help me focus the questions on the diagnosis experience. Looking at the length of time it took to be diagnosed, the challenges with misdiagnosis and failed treatments and the all-too-common phrase of it “being in your head” or terms that make it sound like they believe it is in your head were not just validating, they were key to understanding how to move forward from the diagnosis. In a strange way getting a POTS diagnosis will confirm there is no cure only management, which leads to the labor this paper discusses. The shift from discovery to maintenance still comes with a high level of uncertainty. While the advice is to enter each new appointment or doctor fresh without the baggage of past experiences, there is still a lot of processing that is happening in these places and parents can play both an emotional and practical supportive role.

Conversations in online forums highlighted the various levels of support parents provide their teens and needed for themselves. To explore this with complete autonomy I created categories and tracked entries and responses for one day in each month of June, September, and

December. To allow time for comments I waited a week before collecting. I organized the original posts by questions to the group versus shares of information or memes. I further identified the posts into themes such as questions about school and accessibility, medical with respect to symptoms and medications, and support systems such as tools used for mobility support and comfort. For the comments I was interested in how often advice was offered and how often people commented in solidarity. I also looked at the level of conversation by measuring the number of times the original poster replied and additional levels of engagement with likes or similar emoji versus the replies and comments. On any given day I could see ten or more posts that would result in an average of 200 comments between them. While the majority were questions, a lot of posts share personal updates, new research, and success stories of children (some grown) reaching milestones. Most however asked for advice about medications or treatments, looked for feedback on labs and doctors suggestions, asked for referrals for medical teams, required help with school supports and accommodations or needed disability feedback and advice about legalities around the challenges they were facing, and there was always room for venting about the difficulties of this experience to a group that got it and could support with meaningful thumb-ups and hearts, as well as with inspiring and comments of solidarity. Mostly I was looking to see if these themes tracked on to the conversations I was having with parents, and for the most part they did. Additionally, I used this data to guide which pieces of the autoethnography to include, meaning high mentions of themes that I had personal experience with have been included in this study.

It is important to note that this level of online interaction lives beyond the published work, and I thought about the ethics involved with long-term, ongoing projects. Ethical issues must be addressed in all aspects of anthropological work (Black and Riner 2021, 97) and may have implications for research that will exist beyond traditional avenues and paper discourses but

live in real time and in public spaces. By addressing my positionality as a researcher who needs to manage all the ways my work is experienced, especially as I take on responsibilities beyond that of a researcher, care ethics becomes a tool for addressing inequities not only as they arise in fieldwork (Black and Riner 2021, 98 & 118), but also as they arise in the conversations that comes after being published as connections and relationships within institutions and social networks expand and evolve.

#### ***4.4.1 Dysautonomia International Conference***

In June of 2023 I attended the annual Dysautonomia International Conference in person and in 2024 virtually. I also attended virtually in 2022 as a parent but with a completely different focus. The DI conference has become a gathering place for patients, parents, and practitioners to gather and discuss their latest research. Because some of the research shared in these sessions is in the process of being published, I have only included information in this study of presenters where their research has been published.

The conference is three days with breakout sessions, presentations, and an expo of standard and new treatments, fundraising options, and nonprofits started and managed by moms and their friends. In 2023 the conference was held in a hotel in the Washington, DC area where an area for the session could be sectioned off. Before coming into the conference area, you needed to show a negative covid test that was provided to you during registration. I checked in as a mother and a researcher and was immediately introduced to the contact person of the Georgia Chapter. She was so welcoming, with two ponytail buns and lots of enthusiasm about my project. We talked for almost three quarters of an hour, exchanged numbers, and made plans to connect when we were both back in Georgia. She was excited to introduce me to her doctor who was also

presenting at the conference (also from Georgia) and working on new research and methodologies to help people with POTS.

Many of the presentations offered fantastic information to take home to my daughter and her ongoing quest for answers, but I was fascinated especially by a few observations. The main one was the way mothers and daughters worked like colleagues at a function. A duo sitting beside me discussed which ones they were going to see and where they would meet up later to share notes, each reminding the other to take their pills. I would later see them chatting with their heads together and note pads open. I noticed this a few times. There was a “divide and conquer the data” that seemed to be happening. Second, I spoke with a few 18+ patients, who chatted about where they were in taking over their medical management. One mentioned that on her 18th birthday her mom handed her a binder and said here you go, and she said she was still trying to figure it all out. When I asked her how her mom felt about her coming to the conference, she said her mom was there at the conference supporting her. Third, during many of the sessions I attended, questions asked almost every time included how to access treatments, or how to get insurance to cover this, or how to find someone who does what you do where I live. All of these were answered with the same line, “I don’t have a good answer for you”, followed by discussions on the challenges with insurance companies and with the pathway of research to widespread clinic awareness being a 15-year span. In the end the answer came down to funding and more research. It is harder for insurance companies to turn down treatments if there is research backing it up. There of course is still the 15-year span to contend with.

One session I attended was for parents. It was hosted by a mother and daughter who shared tips and support systems they used for navigating the teen years offering everything from documentation to humor. The room was 90% women. One question that came up was what to do with friends and family members who do not believe in the diagnosis and comment negatively

on how you as the mom were managing the parenting. This seemed like a key point, but the conversation was more supportive and offered nods of solidarity than “here is how you deal with the issue”. This question alone holds why I wanted to speak with these moms. I was not just trying to find out what worked and how they navigated it, I was identifying that they had to do what they were doing because they were filling a gap that opened between their teens’ behavior and needs that did not fill a normative path and was invisible in the social and interpersonal structures they lived in, including some in the home. One sad point to make here is that not all parents support their child’s medical journey, but for those that do, this is a space that aims to support the journey.

#### **4.5 Organizing the Data**

Cheryl Mattingly organized her narrative timelines into six features, one of which identified how timelines can be organized within a gap. Specifically, these narratives highlight desire and not being where one wants to be. Others note uncertainty and how things may not turn out how one wants (1998, 84-85). Mindful of the gaps being covered, and the actions taken in the face of uncertainty, I used these narrative features to track themes. I realized that I was tracking language that shows what I have come to call condition confidence, meaning the caregiver adapts and integrates new information, often medical or specialized terms, into their conversations. This shows more than awareness of the illness; it is also strategic. Once the interviews were transcribed, I continued to manually code the data looking to identify themes and subthemes using word frequency, common or specific phrases (e.g.: “spoonie”, coined by Christine Miserandino (2003), and zebra (Cormier and Buikstra 2021)), metaphors, as well as missing data (Ryan and Bernard 2003 88-92). There is an expectation that language will change, and more phrases will be adopted and integrated into everyday conversation the more time spent

with the illness. This did not show up in the interview because I came into the discussions looking at history and a certain level of confidence had been earned, although I find a subtle trend in using the term ED (Emergency Department) over ER (Emergency Room) when discussing emergency visits, which is to say the ER is a common term used in media and television shows (Suter 2012), but medical staff call it the ED. A nurse told me she would have been corrected at work if she used the term ER. I was challenged with how to use it in this paper. If I were to expect an audience of medial personal, I may be more inclined to use the term ED. This is the term my daughter uses. A simple shift in terminology, possibly tracking families from diagnosis or even before may offer additional insight into this phenomenon. I did observe the local children's hospital in Atlanta using the term ER in public-facing communication announcing the closure of one hospital and the opening of a new one. This indicates an audience awareness on the part of the hospital communication when broadcasting information.

Additionally, I made comparisons between acceptance of illness and the medical treatments explored and tried, specifically pharmaceutical (Midodrine and Florinef) vs non-pharmaceutical (water, salt and compression socks). Given that I have also navigated this world, understanding these terms and language made it easier to identify them. For some, the diagnosis of POTS is the only one they need since symptoms fall along a typical biomedical presentation or what a doctor might call a textbook case. The protocols and treatments work well and offer a return to activity. For many others it is just the middle of the diagnostic journey that requires more support and management. Multiple comorbidities and a medical system that treats multiple symptoms by siloed specialists increases the management needs of some patients, making illness narratives and context the only way to connect the dots; work that is often done by the parent.

## 4.6 Reflection

Informal and semi-structured interviews paired with participant observation and document analysis helped frame my autoethnography. What surprised me most when considering the methods was how often parents were also engaged in doing similar work. In the search for answers, parents were finding in-person and online communities, participating and asking questions, reflecting and implementing ideas. From my point of view this work supports their child and hopes to support the greater community.

Next, I explore some of the findings experienced on the journey to a POTS diagnosis in the 21<sup>st</sup> century United States, from the perspective of my interlocutor interviews, research in virtual spaces and through my own experience as a parent caregiver. I begin with autoethnography and have constructed a part of her illness narrative in the stories that follow.

## 5 EXPERIENCES WITH POTS AND FINDINGS

### 5.1 My Illness Narratives

#### 5.1.1 *She Looks Great*

“She looks great” my friend says, and I smile.

“She does”, I say. Then I think, “please don’t ask it.”

The follow up question is always “how is she doing?” And there are two ways to answer this question. I can say fine and leave it at that, maybe let the dead air hang a bit and change the subject by asking a question myself. Or I can be vulnerable and share some version of the truth. On this particular evening, I answered with, “she is really tired, and we are still trying to figure out how to manage that.”

“All teenagers are tired, mine is home napping right now” my friend replied.

I mimed tucking a phantom loose hair behind my ear that was already perfectly tucked and looked down at the glass of wine in my left hand. The room was filled with friends celebrating the December holidays and the invalidation caught me off guard. My language choice was too weak I thought. Was there another word? My daughter wasn’t just the kind of tired a nap could fix; she was always tired. She was the kind of tired that Meghan O’Rourke describes in her medical memoir as a body made of sand (The New York Times 2022), and she was using all her energy just to hold herself together. She didn’t have the reserves for anything else. A few hours out of the house, dressed up, looking great to snap a few pictures for her Instagram, was costing her days in bed in recovery. But I didn’t have language to explain that (fieldnotes excerpt, Dec 2022).

### ***5.1.2 Too Much Missed School***

I was exhausted. My body ached and my mind felt like it had pushed through its ninth wall. We had just spent thirteen nights in the hospital trying to stabilize my daughter's POTS flare and I hadn't slept more than a few hours at a time in weeks. Now, I was on a Zoom call with the school district and the high school trying to advocate for support while not fully understanding the options (really the lack of options) available. The tone from the district felt harsh and unyielding. They said my daughter needed to be in the classroom. I put my hands up in the air in a sign of exasperation, my voice cracked, and I cried. The school's 504 advocate spoke politically about trying to get to the bottom of the confusion, but it was only once there was just one of us on the call that she really tried to understand our position.

This was the second or third time she and I had met via Zoom. During the hospital stay she was in touch and tried to organize meeting with the teachers. I would find quiet spaces in-between doctor visits to meet with the school trying to find some kind of path forward. In one instant considerable effort had been made to organize a time for all of us to meet and even then, one of the teachers did not show up and absolutely refused to work with us.

At ten days of absence the district wanted to start removal proceedings, so the school wanted her back in the classroom as soon as possible so we would not have to go through the process of reenrolling her. The doctors, citing papers about the dangers of isolation, wanted her back in the classroom and ordered her a wheelchair. No one asked us about this, so when I pushed back the comments were, "why don't you want her back in school?" Not, "what are the challenges with managing a wheelchair?" I had to push hard to explain that she rides the school bus, and we live at the bottom of a steep driveway. The doctor's solution was that I could drive her, with no discussions about my own schedule or about having a wheelchair accessible vehicle.

The 504-advocate said she could try and find a disability bus, but they did not think it was in the budget. They had no suggestion about the safety issues with the driveway, just that it was my responsibility to make sure she was in school. All of this was moot because while a wheelchair sounds helpful for someone not walking without assistance, she also did not have the energy to push herself. The temporality of the situation meant they would not have someone available to push her around the school or help her with her studies.

Additionally, these flares come with extreme brain fog. My daughter was finally home from the hospital, but she was sleeping most of the day. It took another week before she had the energy to get back to school (part-time) and another week before she could actively engage in the class work. I had to advocate hard for them to drop classes without penalty and to allow her to finish out the semester with half days. This meant rearranging my schedule to accommodate getting her to and from class in the middle of the day because in the end there was no other alternative if she was to remain at the school (fieldnotes excerpt, Oct 2022).

### ***5.1.3 Emergency Room as a Last Resort***

The weekend had been a rough one for my daughter. She was fighting nausea and ongoing feelings of sea sickness. Her usual go-to would be to call her neuro clinic and visit their IV center, but their nurse was out this week. After discussions with her GI and Neuro teams, it was decided that she needed to go to the Emergency Department to get IV Fluids and to ask for “a cocktail” to help her migraine. We know that this might help arrest a bigger flare, but going to the emergency department with POTS symptoms is always a gamble and causes immediate levels of stress.

We might get a doctor who knows about POTS, or we might get a doctor who knows about POTS but will not treat or advocate for treatment and instead will lecture on the use of

emergency, or we might get a doctor who doesn't really know but tells you they understand and that their hands are tied. This was her third ER visit, and fifth hospital visit in two months. A few days before her GI doctor had sent her to the ER, where it was suggested that some of her issues were anxiety. While this kind of comment used to be a trigger, it no longer phases us. We have learned it comes with the territory. Two months before, her pediatrician sent her because they were worried about her observable dizziness. The ER doctor looked at me and said something to the effect that "moms always know, what do you think she needs?". I suggested a slow drip IV always seems to help her bounce back quickly. He said he couldn't do that because he didn't have the power to get her admitted. So, he put her on a regular IV slow drip, meaning she didn't get a full liter before they discharged her. By slow drip I meant one with potassium which must go in at a certain rate, but I didn't realize we were not on the same page until she was about to be discharged.

On this ER visit we lucked out. The doctor (who had a great understanding of POTS) was prepared to admit her, if need be, but she advocated for getting home. ER visits highlight the gaps in service for people with POTS. Ideally there would be a specialized clinic for people with dysautonomia where they could go and get fluids and consultations about what is currenting going on with them. But here there is another gap. Not all doctors treat POTS the same way. Some use IV as a first line, some use it as a top up, and some don't like to prescribe it at all. Regardless, IV fluids in the ER are extremely more expensive than in a clinic.

The doctor during this visit let her lead and share what she felt she needed to feel better. I don't know if this is something that is happening because she is older, or a shift in awareness of POTS. During this visit the doctor was explicit about it being because of POTS. He mentioned that it's important for her to know what she needs and to be able to communicate it, because with

this type of illness that is key for proper management. I can feel my role changing (fieldnotes excerpt May 2024).

## **5.2 Findings**

When I started organizing my initial findings of the parent experience guiding teens with POTS, I realized I was identifying the various gaps parents bridge when navigating between spaces of care. Some of these activities fall within the realm of parent responsibility when the child is under the age of 18, but they also include levels of advocacy and activism. For the purposes of this study, I organized the gaps by two themes: those directly associated to activities within the medical system and those outside the medical system but that could also be considered adjacent to it, such as issues with supply chains and shortages. Each stem from the illness, are interconnected, and require various levels of intervention on behalf of the parent. Additional discussions integrate why such interventions are required, identifying the severity of illness through the lens of parent involvement, the individualized support needs of the family, as well as the legal adult status of the child. I also touch on the levels of work involved to develop competence with the illness and its treatments, as well as how the language of the systems the illness touches frame the responsibilities and expectations of the parents.

### ***5.2.1 Gaps in the Medical System***

#### **Diagnosis Gaps**

Challenges with the medical system for POTS patients and their families often start when they are trying to find answers. Diagnosis journeys with POTS and common comorbid illnesses often take years and are accompanied by dismissal of symptoms and rampant misdiagnosis (Shaw et al. 2019; Boris et al 2024). When I spoke with Sharon about their family's diagnosis

journey, she shared that during one appointment her daughter's experience was dismissed even when there were visible symptoms:

Literally one foot was red and purple and cold, and the other was normal. I mean, you could see, physically, the difference. And I remember when the pediatrician early on said to me, it didn't make sense, that it must be in her head.

“In your head” is a common phrase heard in chronic illness. Here, a symptom of POTS could be blood pooling in the lower extremities causing color and temperature changes in the skin (Dysautonomia International: online). It could also indicate co-morbidities or co-occurring illness commonly seen in POTS patients, such as hypermobile Ehlers Danlos Syndrome (hEDS) and Mast Cell Activation Syndrome (MCAS) (Raj 2006). Beyond the stated issues with medical trauma and length of time it takes to find a proper diagnosis, this space of symptoms not making sense and being denied by medical teams can have an impact on the way patients behave in their appointments. By the time Sharon found a doctor she felt comfortable with and felt “got it” with respect to what her daughter was experiencing, and she as a parent was witnessing, her daughter no longer felt comfortable sharing her experience, Sharon went on to explain what happened during such an appointment:

He (the doctor) asked her if she ever was dizzy, and she said, no. And I said, you don't need to lie to him, because she had learned to stop saying she was dizzy to doctors because they all said it must be anxiety.

The experience of being told it is anxiety is frustrating not only due to feelings of being dismissed but because of how often it is mis-diagnosed in patients with POTS (Shaw et al. 2019). This not only causes delays in proper treatment, but it also creates levels of distrust in the medical community. Amanda shared a similar dismissal experience, stating that “every doctor's office we went to pushed it off on gas, um, anxiety, or downright faking it.” During one such

appointment Amanda shared how it was the doctor's insistence that her daughter's chest pain was caused by gas that encouraged her daughter to speak up.

I had gotten to the point that I, I just shut down... she (the doctor) was like, do you have any questions? I was like, nope, because you're not giving me anything. And then (teen name removed) though... that was the moment, she got really upset and was like, why would gas make me dizzy? Why would gas make me feel like I'm gonna pass out?

This "shutting down" was something I had heard in a few of the informal conversations with parents and have experienced it myself when at a loss of how to move a conversation forward. In one waiting room conversation, a mom shared with me that there were times when she would choose not to be in the same room with certain providers because she would just shut down at the lack of ability to have a voice. She was acknowledging that emergency departments and urgent care doctors, and sometimes even the pediatrician's office, were not always the best places to ask questions or try and have a voice early in the diagnosis process. Not because there were not questions, but because it was hard to find answers in these places. It often takes what I call a first line specialist such as a cardiologist to diagnose for POTS. A cardiologist or a neurologist might have an easier time diagnosing because they see more of a particular symptom funneled to them through the referral process. This referral process is one that can transform part of the illness narrative for the patient and the parent caregiver because it begins the process of siloing the symptoms.

When an illness or a cluster of symptoms is not often seen it can take on the myth of being rare which can make it easier to dismiss. It is the "zebra effect" where doctors are taught if it has hooves, it is a horse, but sometimes they really can be zebras (Cormier and Buikstra 2021). The term "zebra" is often used to describe people with rare illnesses. While POTS is not considered a rare illness, I have found the more specialized the physician, the more familiar they are with my daughter's symptoms. Recently we were told by a doctor how medical school taught

them that these illnesses were very rare and that he might see it once in his lifetime, but he sees someone in his office at least once a week with a similar set of symptoms. For the medical side, a lot of this comes down to biomedical understandings and a teasing out of what is causing the symptoms. Basic diagnostic testing is often going to come back “normal”. Emergency department visits can be a bit traumatic for this reason because they have a protocol to follow when someone comes in with chest pains for example, which can be scary early on when there is not an understanding that the pains are a symptom of POTS. It also notates a learning that happens for the family that starts to support a knowing that this is not an emergent situation, but that some kind of intervention is needed. Amanda shared about waiting for care in the Emergency Department after being sent there from her doctor’s office.

She came in for chest pains, like she was experiencing big chest pain, shortness of breath, um, all of this. First of all, we were not called back for a while. Um, chest pains are supposed to get brought back immediately, but because she was a kid, I think they didn't really pay attention to it. So, we finally got back there... and they were like, so, you have gas, like, we're pretty sure you just have gas.

While presenting with chest pains in the ER comes with a certain expectation of when they will be seen, it can feel frustrating as a parent to see the pain in an adolescent not taken as a serious issue. With POTS a prolonged heart rate increase and adrenaline surges can cause pain in the muscles and tissues surrounding the heart and chest area. Even with a diagnosis of POTS, there is a trial and error of understanding what these symptoms can mean and learning to feel confident that it is not a serious issue takes time. This can be further challenged when calls or visits to the pediatrician or specialists’ offices send the child to the emergency department for these work ups because there is no other place to go.

### **The Classic Sprain (autoethnography)**

In our own experience, an ankle injury coded as a “classic sprain” sidelined my daughter from dance long past the six weeks she was told it would take to heal. Initially doctors and physical therapists asked her to push through the pain she was experiencing months after the injury. When my daughter would say that she felt her ankle was stuck and that she could not relevé, a move where the dancer goes up on their toes, the doctors would move it around with their hands, look at the MRI and say everything was fine. She was constantly being told her pain and hesitancy was because she was just afraid of injuring it again. In the meantime, her ankle was still swollen eight months after the injury and doctors continued to tell her that there should not be any issue with the ligament while her trainer continued to tell her that something did not seem right if the ankle was swollen. At one point a physical therapist asked me if I thought that maybe she was too stressed and trying to say she did not want to dance anymore by complaining that her foot still hurt. I noted, “today is the first time I felt like a crazy dance mom” when commenting on it in my notes. While I continued to ask why her ankle was still swollen if there was nothing wrong, no one could make sense of it or the ongoing pain. Eventually it was suggested she had Complex Regional Pain Syndrome (CRPS) because the intensity of the pain did not match the initial injury, and they tried to reorient the sensations of pain by alternating cold and hot foot baths, which did not work. In the end, it was her fifth physical therapist and her fourth orthopedic doctor that discovered what was mechanically happening in her foot and created a plan of care that involved surgery. The timeline from injury to surgery was 23 months.

Two important shifts happened here: One, the physical therapist was a dance specialist and wanted to see how the ankle worked when my daughter tried to do a relevé up on her toes, and two, the physical therapist had awareness of both physical issues and illnesses that can impact athletes. This physical therapist had a theory and encouraged us to get her evaluated for

hEDS because of her awareness of this illness. hEDS is a connective tissue disorder that can cause pain and frequent subluxations of the joints among many additional symptoms that happen to be similar to POTS. While being evaluated for hEDS she was referred to a cardiologist for suspicion of POTS because the geneticist was aware of these comorbidities and suggested that some of the symptoms were most likely POTS-related. It was during this initial appointment with the cardiologist that my daughter learned that the dizziness she had been experiencing for years was a symptom of a problem. She had dealt with it for so long she had just come to believe this was the way it was supposed to be. Previous questions about it were dismissed as getting up too fast, not eating enough, or dancing too much. Although there were times; she presented with dizziness so bad she would need the wall to stabilize her, it was only considered an issue once when a GI doctor witnessed it at my insistence and sent her to urgent care to test for dehydration. With the test showing borderline normal, they dismissed the symptoms and strongly suggested she was abusing drugs. A paragraph-long comment about this suspicion was included in her medical chart. Her dizziness was never fully considered part of a bigger issue to resolve or address with additional testing until she met with these specialists.

The illness narratives of this diagnosis journey feel like an origin story or what in illness narratives may be called a quest story (Frank 1995, 115-136). Without the ankle injury my daughter does not feel like her hEDS or her POTS would have been identified. These issues were running concurrently where we were seeing her pediatrician for stomach pain, dizziness, and issues with eating that followed a lot of the pathways of stress and anxiety and a couple of times she was tested for diabetes. Essentially, we did not know how to understand the patterns until we spoke with a physical therapist that could connect the dots and for that the therapist needed

awareness and the whole story, which unfolded over many follow-up visits as she treated the ankle injury.

### **Diagnosis Gaps (Continued)**

As with other moms sharing the diagnosis journey, it was never just a presentation of the symptoms and a workup for POTS. Amanda, who showed the shortest diagnosis journey of seven months, had the lived experience of a friend to help her craft conversations with doctors. Somewhere, someone is connecting the dots, and it is not always a medical team member. Often it is moms going online to ask questions. It is hearing someone else's story and feeling the kinship within the lived experience, even when a diagnosis has been established.

There seems to be a biomedical need to pathologize everything that is shifting to the wellness space in a way that creates a lot of misinformation, even in the medical world. During one ER visit the doctor explained to my daughter that while she was sure some of these symptoms could be her POTS, it looked like it was also a panic experience. This was because she presented with hands clenched and held in, something seen in panic disorder often because of hyperventilation which causes the body to prioritize oxygen resources in the body. Here my daughter pushed back. She said yes to the experience of hyperventilation, but no to the doctor's cause. The experiences may present similarly, and the symptoms can be related, in some cases the fear and stress of an acute flare could cause a panic attack, but for POTS patients it can also happen even when they do not feel panic. Trying to fit a panic attack into this experience does not support the full picture or honor her awareness or the support she is asking for. She explained to the doctor how panic feels different in her body, but a note on panic still made its way into her chart.

### **Acute vs Chronic: Managing Flares**

To diagnose for POTS, tests are often run to put the body in orthostatic stress. History of symptoms is important, but biomedical proof can support receiving additional care. Testing orthostatic is often done bedside in emergency rooms and hospital stays to test a patient's stability versus a tilt table test for diagnosis. During one of my daughter's flares, it took two people to do the test because she needed one person to hold her upright for the ten minutes of heart rate tracking because she was not stable enough to hold herself up. When speaking with Amanda she shared a similar experience.

I had my gallbladder out [recently] and they were doing the orthostatics on her. But nobody was there. And, there's this one, like, new girl that's just taking them, and I'm watching her [the daughter] waver... just like list kind of back and forth and sway a little. This woman's not looking. And now I kept thinking, I was like, oh, I'm about to have to go back to the hospital because I'm about to pop stitches open because I'm not letting my kid hit the floor. Yeah. And I finally, I was like, can you guys get somebody behind her because she's about to pass out? They were like, oh, no, I don't think. And uh, sure enough... she completely fainted and almost fell off the table.

As explained to me by a bedside doctor this testing helps inform flare status and treatment. As awful and redundant as orthostatic testing is, without a failed test it can be difficult to access supportive treatments for the flare. At one point I asked if we could have something added to her chart so that they would test during emergency department visits, but it was denied because I was told presenting with her symptoms should be enough to warrant receiving care. I was also firmly told I should not be requesting unnecessary tests. I agree, these tests feel harmful, but without them we have had to rely on getting a doctor that will take her word for it, even when the request is sent from a referring physician. To be fair not every flare requires hospitalization; many are managed at home as people become familiar with their own presentation and triggers. However, when hospitalization is required it offers an additional layer of support for the teen population because of the documentation needed to access resources from social services, such as communication with public school systems that is not available when they are too sick to go to

school for weeks but are home and not in a place that can offer a doctor's note. It is in these spaces that patients and parents encounter additional roadblocks in explaining the reality of illness.

A chronic illness diagnosis, especially one that comes with a trial-and-error type of treatment plan, does not always come with an explanatory model that outlines the difference between acute care and a flare up. There is the management of daily symptoms, but there are also moments of crisis or flare that require acute support. There are multiple gaps and challenges in accessing care during a flare, especially when the symptoms no longer feel normal but do not quite fit the medical definition of an emergent issue or one requiring immediate care—something that extends into the POTS experience even with a diagnosis. Patients use Emergency Departments even after a diagnosis (Boris et al. 2024), sometimes to thwart a flare or because they are sent there by other doctors. What is considered an emergent issue for the POTS family can be in conflict with the doctors in the emergency room. This follows a couple of issues. One the patient is often in need of fluids which could be supported by IV, but it can be challenging to access it anywhere else. Pop up IV clinics seem to be everywhere, but the FDA issued a report in October of 2021 highlighting risks about compounding drugs added to the IV fluids as well as observed preparation in unsanitary conditions (FDA 2021). As mentioned, doctors do not always lean into IV as supportive for POTS unless in emergent situations. My daughter visits an infusion clinic on a regular basis to ward off severe flares that could land her in the hospital, but when her clinic is not available, she is often encouraged to go to the emergency department.

Flares can also be an acute emergency; they can mean an increase in symptoms for any number of reasons. Monitoring this becomes an activity in pacing and managing energy levels, or looking for triggers they may indicate an increase in symptoms heading towards a flare. This

becomes another aspect of learning on-the-go and using a trial-and-error approach to finding what works, such as fluid or salt. This all involves a certain level of tracking and communicating with doctors, but also with others in the child's circle that things are under control. Amanda discussed trying to advocate for her daughter when her dance coach sidelined her after a small stumble.

[daughter] got really upset with dance this year because when she first started dance had actually been good for her. But when dance performances started, um, she got dizzy on one turn or something, and she stumbled for a second, and the coach was like, what happened? She's like, "oh, I just got dizzy for a second. I'm fine". Coach immediately pulled her and sat her and was like, "no, no, no, I can't, I can't have you, uh, do that. What if you get hurt?" And [teen name removed] was just sobbing. And she's like, have I ruined my chances, and I'm like, pleading with the coach, she can do it, she knows her body.

This learning of the body and knowing when things are getting worse, or if they are manageable are key features of living with POTS. Yet, this age group is often managed by outside constraints telling them not to trust themselves. Parents are stepping in to advocate on both sides of flare spectrum, but they are also at the mercy of the system. A report out of Tennessee identified that a high school organized their graduation ceremony to isolate POTS and other disabled students away from their peers and were seated in the bleachers with the audience. The students were not permitted to walk across the stage for fear they would "fall out" and instead were wheeled across it in wheelchairs (Barrett 2024). This highlights the level of misunderstandings around the nature of POTS and the different levels of presentations of symptoms. For example, while passing out is a symptom of POTS not everyone experiences it. The large survey promoted by Dysautonomia International highlights that 36% of POTS patients experience full syncope or fainting while 97% experience the dizziness and eyes darkening feelings of almost passing out (Shaw et al. 2019). The 36% is lower than the 58% reported in a UK publication (Kavi et al. 2016) but identifies the wide range of symptom experience and neither have identified the prevalence of

this symptom in adolescence. In the Tennessee high school incidence, the student provided a note from her doctor clearing her to walk at graduation with her classmates, but the blanket protocol implemented by the school prevented a personalized look at her illness experience that did not include fainting (Barrett 2024).

### **Follow-up Care Gaps**

The chronic illness experience is further challenged by 15-minute follow-up doctor's appointments. Typically, a follow-up appointment is used to check on the progress of treatment on an illness, a way to close the loop and mark the end of the medical encounter. In chronic illness these appointments are touch points that check on the progress of treatment but are used to capture a moment in the reality of ongoing care and tend to be longer. A doctor following a POTS patient might meet with them a few times a year until some level of balance is achieved, and even then, with the number of medications being managed follow-up or check-in appointments are probably a good idea. In the medical system, patients are created in these ongoing appointments, meaning the nuance of a good or bad symptom day, the variation of symptoms, and even the mood of the patient can impact what gets accomplished and tracked. In no way can it capture the full experience of the illness if they are only tracking symptoms, but it can offer a window into protocols and medications that help or hurt. With illnesses like POTS that rely on a trial-and-error approach across multiple doctor's follow-up appointments create a chain of communication. But it also is an increase in time management. Virtual appointments help, but there is only so much that can be covered. And ongoing care and treatment plans can shift when providers move or the institutions they work for restructure.

Sharon and her daughter were traveling between the East and West coasts looking for a doctor to help with worsening symptoms, once they found a doctor that agreed that surgery may be warranted, the hospital was not on board.

We came to the East Coast. But the doctor had just lost privileges at the pediatric hospital. Um, they just didn't want these complicated cases. And his adult hospital wouldn't take her. She was six months too young for him to do the surgery. He got us into a colleague of his.

The new doctor also thought surgery may help but noted additional issues that he suggested they handled first, adding,

You don't wanna do that on this side of the country. You should go back to the West Coast. And I knew in the West Coast there was no one who was gonna help us. Um, and I also felt we should do the smaller surgery...

Here we paused and I affirmed my understanding. Sharon continued,

So, through a mom on Facebook, I found out about a doctor, and I called his nurse crying, just saying, I don't know what to do. I can't get on a plane with my daughter because then she'll, you know, be wheelchair bound. She got us in the next day. We drove (a few hours away). The doctor at the time had done two other patients like her where there was no radio radiographic proof. Um, but he knew of [my daughter's] doctor and he did his due diligence. And he said to us, I can't guarantee..., but if you want me to, I am willing to do the surgery. And we said, a hundred percent.

The surgery was a success, helping to reduce her daughter's symptoms and also support a partnership,

... she [the daughter] walked out of the hospital when she got out. I think that incident helped her primary doctor back on the west coast really trust me and believe me that I had done enough research.

Navigating appointments and following up with doctors and the bureaucracy that is medicine often falls to the parent caregiver.

This also highlights the multiple doctors that become involved in a journey toward a diagnosis and treatment. I shared some of what happened during our ankle journey with a new GI doctor, noting that it took four doctors for my daughter to find someone that could help. The doctor, sympathetic to the experience, said you are welcome to find another opinion. But what I was trying to say was that “You are it. You are the fourth doctor, and we need you to figure this out.” Even with this missed communication he seemed to get it. When he was not able to give us answers he was able to explain why. My daughter trusted him, and he worked with her to help her communicate beyond her frustration. The ongoing frustration started and sits with the ankle experience. She believes she would still be dancing had the full issue been discovered and treated earlier. This theme informs her experience as a POTS patient. She is not coming in as a disrespectful teen, she is coming in to follow up appointments with years of medical trauma from being dismissed and trying to learn how to communicate through it in a system that is the same one that dismissed her for years.

**Feeding Tube Experience (an autoethnography):** Experiencing an issue with the feeding tube once home, I called the GI doctor, and the nurse told me that since it was for POTS maintenance they were not responsible for it. So, I called her POTS doctor who was a cardiologist at the time and the nurse there said they could not be responsible for it because NG tubes are assigned to GI doctors. At a loss, we tried to find answers online.

The work to maintain the tube had a learning curve that included trips to the ER when we could not place it or confirm proper placement ourselves. To check for placement, we were given pH strips to check if the tube was drawing acid from the stomach. We also had a stethoscope to listen for air being pushed through the tube with a syringe. We did online searches to understand taping techniques because to maintain placement the tube needs to be taped to the cheek and mis-

tapping was causing the tube to push out of the nose during sleep. We were not told the tube would need to be switched from nostril to nostril every six weeks; we found that out searching online. We were not told about the possible scarring in the nose tissue, or the possibility of increased sinus infections, all of which she experienced. This is part of the trial and error of chronic illness which includes learning about medical equipment management, supply management, and the yearly sign-off on proving medical need to the insurance company.

Eventually her tube switched from being NG to a nasojejunal (NJ), meaning it was now bypassing her stomach and was in her intestine. This afforded the ability to meet fluid requirements and improved her ability to eat without pain and feelings of fullness. It came after her third major flare resulted in another hospitalization, but also came with an in-patient doctor unfamiliar with her case suggesting that her problems were really an eating disorder. While this was never discussed directly, there were signs. They weighed her but would not let her see and they constantly asked her what her favorite foods were, while also telling her that the NJ would not help her symptoms and that her symptoms were just something she was going to need to learn to deal with. As luck would have it, the NJ tube did dramatically improve her symptoms and her quality of life. Asking for placement when the attending said it was not necessary also provided an opportunity for my daughter to advocate for herself. The NJ would need to be placed by x-ray, which add another layer of management, since it too needed to be replaced every few of months.

With the NJ working better than the NG, she became a candidate for a surgery that would move the tube from her nose and place it directly into the stomach and still thread into her jejunal. This gastro-jejunal (GJ) tube helped the issues she has been dealing with her nose while continuing to support her fluid requirements. Key here is that this experience does not just sit

with a checklist of symptoms of POTS but exists in the narrative of care. The tube is a tool that supports the protocol treatment of increased fluids and salts. The presence of it makes her illness visible, which challenges normative narratives and expectations of both the adolescent experience and the expectations of the parent. The journey of illness that takes a person in and out of the hospital and through multiple doctor follow ups adds to the challenge of management.

### **Multiple Doctor Gaps**

The involvement of multiple doctors does not help to connect the dots. This work is left to the parents to bridge what is witnessed between appointments. In Amanda's case she was able to advocate for her daughter after multiple emergency department visits by specifically asking for her to be evaluated for POTS, a suggestion that came from another mom familiar with the diagnosis. Here, parents are advocating for help for the child they feel they know well. Amanda adds, "I understand that you guys are medical professionals, but I am a (daughter's name) professional." In a similar conversation with Sharon she said, "I'm an expert of my daughter". I have also felt a similar awareness. My daughter was an athlete competing at a champion level and had an understanding when something was off with her body that a POTS and hEDS diagnosis helped her explain. But when new doctors got involved, it often created challenges, such as the GI doctor above seeming to suggest an eating disorder. We have come to understand these experiences as a type of care, a check of balances within the system, but in the early days they were frustrating and felt confusing.

Sharon had a similar experience when their diagnosis list was challenged by new doctors.

...When we were giving her [list of] diagnoses... And he goes, you're on those groups, aren't you? I just tell my patients; this is the newest one. Everyone is just coming to me saying they have, it's like, you know, the color of the week. Um, and I said, well, actually she was diagnosed by an allergist immunologist who's boarded in five different areas. So, we feel pretty confident this is an actual diagnosis and that shut him up. Oh. But it was, he was so dismissive. And another neurologist that we waited a long time to see, I'll

never forget at the pediatric hospital... because she immediately... when she looked at [teen name removed] list of diagnoses, said nobody could have this many medical problems.

When her daughter mentioned that her primary was boarded in five areas, the neurologist said, “there is no way he is.” This signaled that the doctor was going to dismiss anything they said.

These narratives are challenging ones because they often follow into additional systems and modes of care. At the end of the day, it feels like there is progress, but the journey was unnecessarily difficult. For my daughter, getting an NJ placement was a two-year journey even as the tube in her nose caused additional trauma and issues. In contrast, getting her wisdom teeth out took a 30-minute consultation. The wisdom tooth procedure, despite being a surgical procedure that involves anesthesia, seemed to be a more normative experience with research and data to reinforce the almost rite of passage it has become.

Both my daughter’s story and my story start with her ankle injury and are highlighted by the journey with her GI issues. The information can be detailed depending on who we are speaking with, but the experience is framed and shaped by the number of doctors who had dismissed her over the years and her experience within a system that sees teenagers a specific way and has a built-in judgement of parents. While a new doctor may not be responsible for past trauma, they do become part of a story encased in a larger experience and their ability to navigate it has a huge impact on what becomes possible.

### ***5.2.2 Gaps Beyond the Medical System***

#### **School Systems**

One of the first challenges parents can face when managing an illness is the gap in knowledge. While this pertains to the illness, it also extends into various supportive categories where what you do not know can have frustrating consequences. In the United States, federal

laws provide pathways for accommodations. The Individual Learning Plan (IEP) and Section 504 of the Rehabilitation Act (504) are federally funded programs used in public schools to support students with additional needs and to prohibit discrimination. Amanda spoke about navigating school without accommodations in place.

We didn't have a 504 for her and I was terrified that they were gonna send me to truancy. Because of having to pull her out or her missing (school). 'cause it was like her last half of the day. Morning time, she was great. She'd just woken up. She had had medicine. She was good. It was always like the last half of the day that she was just having to be pulled out. And it is a terrible feeling as a parent is just to be like almost borderline arguing with her to please stay because you're not sure if you're gonna get in trouble for pulling her out. And that's what I would tell her. I'd be like, no, no, no. Can you just, I mean, just a few more, like, can you make it another hour?

For Amanda, navigating attendance rules added to the family's stress and framed how she responded to her daughter. This is not about a day missed here or there, but an ongoing challenge with teens with POTS and accommodating their needs. Asking Amanda how supported she felt by her team led to a conversation about the challenges and worry her family was having with the school system. The impact of a potential truancy charge influenced the pleading with the ill teen to hang in there for another hour. While most school districts offer 10 days of unexcused absences a year (five per semester), the rest of the missing days require a doctor's note. However, a chronically ill child missing school does not always require a doctor visit, especially once they become familiar with their symptoms, but a collection of unexcused days can be challenged by the school. Missed school time or erratic schedules are problematic for learning, but they are also challenging to the parent because each district organizes their own rules and laws around attendance. While a particular state might have a rule, the rule of the school is dictated by the county, and then of course the school would have its own personal way of managing attendance as well. One principal might very much be engaged with their students and can understand what is happening with an ill child, where another might enforce the limitations

or constraint of their county on the ill child. Missed time then becomes another area parents need to manage at multiple level, with or without doctor notes.

There was another incident at school during a testing day that encouraged Amanda to secure a 504 for her child.

Amanda: ... that's why we went in for the 504, she had been allowed to carry her massive jug of water, you know, because luckily [teen name removed] could drink the gallon that she's supposed to a day.

[Here I interject with "That's amazing" because it is something my daughter continues to struggle with and instigated her need for a feeding tube.]

Amanda: Well, she, um, during testing they wouldn't let her have it. And I was like, why? It's water. And they were like, well, if she had a 504... I was like, I have to give you a legal document for you to tell my daughter that she can drink water. I was like, this is insane. Yeah. I was like, this is nuts that you guys just won't let her drink water. And they were like, no, well, she can't. And of course, those days of testing, she felt kind of like puny because she hadn't had her water.

Water, and often electrolyte drinks like Pedialyte or Gatorade, are the first line of treatment protocols for POTS in the United States. It is not always about dehydration but using fluids to increase the amount of blood volume in the body helps the blood circulate better which leads to fewer symptoms, specifically in reducing dizziness and brain fog (Rai 2013). The impact of not having access to your treatment because of a school rule or testing rule has a direct impact to the ability to function and perform well in that environment. To have access to these protocols federal forms are filled out requiring physician input and meetings are organized with the school to address the list of accommodation needs and what the school is able to provide. This is a process discussed on many online help forums with outcome reported that range from services denied to receiving full support with their list of requirements.

Managing school systems is something parents need to do as caregivers because when a child tries to manage on their own, they do not always get very far. While the language

surrounding teens in school assumes they are taking on more responsibility, they often find themselves in positions where they are not trusted, or their requests are challenged. For example, we were out of the country when seniors were added to the pool for parking spots. Fewer than half the students would get a parking spot near the school, the rest, should they drive, could pay for a spot a little less than a mile up the road in a church parking lot. My daughter's name did not get added to the pool because we mistakenly assumed they would have pulled spots for the people with 504s that highlighted the need for walking support. They did not. When my daughter asked the assistant principal why she did not have a spot he told her it was her responsibility to have figured that out, something she thought she was doing by asking him. He told her to park at the church, but when she said that would not work, he challenged her by asking what illness she had that required parking at the school (something he was not allowed to do) and then told her there was nothing he could do and that she would have to go to the State. I called to ask what kind of accommodation they could offer given it was listed in her 504 and was informed that the 504 personnel had retired and they did not have a replacement. In this case no one had contacted us to let us know of this change. Essentially, without someone to connect you with an advocate in the school, the parent needs to fill that role. Again, I asked how they are helping students that need accommodations and eventually they let her use a temporary visitor spot until we could get a disability parking card from the state so she could park at the school. This required two trips to her pediatrician and two trips to the Department of Motor Vehicles. Without the accommodation further issues would have unfolded that would have made achieving her schedule difficult. On the surface this appears as an issue of organization but in reality, the gap is made when those with power use "student responsibility" as a catch-all. This means parents need to step in for

basic accommodations, further recreating the notion of overreaching or intensive parenting. In reality the system is failing to partner with families and support these teens.

Dekalb County in Georgia has caused another barrier for students with chronic illness by requiring an extra PE credit over and above that required by the state to graduate. It is in direct conflict with 504 protocols which they ignore and do not offer accommodations. For example, a simple exchange in classes to something not requiring physical activity was not offered to my daughter. She had to work with the educator to modify the entire class curriculum in order to graduate. This took much longer than a semester to accomplish and was a source of stress for both my daughter and the school as they found their hands tied a number of times when trying to accommodate her illness. In conversations, parents have suggested they do not have the time to invest in changing laws because they are often dealing with the medical issue itself. Instead, they find solutions on their own by partnering directly with teachers to support their child. In observing online discussion some parents choose to leave the traditional classroom for home school or a virtual school that can be better managed around the illness.

### **Vulnerable Child Syndrome Resulting in Protective Child Services**

These situations can get escalated because families with children dealing with chronic and complex conditions are at a higher risk for calls to Protective Child Services for medical child abuse (Eichner 2016, 206)<sup>2</sup>. This is because doctors and teachers are mandatory reporters, which means that if they see something they feel is abusive or dangerous to the child they can escalate it up to Child Protective Services. They are also trained to see it specifically in complex medical cases (Eichner 2016, 228). Doctors may report abuse because they feel the parents are

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<sup>2</sup> Medical Child Abuse (MCA) is a term that is often used in place of Munchausen Syndrome by Proxy and is also known as Factitious Disorder Imposed on Another (FDIA)

causing harm or making their child sick, but that does not have to be the case for a parent to be accused of medical child abuse. Parents seen as instigating unnecessary or harmful medical care can also be charged (Eichner 2016, 219). This could include asking for additional tests but could also mean pushing extra doctor's appointments and weird off-label use of medications. Off-label medications have been used by physicians of the chronically ill for quite a while, meaning the medication was designed for one thing but may be used to support or manage the symptoms of a completely different illness. For example, duloxetine, which is branded as Cymbalta, is used to help support anxiety and depression; however, it is also used to manage nerve pain, so somebody with fibromyalgia might also be given Cymbalta even if they have no signs of depression.

When Child Protective Services came up in my conversation with Sharon she discussed having a particular challenging discussion with a doctor. At one point the doctor was insisting that they come in, and Sharon just did not feel good about an in-person meeting. Feeling something was in the air, she opted for a virtual meeting. I did not follow up on the experience or ask if she worried that they were going to send somebody to the home. But I felt a kinship when Sharon and I discussed how the new doctor said, "Nobody could have this many medical problems," and she worried that she was being thought of as "a Munchen mom". These worries have crossed my own mind. The seminal medical anthropology ethnography *The Spirit Catches You and You Fall Down* showcases a family struggling to understand a new cultural system and care for their daughter to the best of their ability when their doctor felt they were endangering the child's health by not complying with his orders. In this case it was not about going after the parents as much as it was putting Lia, their child, with people who would give her the prescribed medications. Because of the transfer to new guardians her doctors changed as well. Lia went through more medication changes and the new guardians could see why the parents were not

interested in giving their daughter medication, because it had horrible side effects and did not do what they were told it would—stop her seizures. The foster parents and the parents became close enough that the foster parents would leave their children with Lia’s parents when they took Lia to her doctor’s appointments. Regardless of all the prescribed medications, Lia’s seizures continued and got worse. After proving they would give the medications as directed Lia was allowed to return home, after ten months (Fadiman 1997, 78-92).

However, I want to note that parents are not protected if they agree with one doctor’s treatment and another doctor calls it abuse (Eichner 2016, 205). This was a worry we had every time a new doctor entered the picture. Current medical child abuse protocols can be employed when a treatment instigated by the parent can be deemed unnecessary by a reporting doctor regardless of the parent’s motivation (Eichner 2016, 257). The child can be taken from the family and held within a hospital if need be. Within the chronic illness community this is called medical kidnapping, which shows a shift to diagnosing abuse instead of exploring the experience of the family dealing with an illness. Dr. Newberger, a leader in setting up the child abuse program at Boston’s Children’s Hospital, says “prosecution and punishment, rather than understanding and help, have become woven into child protection work” (Flore, 2019). This is an unfortunate development for the parent caregiver.

A recent case in Florida received national attention because of a Netflix documentary and subsequent ruling in favor of the family. *Take Care of Maya* was released on Netflix in the summer of 2023 and shares the story of how Maya, at age 9, was suffering from a chronic illness flare-up and was taken to the hospital by her parents. The hospital accused the mother of Munchausen by proxy, a mental condition that means the parent was making the daughter ill on purpose for attention or for some personal gain. While her doctors outside of the hospital

vouched for the mother, the doctor inside the hospital and the assigned social worker working under her guidance would not budge on their opinion. Maya remained in the hospital and separated from her family for 87 days. Her mother took her own life, essentially ending the issue for the hospital and the state dropped the charges and returned Maya to her father. The family sued and while the doctor settled out of court, the hospital case went to trial and a jury found Johns Hopkins Hospital guilty and awarded the family \$261 million dollars (Hauser 2023). Parents across the chronic illness spectrum are both mindful and fearful of this type of experience. An upcoming documentary titled *Complicated* is exploring this level of fear and the consequences to both the child and their parents when unfounded charges of medical child abuse are raised (Abrahams 2024). In my review of the literature, I found it relatively easy to find information about medical child abuse and the risk of under-reporting (Egge 2023; Hornor 2021; Sherry et al. 2022), but very little about the risks of over-reporting and the ambiguity in defining abuse (Eichner 2016). Sharing the contradiction has fallen again to those most at risk of being abused by the system. Words like medical kidnapping then create a space for those impacted to gather under and fight back.

An additional side note is to be aware there are circumstances when parents do not always have a say in their child's care even when they remain the point person for care. If a child expresses that they might harm themselves or others they can be detained on a mental health hold in which case, they may be transported outside of the hospital to a mental health facility. While efforts are made to keep the child close, parents do not always have a say in where that facility is. If accepted by a facility the child can be transported unaccompanied by a parent, hours away with charges made to the parent's insurance.

Parents are navigating these additional concerns on top of the health issues. I highlight this because this level of management is not something that will transfer with the child once the child turns 18. They will have more agency to make the decisions they need to make. I am not sure at what point a doctor or hospital steps in and insists on some sort of control or management of somebody who is 18 or older as I shared in Leah Ashe's story, but it seems having a parent or an advocate would be helpful regardless of age. I would like to again highlight Susanna Callahan's story. She wrote her memoir medical narrative on an illness that kept her in the hospital for a month (Cahalan 2012). The doctors were wanting to send her to the psych ward because they could not find any reason for her illness and were about to diagnose her with a form of schizophrenia. She was a journalist and a month prior she had gone from being actively engaged in her work to not functioning and hospitalized. It was the communication and advocating of her parents that kept her from going to the psych ward. They asked her doctors to keep looking, and it just so happened that at one point a new doctor had come in and they decided to do a spinal tap to look for bacteria in the spinal fluid. And they found it. Her illness was caused by bacteria and could be treated. It would take Cahalan over a year to come back to some sense of homeostasis and be able to live on her own. She has written a book about this experience and is an advocate out in the world sharing her experience and talking about how there could be quite a few people who end up in psych wards that alternatively could have some sort of illness from an infection (Cahalan 2012). While these seem like isolated cases there is a current that underpins the parent caregiver, and it could be said that fear of social services can be used to manage parent behavior.

### **The Shift to Adulthood**

Summarizing information already shared, when a child becomes an adult on their 18<sup>th</sup> birthday, in the United States, parents lose access to their medical information, often at a time when the parents are still paying for it. This is not new or unique to chronic illness, however chronic illness does highlight parent behavior in such a way that it can move it out of public discourse and into academic study. In other words, similar phrases from doctors, teachers, and justice systems say “this” could be fine if the parents would just let us do our jobs. All of this points to a future point where the actions of today create a fully functioning adult. This is valid, but it also serves to make invisible this time of adolescence. For example, one suggested reason that POTS improves as teens get older is that once in college and away from parents the child is forced to take responsibility for their illness management (Boris and Moak 2022). However, there is no indication made for those who do not go to college. Does this suggestion assume college, or is there another independent living arrangement that serves the same function? Nor does it mention the number of students who leave or take a break from college to manage their health, or those who return home and live with their parents to help with illness support.

On the surface this can feel like it pegs parents as the problem. I have certainly been told that a time or two. But what I think it really says is that adolescents may not be able to manage their illness—that, they need support, but that by the time they are in college they may be better able to manage it. Additionally, college is set up differently than high school; there is more agency over schedules for example. This, however, sits on a spectrum especially as it assumes college and assumes a level of ableism and accommodation management. It seems to take the parent out of the equation without knowing or asking what work the parent is continuing to do in this situation.

### 5.2.3 *Gaps in the Medical Adjacent*

There are times when medications are not available, which can increase stress and workload for the parent caregiver. For example, during the Covid pandemic, there was a shortage of Adderall, and many people went without their medications or travelled long distances to find it. Adderall is a great example of an off-label drug used to support chronic illness. While known as a key ADHD drug, it can be a supportive therapy for people with chronic fatigue, a common comorbidity in POTS. Because the drug is highly regulated, it is difficult to shop for, meaning if one pharmacy cannot fill it, calling another pharmacy to ask if they have in stock does not always provide answers. It is at the pharmacist's discretion to share information on their stock. What is less known is that the Drug Administration put a 30-day cap on the medication in 2022, meaning to receive a prescription of Adderall the doctor must send in a request every 30 days. They are not renewable. Every month we need to request a refill from her doctor, and the medical staff needs to reorder it. This adds paperwork and time to both the parent and the physician. Additionally, medications like Adderall come with a stigma attached. Using it for a chronic illness can add to the pressure of the backlog of supply. When there is a shortage, this can be controversial because while prescribed by doctors it is not FDA approved for chronic fatigue. Using the medicine for off-label uses is listed as one of the reasons for the shortage, although recent language has softened the direct accusation. The CDC has shared information that outlines the impact to people in need of this medication and warns of an increase in injuries and overdoses (CDC 2024).

We experienced another challenge when hurricane Helene shut down the IV fluid manufacturing in North Carolina instigating a widespread shortage. As a POTS patient who relies on fluids to support her quality of life my daughter is left in a state of limbo weekly as she

waits to hear if her clinic has product while also knowing some surgeries are being cancelled while hospitals wait for their supply (O'Reilly 2024). A key discussion here is how easy it is for a natural disaster in one area of the country to cause such a massive disruption of an essential drug product across many medical facilities.

### **5.3 Reflection**

Parents navigate multiple gaps across multiple systems. Depending on where in the life path the illness arrives, and its severity can impact the level of care required. From bridging conversations in doctor appointments to supporting research and connecting the dots when observing symptoms, parents are creating and sharing knowledge. This labor goes beyond medical systems and reaches into the social and interpersonal. Highlighting that parents are both tasked with caring for their child and can be monitored and judged for how they do it. Parents are creating safe places such as online forums to discuss and share their experiences and are creating collections of knowledge in the process. In the next chapter I discuss how the environment, language, and being a parent in the chronic care space leads to advocacy and activism.

## 6 DISCUSSION

### 6.1 The Environment

Pulling together these experiences and literature threads suggests an environment that is not equipped to deal with or manage the growing number of people with chronic illnesses or their care without unpaid care work. At a basic level, living in the United States means having no access to universal healthcare options. The state has created a system that is set up to offer the potential for access but operates knowing every citizen does not have access. This potential is situated in neoliberal policies that lean into individual responsibility and self-sufficiency that further create barriers that limit and regulate access to accommodations. While these social systems can impact the care of those living with chronic illness and experiencing disability, interpersonal systems can both marginalize and stigmatize. All of this can increase the runway to fully actualized adulthood, creating levels of extended parenting and the need for direct support and guidance. This is a reality acknowledged by and possibly aided by buffer systems such as health insurance which allows a child to remain active on a parent's plan until they are 26 years of age.

Insurance companies are run by medical adjacent corporations that have a huge voice in who gets treated, what gets treated, how it gets treated, and for how long, while also dictating and having a hand in how much the treatment is going to cost. Essentially, tests ordered and treatments prescribed by a physician can be denied by insurance and can be cost prohibitive for the patient. On the physician's side, they have the power to choose which insurance plans or companies they will accept. This creates the additional challenge for the patient or family that has insurance but not guaranteed access to the care provider of choice. This can be especially challenging when you have a condition like POTS where doctors familiar with the disorder are

hard to come by or have long wait times in the best of circumstances. For the POTS community this has put a focus on more biomedical testing and disease boundary-setting, that puts a direct and identifiable definition and presentation on a disease that then can be treated with a set medication and protocol—something many nonprofit groups are creating funding for and pursuing, but there is a paradox here. This push is done with the awareness that POTS is on a spectrum and that the medicalization of symptoms could lead to unintended pathways and consequences, meaning a one-size-fits-all protocol could ease access to a diagnosis and treatment for some patients, but it may not be the appropriate approach for many patients and their specific presentation of illness. For example, recent studies show that non-pharmacological treatments such as an increase in fluids and salt that are promoted first in the United States are insufficient in controlling POTS symptoms in 75% of cases (Tidd et al. 2024). The next step would be trial medications in addition to the salt and fluids and that needs to be a personalized approach, but one that could be better supported with a collection of data from other trials and testing.

Additionally, a huge complication in treatment is the average of a 17-year delay from testing to widespread clinical awareness and use of a targeted treatment (Morris et al. 2011). Essentially, any meaningful treatment being researched today could potentially take 17 years to reach its audience in a widespread and formal way. It also means chronically ill populations are encouraged to seek out medical trials to both access and afford treatment which has another layer of ethics to consider. Of concern for this project is this time lag or delay also leads to bridging efforts by parents as they find and read research and bring them directly to the medical teams to not only show advancements in diagnosis and treatment trends but to gain access to them.

By maintaining a system meant to address acute medical issues and leaving those with chronic illness in the margins of care, access to healthcare in America is dismal for a large

portion of the population. Chronic illness further challenges a system not set up to manage the ongoing care that for many is a lifelong journey. Further, the health care system is set itself up in a way that separates the mind and the body into difference spheres of care, and then is further separated into specialties, without having a provider that can truly manage the whole human. If this work is meant to fall on the patient and their caregiver than finding tools that support partnerships could help all stakeholders. Currently it seems people are meant to take on and handle their own health, but also expected to submit to the medical team in charge of their care. This is ever-present in the ability for medical teams to render a child to be in danger and have them removed from their family, which has an impact on how parents learn to navigate the system. Therefore, the environment travelled by the parent is different than the one that is created when the children transition to adult care. The parent is often still involved in the transition and in parent caregiver activities but the stakes change.

Social systems in the United States put a lot of emphasis on parents raising children capable of turning into independent and self-reliant adults. Adolescence is a very specific time when children are wanting to exercise this expectation, but a chronic illness may bring this age group face to face with choices that can have long-term consequences at a time when executive functioning may not be developed enough to make such choices. This means parents become more involved at a time when teens are looking for more autonomy in their actions and with their body (Damour 2023). This has come up in conversations with doctors who explain that treatment to support quality of life is one that can be debated, unlike the use of insulin to support diabetes which can have fatal consequences if not followed. Here teens with POTS have options and agency when supporting their quality of life and those choices can also have devastating and disruptive consequences. For parents this often means mindful changes to parenting styles and

relationship cues, but also supporting this need for their child's autonomy as well, including in doctors' offices, education environments and at family functions. This work can bring stigma and judgment due to the level of involvement from both sides. While this level of parental involvement often makes it possible for the child to experience normative life events, it also brings judgment upon the parent for how they do it. These gaps can become battlefields that cause additional stress and relationship strain during a period when support is needed for the child and for the caregiving parent. In this way these acts of resistance and advocacy that aim to put this experience into words that communicate the impact of illness as well as instigate change become a form of self-care for the parent. While parents did not explicitly identify self-care acts, they speak in terms of purpose and acceptance which can benefit well-being and discussed how important community became, both as a way to find answers and to also offer support from their lived experience. For example, one mom shared. "I think the medical moms are amazing. What an amazing resource and support." Additionally, being in conversation with community is a great way to explore language.

## **6.2 Finding Words**

The idea of finding language to explain the behind-the-scenes work stuck with me from early on. It would present itself multiple times and led me to thinking about this missing language as a gap that threads through the experience. It was not quite that parents could not share the exact work they were doing. The details of setting my alarm every two and half hours to monitor the feeding tube pump, mix up the new Pedialyte and formula, and add the fluid to the 500ml bags could be discussed and shared. What I could not seem to communicate was the impact and why it took months of sleepless nights and asking multiple doctors and nurses for help when learning the right words meant a quick search on Google would tell us we could get

1000ml. The five hours of sleep this small piece of equipment allowed after three months were glorious but came with hoops to jump through just to access them. It would take another 18 months of trying to explain how unsustainable and disruptive the treatment was before alternative suggestions were made. Being heard was not just the issue here, but that it took time and trial and error to find language that netted results.

While there are a lot of factors that contribute to these situations, I believe the gap between acknowledging a problem and looking for a solution serves as a good metaphor to describe the in-between, and the conflictual and contradictory space parents find themselves in. First this highlights the challenges with biomedicine's focus on situating disease only with the patient or with the body, specifically in children and adolescents. Parents are enmeshed into the illness experience of the child, but also into the care. They are expected to perform these duties but also instill independence and self-sufficiency, often while trying not to be perceived as a thorn in the side of the medical team. In some ways this feels more about hitting normative milestones than actual wellness. Creating protocols and safety plans in the home so your child can attend events can mean engaging in activities that feel over the top to the gaze of others. For example, my daughter wanted to attend a live concert with her friend, but was feeling "potsie", meaning she was feeling a little dizzy and had heaviness in her legs. She felt with fluid and extra salt she could manage, but asked if I would mind hanging out close to the venue in case there was an issue. Interested in seeing her get out and do something fun, I agreed. This kind of behavior is something that I would not typically share because it receives "the look" of being overprotective. Even when I explained that I was doing this at her request, I was told by a family member that I should let her go and see what happens. The nuance of this is not lost on me. I am tasked with bridging this gap so she can both have an experience and feel safe, but it is intensive.

She has since become much more comfortable and aware of her symptoms and has a better handle on how to manage them, but early on there never seemed to be the right words that would lead to any kind of validation of my experience; there always seemed to be some kind of push back that related to my parenting and her challenges to conform, none of which ever felt grounded in her illness.

Finding the words is not just about learning the language but understanding and owning it so it can be used to some level of advantage. This is a building of social capital as Bourdieu would say. I saw this when Sharon identified how much easier building a partnership was with the doctor once he trusted her judgement, but it took time and experience to get there. Shifts happen throughout this experience. One parent shared that they went through a period of feeling that their daughter's illness was laziness. It took time and a lot of investment on behalf of his wife to see that something "real" was going on with his daughter.

Finding language was an observation but a retrospective one and no direction conversations about the search for language was discussed save for one in which the request for language that describes the behind work was explicitly asked. This has bigger implications for the behind the scenes work of mothering in general. It highlights that mothering is both framed by the expectation to produce an independent adult, but to intensively control the pathway there, except when it looks like we are parenting too intensively. I do not feel this is a fine line, but a blurred and constantly changing gap that parents' bridge. Here the gap might be built by an acceptance that allows the parent to hold space for the illness against external expectations. This was observed when someone would respond with something like, "she will need to figure it out soon she won't always have her mom," when discussing the latest health update. This future casting omits the reality of today and the actions needed to manage it. No one else is on the

journey with you and may not be able to follow the same path of acceptance. This may mean as language is learned in medical encounters, the same level of learning might not be possible for those outside of it, which becomes a form of acceptance as well. An experience highlighted by how many times parents discussed hearing someone say to them, “I don’t know how you do it,” which might further acknowledge a widespread lack of language around care activities. Future studies might look at this gap in language and the space between validation and acceptance to support the caregiver and lean into the possibilities they are working towards.

### **6.3 Parents: Problems and Possibilities**

The problem with parents is hidden in the everyday perceptions of people and to what level it impacts their judgement of them. This is key because it points to how often family dynamics are not part of the conversation and that there is an expectation of the parenting role. Yet, cited sources on parenting styles do not always include chronic illness as a factor in their studies. For example, an excellent and informative article on POTS also cited a paper on the sometimes positive but mostly problematic aspects of helicopter parenting. While the paper reports on the nuances of control and impacts to the parent-child relationship focused on the self-worth of college students and their engagement in school, there is no mention of illness anywhere in the report, not even as a suggestion for future study. The study did outline its limitations, given there is plenty of work that highlights how a child’s behavior can influence the way their parent needs to parent them, which I believe could fall under the umbrella of chronic illness. However, in the end the paper identifies the overall problem with overprotective parents as limiting the development of “important skills needed for becoming self-reliant adults (Padilla-Walker and Nelson 2012). While self-reliant independent adults are the focus of neoliberal

American culture, and worthy of discussion, this model is also reductive and compares apples to oranges when assessing the needs of the chronically ill and their parent caregivers.

A shift in American medicine that opened the door for more parent involvement happened when parents could start spending the night in the hospital with their sick child. Claire M. Fagin was a leader in advocating for patient care through the role of nursing. In the 1960s her child was sick, and she (a nurse) was upset by the reality that she was not allowed to stay with him overnight in the hospital. This infuriated her and inspired her to focus her research on the harmful impact that limiting night visits had on the well-being of children. Her findings gained media attention which created a transformation in the practice (Dean 2024). Fagin noticed that when parents stayed with the child, the child felt better, they healed faster, and there was a better emotional experience for the child and probably even the parent (Fagin and Nusbaum 1978). This changed a cultural practice and created a massive shift in parents having more access to hospitals and their child's care. In turn, children's hospital designs changed to support this practice. As a modern example the new children's hospital in Atlanta that opened in September of 2024 showcases larger rooms that feature a double bed for the parent or caregiver in a space with its own television and a workstation so they can check in with the office.<sup>3</sup>

Spending time in a hospital comes with its own set of challenges and new ways of being. The ability to blur lines of care is often felt in the hospital because of the isolating and out of space and time experience. There is a line in writer Joan Didion's memoir where she shares her experience during a five week stay in the hospital with her grown daughter in which she discusses how so "profound was the isolation" that it did not occur to her that she might be violating boundaries when she showed up to her daughter's hospital room wearing blue cotton

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<sup>3</sup> Video of the hospital rooms: <https://www.youtube.com/watch?v=xaGquA3M40s>

scrubs, something she had come to wear around the house because they were comfortable on her small frame (2005, 106). I did not reflect on the idea of violating boundaries in medical settings until I read this line. Didion showing up to the hospital dressed like a nurse and not being in the state of mind to consider the implications made me chuckle, but it also made me consider all the ways parent behavior is perceived when accessing care and how hospital stays may be a way of life for certain chronic illnesses. Hospital stays and interactions are stressful which can result in uncomfortable behavior from the parents. While there was some discussion of this with the parents I spoke with, often around the idea of shutting down in communication, a quick search on social media can locate a parent upset and sometimes verbally abusive. I could not find numbers for “difficult parents” in hospital settings. I did find numbers for difficult encounters with adult patients in clinics cited as one in six, but when I followed the threads, the paper being cited discussed how the median number of “heartsink patients” (difficult patients that when they come in cause the doctor’s heart to sink) to be around six, total. Which was fewer than 1% and not higher than 3% of their entire patient list. This gap in reported numbers may highlight perceptions of difficult patients and parents, but what constitutes a difficult patient does not have a standard definition and can range from rude behavior to a difficult diagnosis to care for (Mathers et al. 1995).

While I have had it explained to me by nursing staff that the idea of the challenging parent can be blown out of proportion, I wonder how much training medical teams receive in how to manage these situations from the perspective of a parent? Instead of framing how difficult it is to “deal with parents”, could we study the level of discomfort medical teams have in dealing with emotionally upset parents, who may be at their wits’ end, or are overwhelmed with the reality of illness in the home, regardless of the illness severity, because their individual

situation has not been considered in the whole picture of care? I am not suggesting any kind of abuse is okay, only that this disconnect does little but encourage parents to engage in therapy. While therapy can support how parents deal with the stress of an illness (and I recommend it), it does little to change the system they are experiencing the illness in. This is not just an understanding of proper bedside manner but underlines that an illness impacts more than the ill person. Illness impacts the whole family. When you have an illness like POTS, doctors might be meeting people that have been on a long diagnosis journey, they may have been involved in a lot of misdirection and misdiagnosis and treatments that have not worked. This alone inspires parents into research and keep track of symptoms, steps that in the long run may be seen by medical professionals as problematic behavior. Focusing on the lived experience and evolving narrative of a syndrome that could present in any number of ways could offer clarity for both the doctor and their patient, as well as the patient's family. What comes up in conversations with the parents I spoke with seems to be both a respect for what their doctors know, and a firm connection to knowing their own child.

However, not every doctor is interested or open to hearing the opinions of parents of what the illness is. My daughter asked a question of a doctor and was told if she had that she would be dead by now. She was talking symptoms and lived experience, and he was talking biomedical disease. From there the conversation was skewed away from any real answers to a lecture on not getting medical information on TikTok. Biomedicine wants clean symptoms, tests, diagnosis, treatment, but complex syndromes such as POTS may not fit into easy diagnostic categories. And while it is the goal of medical research to create such support for medical teams and their work, biomedical jargon that points to particular symptoms can miss a lot when the symptoms do not look or act like a textbook case of chronic illness, especially complex ones like POTS that

impacts multiple systems and functions. The management of all this falls to the parent caregivers, which ironically means observing and detailing the very thing that can tag them as catastrophizing and obsessing. But this activity can also offer the details to the very questions doctors will ask. In an emergency room experience parent caregivers are asked what triggers a flare and we do not always know. Sometimes it could be a busy week, but other times it might be the weather. Doctors can push for a direct cause and effect but may not be receptive to the answer. Unless you meet a member of the medical team with some kind of lived experience, or where their clinical work has taken them to a place of deep awareness, they do not seem to understand this complexity. Researcher Marie-Claire Seeley, herself a POTS patient, calls this the “ultimate pragmatic combination of scientific training, clinical relevance, and personal lived experience” (2024, 14 in Stranieri et al. 2024).

Buchbinder’s study on a pain clinic in North Carolina in which she highlights both the facing experience with parents and how the behind-the-scenes doctors were pathologizing and diagnosing parenting behavior, and often discussing how if the parents would just get out of the way they could fix the child. This serves to make parents part of the problem (Buchbinder 2015). They are demoralized by a system that cannot help and cannot see the problem it creates. For me this felt like I was not being trusted to make decisions. I was repeatedly asked, “Are you sure she isn’t on drugs?; this could be some kind of reaction to drugs” from a GI PA after I explicitly said no and my daughter said no. This happened four months before she was diagnosed with POTS. I was told, “You know it is your job to protect her, right?” in an emergency room intake interview when I was sharing how confused I was with her symptoms and feeling like I did not know what to do for her. I was told that “This sounds like codependency” from a friend after sharing some of the activities I have had to take on so she would have enough energy to complete school tasks

and have any kind of social life. Granted all of these are valid concerns on some level, but they do not just happen once. Participating in online support forums identifies that they are hoops parent-caregivers navigate regularly and part of the reason the role of parent caregiver involves advocacy and activism.

#### **6.4 Advocacy and Activism**

The learning curve goes beyond the illness and includes navigating social and legal systems. Longer involvement in medical care is not understood against a normative model of the parent child experience. Here, parents are developing websites and online message boards and forums to vent about medical experiences and how much their child is missing out on, as well as the crowdsourcing of ideas for practitioners and protocols of care that can involve fundraising for future research.

There is language to share these situations, but it does not always match up to cultural understanding of terms nor fully explain the lived experience. Here language itself is challenged. A simple exchange about the fatigue their teen is experiencing can be met with comparison comments like “all teens are tired.” While this seems like a valid general statement it invalidates the mom of the chronically ill teen. The challenge to find words to explain something you are not experiencing yourself but are using to try and find help and support to manage the effects of is mental work that can be lost in narrow perceptions of language. As previously mentioned, POTS patient and advocate Meghan O’Rourke described on a podcast (2022) being so tired that it felt like her body was made of sand and the energy it took to keep her body together was all she had energy for someday. An entire theory using spoons to measure energy levels is both language producing, self-advocacy and activism for the community of chronically ill that use it (Miserandino 2003). POTS fatigue is not comparative to words as much as it is to the physical

experience. Imagine how much energy it takes for a body to sustain a heartrate of 150 beats per minute for ten minutes. This ongoing energy output is what a POTS body is managing. But what do you say when someone asks how your child is feeling?

Informally parents talk about going through a skeptical period of trying to understand what their child is experiencing. Is it laziness, trying to get out of chores, etc., and eventually finding peace with their child's lived experience. Society has not had this space to cultivate this compassion and acceptance, so it is the parent that wedges themselves in between to create a safe boundary and bridge for the family (Bluebond-Langner, Myra 1996). In this way there is a waning of support that is based on the needs and desire of the child to take over their own care when they are ready to do so. This is almost revolutionary in that it highlights dealing with the present, and not some unknown normative future that has been modeled for both teens and parents as an ideal trajectory.

Instead, Moms are forming communities and bringing together a group large enough to offer support around this diagnosis, share stories, and instigate change. While this initially lies in the diagnosis journey and connects the need for the biological and medical communities to get in line with the lived experience of the illness, the shift toward nuance and context is happening here and creates spaces designed by patients and parents and not just in the world of scientific discovery. Highlighting the need for this partnership leads to one key interweaving of these communities: funding for research.

The recognition of chronic illness and the shifts of illness causation create a framework of rising and falling numbers which may look simple but sit in a complex transitional matrix that can have implications on which diseases receive research funding (Gage 2005, 104). For example, the CDC webpage lists key lifestyle risks as if to indicate personal responsibility is the

driver of these types of illnesses when the reality is illness has multiple factors. When plans are made to distribute research funds it seems illnesses associated with lifestyle choices are lower on the list. According to the National Institutes of Health (NIH) report, infectious disease funding is in the top ten percent, while mental health and Alzheimer's do not crack the top twenty, and autoimmune disease is not in the top 50. Here, hierarchies seem to be formed based on a set of guidelines that do not fully benefit the whole of chronic illness sufferers. In March of 2022, Dysautonomia International, a non-profit supporting education and research in dysautonomia marched on Capitol Hill asking Congress for 50M in NIH funding to support POTS research in 2024.<sup>4</sup> This would be a massive jump in the less than \$2M POTS has received in the last several years.<sup>5</sup>

## **6.5 Reflection**

Understanding the greater environment as well as the family environment in which the illness sits, impacts the use of language and the validation that language affords parents. Balancing the gap of being a problem and builder of possibilities, means parents often act as advocates and activists creating change from the center. In the final chapter I share how language and acceptance thread together to create spaces of possibilities through the idea of extended parenting.

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<sup>4</sup> Dysautonomia International Instagram Post: <https://www.instagram.com/p/CqKcdM1uwbo/>

<sup>5</sup> NIH Funding Report by category: <https://report.nih.gov/funding/categorical-spending#/>

## 7 CONCLUSION

Exploring the parent caregiver experience in POTS highlights fundamental questions about parenthood, motherhood, and womanhood against the backdrop of a culture who idealizes the appearance of individualism and self-sufficiency. Illness however creates gaps for the teen in the normative or idealized pathway toward adulthood. Identifying and trying to bridge these gaps often leads parents to advocate on behalf of their child and to levels of activism within their communities. Exploring parenting behavior meant discussing the activities and experiences performed within and outside of the medical system, as well as activities performed in adjacent social and interpersonal systems. I found myself agreeing about the need for language even as the parents I spoke with shared their experience without pause. There is a need to validate and make visible this work with language. I wondered more than once if our ease in conversation came from places of experiential knowing. A shared anecdote. A real story validated and made reliable by community.

Here the gaps in research follow similar threads of what can be considered real and reliable data. I often found myself looking for studies and data that as an idea exists in popular narrative but were not found in structured research. Finding the anecdote in quotes to share a nuance while also being identified as having less value than a standardized trial data point. I see the ethnographic record as a necessary bridge between the gaps in biomedical explanations of illness and the lived experience of it. The gap between these perceptions and what constitutes scientific data perpetuates the divide. Not just because of language and tone but because the personal experience against a data ratio can be denied and dismissed. This kind of framing of an objective science about biomedical humans is also immersed in its own culture which continues

to create margins, puts people in those margins, and then denies the experience when it is lived in those margins. Finding a story about an outlier medical experience is not difficult.

This past summer I was sent an opinion article written by a teen whose parents were at such a loss in accessing care for her that they ended up going directly to the hospital administrator to ask for an MRI so they could rule out an appendicitis (Tapper 2022). Here the mother reports knowing her child and seeing that something was not right while also being urged by their outpatient pediatrician to check for an appendicitis<sup>6</sup>, but the hospital's doctors did not believe it was an appendicitis and said they did not need imaging "data". In the end, imaging would show that Alice's pain was a perforated appendicitis (Tapper 2022). This common and treatable illness was misdiagnosed because it did not present in a typical manner—pain in the lower right quadrant of the abdomen versus all over the stomach as Alice presented with. If the experience of a well-known and treatable illness can create a gap for up to 15% of child suffering (Mahajan et al. 2020), then is it reasonable to comparatively see an increase in challenges with illnesses that are not well known, and where clear protocols do not exist, as outlined in the POTS experience. An additional note Mahajan identifies in his research and Tapper highlights in her article is how often it is female-presenting women and girls who are misdiagnosed when it comes to appendicitis, sometimes causing a fatal outcome (Mahajan et al. 2020; Tapper 2022), suggesting that there is a noted bias in this group like that seen in POTS diagnosis trends (Shaw et al 2019). The challenge of a misdiagnosis is further complicated by a system that makes the patient and their families feel dismissed and unheard. Alice Tapper has since written a children's

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<sup>6</sup> "Jack Tapper shares harrowing story of daughter's near-fatal misdiagnosis" CNN, <https://www.cnn.com/videos/health/2022/12/15/tappers-daughter-appendicitis-misdiagnosis-gupta-pkg-lead-cntd-vpx.cnn>

book titled *Use Your Voice* to help other families advocate for care.<sup>7</sup> This underlines that the activities that bring light to these experiences and advocate for changes within the systems that touch them rest with the patient and their families. These stories may sound like outliers, but when they are put into the collective, they shine a light on the gaps in care that patients and parents navigate.

By speaking with parents, most of whom were moms, I was able to highlight the gaps they are navigating, noting that covering these gaps has created parallel online environments where information is exchanged and where informal hierarchal structures control access and discussions to manage and protect the space. These discussion threads hold an incredible amount of lived experience and data that creates community for those spanning the almost diagnosed to the extremely experienced. These communities thoughtfully organize questions and answers and offer rich histories of experience. Additionally, these spaces create opportunities to crowd source knowledge from the perspective of living with and caring for the illness, an insider view. For some parents, this level of research and involvement extends through the teenage years into adulthood.

While the findings here highlight gaps within the physical, emotional, and social environment that follow chronic illness, making meaning of the experience falls into the realm of living with the chronic illness, not just in curing or fixing it. The journey towards illness acceptance is paved with crisis and trauma, but also with hope and possibilities. The reality is an ongoing experience that continues to disrupt the lives of those living with illness and their caregivers. Beyond the medical, this experience is framed by financial and employability concerns, challenges with isolation and social integrations, as well as offering moments of hope

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<sup>7</sup> “Alice Tapper opens up in new book about her painful medical condition”, CNN, <https://www.cnn.com/2024/08/27/health/video/alice-tapper-use-your-voice-book-intvu-ctm-digvid>

born out of the acceptance and a rewriting of what is possible for the family. While the parent role and relationship transform, and support roles may shift to friends and partners, there is space here to identify levels of caregiving required for chronic illness. While the development period of adolescence comes with blurred edges, the need for parental support is reimagined and redefined from that of a normative role, shifting a perpetual liminality into a third space of what is possible for the teen and the parent.

### **A note on mothering**

Identifying the invisible reproductive work in chronic illness care showcases gaps in how we identify and conceptualize motherhood, and expectations for the role. If done well, the idealization of the role of mothering in the United States is invisible. Mothers are expected to be like the wind in the trees. You do not see the work, but the effect of a grown and independent adult equates to the rustling leaves. In this way chronic illness further shows the impossibility of parenting because it makes visible behavior that is often seen as problematic simply because of the work it takes to make their child seen and heard. It is also important to point out here that the issues presented for the parent caregiver are problems many parents experience. Parenting a child without a chronic illness does not mean everything works out okay, but the experience of POTS and teenage chronic illnesses does offer a lens in which to explore these ideas and possibly add language to them.

By occupying the gap between advocating for their child and being problematic when crossing invisible lines that somehow encourage doctors to contact child protective services can identify the precarious space the act of parenting navigates. These spectrums of expectation sit firmly in social reproduction models that are slow to change and adapt to the needs of its people

all ensures the need for extended parenting. Within in this space parents use the collective possibility of a diagnosis to bridge gaps, hold boundaries, and advocate for change.

### **7.1 Why Study POTS and Parents**

Overcoming public opinion is another aspect of life with chronic illness. What the public conceptualizes as disabled, and where the lines of inclusion and segregation fall create additional challenges. Western biomedical experience rests on the intersections of medical practices and public opinion. In the case of adolescence and parenting there are unwritten but highly ableist norms to navigate. Parents are changing the model and these biological changes to the body—the illness—are making necessary a change in parenting culture.

Beyond extrapolating to support the chronic illness communities, POTS can mimic many mental health issues, as well as instigate problems with mental health. Most mental health facilities are not equipped to manage or deal with the multiple threads of care needed to support both paths of treatment. The impact of not being able to address a full body and holistic form of care is detrimental to a person with POTS. On one had this has led to rampant misdiagnosis and dismissal of POTS symptoms, especially in those presenting as female. It also hides or underrepresents the work required to learn how to cope with a chronic illness, skills that would most likely also be beneficial to the community at large.

POTS is also a bit of an anomaly in that many of those diagnosed are in their teen years. The disruptive nature of this illness challenges systems beyond medical. Parents are navigating social and interpersonal systems with a shortened period before a typical launching to adult period. Additionally, studying chronic illness in teens highlights the world parents manage that will not transfer into adulthood with the child. Issues with child protective services and truancy are a common thread found in the chronic illness community. While it informs many aspects of

the illness journey, it is not necessarily one that the child will need to know or take on. Additionally, this is a time of socially structured education. When education systems cannot support these teens, parents often take on finding alternatives like virtual and home school options to lessen paperwork and red tape when accommodations cannot be met.

All this is invisible labor not often recognized and relies on parents willing to share what they learned to help other families. When my daughter was first diagnosed with hypermobile Ehlers Danlos, I was repeatedly told to pick up the book *Disjointed*. Once I did, I realized the book was a collection of essays written by multiple doctors that was produced and edited by a mom whose child initially asked her to put together all the things she had learned on their illness journey (including a full chapter on dysautonomia) to help her manage her health as an adult (Jovin et al. 2020, 7). The book is 677 pages of information and supportive content organized to support other patients and parents and highlights some of the work that often sits in the behind-the-scenes.

## **7.2 Recommendations**

Illness impacts the entire family, but in the health care system only the patient is treated. Opportunities are missed to both manage and understand the lived experience of an illness at the family level because illness narratives are not asked of parents and caregivers. For this reason, I offer these recommendations that could be supported by capturing the illness narratives of parents.

### **Protocol Management**

I recommend medical teams aim to consider the complexity (and sometimes impossibility) of protocols that are supposed to be managed by family caregivers at home. It is not enough to ask parents if they have questions, they may not know what to ask or even have

language for it in the beginning. Using the example of 500mg and 1000mg fluid bags would have completely changed the experience of the first three months with the feeding tube.

Additionally understanding how the parent plans to implement and manage the protocol further supports the child, but also identifies compliancy issues that could be mitigated through conversation and awareness.

### **Medical Notes**

Managing multiple doctors comes with the issues of continuity of care across medical notes. Systems like MyChart, which many providers use in the U.S., are meant to organize and streamline communication allowing anyone within the system to access the notes. My daughter has four different MyChart accounts, and those accounts do not speak to each other unless she proactively ties them in. This is a good tool that comes with challenges. The notes seem extremely difficult to change if a mistake is made. In my daughter's case misdiagnoses continue to show up in current reporting, no matter how often we have explained the error. The most I have been afforded is to add an addendum, but that never follows forward.

In one example I was asking questions about a particular symptom they were tracking during a hospital stay. The doctor was not sure why she was experiencing it or what it meant. Nor could he answer what would happen if it continued, but instead of adding those questions to the chart for another doctor or follow up on, he simply wrote "mother does not feel her questions are being answered". To be fair, this was factual. My questions were not being answered and I was frustrated by it, but this notation did not add anything to the experience nor was it supportive to the next doctors needing to access these notes. During a follow up appointment with her cardiologist, she turned to me and asked if she could see my notes because MyChart was not giving her anything useful. Upon reflection of my notes, she sent me a recent research article and

suggested the testing we should ask her endocrinologist for. Unfortunately, her cardiologist's distinction prevented her from ordering the tests, but she felt it would be helpful and would like to know the results. The endocrinologist did not think it was important and wanted to wait six months until the follow up appointment. I was sharing this experience to her neurologist, and they thought it was a good idea to run the test so we could understand her baseline to see if it fluctuated during a flare. It was a simple blood test. I mention this only because none of this followed across medical notes to the different doctors. If I did not keep track and ask questions no one else was going to connect the dots. A system that can track outstanding questions and concerns similar to project management software might aid in complex care.

Here I propose a note system that better tracks the trial-and-error approach common in chronic care. Possibly an integration for patient or parent feedback on medication and protocols done in real time. A system that flags issues and concerns that are queued for follow up. These would increase opportunities for communication, priorities continuity of care and validate care work. In the meantime, some patients and parents are using their own tracking and annotation systems to keep track of notes, often called "the binder" and bringing it with them during appointments to support the level of organization needed to manage a chronic illness.

### **Adolescent Medical Buffer**

Additionally, I propose a medical buffer that does not cut the parent caregiver out the minute the child turns 18. Supporting a chronically ill child through their medial journey does not impact their pathway to adulthood any more than caring for the sick makes them less likely to want to get well. While one minute into the 18<sup>th</sup> birthday creates an adult on paper, the legal aspects of signing off on giving parents access cannot happen until they are 18. This is not something that cannot be pre-organized because they must be 18 to sign the contract which

leaves a window of time that can have challenging consequences in an emergency. Extending access during the time when the child can make legal decisions would prevent the system from creating grey areas that increase the workload of caregivers. Not every person would need or want this level of support, but a buffer would create space to manage those that do. This exists in theory. There are places within MyChart for example that allows for parental access after consent by the child. However, these systems do not always work the way they are supposed to and pathways to access are not always clear. Nor is there a transition period. With access to communication pathways, hospitals and medical groups can be engaging with families to support a transitional period, especially for those with chronic and ongoing illnesses.

### **Acceptance**

When I first started organizing the data I thought I would find the missing language and offer recommendations. As I began to understand the gaps parents navigate, I saw how much of what we do is to validate our child's experience, and I wish there was a way to have all these systems validate ours. What I have seen thread through this study is the parent's ability find acceptance and then create possibilities. So, while I do not want to feel trite about recommending finding ways to build resilience through acceptance it seems like it is a tool that can help build new pathways. This might be in a form of therapy or support group or journaling or anyway that supports understanding and meaning making. In a way acceptance is a gateway to self-care and well-being, which is something all caregivers need.

### **7.3 Reflection**

Moments of crisis have a way of focusing one's energy on what is vital. Parents of chronically ill teens can feel like they live in loops of crisis and in a heightened state of awareness, always on guard for the next emergent issue (Boris 2018, Kluck et al. 2017). Here,

parents, often the mothers try to normalize a safe space for their child, to have them included in social events and have them be recognized and treated as fully human. This is work that offers no real breaks or time off. The contradiction of a family living with chronic illness is that because the world does not change, it can become foreign when the family's life is altered to such an extent that it lays bare inadequate systems of care that relies on the very people it cannot seem to help—the parent caregivers. In doing so, it can make parents reevaluate their sense of self and the language needed to share their experience. Conversations in online forums not only share information about navigating the illness but offer much needed emotional support. For example, a question about how much to push a symptomatic teen can be framed around learning about POTS but it is also about expectations and confronting a change that has an impact on the whole family. Of the 59 comments shared on this particular day, 31 of them offered advice, 11 were replies from the original poster, and 17 shared a similar experience in solidarity and support. If it is indeed up to the parents to bridge the gaps in these systems of care, then the work of a parent must be recognized if only to highlight the unsustainability of it all. While the term parent is often used, it is most often the mother placed in this care role. Here, the paradox of modern motherhood, is situated in the gap between enculturating her children and challenging the status quo they are being raised in. The added stress of guiding a child with a chronic illness not only shines a light on the impossible standards imposed on mothers, but it further highlights the challenges and added work needed to try and morally embody the role. Mothers are made, they are forged through an ever-changing period of trial and error with an identity that is always in flux.

Here, chronic illness highlights extended parenting. While these added layers of support may also be observed in normative parenting chronic illness provides a window into modified

behavior and the constraints that instigated it. Because accommodations are needed there is a push for a diagnosis, in doing so, the diagnosis not only affords treatment it provides a community for those who choose to engage. It is the ground swell of community that shifts the single problematic narrative into a collect that can then resist normative models, advocate for change, and lay a path for new possibilities.

## APPENDICES

### Appendix A

#### Glossary of Terms

Potsie – A term someone with POTS might call themselves or a term someone might use for someone with POTS. POTSie is also the name of an app designed by POTS patient Madeline LeClair to help other POTS patients manage their protocols (2024).

Spoonie – The Spoon Theory comes from the idea that we only have so much energy to spend in a given a day. Chronic illness sufferers often use spoons to measure out how much energy they have by equating it to how many spoons it takes to manage or complete a task and identifies the conscious choices made on a daily basis that many never need to think about, like how much energy it will take too have a shower and get ready for the day. The theory was developed by Christine Miserandino when sharing her experience with Lupus (2003).

Zebra – describes a person with a complex or rare illness. It comes from the idea that doctors are taught that if it sounds like a horse, it is probably a horse. Chronic illness suffers say sometimes it is a zebra.

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