

Parent-Child Dyadic Experiences Living with Postural Orthostatic Tachycardia
Syndrome (POTS) during Emergent Adulthood

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ABSTRACT

Chronic illness and invisible disability are impactful contexts during emerging adulthood and the launching stage of the family life cycle (Beatty, 2011; Capelle, Visser, & Vosman, 2016; Young et al., 2010). The parent-child relationship is important to both developmental and health outcomes in families coping with chronic illness during emerging adulthood (Crandell, Sandelowski, Leeman, Haville, & Knafle, 2018; Fenton, Ferries, Ko, Javalkar, & Hooper, 2015; Waldboth, Patch, Mahrer-Imhaf, & Metcalfe, 2016). While informed clinical competency in counseling families experiencing disablement is a diversity-affirmative ethical imperative among psychotherapists (Mona et al., 2017), little is known in family therapy about how parents and emerging adult children experience launching with chronic illness. This qualitative study explored the parent-child dyadic experience of living with a chronic illness called Postural Orthostatic Tachycardia Syndrome (POTS) during emerging adulthood. Seven dyads of parents and their emerging adult children with POTS were interviewed. Data analysis of in-depth interviews using Moustakas's (1994) transcendental phenomenology uncovered eight thematic clusters of meaning in the shared lived experience of POTS at the launching stage of the family life cycle. Clinical implications for family therapists were explored using Rolland's family system-illness (FSI) model of medical family therapy. Study limitations and future directions for further research were discussed.

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GENERAL AUDIENCE ABSTRACT

More and more young adults are living with chronic illness. Postural Orthostatic Tachycardia Syndrome (POTS) is a little-known chronic illness that tends to begin during adolescence. Like many health problems that disproportionately affect women, POTS is often overlooked by doctors. POTS symptoms, such as dizziness and cognitive difficulty, impact a person's ability to engage in preferred activities and identities. Family therapists can play an impactful role in supporting parents and children with POTS through developmental tasks related to launching an emerging adult in the context of this complex and widely misunderstood chronic illness. This thesis presented the first qualitative study of parent-child dyadic experiences living with POTS. Clinical implications for medical family therapy were highlighted. To construct an interview framework, Rolland's Family Systems-Illness (FSI) clinical model for helping families cope with illness and disability was used in conjunction with Arnett's description of emerging adulthood as a developmental stage in life. Seven parent-child dyads were interviewed for 1-2 hours in fourteen separate interviews generating transcripts about 140,000 words long in total. Analysis of these interviews identified shared themes composing the essence of the parent-child experience living with POTS during emerging adulthood. Results were described through tables and narratives. Clinical implications for family therapists working with parents and children with POTS during emerging adulthood were proposed. Limitations and ideas for future studies were discussed.

Dedication

To all the dreams of our hearts—and this is one of them.

To my family, who are my biggest and best dream.

And to tomorrow.

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List of Abbreviations

Emerging adult (EA)

Complimentary alternative medicine (CAM)

Family Systems-Illness Model (FSI)

Marriage and Family Therapy (MFT)

Medical Family Therapy (MedFT)

Postural Orthostatic Tachycardia Syndrome (POTS)

CHAPTER I: INTRODUCTION

Chronic Illness in America

More than half of American adults live with chronic illness, which may be defined as a physical or mental health condition lasting at least a year and demanding ongoing management or functional adaptations (Buttorff, Ruder, & Bauman, 2017). Chronic illness accounts for 90% of healthcare costs in the U.S. while simultaneously causing loss of career productivity for individuals with chronic illness and their caregivers (Beatty & Joffe, 2006; Buttorff et al., 2017; Gerteis et al., 2010). Nationally, chronic illness is widespread and increasingly prevalent among emerging adults due in part to technologies to extend life with chronic illness (Gledhill, Rangel, & Garralda, 2000; Maslow, Haydon, McRee, Ford, & Halpern, 2011; Rolland, 2018; Waldboth, Patch, Mahrer-Imhaf, & Metcalfe, 2016). For example, individuals with congenital genitourinal conditions, such as spina bifida, were not expected to survive into adulthood five decades ago but are now entering emerging adulthood in “a veritable tidal wave” (Hsieh et al., 2017, p. 261). With an estimated 500,000 individuals living with chronic illness turning 18 each year in the U.S. (Maslow et al., 2013), increased understanding of family resilience in the presence of chronic illness at emerging adulthood is needed in family science literature. This study seeks to explore the parent-child relationship, parent experience and emerging adult experience of 18-29 year olds living with a multi-systemic condition called Postural Orthostatic Tachycardia Syndrome (POTS).

Emerging Adulthood

Arnett (2004) identified emerging adulthood as a distinct period in development among postindustrial societies. Arnett described five distinguishing psychological

characteristics of emerging adults: (a) identity exploration in love, work, and world view; (b) instability; (c) self-focus above and beyond any other stage in the lifespan; (d) feeling in-between childhood and adulthood; and (e) unparalleled spirit of possibility and hopefulness that one's life will be generally successful and at least better than previous generations in one's family. Emerging adulthood is a culturally-bound phenomenon of extended moratorium less likely to occur in settings where pressures and opportunities to settle into marriage, children, and the workforce are higher, such as among certain religious communities and rural areas (Arnett, 2014). Lasting from age 18 to 25 and extending to 29 in some individuals or groups, emerging adulthood is the longest period of development in human lifespan leading up to adulthood. Furthermore, emerging adulthood is a pivotal moment in development owing to the newfound freedom to act in one's own agency and the consequences thereof to an individual's social and vocational trajectories.

Among the many developmental tasks of emerging adulthood, separating from parents reigns preeminent. According to Arnett (2004), emerging adults' perceptions of becoming an adult include three cornerstone achievements, all of which involve separation from parental involvement and care: (a) accepting responsibility for oneself, (b) making independent decisions, and (c) becoming financially self-sufficient. Parent-child relationships change in other important ways during emergent adulthood. Arnett (2004) described a relationship shift to one of friends or near-equals characterized by decreased conflict and increased ability to perspective-take and view parents in a multidimensional manner as compared to adolescence. Most emerging adults feel closer to their parents as they experience release from subordinate roles of childhood, and both

parents and emerging adults report enjoying spending time together more as compared to during adolescence (Arnett, 2004).

Parent-Child Dyads of Emerging Adults with Chronic Illness

Emergent adulthood has been identified as a particularly high-risk period for individuals managing chronic illness (Ferris et al., 2015; Kuo, Ciccarelli, Sharma, & Lotstein, 2018; Wiebe, Berg, Mello, & Kelly, 2018). “Understanding the challenges of parenting a youth or young adult and evolving parenting roles in health care decision-making and chronic disease management,” (p. 351) is one goal identified by medical experts surveyed in a Delphi qualitative study on curriculum for physicians who are treating emerging adults with chronic illness as they transition to adult health care systems (Kuo et al., 2018). Across medical conditions, parent-child relationship dynamics have been implicated in self-care behaviors during transition to adulthood among families coping with chronic illness (Distelberg et al., 2016; Fenton, Ferris, Ko, Javalkar, & Hooper, 2015; Rolland, 2018). Parenting behaviors have been correlated to health quality among chronically ill adolescents and young adults (Crandell, Sandelowski, Leeman, Havill, & Knafl, 2018). More specifically, parental warmth and structure were found to be associated with less depression as well as better quality of life and physical functioning in children with chronic illness while parental rejection, coercion or chaos was found to be associated with poorer physical functioning (Crandell et al., 2018). Shifting parent perspective on their emerging adult child’s illness-related pain and disability has been shown to help reduce the emerging adult’s functional disability, increase self-efficacy and self-esteem, and reduce use of opioid pain management (Bruce, Weiss, Ale, Harrison, & Fischer, 2017). While research on parents

of emerging adults with chronic illness has focused on health outcomes, Heath, Farre, & Shaw (2017) pointed out, “It is important to understand how parents experience their child’s transition to adulthood because how parents manage and cope with their own change in roles and responsibilities will likely impact on both their child’s transition to independent self-care as well as their own psychological well-being” (p. 77). Parents’ health and “quality of life of the whole family system” are also affected by the emerging adult’s chronic illness experience during transition to adulthood (Waldboth, Patch, Mahrer-Imhof, & Metcalfe, 2016, p.45).

Postural Orthostatic Tachycardia Syndrome

Postural Orthostatic Tachycardia Syndrome (POTS) is a little understood disorder estimated to affect 500,000 to 3,000,000 Americans today with typical onset in adolescence or early adulthood (Bhatia et al., 2016; Grubb, Calkins, & Rowe, 2005; Kizilbash et al., 2014; Rea, Campbell, & Cortez, 2017; Pavlik, Agnew, Stiles, & Ditoro, 2016). POTS is characterized by dizziness upon standing up accompanied by an increase in heart rate of 30-40 beats per minute (Rea et al., 2017). Low et al. (1995), who originally coined the term POTS, described symptom severity along an orthostatic grade of symptoms (OGS) ranging from zero or no dizziness upon standing to four or able to stand less than a minute without fainting. Though POTS is a relatively new term, the phenomenon has been documented under other names, such as soldier’s heart observed by civil war physician Jacob Medes Da Costa in 1871 (Pavlik et al., 2016).

For approximately one-fourth of individuals with POTS who are disabled by the condition, daily activities such as work, school, house chores, and even personal care exacerbate symptoms and may be untenable (Bruce et al., 2016; Grubb et al., 2005).

Family members often serve caretaking roles in POTS illness management (Vycoupil, 2015). In talking about adolescents with POTS, Boris (2018) mentioned, “Parents are a strong and persistent presence in the care and growth of this specific group of patients” (p. 99). He highlighted parents’ vital role as advocates in healthcare as the family sorts through commonplace misdiagnoses, in educational accommodations like individual education programs (IEP) and 504 plans or home-bound alternatives, as well as day-to-day emotional support (Boris, 2018). Conversely, family denial of symptoms can add stress and delay treatment (Uhrich & Hartung, 2015). Parental catastrophizing has been found to correlate to depression and functional disability in youths with POTS (Kluck, Junghans-Rutelonis, Jons, Fischer, & Weiss, 2017; Junghans-Rutelonis et al., 2018). Having POTS means psychosocial changes and challenges for the whole family as members accommodate to the young adult’s tenuous energy and unpredictable health dilemmas.

Many families struggle to support youth with POTS through age-appropriate developmental tasks such as attending school, social functions or extracurricular activities (Kizilbash et al., 2014). In the context of high stakes health consequences to self-care lapse, parents of emerging adults with POTS sometimes experience difficulty relinquishing control and responsibility (Boris, 2018). Young et al. (2010) pointed out that families transitioning a child with disability to emergent adulthood navigate launching in the context of unique constraints and challenges. How parent-child dyads of emerging adults with POTS go about balancing centripetal care demands of chronic illness and centrifugal autonomy demands of emerging adulthood is not reflected in current family science literature. Using family systems-illness (FSI) model (Rolland,

1987, 2018) as a theoretical lens, this proposed phenomenological study seeks to explore the lived experiences of parents' and children's coping with POTS during emergent adulthood.

Theoretical Framework: Family Systems-Illness (FSI) Model

Family systems-illness (FSI) model examines family coping and adaptation to the psychosocial demands of illness, taking into account family life cycle stage and family structure (Rolland, 2018). FSI is a collaborative clinical model, drawing from couples and family therapy concepts of family systems and resilience theories. Rolland (2016) called his model a “normative, preventative framework for psychoeducation, assessment and intervention with families facing chronic and life-threatening conditions” (p. 431). Among medical family therapy (MedFT) approaches, FSI is well established by more than 40 years of efficacious clinical applications among families coping with chronic illness, terminal illness, and medical complexity (Rolland, 2018).

Consistent with overarching medical family therapy framework, FSI looks at illness experience in families through a biopsychosocial lens (McDaniel, Doherty, & Hepworth, 2014). Understanding of the family's experience of illness in FSI requires understanding of the illness in several dimensions: time phases, illness type, and family functioning (Rolland, 2018). FSI conceptualizes the illness as a participant in the triadic system of the family with healthcare support the third member of the system. Timeline of illness with particular attention to transitions between phases of pre-diagnosis, initial adjustment to diagnosis, chronicity or “the long haul”, and ultimate course of the disease are taken into consideration (Rolland, 2018, p.44). Demands the illness places on family functioning and family response are viewed in a systemic, dynamic way. Rolland

adopted Combrinck-Graham (1985) concepts of family oscillation between closeness and separation expressed in centripetal and centrifugal relationship forces that become central concerns when illness presents at adolescence or emerging adulthood when the family is transitioning into new roles and responsibilities related to autonomy and dependency. Centrifugal phases of family functioning organize the family with more diffuse boundaries, less family closeness and cohesion, and more engagement of individuals with systems outside the family (Rolland, 2018). Centripetal phases of family functioning pull the family together in more internally directed behavior with more rigid boundaries between the family as a unit and other systems around the family (Rolland, 2018). FSI considers family functioning in terms of communication, problem-solving, role expectations, coping, meaning making, utilization of social support and other resources, asking all along, “What is the role of the illness in this family’s life?” (Rolland, 2018).

Valuable to this proposed study’s participatory approach, Rolland (2018) developed his theoretical framework from an emic perspective. While seeking help during personal family experience with serious illness, Rolland encountered unhelpful psychotherapy models “based too much on theories of psychopathology rather than on the normative strains of families coping with adversity” (p. vii). FSI’s departure from the medical model pathologization of families living with chronic illness enhances its compatibility with social ethics the study of disability.

Participatory Study Approach: Qualitative Interviews

A qualitative phenomenological approach is warranted by the exploratory nature of studying parent-child dyadic experiences living with POTS during emergent adulthood. In medical literature, POTS is an under-researched and relatively newly-

termed diagnosis. Medical journals repeatedly recommend family education and family therapy in integrated treatment for young adults with POTS (Bruce et al., 2016; Cuttita, Self, de la Uz, 2017; Revlock, 2018), often highlighting parental involvement and parent-child relationship dynamics in coping with POTS (Boris, 2018; Junghans-Rutelonis et al., 2018; Kizilbash et al., 2014; Kluck, Junghans-Rutelonis, Jones, Fischer, & Weiss, 2017). Yet little is known about how parent-child dyads experience POTS. In family science literature, POTS has been under-explored. Arnett (2004) argued for qualitative interviews in research with emerging adults because the method produces a rich picture of their lives. In fact, he described emerging adults as “remarkably insightful”, crediting their increased tendency to be self-focused and “a striking capacity for self-reflection” (p. 25).

Qualitative research is a good fit for disability research in general and invisible disability research in particular due to the method’s empowerment of participants. Historically, studies of disability have been designed in a manner which disempowered participants, portrayed negative images of disabled persons in society, and exploited researcher-participant power hierarchy isomorphic to societal ableist political dynamics (Castrodale, 2018; Richards & Clark, 2017). Disabilities rights movements in application to research have espoused, “Nothing about us without us” (Berwick, 2009, p. 560), which, in research, calls for actively listening to and transparently reflecting the perspectives of participants with disability. Wieseler (2018) suggested that phenomenology provided a research methodology for disability theorists to move beyond disempowering dominant social narratives, beyond even the social model of disablement,

to comprehensively embrace the embodiment experience and every lives of people with disability.

Phenomenological qualitative study empowers participants by making their voice the authoritative source of understanding (Finlay, 2011; Merriam & Tisdell, 2016). Moustakas' (1994) transcendental phenomenology in particular gives preference to participants as sources of generating knowledge by its "epoche" stance, which is a process of researcher self-bracketing whereby the researcher acknowledges and sets aside preconceived impressions of the study subject in preparation to encounter the subject with openness to participants' experiences (Finlay, 2011; Hays & Wood, 2011). Other aspects of phenomenological qualitative research approach that allot participants involvement and control over knowledge production include use of participant language and phrasing in reporting through interview extracts, member checking validation procedures, and approaching thematic analysis by gathering clusters of meaning rooted in interview scripts (Moustakas, 1994). Privileging participant perspectives is an ethical imperative of disability studies and can be accomplished through a qualitative approach to research on individuals with chronic illness and other invisible disabilities.

Why Study POTS?

Parent-child experience living with POTS at emergent adulthood is likely analogous to transitioning to adulthood with other chronic illnesses, rare diseases and invisible disabilities in many ways. Common psychosocial factors and shared emotional themes of families living with chronic illness have been found across conditions (McDaniel et al., 2014). McDaniel et al. (2014) described eight shared emotional themes and three behavior trends encountered by many families across diverse illness

experiences, saying, “They describe universal tensions that may be triggered by an illness, tensions that activate the most basic of human concerns about the meaning of life, relationships, and spirituality” (p. 86). For example, illness experience may trigger different behaviors in social connection, such as social withdrawal. Social isolation was found to be prevalent among adolescents with POTS and their parents as youth dropped out of normal activities due to chronic fatigue, pain, and triggering of symptoms, and parents dropped out of normal hobbies, work, and social engagements due to caregiver strain (Kizilbash et al., 2014).

As with other chronic illnesses impacting access to social support, families and individuals with POTS and other chronic illnesses have high rates of depression, anxiety and other mental health care needs (Anderson et al., 2014; McGrady & McGinnis, 2005; Pederson & Brook, 2017). Anderson et al. (2014) report, “Patients with POTS experienced markedly diminished health-related quality of life across both physical and mental health domains” (p. 6). Parents of adolescents and young adults with POTS have reported feeling that their lives center around managing the multifarious challenges posed by their child’s complex condition (Kizilbash et al., 2014).

Mental health systems are ill prepared to service families with POTS and other rare diseases, invisible disabilities or chronic illnesses due to lack of understanding of how the disease impacts mental wellness, family functioning and other outcomes. As Vykoupil (2016) pointed out, “Many aspects of this multisystemic orthostatic disorder still remain unclear” (p. 429). Describing the shared experience of parent-child dyads living with POTS during emergent adulthood will likely bear meaningful clinical implications for better mental health support, which in turn may translate into decreased

symptom severity, improved functioning and more successful transition to adulthood for families with POTS and similar medical complexity.

One feature distinguishing POTS from many other chronic illnesses at the launching phase of the family life cycle is that usually individuals experience illness onset during adolescence or early adulthood (Arana et al., 2017; Wells et al., 2018), and so the family has not had much time to adapt to the disease at launching. Their experience of living with chronic illness might sharply contrast their experience as a family before the onset of the disease, as teens and young adults with POTS are typically healthy before onset (Boris, 2018; Johnson et al., 2010; Kizilbash et al., 2014). Families describing their experience living and launching with POTS during emergent adulthood may likely describe the impact on the family in unique ways compared to families who have survived ongoing chronic illness since birth or childhood or families who have never experienced chronic illness. Indeed, Maslow et al. (2011) found significant differences in educational and vocational attainments between emerging adults with chronic illness with childhood onset versus adulthood onset. Through its relapsing-remitting patterns, too, POTS situates a crossroads between the two worlds of health and disability. A distinctive viewpoint is expected to emerge from the participants' responses.

Research Question

Through qualitative transcendental phenomenological inquiry, this study proposes to explore the research question: How do children living with POTS and their parents experience emerging adulthood, also known as the launching stage of the family life cycle?

CHAPTER II: LITERATURE REVIEW

Chronic Illness at Emerging Adulthood

Developmental themes. Autonomy, separation from family of origin, formulation of personal life goals, and building an interpersonal network are a few of the major themes inherent in the launching stage of family development (McGoldrick & Shibusawa, 2016). Rolland (1987) highlighted the importance of individual autonomy of both parents and children at emerging adulthood living with chronic illness, stating, “The crucial task of this period: the maintenance of maximal autonomy for all family members in the face of a pull toward mutual dependency and caretaking” (p. 155). Studies of launching emerging adults have suggested the context of disability introduces unique tasks for parent-child dyads and often requires creative accommodations (Capelle, Visser, & Vosman, 2016; Weingarten & Worthen, 2017; Young et al., 2010). For many emerging adults with disability, the concept of establishing autonomy involves learning to manage social support rather than living alone or becoming financially independent (Wiebe et al., 2018). Parents undergo a parallel process of letting go while their emerging adult children step into the world of independence and self-direction (Heath, Farre, & Shaw, 2017). How parents cope with their changing roles and responsibilities impacts emerging adults’ self-care and psychological well-being (Heath et al., 2017). In their examination of independence among emerging adults with chronic illness, Waldboth et al. (2016) showed emerging adult perceptions of their relationships with parents as a double-edged sword, offering both support and tension. Waldboth et al. (2016) described adaptation to chronic illness at emerging adulthood consists of creating new support strategies.

Emerging adults with chronic illness may face health-related and socially-created challenges in living, loving, learning and working (Beatty, 2011; Maslow et al., 2011; Thompson et al., 2009; Waldboth et al., 2016; Weingarten & Worthen, 2017). In an autobiographical case study, mother-daughter dyad Weingarten and Worthen (2017) reported that for Worthen, launching meant taking over medical healthcare management from her parents, setting up reliable social networks to replace parental support, and negotiating health risks in marriage and childbearing with prospective coupling partners. In terms of entering the workforce with chronic illness, Beatty (2011) examined career barriers in working adults with chronic illness and found sources of difficulty emanating from illness symptoms, others' reactions to their health status, and institutional structures. In a study comparing developmental outcomes among young adults with and without chronic illness histories, emerging adults with chronic illness were less likely to have graduated college or be gainfully employed and more likely to receive public assistance (Maslow et al., 2011). Waldboth et al. (2016) describe working lives of emerging adults with chronic illness require additional effort and at times re-evaluation due to symptom management and changes in illness experience over time.

Emerging adults with different chronic illnesses may also have between-group differences in launching. Thompson et al. (2009) looked at ways adult cancer survivors navigate intimacy and romantic relationships and found lower rates of marriage and cohabitation and delayed formation of intimate relationships. Age at diagnosis was inversely correlated to social quality of life (Thompson et al., 2009). However, Maslow et al. (2011) found no difference between social outcomes among young adults with and without chronic illness, quantitatively examining marital status, parenthood status, and

relationship quality with romantic partner among adults with illness histories of cancer, epilepsy, diabetes and heart disease. Waldboth et al. (2016) found emerging adults with diverse illnesses without cognitive impairment including muscular dystrophy, cystic fibrosis, hemophilia, and sickle cell disease experienced different levels of social acceptance, apparently due to differences in visibility of symptoms. While symptom camouflaging led to less discrimination, it was also associated with less interpersonal closeness (Waldboth et al., 2016). For both apparent and invisible disability statuses, many youth reported feelings of low self-worth, loneliness and frustration in their search for a romantic partner (Waldboth et al., 2016).

Emerging adults with chronic illness may experience unique growth, apart from typical developmental themes such as autonomy and social connectedness. Yi, Tian, and Kim (2017) speculated that emerging adults with chronic illness may benefit from endowments of survivorhood through “internal and essential criteria for adulthood” (p. 566). Specifically, they noted surviving chronic illness often results in gains such as resilience, appreciation and gratitude, tolerance for life challenges, optimism, presence in the here and now, empathy and sympathy for others, resistance to health-related risk behavior, and a general feeling of being more mature than peers without health challenges (Yi et al., 2017).

Mental health implications. In clinical presentation, Rolland (2018) described emerging adulthood as a time when families of chronically ill young adults are particularly vulnerable to feelings of “anticipatory loss” (p. 209), meaning feelings of grief over future dreams and plans that no longer seem hopeful due to limitations imposed by disease. Parent-child relationship conflict over autonomy and dependency at

this stage, according to Rolland (2018), can be exacerbated by ambiguities in symptom triggers. In a study of parental experience in families of emerging adults, Heath et al. (2017) found that parent-child conflict correlated with protective parenting behaviors and parent anxiety. Parents in their study described their feeling “stress, turmoil, and fear” (p. 87) while their emerging adult child with chronic illness gained autonomy and learned self-management of their disease.

Living with POTS: More Questions than Answers

Information on psychosocial aspects of POTS such as family relationships, social support, academic or work functioning is limited. Some studies on medical aspects of POTS minimally mention psychosocial aspects of living with POTS in relation to symptom burden (e.g., Kizilbash et al., 2014). Some studies have examined interplay between health-related catastrophizing cognitions, anxiety, and functional disability in POTS (Benrud-Larson, Sandroni, Haythornthwaite, Rummans, & Low, 2003), behavioral health care in treating POTS (Ralston & Kanzler, 2016), psychological or cognitive profiles in POTS (Raj et al., 2009; Raj, Opie, & Arnold, 2018), and the efficacy of integrated care with biopsychosocial approaches in treating POTS (Bruce et al., 2016). Recently, one qualitative study captured some of the angst many families coping with POTS experience interacting with healthcare systems (Stiles, Cinnamon, & Balan, 2018). However, resilience factors and family systems dynamics remain unexplored in POTS research. The following review reflects the paucity of psychosocial and family science research on POTS and is consequently heavily reliant on medically oriented literature.

Invisibility of POTS. Individuals with POTS may appear healthy to others and therefore often experience difficulty accessing appropriate care and accommodations

(Boris, 2018; Stiles et al., 2018). On average, individuals with POTS in the U.S. seek medical support for five years before obtaining a correct diagnosis (Mohr, 2017). Medical training in recognition, diagnosis, and treatment of POTS is not widespread (Kizilbash et al., 2014; Pavlik et al., 2016; Stiles et al., 2018). Many patients with POTS are misdiagnosed with panic or anxiety disorders (Dahan, Tomljenovic, & Shoenfeld, 2016; Pavlik et al., 2016) or told, “Some version of ‘it’s all in your head’” (Stiles et al., 2018, p. 122). Youths’ complaints of fatigue and dizziness are often disbelieved by family, teachers and peers (Uhrich & Hartung, 2015). As one study found, “Looking ‘fine’ when a patient cannot participate in all of the activities they would like to, can result in judgment, disbelief and shaming from peers or family members who cast doubt on their POTS diagnosis” (Stiles et al., 2018, p. 122). Uhrich and Hartung (2015) noted the important advocacy role school-based nurses can play by validating symptoms experienced by adolescents with POTS. Kizilbash et al. (2014) reported cases of child protection authorities threatening to remove adolescents with POTS from parental custody due to mislabeling POTS symptoms and functional impairment as malingering and school truancy. Even the most textbook and severe cases of POTS can sometimes be invisible to healthcare providers. Mohr (2017) reported a shocking case of misdiagnosis in which a 19-year-old woman spent a year of high school hospitalized in a mental health unit for “manipulative malingering behavior” before her mother located a physician who recognized her daughter’s dizziness, fainting, fatigue, headache and abdominal symptoms as POTS (p.718).

Uncertainty in POTS illness course. POTS is a complex disorder with highly uncertain course from day to day and in the long-term (Wells et al., 2018). A recent

study conducted by Mayo Clinic demonstrated that most individuals treated for POTS during adolescence recover significantly after puberty, although a small percentage (3.5%) worsen over time (Bhatia et al., 2016). A similar long-term follow up study conducted in Peking Hospital found 85% of 115 patients treated during adolescence were symptom-free in adulthood (Tao et al., 2019). Wells et al. (2018) suggested that most POTS symptoms reduce over time and a minority completely remit. Arnold, Ng, and Raj (2018) recommended adults with POTS aim for functional improvements with ongoing medical support rather than hoping for a cure, which they have found rarely occurs in the adult POTS population. Rolland (2018) highlighted the role of uncertainty as a meta-characteristic of illness experience that places extraordinary demands on families, who must adapt to uncertain illness course and daily symptom fluctuation with dexterity and endurance. Rolland (2018) mentioned flexible contingencies in plans, decision-making, and creative problem-solving which can lead to caregiver burnout. He suggested that minimization in the form of positive illusion balances illness uncertainty for optimal family adaptation in highly uncertain disease (Rolland, 2018).

Symptoms of POTS. POTS symptoms fluctuate along a broad continuum and may include dizziness, fainting, shortness of breath, headache, cognitive impairment, chronic fatigue, palpitations, nausea, gastrointestinal and bladder dysfunction, visual disturbances, chronic pain and neuropathy (Kizilbash et al., 2014; Rea et al., 2017; Anderson et al., 2014). POTS patients are more sensitive to environmental conditions and often experience photophobia, sound sensitivity, and heat intolerance (Uhrich & Hartung, 2015). Additionally, individuals with POTS frequently report symptoms of anxiety and depression (Anderson et al., 2014; McGrady & McGinnis, 2005). Most

individuals with POTS experience some form of sleep disorder (Miglis & Barwick, 2018; Penderson & Brook, 2017). POTS symptoms may be experienced constantly or intermittently in phases of recovery and relapse or flare-up (Bhatia et al., 2016).

Causes of POTS. POTS is a multisystemic, pathophysiologically heterogeneous disorder, meaning it involves problems across more than one anatomical system in the human body with dissimilar manifestations of symptoms (Grubb et al., 2005; Johnson et al., 2010; Vykoupil, 2015). For many individuals with POTS, the cause is unknown (Johnson et al., 2010; Vykoupil, 2016). Recent efforts to delineate subtypes of POTS based on symptom presentation are uncovering diverse etiologies (Pavlik et al., 2016).

POTS can be a primary, secondary, or comorbid condition. When POTS occurs secondarily, it is a complication emerging from a primary disorder such as multiple sclerosis, diabetes, lupus and other disorders affecting the autonomic nervous system (Johnson et al., 2010). In addition, POTS often presents comorbid with disorders that exacerbate POTS symptoms, such as Ehlers-Danlos syndrome (EDS) and mast cell activation syndrome (MCAS) (Johnson et al., 2010; Pavlik et al., 2016). This study will focus on idiopathic POTS, in which POTS is the primary illness, irrespective of etiology and comorbidity.

POTS is often referred to as a form of autonomic nervous dysfunction (Johnson et al., 2010; Kizilbash et al., 2014). However, theories of cardiac origin have suggested that dysautonomia is not necessarily involved (Fu et al., 2010; Fu & Levine, 2014; George et al., 2016). Some researchers have categorized POTS as an autoimmune disease (Dahan et al., 2016). Fedorowski (2019) pointed out, “The onset of POTS is typically precipitated by immunological stressors such as viral infection, vaccination, trauma,

pregnancy, surgery or psychosocial stress” (p. 352). Blitshteyn (2015) studied blood samples from 100 POTS patients and found that one-third had autoimmune markers. More recently, Gunning, Kvale, Kramer, Karabin, and Grubb (2019) found specific autoantibodies in 89% of POTS participants (n = 55). Other researchers have pointed out that POTS seems to run in some families, linking it to genomic disorders (Johnson et al., 2010). Still others have framed all these etiological theories with skepticism and have concluded that POTS is merely a complex result of deconditioning (Joyner & Masuki, 2008).

Women and POTS. Sixty-five to 90% of POTS patients are female (Johnson et al., 2010; Kizilbash et al., 2014). Many women with POTS report that their symptoms change with menstrual phases, pregnancy, and menopause (Johnson et al., 2010; Mohr, 2017). Female contraceptive medications can have deleterious effects on POTS symptoms (Wells et al., 2018). Like other autoimmune diseases similarly impacting mostly women, onset of POTS often begins during endocrine transitions, i.e. puberty or pregnancy (Desai & Brinton, 2019; Paulson, 2014).

Diagnosis of POTS. The current gold standard diagnostic metric for POTS is the tilt table test (TTT) (Pavlik et al., 2016). The TTT measures heart rate, blood pressure, and blood flow to the brain while tilting the patient at a 70-90 degree angle to the ground with head up (Pavlik et al., 2016). Patients usually undergo additional electrophysiological tests to rule out other cardiologic and neurologic diseases before confirming the POTS diagnosis (Kizilbash et al., 2014). During treatment, various symptoms might be managed by a multidisciplinary effort, including internal medicine,

neurology, cardiology, physical therapy, and behavioral health (Bruce et al., 2016; Kizilbash et al., 2014).

Treatment of POTS. Treatment regimes typically involve salt and fluid increase, tolerated exercise, and off-label pharmacotherapies, primarily beta-blockers, SSRIs, fludrocortisone, and vasopressors (Bhatia et al., 2016; Kizilbash et al., 2014; Vykoupil, 2015). Patient education is vital to successful symptom management (Kizilbash et al., 2014; Vykoupil, 2015;). Stiles et al. (2018) reported families taking two years to learn how POTS impacts the body and effective management of symptoms. Kizilbash et al. (2014) emphasized the importance of family-based approaches to treating POTS, including family counseling. Vykoupil (2015) promoted psychoeducation for parents and youth with POTS. Recent research has pointed promisingly to the efficacy of non-pharmacological strategies in treating POTS (Bhatia et al., 2016; Fu & Levine, 2014; George et al., 2014; Vykoupil, 2015). A clinical trial in neurotechnology therapy utilizing closed-loop acoustic stimulation intervention showed improved autonomic functioning and reduced POTS symptoms after two weeks of daily, noninvasive sessions (Fortunato et al., 2016). Cardiac remodeling exercise-based treatment programs have shown promising results in reducing and even eliminating POTS symptoms (Fu et al., 2010; Fu & Levine, 2014; George et al., 2016).

Mental health and POTS. Anxiety, depression, sleep problems, and suicidal ideation are common and interconnected phenomena among individuals with POTS (Anderson et al., 2014; Pederson & Brook, 2017). Additionally, McGrady & McGinnis (2005) found comorbidity between POTS and substance abuse. Poor sleep quality was found among more than 98% of POTS patients and was significantly associated with

suicidal ideation in regression analysis (Penderson & Brook, 2017). In a screening study, children and adolescents age 7-18 were nearly six times more likely to qualify for POTS diagnostic criteria if they had less than eight hours of sleep a night (Lin et al., 2014). Sleep hygiene is an important facet of treatment and self-care for adolescents and emerging adults learning to manage their POTS (Boris, 2018).

Because of the etiological role autonomic dysfunction is suspected to play in POTS, anxiety has physiological overlap with POTS (Owens et al., 2017). McGrady and McGinnis (2005) pointed out that 25% individuals with POTS who faint have anxiety as a result, while conversely, individuals with Generalized Anxiety Disorder (GAD) and no cardiologic problem may have syncope as a result of anxiety. Owens et al. (2017) found that affective symptoms in POTS “appear to be driven by anxiety and vigilance of physical sensations/symptoms, rather than trauma or neurosis” (p. 81). Respondents in a large online survey likewise described the “truly frightening” nature of fainting, dizziness, pain and palpitations experienced in POTS (Stiles et al., 2018, p. 122). Given that the majority of families coping with POTS have endured multiple misdiagnoses, including dismissal of physical symptoms as “all in your head” (Stiles et al., 2018, p. 122), teasing apart factors around anxiety and POTS symptoms may be useful in counseling families on anxiety management without invalidating the “realness” of their illness experience.

Mental health problems associated with POTS may be best serviced by behavioral health. Anderson et al. (2014) concluded their study of cognitive difficulties in POTS by recommending psychological interventions targeting anxiety and depression. Bruce et al. (2016) found a significant reduction in depression, catastrophizing, and functional

impairment in 33 adolescents with POTS after three weeks of intensive interdisciplinary intervention with parent-child dyads. In a single case study using CBT, Ralston and Kanzler (2016) found that learning to discriminate between anxiety symptoms and POTS symptoms significantly decreased POTS-related functional impairment. McGrady & McGinnis (2005) outlined detailed recommendations to clinicians treating POTS clients to reduce syncope, including utilization of support groups, behavior therapy, biofeedback, hypnotherapy, CBT, and specific bio coping strategies reported to have been successfully employed by many with POTS to prevent fainting, such as leg crossing and muscle tensing. Use of antidepressants may prove useful with POTS with due caution against ones with side effects that exasperate dizziness or hypotension (McGrady & McGinnis, 2005).

Launching with POTS. Little is known about how emerging adults with POTS and their parents navigate family development during launching. In their investigation of recovery among 172 teens treated for POTS during adolescence, Bhatia et al. (2016) noted the majority of respondents had completed college or were attending college at the time of a five-year follow-up survey although only 19% reported total resolution of symptoms. On the other hand, Kizilbash et al. (2014) described a case of a 21-year-old emerging adults with POTS who seemed virtually frozen in time since before high school in terms of education, friends, and basic life skills such as learning to drive, her parents likewise seemingly suspended in perpetual anxiety over their child's health. Boris (2018) suggested that parents of emerging adults who had POTS during adolescence sometimes encounter difficulty embracing the young adult's independence, and might benefit from individual or family-based counseling. Marriage and family therapists (MFT) are not

well equipped to provide effective counseling to families of emerging adults with POTS. Further exploration of parent-child dyads with POTS at the pivotal family life cycle stage of launching is needed to create a more detailed picture of what these families experience.

This study explored the experience of parent-child dyads of emerging adults age 18-29 living with POTS. A family systems-illness model lens was used to investigate biopsychosocial descriptions of the disorder and ways families maneuver this stage of family development. This phenomenological qualitative study aims to answer the question: How do parent-child dyads experience living with POTS in the launching phase of the family life cycle?

CHAPTER III: METHOD

Design

The primary research question of this qualitative study is, “How do young adults living with POTS and their parents experience emerging adulthood, also known as the launching stage of the family life cycle?” An empirical, transcendental phenomenological design as described by Moustakas (1994) was used. In-depth interviews with participants began with Moustakas’s two open-ended inquiries of experience and context of the phenomenon. Other open-ended follow-up questions sought to elicit full, rich descriptions of the person’s lived experience. More specific sub-questions generated from Rolland’s FSI (2018) timeline of family coping with chronic illness and Arnett’s (2014) developmental features of emerging adulthood probed into parent-child experiences at the intersection of family development and illness phases.

Because POTS is a syndrome with broad-spectrum symptom severity, diverse etiology and variable illness course, a brief medical history survey was administered before grand tour questions during the interview. See Appendix D for medical history survey details. Participant medical history responses helped to inform and provide context to analysis of interview data. Because some participants were eager to express their feelings about the medical system or the functional impact of POTS on their daily lives, the medical history and symptom questions proved to be a valuable starting point and effectively brought interviewer and interviewee into communion.

The study design was approved by Internal Review Board (IRB) of Virginia Polytechnic Institute and State University on May 11, 2019, IRB approval number 19-263, expiring January 29, 2021.

Purposeful Sampling Criteria

Recruitment aimed for a purposeful sample of 8-10 emerging adults living with POTS age 18-29 and their parents. The unit of analysis was the parent-child subsystem consisting of the emerging adult with POTS and their respective parental figure. Inclusion criteria for “parent” was left open to emerging adult identification, and could have been a single parent or couple or other constellations of parenting family subunit such as grandparents or foster parents. The emerging adult with POTS and one parent were interviewed separately. Siblings and other members of the household outside the parenting-child subsystem were not directly included in the study, though participants discussed them. While meaningful, sibling and other household relationships to the emerging adult with POTS, which may be of interest in future research, represent a scope outside the current study and its focus on launching.

Rationale for parent-child subsystem unit of analysis. Launching processes include dynamic parallel and interactive processes involving parent, child and parent-child relationship changes (Arnett, 2014; Heath et al., 2017). Although siblings, extended family, and others in the family social system experience an impact of POTS or other chronic illness, such as sibling worry and vigilance (Waldboth et al., 2016) or extended family blame and denial (McDaniel, Doherty, & Hepworth, 2014), parents are generally the caregivers and primary social support of an ill child or adolescent (Rolland, 2018). Parent-child relational dynamics are central to developmental landmarks of emerging adulthood (Arnett, 2014), and, parental involvement in POTS treatment and dyadic coping has been noted in medical journals (Boris, 2018; Bruce et al., 2016; Junghans-Rutelonis et al., 2018; Kizilbash et al., 2014; Kluck et al., 2017).

Rationale for separate interviews with emerging adults and parents.

Separate interviews were conducted rather than conjoint interviews in order to provide privacy and confidentiality to both parent and emerging adult participants. Additionally, to further protect confidentiality, measures were taken to ensure data such as constituents or extracts were not easily identifiable among dyad members (e.g. using multiple codes in presenting data between tables). Emerging adults might feel hesitant to share about romantic relationship and sexual identity exploration in conjoint interviews (Morgan, Thorne, & Zurbriggen, 2010), and parents might feel hesitant to share experiences related to caregiver strain, such as grief, financial burden, and other difficulties they may tend to protect their child from hearing or witnessing.

Diagnosis. The emerging adult child must have received a formal diagnosis of POTS by a qualified physician. Individuals who suspected they had POTS but had not

been diagnosed were excluded by criterion sampling. Diagnosis was confirmed in pre-interview screening by communicating participation criteria in initial recruiting email and by participant oral report through medical history questions at the beginning of interviews. Additional confirmation was deduced by congruence between parent and child responses. No objective third party diagnosis confirmation or physical examination was conducted.

Recruitment. Participants for the study were recruited through word of mouth, public advertisements via online POTS support groups and awareness-oriented websites, and networking with the office of a pediatrician who specialize in treating POTS. The study was advertised online through websites frequented by young people with POTS and their parents, such as Dysautonomia Information Network (DINET.org). DINET and Standing Up to POTS fund research on POTS and routinely advertise for participant recruitment. Social media groups whose members have POTS or are family members of individuals with POTS include “POTS Support Group” and the DINET organization’s group on FaceBook, which serve international populations. Children’s Heart Institute is a cardiology clinic local to Northern Virginia that treats families with POTS from all of the U.S. also posted participant recruitment ads. See Appendix C for advertisement.

Participant Demographics

Seven parent-child dyads were interviewed, a sample size sufficient to reach thematic saturation for this type of qualitative research (Schreier, 2018). See Table 1 for basic demographic information and medical history for the seven participating dyads.

Table 1

Participant Information

		Dyad 1	Dyad 2	Dyad 3	Dyad 4	Dyad 5	Dyad 6	Dyad 7
Emerging	<i>Age</i>	18	19	19	20	23	24	27

Adult	<i>Gender</i>	female	female	non-binary	female	female	female	female
Parent	<i>Age</i>	46	47	47	47	67	62	49
	<i>Gender</i>	female	female	female	female	female	female	male
Medical History	<i>Time since diagnosis</i>	3 years	1 year	6 months	4 years	8 years	3 years	11 years
	<i>Age at onset</i>	15	6	17	16	14	12	16
	<i>FSI typology</i>	ACNF+	GCNF+	GPNF+	ACNF+	ARNF+	GCNF+	ARNF+

Note. Rolland’s FSI (2018) illness typology and time phase matrix composes the following medical dimensions: A/G = acute or gradual onset; P/C/R = progressive, constant, or relapsing course of illness; F/NF = fatal and life-limiting or nonfatal illness outcome likely; +/- = presence of disability or no disability experience associated with illness.

Age. Emerging adult participant ages ranged from 18 to 27 with a mean of 21 years old. Parent participant ages ranged from 46 to 67 with a mean of 52 years old.

Gender. Emerging adults were all assigned female gender at birth. One identified as non-binary and preferred they/their/them pronouns, and six identified as female (she/her) at the time of the interview. Of the parents, six were assigned female gender and one male gender at birth. Six parents identified as female (she/her) and one as male (he/him).

Relationship status. Various family constellations were represented in the participating sample. Of the seven participating families, four emerging adults with POTS had parents who were divorced, one’s parents were never partnered, and two had parents who were married to each other. One of the parents interviewed was divorced from the parent of the emerging adult with POTS and remarried in a blended family. One was single, never partnered. Three were divorced and currently unpartnered, and two were married. Romantic partnership status among emerging adults included never dated,

used to date but broken up with former boyfriend and not currently dating, casually dating, partnered in long-term relationship but not cohabitating, and cohabitating and engaged to be married.

Occupation and work status. All participating emerging adults with POTS reported experiencing limitations in work/study and other activities due to severity of symptoms at the time of the interview. Six emerging adults worked part-time and/or engaged in part-time study. One emerging adult was employed full-time, working from home three days a week. Of the seven parents, two worked part-time and five worked full-time.

Education. Higher education was valued in all of the families, and all of the parents interviewed had completed associates, bachelors or masters degrees. Several parents described their children with POTS as “definitely above-average”, “extremely intelligent”, “overachiever”, “straight A’s”, and “a gifted child”. All of the participating emerging adults were enrolled in higher education or had completed a bachelor’s degree, though some took courses online or one course at a time.

Racial/ethnic identity. All of the participants identified as Caucasian or White.

Socioeconomic position and geographic location. Five of the parents’ families had incomes ranging above 100,000 dollars a year; one ranged 65-100,000; and one ranged 25-35,000. Two of the emerging adults lived independently or with romantic partners, and their household incomes ranged less than 25,000 dollars a year and 25-35,000. Participants lived in small towns and larger metropolitan areas across the United States. States of residence included Arkansas, California, Kansas, Ohio, Oregon, and Virginia.

Procedure

Informed consent and pre-interview screening. Informed consent forms were emailed for participants to review and contents were reviewed briefly at the beginning of interviews with oral consent recorded and witnessed through audio recording. See Appendix B for informed consent form.

A pre-interview screening process excluded prospective participants who were undiagnosed, outside the age bracket (18-29 years old), were not fluent in English, resided outside the U.S., or whose parent-child subsystem was unavailable to participate. The screening process consisted of email communication describing the purpose and process of the interview along with a short confirmation checklist. Two prospective participating dyads were excluded during this process, both due to unavailability of the other part of their parent-child subsystem. See Appendix C for pre-interview screening email script.

Surveys. Demographics were collected, including participant age, racial-ethnic identification, education and work status, socioeconomic position, gender, and spiritual/religious identification. In addition to these standard demographic questions, diagnosis-related information was collected, such as year and type (sudden/gradual) of onset, timing and method of diagnosis, and comorbidity. Demographic and medical history information was collected orally at the beginning of the interview. See Appendix D for demographics and medical history questions.

Interviews. Interviews of 50-120 minutes in length were conducted by phone. Emerging adults and their parent were interviewed separately and scheduled at their availability. Audio recording and verbatim transcription by researcher were used.

Specific language in the questions was modified to suit the participant's role in the family. See Appendix A for interview protocol.

Grand tour questions. Grand tour questions began with Moustakas's (1994) two open questions: (a) "What have you experienced in terms of living with POTS during emerging adulthood?" and (b) "What contexts or situations have typically influenced or affected your experiences of living with POTS during emerging adulthood?" A third grand tour question inquiring into the parent-child dyadic experience of POTS included, "What are some ways living with POTS has impacted your parent-child relationship?" Open-ended prompts sought to clarify, focus, concretize, and explore participants' responses of grand tour questions, such as "Tell me more about that."

Follow-up questions. Follow-up questions were generated from Rolland's FSI (2018) and Arnett's developmental themes of emerging adulthood (2014). These included explorations of illness-related parent-child dyadic experience and its intersections with developmental tasks of launching.

Features of chronic illness experience. "What has changed for you since living with POTS?" "How did family members initially react to your/their change in health?" "In your experience living with POTS, what gives you hope and courage, relief and renewal?" "What makes you feel angry or sad?" "How have you navigated uncertainties in living with POTS?" "Tell me about your experience living in the world with POTS in respect to social reactions." "How has POTS impacted relationships within the family?" "How has POTS impacted relationships outside the family, for example with extended family, friends, neighbors, and others in your social circle?" "What significant lessons,

meanings, or values do you feel your family has gained from its health experience with POTS?”

Features of emerging adulthood. “Many people your age are exploring their identity, asking themselves questions like, ‘*What kind of person am I? What kind of person would best suit me as a partner in life?*’ and, ‘*What kind of work am I good at? What do I believe about the world?*’ How have you navigated exploring your identity while living with POTS?” “What are some ways living with POTS has impacted your romantic life?” “What are some ways living with POTS has impacted your financial life?” “Tell me about your experience learning to take care of yourself or to pro-actively enlist support you need as an emerging adult living with POTS.” “Tell me about your experience as a parent as your emerging adult child learns to take over their self-care or proactively enlist the help they need while living with POTS.” “Please describe your relationship with your parent(s)/child during this stage of life compared to adolescence or childhood?”

Data Storage

Research data included audio recordings of interviews, transcriptions, and data analysis notes. Data was de-identified by removing and separately storing participant names and identifying information such as email addresses and phone numbers. A key linking identifying information to participants was accessible only to investigators and will be destroyed after the research is completed in approximately one year. Only first names of emerging adults and their parent were collected. Residency information was limited to state and country. The key was stored in a double-lock system on campus at the Northern Virginia Center for Virginia Polytechnic Institute and State University.

Audio recording files and de-identified transcriptions were stored on a secure Google drive associated with co-investigator's student account, which was IRB-compliant. Participants were identified by pseudonyms of their choice in data analysis notes and study reports.

Role of the Researcher

The researcher bracketed herself out of the study by self-disclosing personal family medical history with POTS. In order to approach describing the essence of research participants' family experiences of launching a youth with POTS from a fresh perspective, the researcher acknowledged the breadth of diversity and changing times of POTS. Participants' experiences are likely to be different from that of the researcher's family. In accordance with Moustakas's (1994) epoche stance of the self-transparent investigator, the researcher underwent a reflexive process of writing her experience and identifying her views and notions of POTS, launching, and living with chronic illness in the family.

The researcher immersed in research and literature on POTS and theories for medical family therapy to appropriately prepare for IRB proposal. These theories and outside information then had to be set aside in order to give data collected from participants a privileged voice. This was achieved in part by setting a time of several months between writing the literature review and conducting data collection and analysis. Data analysis was conducted almost a year after the IRB proposal was written.

Data Analysis

Moustakas's (1994) qualitative data analysis procedures were followed. First, in horizontalization, significant statements were identified from transcripts of participant

interviews. These were statements that seem to capture important aspects of the interviewee's parent, child, and parent-child dyadic experiences living with POTS at emerging adulthood. Repetitions and extraneous statements were omitted. Demographic and medical history information was filtered into a table. Second, significant statements were organized into themes along "clusters of meaning" (Moustakas, 1994). Data analysis up to this point produced three documents for each interview: a) raw transcript, b) horizontalization, and c) clusters of meaning. Third, textural and structural descriptions were developed to place themes in context. Textural descriptions articulating the "what" of the experience were developed through phenomenological reduction, in which components of the experience are broken down, viewing the whole from various points of focus. Structural descriptions postulating the "how" of the phenomenon were achieved through a process of imaginative variation, approaching the phenomenon from a freeing perspective that accepts all possibilities of the experience. Fourth, textural-structural descriptions of the experience combined textural and structural descriptions. Horizontalization, clusters of meaning, textural, structural and textural-structural descriptions were developed for each individual interview. A data analysis adaptation to incorporate dyadic perspective was added wherein individual interview clusters of meaning and textural-structural descriptions were compared and contrasted for "agreeance and divergence" (Tkchuk, Russell-Mayhew, Kassin, & Dimitropoulos, 2019, p.361) within and between dyadic membership groups (emerging adult or parent) and within dyads (each parent-child dyad). Finally, a composite textural-structural description was achieved by consolidating underlying similarities between the fourteen individual textural-structural descriptions, producing the essential invariant description of

the shared lived experience. Results of data analysis reported the essence of launching with POTS utilizing participant extracts, called constituents in Moustakas's methodology, and rich descriptive narration.

Validation

To validate data analysis, the researcher checked consolidated thematic clusters of meaning against transcripts of all participants and extracted constituents as individuals and as dyads. Tables were created to organize comparisons and consolidations of verifiable themes. Themes were then re-organized and listed by strength according to the unanimity of participants' constituents. (See Appendix F for table used during validation.) Strength of theme was considered in emphasis in writing the invariant description. Validation strategies of member checking were also utilized (Creswell & Miller, 2000), wherein participants were emailed a summary of findings by sharing Google documents. During member checking, participants were invited to comment directly on the document or to send feedback by email to check for accuracy of data analysis results. Participants' corrections, additions, and deletions were considered and synthesized with the essential, invariant description.

Reliability

Reliability was established through supervision utilizing "the four R's", namely rigor, relevance, resonance, and reflexivity (Finlay, 2011). Rigor ensured researcher competency, systematic methodology, and adherence to data (Finlay, 2011). Relevance highlighted applicability and contribution to the social issue (Finlay, 2011), in this case describing POTS for family science and family therapy. Resonance implied findings are vivid and evoke a sense of verisimilitude (Finlay, 2011; Creswell, 2013). Reflexivity

demonstrated how the researcher achieved openness to data and integrity in interpreting findings (Finlay, 2011).

Ethics

Chronic illness and disability are features of the participating sample that open them and their families to vulnerabilities and widen the power differential between participant and investigator. Respect and empathy were guiding principles in all interactions with participants. Institutional Review Board (IRB) approval was obtained to ensure proper consideration of participant protections. Consent forms included predicted benefits and risks associated with participation, including the potential for family members to disclose sensitive information around their struggles living with POTS. Consent described limits of confidentiality, including mandatory reporting of certain disclosures of abuse or suicide risk. Participants were informed that they can withdraw from the study at any time. Additionally, they were alerted that they do not need to answer any questions that make them feel uncomfortable.

Participants' wellbeing was considered throughout the investigative process. References to relevant mental health services were on hand in case of participant request (see Appendix E). However, no therapy was offered or conducted during the proposed research study. In reporting study results, participant identities were protected by using pseudonyms of their choosing. Ethical reciprocity was employed in the form of sharing information gained, sending participants research conclusions.

CHAPTER IV: RESULTS

Seven parent-child dyads participated, a total of 14 individual interviews. Participants in this study represented the more severe end of the POTS

spectrum. Overwhelmingly, parents and emerging adults described a pervasive impact of symptoms on the emerging adult's life. Phenomenological analysis identified four themes and eight subthemes related to the shared experience of living with POTS during the launching stage of the family life cycle. The themes and subthemes are compiled with clusters of meaning below in Table 2. A richer narrative description utilizing participant constituents follows. Lastly, a consolidated textural-structural description articulates the invariant description, or the essence of the shared experience of parent-child dyads living with POTS during launching.

Table 2

Thematic Clusters of Meaning

Theme	Subtheme	Clusters of Meaning
Disease experience in daily life of parent-child dyad	1) Reduced quality of life and related functional limitations	<ul style="list-style-type: none"> • EA functional limitations <ul style="list-style-type: none"> ○ Loss of roles/identities ○ Disrupted daily plans, chores, self-care ○ Sexuality (problems related to orientation, libido, activities) • Reduced quality of life <ul style="list-style-type: none"> ○ Narrowed horizons and possibilities ○ Unpleasant symptoms (pain, nausea, fatigue) ○ Mental health problems ○ Uncertainty about the future (waking up, 5 minutes, long-term)
	2) Parents shared emotions	<ul style="list-style-type: none"> • Powerlessness • Sadness/grief • Worry about EA's financial future, health, wellbeing • Anger at medical system/ public • Pride in child • Self-sacrifice (career, financial, time, social, leisure) • Inspired by child (hope, courage)
Disease experience of parent-child dyad in the world	3) Invisibility	<ul style="list-style-type: none"> • "All in their head" mislabel • Interference with acceptance process for family • Appearing malingering (ongoing fear, accusations)
	4) Social life	<ul style="list-style-type: none"> • Loss of some friendships • Deepening of other friendships • POTS community support • Hard to make new friends • Difficult to explain/ People can't understand • Invisibility in public • Pressure not to be/appear sick (stigma) • EA limited social stamina

**Parent-child dyad agency
over disease experience**

frustrations	<ul style="list-style-type: none">• Lack of information about the disease• Ineffective, overly complex, or no treatment options given• Delayed diagnosis• Mislabeling (psychosomatic, malingering, hovering)• Treatment expenses not covered by insurance• Accessibility of POTS expertise (geographic, patient age)
6) Family gains	<ul style="list-style-type: none">• Appreciation (time, people, life)• Celebrating small victories• Family cohesion<ul style="list-style-type: none">○ Coming together to solve problems○ Showing more kindness○ Talking/listening more○ Feeling “there” for each other• Understanding (disablement, other people, illness)• Compassion/empathy• Feeling “stronger” (mental/emotional fortitude)
7) Coping	<ul style="list-style-type: none">• Physical, symptom-reduction strategies<ul style="list-style-type: none">○ Hydration diligence○ Taking breaks○ Symptom awareness and not “pushing” too far○ Exercise○ Utilizing work/study from home options○ Slowing the pace• Emotional coping strategies<ul style="list-style-type: none">○ Optimism and reasonable hope (“part”, “somehow”, “some day”)○ Social support from POTS community○ Acceptance of illness○ Focusing on the present (one day at a time)○ Not comparing to pre-illness expectations○ Self-compassion/tolerance for limitations
8) Developmental gains	<ul style="list-style-type: none">• Parental letting go and trusting the child• Feeling stalled/ in limbo• Dependency in care and economics

- EA leadership, decision-making
- EA early maturity in self-management, values
- Becoming near-equals (parent-child relationship)
- EA hope and optimism in future

Note. EA stands for emerging adult. “Disease” specifically refers to chronic illness and disability related to POTS.

Theme One: Disease Experience in Parent-Child Daily Life

Illness context had a pervasive impact on parent-child dyadic experiences of daily life, with associated shared emotional experiences for parents. Quality of life and related functional limitations of the emerging adult and parental shared emotions were subthemes related to POTS experience in parent-child daily life.

Subtheme one: Reduced quality of life and related functional limitations. One emerging adult participant summarized the functional limitations imposed by POTS, calling the disease, “A severe wrench.” All participants described day-to-day functional challenges living with POTS symptoms and associated problems in quality of life.

Reduced quality of life. One parent described her child’s limitations, “Life was reduced to a recliner.” Symptoms fluctuated day-to-day and even minute-to-minute. Course of illness differed from person to person, with some participants experiencing a long-term trend of partial recovery, some remitting and relapsing, and some worsening over the past several years. (See Table 1 in participant demographics for details of illness typology and time phase of illness.) Fatigue, nausea, dizziness with or without fainting, and cognitive difficulties interfered with preferred activities across multiple settings, including domestic chores, self-care, work/career and education, social life, and romantic partnerships. As one participant described, “This is a severe wrench because of just how limited I am because of my health problems, and that causes a lot of stress.” Threat of relapse or worsening of symptoms due to over-activity (which was difficult to define or predict and changed with fluctuating symptoms) or slackening of self-care (e.g. exercise,

sleep hygiene and hydration) kept emerging adults and their parents vigilant and fearful and complicated decision-making. One participant described, “Since I only have a certain amount of energy, I have to decide” between activities in a day. Participants described processes of loss and adaptation in response to the stressor of POTS, in which they learned to accept limitations and push through difficult and confusing symptoms with insufficient medical information or support.

Loss and adjustment to disability at onset. As one emerging adult participant described, “Everything! I really can’t think of anything that’s not affected at all.” Participants described contexts affected by POTS as “everything, literally.” Impairment during sudden onset of POTS was described by one participant, “I was completely independent and was doing volleyball and swim at the same time, and getting straight A’s, and then all of a sudden like I couldn’t move. It was such a quick change.” A parent described her parental perspective at onset, “I was the only thing in her world. She lost everything.” Children’s perceptions of their parents’ experience included worry and stress that impacted their interactions, “They’re constantly worried about me, and I know that they think about it all the time. And it affects how they treat me and how they approach doing things with me.” Some of the adaptations dyads made included home study through 504 plans during high school and online classes in college, part-time work and telework options, family vacations in colder climates without air travel due to adverse reactions to heat and high altitude, family meals adapted to dietary restrictions of the emerging adult with POTS, changes to shared custody living arrangements to a single residence during teen years, choosing work settings and jobs that do not require any standing, re-organizing household division of labor with symptom fluctuation and around

specific limitations, reducing work hours and class load through a slowed pace during relapses, and a generally narrowed scope of social activities and relationships. (See Table 3 for a list of coping strategies.)

Parent adaptations to functional limitations and symptom burden of EA. For parents, dedicating household and personal resources to managing the illness, reducing their child's discomfort and supporting their functioning, impacted their relationships with other children, retirement plans, friendships and relationships with extended family. Parents described worrying about their child with POTS, and trying to maintain contact and provide necessary care without crossing boundaries of respect for the child's adulthood or need for illness-free conversations. One parent described a structured parental psychoeducation program that helped her and her husband reduce illness talk, which she appreciated and perceived as effective, but she also expressed, "Her daddy and I are always kind of like almost on call." In regard to finances, one parent commented, "It's dictated all of my financial choices for the last 12-15 years, all the way up until I die. That's the impact." Another parent described a limited sense of personal freedom as a caregiver for her emerging adult child with POTS, "It's really hard to make plans, and I don't do a lot for myself... We have very little time apart from each other."

Subtheme two: Parents shared emotions. One parent expressed, "What gives me courage? She does!" Parents expressed similar emotional themes. Several parents conveyed feelings of powerlessness, such as, "Your child is struggling and you can't do anything about it." Parents felt sad about their child's losses and daily discomfort. They worried about their child's future financial life and overall wellbeing. One parent of an emerging adult whose POTS remits and relapses commented, "It's a rollercoaster ride of

disappointments. You worry about the quality of life.” They also expressed pride in their child’s will and perseverance. In fact, parents seemed deeply awed by their child’s courage, “What gives me hope? Well, her! Just the phenomenal way she handles these challenges.” All the parents had made sacrifices in time, energy, and family finances in order to prioritize their child’s care. Several stated feeling focused on the child with POTS, “My life revolves mostly around her.” Two described managing their child’s healthcare as “a full-time job” in addition to their actual full-time job.

Parent-child perceptions of each other’s emotional coping. “It really weighs on your heart,” one parent articulated. Emerging adults perceived their parents’ stress and sacrifices around coping with POTS, as well as that of siblings in many cases, and reported feeling closer and more appreciative of parents. These parents and emerging adults seemed in many ways to be each others’ heroes, giving each other comfort, courage, and motivation in their daily coping. Not all parent-child relationships were as positive, however. Some participants reported parent-child conflict and cutoff, explaining that the distanced parent had trouble accepting or coping with POTS. Gender dynamics seemed to play a role as distancing and withdrawal was mostly described in regard to fathers. One emerging adult participant described perceptions of her father’s distress about her illness, “He sort of let himself fall apart because of it.” Emerging adulthood may be an opportune time to repair parent-child relationships stressed by chronic illness, as parents may experience a release from the feelings of personal blame/shame for their child’s illness. One emerging adult stated, “Now that I’m older, I can kind of take almost comfort in knowing that they can’t fix it... You finally do get to mend that relationship with your parents.”

Theme Two: Disease Experience of Parent-Child Dyad in the World

Participants described shared experiences living in the world with POTS. Invisibility of the illness generated a range of invalidating and unsupportive responses from others who viewed the emerging adult as “young and healthy” and “normal”. Social life changes for parents and emerging adult children included feelings of isolation and filtering of “true friends”. Ongoing issues navigating the medical system with POTS were consistently described as a source of frustration and stress as well as critical resource towards accessing information and care.

Subtheme three: Invisibility. POTS symptoms were often invisible to others, mistaken for stress responses or behavior problems. As one parent related, “It has nothing to do with stress... It’s just very upsetting.”

Missed and mislabeled symptoms. Invisibility and fluidity of disability status contributed to an ‘*all in their head*’ mislabel that in turn created conflict and distancing among important support relationships, delayed healthcare delivery, reduced self-esteem, and disrupted parental resolution processes around accepting a life-altering diagnosis. One mother recalled doctors missing her child’s severe symptoms, “Because all these other tests came back like ‘she’s healthy,’ they literally wanted to sign off that she could play volleyball. And she couldn’t walk into the building without passing out!” One participant described her manager at work surprising her at the hospital during a relapse, “I was hospitalized for a week because I overdid it at work, and she came in and asked if it was all in my head.” Another parent-child dyad described a passenger during an airplane trip refusing to move seats, “We told him, ‘Hey, I have a chronic illness, can you please let me sit with her.’ And he said, ‘She looks fine to me.’” Obtaining disability

benefits or supplemental security income (SSI) was also a challenging process, and one of the three participants who had applied was denied. The others reported a long battle of proving disability status.

As one emerging adult reported, “They just don’t believe you.” Social invisibility of POTS-related impairment seemed to provoke blaming and denial responses that were not supportive of emerging adults with POTS and their families instead of empathy, informed care and appropriate accommodation generally afforded better-recognized illness experiences. One mother stated, “They see a healthy-looking young person, and they don’t understand the limitations they have.” Emerging adults interviewed tended to express lingering fears that others perceive them as lazy, faking or malingering rather than chronically ill. As one emerging adult expressed, “It’s really frustrating when you have something that so severely impacts your life, but because it’s not as heard of as most conditions, people just kind of, they just don’t believe you.” When asked what they would like others to know about living with POTS, several participants articulated wishes for social acceptance of the fluidity of disability experience with their day-to-day fluctuation of symptoms.

One emerging adult recalled her mother’s persistence in advocacy to access appropriate medical diagnostic assessment and support, “My mom just kept pushing and pushing and pushing.” Parents described strong advocacy measures to win school accommodations and doctors’ acknowledgement of their child’s illness, a process that sometimes led to parent-provider conflict and the parent also being mislabeled. One parent described her doctor finally conducting the tilt table test to confirm her daughter’s POTS diagnosis, “He did that grudgingly, and in the diagnosis, he wrote ‘hovering

mother.”” At home with loved ones, POTS was paradoxically omnipresent and overlooked, as one emerging adult described, “Because sometimes it’s difficult for her and other people to remember that I am sick. [sigh] It’s also kind of taken over a bit, I guess. It’s hard to ignore at the same time that it’s easy to forget it.” Emerging adults with POTS often did not appear chronically ill to others.

Subtheme four: Social life. “It’s hard to make new friends,” one emerging adult explained. Emerging adults and parents reported changes in their social lives due to POTS. It was difficult to explain, understand, or adjust to POTS within friendships. Most participants reported losses in friendships and community belonging during the family’s adaptation to chronic illness. Several described friendship loss in terms of filtering out superficial, unaccepting or unsupportive relationships. One participant stated, “It helped me realize who my true friends are and who stood by me the whole time.” New friendships evolved, as one parent stated, “New relationships have developed around people who understand and are supportive.” For some participants, however, their narrowed social life was experienced as painfully isolating, “She lost social interaction. That’s probably distressing her more than anything else,” and, “I feel very isolated.”

One parent described, “Your world kind of shrinks with this illness.” Socializing with POTS—for both parent and emerging adult—was complicated by uncertainty of symptoms that disrupted plans and functional limitations that curtailed possible activities. Plans that landed on “bad days” were often turned down, canceled, rescheduled or went on without the emerging adult with POTS. Social stamina was limited, as one participant phrased it, “My social meter’s out, sorry!” Other emerging adults with POTS similarly

described, “Some days, I just have no energy and I can’t hang out with my friends. I can’t do stuff that a normal kid can do.” Another stated, “It drains you socially, as well as physically and emotionally. So you have a hard time feeling close with other people.” Friends who were flexible and accepting, or “those friends that stick with you” as one participant put it, were highly appreciated and valued sources of social support, although they were perceived as still not necessarily understanding POTS.

Subtheme five: Medical system frustrations. One participant summarized medical support for POTS, saying, “It’s kind of a big mess.”

Parent-child anger and conflict with unhelpful medical professionals. One emerging adult described her parents’ mounting exasperation with unhelpful medical consultations while the family was searching for answers, “They were both just beyond their threshold of patience when it came to medical professionals.” Participants expressed frustration with medical care, and for some, this was the most angering part of their illness experience. Participants also mentioned feeling frustrated with the paucity of research, effective treatment options, and understanding about how or why POTS happened. All participating dyads reported stressful encounters with doctors and other healthcare workers who were misinformed or uninformed about POTS, stating they often knew more about POTS than their doctors. Besides often finding themselves a step or two ahead of doctors, many participants felt at odds with doctors, or “up against the medical system”, and described seeking medical support in conflict terms, such as, “You really have to keep fighting until you get a diagnosis.” Although some doctors were supportive and competent, others were dismissive and unwilling to learn or collaborate.

One participant described, “A medical professional should not be part of the problem,” and another reported, “It’s not fun to be treated like not a human being.”

Diagnosis turning point. “It’s really getting a weird diagnosis for something nobody knows about and having to deal with it yourself,” one emerging adult described regarding post-diagnosis support from her doctors. Still, having a label was a step towards answers in the family’s coping with POTS. Receiving the correct diagnosis was described by most parent-child dyads as a major turning point in their family’s illness experience. One participant described pre-diagnosis years, stating, “There was a lot of frustration in my household about the fact that I wasn’t getting any diagnoses and no doctor was really figuring out what was wrong with me.” In families in which diagnosis was delayed by years, participants described very different pre-diagnosis and post-diagnosis family organization around the illness experience: one full of stressful “what if” catastrophizing thoughts; interpersonal conflict (i.e. conflict between parent-child, siblings, co-parents, family-medical provider); and confusion and the other more peaceful though still painful. Even before mapping out an effective treatment plan, one parent described the reduction of stress she experienced by having a diagnosis in hand, “I’m comfortable, at least we have a game plan now.”

Ongoing challenges with access and effective care. Parent-child dyads had many unresolved complaints regarding ongoing medical system failures and shortcomings in care. “I’m most frustrated with the medical system,” one mother reported. Participants reported problems accessing competent medical care for POTS as well as short and long-term financial burden from helpful treatments not covered by insurance. Many had fears about continuity of healthcare access as the emerging adult

ages out of family care plans, gains employment insufficient to cover the cost of living but enough to disqualify Medicaid, or becomes otherwise ineligible for current coverage. Treating POTS added variable monthly and periodic financial expenses to participants' lives. Expenses included travel for treatment, out-of-pocket treatments, treatments not covered by insurance due to being off-label or lack of research supporting their use with POTS, supplemental and complementary treatments, and cost of lifestyle to accommodate disability (e.g. bathroom modifications, service animal, compression clothing). Several participants had taken on debt to pay for costly treatments.

Managing complexity. One parent described navigating medical assessment and treatment, “So much medical complexity.” Although at the time of this study there were no prescriptions or treatments on-label for POTS (Miller & Raj, 2018), many treatments existed and were tried or currently used by participants off-label, including increased salt and fluid intake, regular exercise, beta-blockers, vasopressors, gynecological treatments to stop menstruation, strict sleep/wake schedules, compression stockings, weekly intravenous fluid infusions, and other measures. Some participants were also utilizing complementary alternative medicine (CAM), such as acupuncture. Managing the complexity of how much to take when for what symptoms was described as cognitively challenging as well as time-consuming. The financial management and advocacy measures involved in many of these complex treatment regimens were taxing as well, as participants galvanized resources such as multiple insurance plans and negotiated for coverage of off-label treatments.

Theme Three: Parent-Child Dyadic Agency over Disease

Parent and emerging adult participants described a range of expressions of agency of their disease experiences. Family gains included increased family cohesion, dyadic closeness, and development of appreciation, empathy, and personal fortitude. Participants uncovered many effective coping strategies to reduce symptoms and to emotionally overcome the stress of the disease experience. Although launching looked different from how they expected, participants described many typical developmental traits of emerging adulthood, including a feeling of becoming near-equals or friends as a parent-child dyad.

Subtheme six: Family gains. Participants described transformative experiences living with POTS, as family members shifted life perspective and worldview, come together to meet daily demands of symptom and treatment management, and grew inwardly to meet the challenges they lived.

Appreciation. Participants described family gains in response to the stressor of living with POTS, including increased appreciation of people, time together as a family, and life. Participants reported their families had learned, “Life is precious,” and, “You can’t take anything for granted.” They reported family growth in understanding, compassion and empathy not only for each other but for others living with disability.

Family cohesion. Participants described closer family bonds, especially between the emerging adult with POTS and their caregiving parents. One emerging adult described her mother, “She has become everything to me.” Participants described increased family cohesion through joint problem-solving, and feeling “there” for each other. Parent-child dyads described talking and listening more, showing more kindness

and compassion, and helping each other more. Siblings “pitched in”. One emerging adult described her younger siblings’ emotional support, “They just really caught on that I needed someone, and they were there.” As one emerging adult participant stated, “If you all just stick together, it gets better.”

Strength and compassion. Personal fortitude was another gain recurrently expressed by both emerging adult and parent participants. One parent stated, “The mental and emotional fortitude to cope with this illness is a learned skillset for sure.” An emerging adult described feeling confident that she was able to cope with and problem-solve around other major life challenges her family encountered because of the maturity she had gained from surmounting her POTS symptoms every day, explaining, POTS “made me strong.”

Subtheme Seven: Coping. One parent summed up the evolved coping stance she and her daughter used, stating, “What can your new self do?”

Coping together. Participants described effective coping strategies to reduce stress related to living with chronic illness and to reduce symptoms of POTS. Dyads reported joint and individual stress management and coping around POTS, both problem-focused and emotion-focused, with associated gains in family cohesion and reduced mental health strain. One participant described their parent-child dyadic coping, saying, “A lot of hugging. A lot of just saying that everything’s going to be okay. Very reassuring.” Another emerging adult described her family’s flexibility in adapting to her limitations in daily living together, “They help compromise every situation with me.” One parent described her approach to emotionally easing her child’s homebound lifestyle, saying, “It requires some effort and planning and space and love from my part, so she

doesn't just get so angry that she can't deal or withdraw. To help her help herself keep going." Her daughter stated, "My mom gives me courage."

Learning the disease as coping. Several participants described an about two-year-long adjustment process, in which they became familiar with physical limitations and learned effective coping strategies through trial and error, online research, medical support, and networking within the POTS community. In-group social support from others with POTS was particularly valued by participants. One participant stated, "It's really inspiring to see someone who just keeps pushing. And it makes me feel like I can, too." Complexity of living with POTS was described by one participant, "It's taken ten years to learn what really makes a difference and what's more hurtful for me to do, physically or emotionally, for living with this." Symptom-reducing strategies included compression socks, wheelchairs, motorized scooters, body awareness, hydration diligence, and maintaining a strict schedule in regard to sleep/wake, meals, and exercise.

Dyadic resilience. Dyads reported resilient emotional coping strategies, such as optimism, "I hope for the best," and perseverance, "Sometimes you'll take two steps back and sometimes you'll take three steps forward. But you just got to keep on walking, no matter what life deals you." Other emotional coping strategies included taking time to grieve losses, talking with friends, focusing on the present to reduce stress over uncertainty, not comparing oneself now to pre-illness abilities or peers who are not coping with chronic illness, giving oneself a break and being easy on oneself, pivoting with symptom fluctuation in a flexible manner as a family, and taking things one day at a time.

Coping with high uncertainty. As one emerging adult described learning to accept and be flexible with fluctuating symptoms, “Be flexible and go with what my body tells me.” Participants coped with very high uncertainty. Acceptance was an ongoing, dynamic process complicated by uncertainty factors. Fluctuation of symptoms and unknowable prognosis contributed to participants’ experience of high uncertainty living with POTS. One parent described, “The illness is so unstable. One little thing can tip it one way or another.” Another parent stated, “Everything is a balancing act. And it’s like the whole household is sitting on that teeter-totter, trying to see where you’re at for the day.” Participants described the impact of illness uncertainty on relationships, work, and long-term plans (e.g. loss of friendships, difficulty making new friends, narrowed work opportunities and having to quit jobs even with flexible employers, and unreliable long-term planning). As one parent commented, “Plans are more suggestions than reality.” To cope with the stress of high uncertainty, participants developed flexibility and acceptance around fluctuating limitations and abilities. “Take each day as it is,” one participant described. Another participant described, “Not having expectations when you wake up in the morning, and accepting how the day is going to be.” Emerging adults learned a fine tuned body awareness to be able to take reasonable risks and engage in activities without provoking flare-ups, “I just have to be flexible and go with what my body tells me.” Their somatic vigilance was linked to self-soothing and self-care, “What works for me, listen to my body as much as I can for what activities I can feel and when to stop. ... Whatever’s going to happen is going to happen, and I’ll deal with it and find out something new about myself.”

Confronting ableism, producerism, and meritocracy myths. Living with chronic illness and invisible disability illustrated the fallacies of certain dominant oppressive social narratives. “People don’t want to hear that you’re sick,” one emerging adult described. Some participants described grappling with social stigmatization around disability and illness, including meritocracy myths, producer-consumerism, and social pressure to be or appear recovered. One parent participant described feeling isolated in coping with POTS as a socially stigmatized stressor, stating, “The general public doesn’t deal with disability very well. And so when you are in a family with disability, you’re kind of on your own.” An emerging adult participant described ongoing sadness from limitations on work and associated stigmatization, “Sometimes I do feel like a leech because I’m not working as much as I would like to be.” All emerging adult participants expressed a yearning to socially contribute meaningfully by some form of “helping others”. One participant expressed feeling social messages, “Like if I don’t get better, I will have failed.” They were frustrated by social messages, such as, “You hear all the time, ‘If you work hard, you can accomplish your dreams and goals.’” Yet no matter how hard they worked, certain life goals were out of reach due to incapacitating symptoms of fatigue, dizziness, nausea, and difficulty concentrating. Another participant articulated her shift in mindset replacing the social myth “You can do anything you put your mind to,” with a more realistic and self-accepting, “I can do anything I can do.” She described coping with oppressive social messages of meritocracy myths by revising her beliefs, “You have to modify everything and change your beliefs about a lot of things.” Dyads learned not only self-acceptance but advocacy to cope with their illness experience.

Subtheme eight: Developmental gains. One parent described her attunement with her child's needs and her child's leadership of directing care, stating, "I just try to play along with first cello."

Old beyond their years. Although most dyads described increased parental involvement in healthcare and financial support as compared to their expectations of emerging adulthood without health problems, they expressed many salient themes of successful development. In fact, parents described emerging adults as old beyond their years, and emerging adults reported feeling more mature than peers, such as, "I've definitely grown up fast because I had to learn how to manage this by myself." Sometimes this maturation was ascribed negative aging terms, such as needing "modifications best suited to the elderly," and "I feel like I'm 80 years old sometimes." Emerging adults utilized appropriate assistance from parents and others but most often occupied decision-making roles and followed up their own well-disciplined self-care. Parents described parallel processes of learning to let go and trust their child, such as, "I had to step back and leave it up to her." Another parent described medical caregiving at this stage of their child's life, "We walk beside her, not in front of her."

Comparisons to typical emerging adulthood themes. Parent-child dyads expressed typical emerging adulthood themes of becoming near-equals, but with some added closeness and adaptive child dependencies. Several emerging adults echoed the statement, "The biggest thing is learning how to ask for help," and struggling with their independent personalities and interdependency care needs of POTS. Typical to psychological trends of emerging adulthood and in spite of uncertain prognosis and sometimes worsening course of illness, participants expressed persistent hope in their

futures. Although they also expressed fear and uncertainty in regard to their future physical ability and health, many articulated adaptations of their pre-illness aspirations for their futures. They believed they would accomplish their dreams somehow, in part, or on a slowed timeline, showing resilient integration of anticipatory loss and reasonable hope. Due to slowed pace of work/study and economic barriers of disablement as well as complexity of medical care, many dyads also reported feeling “in limbo” and unable to move fully into adulthood and independence from parental help. Though feeling in-between childhood and adulthood is again a typical theme of emerging adulthood, medical complexity was involved for these dyads. The central theme of emerging adulthood that was not confirmed in this study for participants was Instability. They coped with illness and symptom uncertainty partly by rigidity of scheduling and more closed social networking and therefore did not tend to move from place to place or relationship to relationship as typically occurs in exploration of identities during emerging adulthood.

Sex and romantic partnership. As one emerging adult expressed, “Sex is a big thing.” Romantic pairing was impacted by POTS in significant ways. All participants reported fewer emerging adult romantic and sexual experiences. Many reported low libido or no desire, ambiguity about their orientation associated with absent arousal, and problems engaging in sexual activity with their romantic partner due to symptoms like fatigue and pain. None of the emerging adult participants had children or had tried to conceive. One emerging adult commented, “I don’t plan on ever having kids.” Emerging adult participants in this study who were coupled described coming to terms with their unique balance of give-and-take within their intimate partnership. One

described adapting through adjustment of expectations, “Having the right expectations is really important. And having a good partner that understands that you, it’s not always going to be 50/50, especially with us because that’s just not realistic.” Single participants expressed trepidation about finding a partner who could understand and adjust to POTS. They also expressed fears related to incorporating physical intimacy into the medical complexity of their self-care. “I don’t even know what physical stuff I could do,” one participant stated. Another, who was partnered, described, “Sometimes I’m in so much pain, I can’t be touched.” One participant commented, “It’s hard to find someone that’s understanding enough... It’s not just one accommodation, it’s like 20.” However, two of the seven participating emerging adults were in stable romantic relationships and reported that their partners were extremely understanding and provided emotional and instrumental support. The emerging adults and their parents expressed appreciation for these understanding and supportive long-term romantic partners.

Essence of the Shared Lived Parent-Child Dyadic Experience Launching with POTS

In summary, participants described a pervasive impact of POTS on their lives. Participants described loss and adaptation in response to the stressor of POTS. They described frustration with insufficiencies in the medical care system: providers who were not informed about POTS, lack of research and effective treatment options, and mislabels ascribed by doctors. All the participating emerging adults were talented individuals whose families valued achievement. School, work, love and friendship were constricted for these young people, and their parents grieved their losses with them. Daily discomfort of chronic pain, nausea and fatigue reduced emerging adults’ quality of life

and worried and saddened parents. Parents also expressed pride in their children's perseverance and joy in their children's triumphs, emphasizing the importance of celebrating their child's life. Emerging adults described feeling more mature than peers due to the learning process associated with managing medical issues.

Uncertainty created by fluctuating symptoms and unknowable prognosis added stress to the illness experience of launching with POTS. Invisibility of limitations and appearing "normal" and "healthy" to others contributed to conflict, blame, and denial of appropriate accommodations. Parents and emerging adults reported reduced work hours and productivity as a result of POTS symptoms and caregiving. Cost of POTS treatment, lifestyle adaptations, and complementary alternative medicine imposed a hefty financial burden to both parents and emerging adults. Mental health strain of living with these narrowed horizons and daily symptoms may have contributed to emerging adult experiences of self-reported anxiety, depression, and obsessive-compulsive disorder. Nearly half of the participating emerging adults reported self-harming behaviors and suicidal ideation. The most common mental health experience was anxiety, which six of the seven emerging adults self-reported was a problem in their lives or was currently managed by psychotropic medication.

Participants also reported individual and family gains as a result of their illness experience. Parents and emerging adults reported feeling closer to each other, and most reported increased closeness as a family. Family cohesion was expressed through joint problem solving, emotional support, and feeling "there" for each other. Participants also reported gaining understanding and empathy about disability, particularly invisible disability. Many articulated feeling stronger and viewed their family members as having

grown characterologically because of the family's experience living with chronic illness. Participants described many effective coping strategies that helped to reduce stress and POTS symptoms. Many described developing advocacy skills and evolved worldviews in confronting social stigma, social exclusion, and societal myths related to disability.

CHAPTER V: DISCUSSION

This is the first qualitative study to explore parent-child dyadic experiences launching with a chronic illness called Postural Orthostatic Tachycardia Syndrome (POTS). A strengths-based medical family therapy model (MedFT), namely family systems-illness (FSI) developed by Rolland (2018), and Arnett's (2014) developmental description of emerging adulthood were utilized as theoretical frameworks. Data analysis of in-depth interviews using Moustakas's transcendental phenomenology produced a rich description of the shared lived experience of seven parent-child dyads with emerging adults age 18-27 living with severe POTS. Mild and moderate POTS were not represented in the self-selected sample.

Invisibility of illness and disability, uncertainty about daily and long-term future health, and narrowed social and vocational horizons were powerful psychosocial features of the illness. The illness was a source of grief for the emerging adults and their parents, but learning to live with the stressor was a source of family closeness, appreciation for life and relationships, personal strength, and empathy for others. While emerging adults generally had more financial and medical dependence on parents compared to their expectations of the launching stage of the family life cycle, both emerging adults and their parents generally viewed the emerging adults as more mature than their peers as a result of managing the medical complexity and stringent self-care demands of the

disease. Of the many complex POTS symptoms experienced, fatigue, nausea and vomiting, and dizziness and fainting/pre-fainting interfered with daily functioning at work/school, home and in social life. Parental trust in the emerging adult and emerging adult body awareness were important adaptations that helped families work around symptom-related impairment. Social experiences living with POTS in the world involved frustrations with the medical system, confrontations with meritocracy myths, and adjustment to disability identity and minority status.

Much of this study's findings reflect previous research on POTS and extend our understanding of the disorder by richly describing the daily life, developmental challenges, and family dynamics of living with severe POTS. While previous literature on POTS documented a medical catalogue of symptoms (Bhatia et al., 2016; Blishtyen, 2015; Grubb et al., 2005; Johnson et al., 2010; Miglis & Barwick, 2018; Rea et al., 2017; Vykoupil, 2016), this study more specifically explored how symptoms impacted participants' lives. Of the many complex POTS symptoms experienced, fatigue, nausea and vomiting, and dizziness and fainting/pre-fainting interfered with daily functioning at work/school, home and in social life.

Our findings are consistent with previous documentation of significant parental involvement in medical care of young adults with POTS (Boris, 2018; Cutitta et al., 2017; Kizilbash et al., 2014; Stiles et al., 2018; Vykoupil, 2015). This study also contributed more detailed exploration of parent-child dynamics in coping. For example, parental trust in the emerging adult and emerging adult body awareness were important adaptations that helped families work around symptom-related impairment. Furthermore, our findings extend the conversation to the role of romantic partners, for those with

POTS who were living apart from parents. Previous literature on POTS documented its often invisible status (Boris, 2018; Dahan et al., 2016; Kizilbash et al., 2014; Mohr, 2017; Stiles et al., 2018; Urich & Hartung, 2015). Results of this study confirm and highlight the impact of invisibility of POTS in delayed diagnosis and care, social responses and accommodations, and psychological processes related to acceptance and coping with disability and chronic illness. As with all other research on POTS to date, this study indicates that there are many unanswered questions and a need for further investigation of the disorder (Bylarly, Phillips, Fu, Vernino, & Levine, 2020; Fedorowski, 2019; Miller & Doherty, 2019; Tao et al., 2019).

Our findings echo broader literature on parent-child dyadic experiences of chronic illness at emerging adulthood (Capelle et al., 2016; Heath et al., 2017; Weingarten & Worthen, 2017; Wiebe et al., 2018; Young et al., 2010); family experiences of serious illness and disability in general (McDaniel et al., 2014; Rolland, 2018); and launching differences among emerging adults with serious chronic illness in regard to love, work, and personal growth (Beatty, 2011; Thompson et al., 2009; Waldboth et al., 2016; Yi et al., 2017). Participants utilized creative problem solving strategies to accommodate symptoms and care needs while moving forward with family members' individual development and preserving family relationships, as proposed by Capelle et al. (2016) and Young et al. (2010). For example, one of the emerging adult participants was a top-ranking competitive swimmer before she became ill with POTS. Although she was told by doctors that competitive swimming was not a sport she should continue with POTS, she and her parents found ways to ensure her safety and continue her passion by attending the meets, reducing practice hours, shortening her distances, and having a

“catcher” present to help her get out of the pool without hitting her head if she fainted after the race. With these accommodations, she broke 9 of 11 school records and won a swim scholarship.

In regard to financial independence, our results confirm previous literature on disability and chronic illness at emerging adulthood that document challenges in employment-setting disablement (Beatty, 2011) and describe processes of learning to utilize support effectively rather than moving away from support systems to achieve independence (Heath et al., 2017; Waldboth et al., 2016; Wiebe et al., 2018). While emerging adults generally had more financial and medical dependence on parents compared to their expectations of the launching stage of the family life cycle, both emerging adults and their parents generally viewed them as more mature than their peers as a result of managing medical complexity and stringent self-care demands of the disease, developmental gains confirming Yi et al.’s (2017) conceptualization of endowments of survivorhood among emerging adults with chronic illness. In social life, participants described activity constrictions, interpersonal challenges, and obstacles of stigma in friendship, romance, and some family relationships, adding a richer picture and more complete description of the impact on family dynamics and other family members to previous literature documenting challenges in romantic pairing among emerging adults living with chronic illness and disability (Addlakha et al., 2017; Brown & McCann, 2019; Shakespeare & Richardson, 2019; Thompson et al., 2009; Waldboth et al., 2016).

Shared emotional themes in medical family therapy related to dialectics of denial/acceptance, anger/peace, despair/hope, guilt/forgiveness, burden/relief, fear/courage, loss/renewal, senselessness/meaning and coping approaches of

secrecy/sharing, isolation/connection, and passivity/taking charge (McDaniel et al., 2014) were relevant to participant experiences of living with POTS during launching. For example, dyads in this study expressed both fear and courage in coping with daily health challenges and unknowns of POTS. One emerging adult described her and her parents' differences in coping with secrecy/sharing, as her parents wanted to enter into public advocacy while she preferred not to think more than necessary about the disease and not to tell others about her illness experience. Parent-child dyads also described grappling with guilt/forgiveness dialectics, for example around risks emerging adults took to take on more activity that resulted in debilitating relapse or around emerging adult's experience of parental caregiving limitations and failures early in identification, diagnosis and adjustment stages.

Arnett's (2014) conceptualizations of emerging adulthood proved a useful lens. Arnett's (2014) observation that emerging adults generally have an unrealistically high hope in their future may provide some protective factors for emerging adults with POTS coping with uncertainty of future health, as optimism is linked to better medical outcomes in chronically ill youth (Taylor, Kemery, Reed, Bower, & Gruenwald, 2000). The generalization that emerging adults tolerate a high level of instability from moving place to place, job to job, and relationship to relationship as they explore possible life paths (Arnett, 2014) may also provide a protective factor for emerging adults coping with POTS, who inherently experience high levels of uncertainty and must tolerate loss and adaptation processes related to physical impairment. Integrating Arnett's developmental description of emerging adulthood with Rolland's family systems-illness model produced useful insights and perspectives into the family processes of members' growth and family

re-organization while coping with severe POTS. Utilizing Rolland's family systems-illness model as a theoretical lens for exploring participants experience of POTS during launching was fruitful and produced several important clinical implications discussed in detail below.

Clinical Implications

This study's findings contribute exploration of a specific illness experience (i.e. severe POTS) at a specific stage in family life cycle (i.e. launching). Our results are congruent with wider literature on family systems perspectives regarding the impact of serious chronic illness in a family (Cipolletta, Marchesin, & Benini, 2015; Landry et al., 2015; Popp, Robinson, Britner, & Blank, 2014; Rolland, 2018; Wallace, McCracken, Weiss, & Harbeck-Webber, 2015). Central medical family therapy principles highlighted by Rolland's (2018) family systems-illness (FSI) model were indicated in the shared lived illness experience of parent-child dyads in this study, including: a) stressfulness of high uncertainty in illness; b) family processes related to invisibility of illness (i.e. denial, minimization, rumination, catastrophizing, conflict, and power imbalances); c) medical management demands of highly complex treatment regimen; d) family resilience processes of flexibility, connectedness, and resource activation; e) the power of consultant labels; f) anticipatory loss related to career dreams, relationships, and independent adult life; and g) the influence of larger system values on family beliefs about their illness experience. Rolland's (2018) description of disease characteristics that impact psychosocial experience of illness, adjustment to chronicity, and the role of life cycle stage would be useful constructs in family therapy with persons with POTS. Expanded below are some aspects of medical family therapy (MedFT) and marriage and

family therapy (MFT) that stood out in this study's data as particularly relevant to working with persons with severe POTS at emerging adulthood (i.e. the launching stage of the family life cycle).

Dyadic clinical implications. Clinical implications related to parent-child dyadic experience included: anticipatory loss, somatic vigilance, consultant labels, and social adjustment to disability.

Anticipatory loss. One of the most poignant themes that arose from interviews was grief and adjustment to anticipatory loss, which can be defined as “living with possible, probable, or inevitable future loss in the context of illness and disability” (Rolland, 2018, p.159). As one participant articulated, “Thinking about the future is the hardest thing to deal with. I don't know what I'll be able to do.” Life cycle stage was an important facet of participants' experience of anticipatory loss. Their descriptions of living with severe POTS during launching and emerging adulthood mirrored Rolland's words, “Untimely conditions that occur early in the life cycle come with additional pressures to keep up with socially expected developmental milestones of age peers. Life goals may take longer to achieve or need revision” (2018, pp. 132-133). In fact, participants described coping with caregiving during emerging adulthood and functional losses partly by giving up social comparisons and comparisons to pre-illness abilities. Accepting the quality of life issues associated with severe chronic illness and functional impairment were summarized by one parent who stated, “It's a modified life. But it's a still a life nonetheless.”

Emerging adults had revised their life goals yet expressed hope to one day, “somehow” fulfill “part” of their pre-illness dreams. Slowed pace through part-time

study and part-time work was an important coping strategy described in this study. For some, whose POTS symptoms were severe and unrelenting, the process of constructing dreams started with eliminated choices with illness-related restrictions and then looked to what options might be possible, a complete re-authoring. Parents and emerging adults collaboratively enacted what Rolland (2018) describes in resilient coping with anticipatory loss in the context of long-range risks, “Family and individual members’ life-cycle planning that conserves and adjusts major goals” (p. 160). Parents indicated that their own long-term financial plans, plans for retirement, and living arrangements were under revision alongside their emerging adult child’s career and life plans.

Family therapists working with families living with POTS during emerging adulthood can play an important role in supporting family resilience and activating protective factors related to anticipatory loss (Rolland, 2018). This study’s findings reinforce previous literature on family strengths and resilience in adjusting to serious chronic illness and disability, such as the vital role of reasonable hope (Cheavans, Michael, & Snyder; Weingarten, 2010), and the adaptive role of positive illusion and balancing humor and minimization with acceptance processes (Rolland, 2018; Taylor, Kemery, Reed, Bower, & Gruenwald, 2000). Findings of this study support family resilience theories identification of flexibility, connection, acceptance, hope and resource activation toward positive outcomes in family functioning, healing and growth in the context of the stressor of chronic illness and disability (Hartshorne, Shcafer, Stratton, & Nacarato, 2013; Rolland, 2018; Shapiro, 2013; Yi et al., 2017).

Somatic vigilance. One coping strategy that was utilized by participants to reduce POTS symptoms was somatic vigilance. Emerging adults learned a fine-tuned

body awareness to be able to take reasonable risks and engage in activities without provoking flare-ups. This finding differed from previous studies documenting somatic vigilance in persons with POTS. Benrud-Larson et al. (2003) hypothesized that somatic vigilance resulted in catastrophizing, depressive symptoms, and state anxiety that increased functional disability in people with POTS. Vykoupil (2016) described the role of somatic hypervigilance in misappraisals of physical limitations leading to POTS through deconditioning. Our study's participants, on the other hand, appeared to utilize body awareness as an important coping strategy to increasing functionality living with POTS by reducing incidents of flare-up and relapse. Their somatic vigilance and body awareness did not seem linked to cognitive distortions of catastrophizing but to self-soothing and self-care. Other family members similarly monitored symptoms and offered helpful verbal feedback to the emerging adult regarding "pushing" beyond limits. One participant with a service dog found the dog's alert behaviors important feedback that enabled her to engage in activities without fainting or provoking days of bedridden fatigue. Participants and their family members developed heightened attention to symptoms and adherence to limitations through costly trial and error experiences, in which too much physical activity resulted in the emerging adult with POTS spending several days in bed or in hospitalizations with markedly increased symptoms. Somatic vigilance, in this study, appeared to be adaptive—an appropriate coping strategy. McGrady and Moss (2018) stated, "Self-awareness, monitoring, and self-regulation are important, and it is fair to say even critical components to management of chronic cardiovascular disorders" (p. 196). This study's findings related to self-awareness expand McGrady's and Moss's (2018) description of adaptive self-awareness coping strategies

among cardiovascular patients in general to details specific to POTS and the potentially helpful role of feedback from family systems. Marriage and family therapists working with families with POTS who engage in body awareness and somatic vigilance can help validate families' experiences without pathologization of this coping strategy, thoughtfully differentiating it in their assessment from catastrophic cognitive distortions or secondary gain of family member attentive caretaking that may sometimes also occur. Because of the historical mislabeling of the POTS community, explicitly recognizing the physical symptoms at play in somatic vigilance may be helpful to the therapeutic alliance and family's feelings of being understood, believed, and supported by their therapist.

Consultant labels. Rolland (2018) identified medical professional consultations as impactful for family's story of their illness experience, stating consultations were, "Powerful 'framing event' that determines whether families create affirming or destructive narratives" (p.77). Tao et al. (2019) noted that earlier accurate diagnosis and treatment initiation led to better long-term outcomes for POTS prognosis. In this study, misdiagnoses and mislabels given to emerging adults with POTS and their parents were indeed impactful, both psychosocially and apparently medically. Health provider mislabels delayed treatment and incited conflict, which either played out between family members or between families and the medical care system. Receiving the correct diagnosis, on the other hand, was described by most parent-child dyads as a major turning point in their family's illness experience. Family experiences tended to organize around the consultants' labels. Rolland's (2018) articulation of structural dynamics in the therapeutic triangles of chronic conditions (p.52), which highlights the relationship and powerful position of medical health care professionals, would be a useful clinical concept

in family therapy with persons with POTS. It may be timely to schedule family therapy sessions in conjunction or close proximity with medical consultation events to process family reactions in a productive manner and empower the family's agency in medical healthcare. While it would be erroneous to assume that all families of individuals with POTS have encountered negative experiences with unsupportive medical professionals, it may be helpful for family therapists to be aware of the potential power of medical consultations, frequency of misinformation and misdiagnosis around POTS, and further that members of the family may have different perspectives and understandings of the illness based on inconsistent information from medical professionals. Family therapists working with families impacted by mislabeling and poor quality of care for POTS may have an opportunity to aid in healing and repair through corrective emotional experiences of appropriate support, validation, and empowerment of families.

Social adjustment to invisible disability. This study uncovered many aspects of living with invisible disability and adjustment to chronic illness and functional impairment that support previous literature in disability research. Disablement has been described as a complex interaction between bodies, environment, and social structures (Grue, 2015). In learning to cope with invisible symptoms, participants in this study encountered social stigmatization and perceptions that they were “lazy”, “faking”, “stressed” or “needed attention”. Participants confronted societal meritocracy myths that personal success is formulated on strong work ethic with presumptions of ability and no need for accommodations. They found it difficult to describe POTS and stated, “People can’t understand.” Emerging adults’ illness experience was often met by withdrawal and abandonment by friends and even some family members, a confusing and painful social

change, although participants reported it worked like a filter for “true friends”. It has been theorized that stigma and social rejection of people with disabilities, in its psychological roots, is a fear reaction to death, which is generally no surprise to people with disabilities; yet these fears may be assuaged and decoupled from the person by information and open communication (Hasson-Ohayon, Hertz, Vilchinsky, & Kravetz, 2014). Garland Thomson (1997) stated, “Disabled people must use charm, intimidation, ardor, deference, humor, or entertainment to relieve nondisabled people of their discomfort. Those of us with disabilities are supplicants and minstrels, striving to create valued representations of ourselves in our relations with the nondisabled majority. This is precisely what many newly disabled people can neither do nor accept: it is a subtle part of adjustment and often the most difficult” (p.13). Exploring minority identity issues as a person with invisible disability may be salient in family therapy with individuals with severe POTS. In family therapy, it may be helpful to externalize the illness and deconstruct de-humanizing dominant social narratives that reinforce blame/shame experiences in parent-child dyads living with chronic illness and disability like POTS.

Parent clinical implications. Other clinical implications of this study’s findings related to parental experience centered on processes of letting go and negotiating changing boundaries of parental authority or caretaking and emerging adult autonomy.

Parental “letting go” processes. Previous studies of POTS and other chronic illness experiences documented parental processes of “letting go” of control and care of emerging adults with disability (Boris, 2018; Heath et al., 2017). This study supports previous findings and extends exploration of the parental internal conflict between acknowledging and supporting their adult child’s autonomous development while

ensuring their physical wellbeing in the context of high stakes healthcare and medical complexity. Our findings further indicate a collaborative process of the emerging adult child and the parent working through daily fluctuations of needs for help versus needs for independence. Emerging adults and parents with the severest symptoms and most need for caregiving in this study expressed awareness about the delicacy of their predicament, such as, “We grapple with that every day... the issue of respect,” and, “Learning to listen when I am saying I need help or a don’t need help, really listening and not overstepping that but also giving enough help.” This study reinforced emerging adults with chronic illness learning to maneuver dependency toward a revised independence, or as Joly (2015) previously described, a “paradox of independence” (p. 98). Some parents seemed to struggle more with “letting go” than others. They self-reported tending in general to perform more controlling behaviors, not only as parents but as a way of functioning in life. As previously recommended by Boris (2018), this study’s findings indicate a potentially helpful role of family therapy in facilitating parent-child dyadic adjustment during this stressful family life cycle stage transition with POTS. Validation of the realities of high stakes health consequences alongside the realities of emerging adults’ needs for agency in their healthcare and lives in general may be helpful in work with parents who find it difficult to step back and allow their emerging adult child with POTS to gain experience through trial and error and experimentation with autonomy and independence. Recognition of the parents’ emotional needs during the process of launching, and the meanings of letting go and moving through developmental transitions in their own lives, would be helpful in work with parents who are launching in a context of chronic illness.

Emerging adult clinical implications. Clinical implications related to the emerging adult's individual wellbeing and development included sexual wellbeing, romantic partnership, and mental health issues.

Sexual wellbeing. Illness-related challenges in romance and sexuality were a significant finding in this study. Sex therapy sensitive to issues of chronic illness and disability may be indicated in couples living with the chronic pain, fatigue, and daily drain of POTS. As Mona, Cameron, and Cordes (2017) urged clinicians, "Discussion of disability culturally affirmative practice inclusive of sexual well-being can be conceptualized as directed by ethical standards and facilitated through culturally relevant knowledge and skills" (p.1001). The psychosocial and physical realities of sexuality with disability may be important clinical considerations in working with individuals with severe POTS or similar chronic illness and disability. Therapists can serve an essential role in the conversation of disability and sexuality to empower clients toward more fulfilling sexual wellbeing and increased access to what all couples want: love and intimacy.

Sexual wellbeing, sexual agency and citizenship, and sexual self-esteem of persons with chronic illness and disability are important issues to consider (Gallop, 2019; Grue, 2015). Loeser, Pini, & Crowley (2018) pointed out that genito-centric language can be experienced as invalidating by persons with disability. A sex therapist working with people with POTS might do well to start with desire, pleasure, satisfaction and tread carefully on biological terms related to sexual performance or response cycle. A performative approach, free from essentialist focus on biology or normativity may be helpful in sex therapy with individuals with unique physiology (Ruiz, 2017). Kaufman

Silverberg, and Odette (2007) advised creativity, open communication, and a spirit of humor and invention can help persons with functional limitations and their partners overcome trepidations and find meaningful and satisfying ways of engaging with sexuality.

In addition to sex therapy, clinicians working with persons with POTS might encourage them to open conversations with their doctors regarding sexuality, to explore medication side-effects that may be impacting their sexual health and investigate treatments to aid sexual functioning. Unfortunately, conversations about sexual health are seldom initiated by healthcare professionals. Furthermore, women with disabilities are particularly underserved in the medical care system in areas of sexuality, partly due to societal fears, stereotypes and stigmatization related to childbearing and motherhood for women with disabilities (Addlakha et al., 2017). One source reported, “It is common for both healthcare providers and rehabilitation professionals to ignore issues of sexuality for women with disabilities” (*A Woman’s*, 2003, p.17). Psychotherapists should have a general idea of medical options for their clients, as many doctors may be unaware of available treatments for sexual functioning; clients can be encouraged to take a proactive role in their sexual health (Rolland, 2018).

Romantic partnership. Arnett (2014) described, “Emerging adults believe they *should* explore different love relationships” (p.84). In this study, several participants were dubious about finding an accepting romantic partner. This perception of constricted opportunity supports other research on romantic partnerships and social stigma (Shakespeare & Richardson, 2019; Thompson et al., 2009; Waldboth et al., 2016; Weingarten & Worthen, 2017). The most common impediment to sexual opportunity for

persons with disability is not functional impairment but social stigmatization (Shakespeare & Richardson, 2019). Not only are sex and sexuality made more complex by social processes of disablement, but by extension intimacy, friendship, and the emotional and instrumental social supports of romantic partnership are likewise curtailed (Addlakha et al., 2017; Brown & McCann, 2019). Indeed, Tepper (2000) noted seminal disability movement scholars summarizing exclusionary sexual culture as, “a source of our deepest oppression and our deepest pain” (p.284).

This study uncovered experiences of sexual orientation ambiguity, possible asexuality, as well as experiences of choosing to withdraw from romantic life due to its toll on health. This finding supports other research on sexuality in populations with chronic illness (Lund & Johnson, 2015). Societal asexuality myths and de-sexualization of people with disabilities through tragedy metaphors and infantilizing images generally represent oppressive stereotypes unfounded in local knowledge of how people with disabilities describe their sexuality and emanating instead from ableist stigmatization of disabled bodies, making them “undesiring and undesirable” (Loeser et al., 2018, p.256). However, some individuals with disability do identify as asexual or have decided that sex or romantic relationships are not for them, not worth the effort or risk, not high on their list of needs; this should be honored and acknowledged, not pathologized or challenged, by marriage and family therapists working with individuals with chronic illness or disability (Shakespeare & Richardson, 2019; Lund & Johnson, 2015).

Mental health. This study reinforces previous research indicating a somewhat heightened risk of mental health strain in populations living with serious chronic illness and disability in general (Shaw et al., 2019) and POTS in specific (Anderson et al., 2014;

Bruce et al., 2016; Junghans-Rutelonis, Postier, Warmuth, Schwantes, & Weiss, 2019). Findings echo recommendations that counselors consider, “personal adjustment to disability, developmental tasks, career aspirations and transitions, cultural identity, advocacy skills, and quality of life” (Woo, Goo, & Lee, 2016, p.229) as well as pain management (Cook & Sandroni, 2018; Junghans-Rutelonis et al., 2019; Keating et al., 2017). Because of study design limitations, it is not clear to what extent POTS illness experience impacted mental health of emerging adult or parent participants. This study supports a growing body of research on POTS indicating that mental health services, and particularly family therapy, may be helpful to reduce anxiety and depression, support healthy psychosocial adjustment, activate protective factors, support resilience, and reduce the emotional burden of POTS symptoms (Bruce et al., 2016a; Bruce et al., 2016b; Keating et al., 2017; Kizilbash et al., 2014; Kluck et al., 2017; McGrady & McGinnis, 2007; Ralston & Kanzler, 2016; Strassheim, Welford, Ballantine, & Newton, 2018). All seven emerging adults with POTS reported at least one form of mental health condition, most commonly anxiety.

Previous studies on POTS and anxiety showed that individuals with POTS may experience higher levels of anxiety due to the symptoms of POTS, interactions between POTS and anxiety through autonomic nervous system and other pathways, and/or shared predisposition factors (McGrady & McGinnis, 2007; Owens et al., 2017; Owens, Low, Critchley, & Mathias, 2018). One study separated somatic anxiety measures, which overlap significantly with POTS symptoms, and cognitive anxiety measures and found that POTS patients did not have higher prevalence of anxiety on cognitive measures compared to healthy controls and in fact averaged less anxiety than the general U.S.

population when somatic measures were omitted (Raj et al., 2009). POTS is often misdiagnosed as anxiety (Gunning et al., 2019; McDonald, Koshi, Busner, Kavi, & Newton, 2014; Paulson, 2014). Reducing anxiety symptoms was shown to reduce POTS symptoms of cognitive impairment (Raj et al., 2018; Ralston & Kanzler, 2016).

This study's findings raised questions about obsessive-compulsive disorder and self-harming behaviors in the POTS population, as these were surprising findings among participants. Four of seven emerging adult participants self-reported experiencing obsessive-compulsive disorder symptoms. Though this finding was surprising, it may be more related to "overachiever" identity (see study limitations) rather than a wider phenomenon. Three of seven emerging adult participants reported experiencing self-harming behavior with suicidal ideation. Parents of emerging adults in this study who had self-harmed at some point during their adjustment to living with chronic illness reported that suicidality was their most pressing and heartbreaking worry related to their child's illness. Previous studies of persons with POTS similarly uncovered high rates of suicidal ideation (Pederson & Brook, 2017). While this qualitative study found three of seven participants experienced suicidal ideation and self-harming behaviors, Pederson and Brook (2017) surveyed 705 POTS patients using a standardized psychometric to measure suicidality and found 333 scored at high risk. While self-harm and suicidality were not universally experienced by participants of this study, they posed a significant clinical finding that warrant attention among marriage and family therapists working with persons whose quality of life is severely impacted by POTS or other similar chronic illnesses. Strengthening coping strategies, social support, and improving quality of life

may be helpful in family therapy with persons with POTS who experience mental health strain.

Study Limitations

There are several critical limitations to this study. Mental health status and conditions were self-reported and it is unclear whether participants confirmed conditions based on subclinical symptoms or professional diagnosis. Self-selection resulted in significant study limitations. Because the study aimed to describe the parent-child dyadic experience, and purposeful sampling stipulated a parent participate, emerging adults who were not connected to at least one parent were excluded from the participation base. This might have skewed the sample toward dependency on parental care and support. Only one of the participating emerging adults was fully separated from her parents' care. Additionally, recovered individuals were unlikely to participate in communities of recruitment pools and therefore unlikely to be represented.

Self-selection produced several other meaningful skews in the participant representation. Similar to other studies on POTS and the diagnosed population of POTS patients in the U.S. (Johnson et al., 2010; Junghans-Rutelonis et al., 2018; Kizilbash et al., 2014; Ojha et al., 2011), the sample of parent-child dyads who participated in this study were primarily female and Caucasian. One parent identified his gender as male, and one emerging adult identified their gender as non-binary. Parents primarily occupied upper socioeconomic position (SEP) and had completed at least one college degree. Emerging adults were described as “overachievers” pre-illness. Emerging adults were experiencing severe symptoms with associated loss and adaptation processes; they shared some comorbidity as well.

Illness severity. All seven emerging adult participants were experiencing moderately severe to severe POTS symptoms and associated impairment at the time of the interview. They all described bedridden days or periods when they “can barely get out of bed.” Mild forms of POTS illness experience, estimated to represent more than half the POTS population (Bruce et al., 2016; Grubb et al., 2005), were not represented in the study. It is likely that milder symptoms, such as mild fatigue, headache and light dizziness without fainting, would impact the parent-child dyadic experience of launching and emerging adulthood differently than severe POTS symptoms. For example, while the symptoms might be less incapacitating, they might also be more invisible and difficult to understand.

“Overachiever” academic identity. All of the emerging adult participants who acquired POTS in their teens were described as highly achieving students pre-illness. Whether in sports, music, science, or history, these young people were talented, driven, and highly invested in their performance of these identities. “High achievers” or “high-performing” descriptors have been used to describe youth with POTS in other studies (Bryarly et al., 2019; Johnson et al., 2010; Kizilbash et al., 2014). One can speculate that seeing a child lose their ability in preferred identities would prompt parents to seek medical care with more urgency and persistence, contrasted with students who were not as invested in performance of such identities. Given the lengths parents had to go to obtain a diagnosis, and the invisibility of the illness, being an overachiever pre-illness might serve as a protective factor against being mislabeled or treated as malingering rather than ill. One of the participants in the study was ill her whole life, and she was in fact mislabeled and treated as though she were faking, lazy, or attention-seeking by

doctors and teachers for more than a decade before her parents met someone with POTS and recognized all the symptoms their child had been experiencing.

Comorbidity. All of the participating emerging adults were living with either confirmed or highly suspected comorbid conditions. Comorbidity is very common for POTS (Pavlik et al., 2016). This did not cause problems in identifying the essential experience of POTS partly because the interviewer and the participants were familiar with which symptoms came from which disorder. Comorbid disorders included: Ehlers-Danlos syndrome (EDS), endometriosis, fibromyalgia, gastroparesis, mast cell activation syndrome (MCAS), median arcuate ligament syndrome (MALS), migraines, neurocardiogenic syncope, osteopenia, and seizure disorder.

Future Study Directions

This study left several aspects of the shared lived experience of launching with POTS unexplored. The perspective of siblings and other family members, doctors and teachers, and romantic partners would help complete the description. Other fertile research topics were uncovered during interviews. Topics for further research include: experience of fathers of emerging adults with chronic illness, parent-child relationship reparation, sexuality differences in POTS, social justice dynamics of POTS detection and low family income, family-provider conflict, strategies to support and shorten POTS adjustment period, and general POTS research to better understand and treat the disorder.

Parent gender dynamics. Data collected for and about fathers of emerging adults with POTS was limited in this study but inspired a mixed picture potentially very different from that of mothers. The experience of fathers of young people with POTS was touched on by several participants' third-person report. One father participated in

the study. While the father self-reported experience seemed very similar to mothers' self-reported experience, the third-person reported experience bore significant differences. Many fathers were described as emotionally and instrumentally supportive and very involved in their child's life. However, while all of the mothers stayed involved in care despite emotional challenges, some of the fathers eventually withdrew. These fathers were described as having difficulty accepting the diagnosis. Social structures around gender roles and social messages around gender and emotional coping may influence the experience of fathers differently than mothers of emerging adults with POTS or other chronic illness. Different parent-child relationship dynamics may emerge as a result. Heath et al. (2017) found differences in mother versus father roles in families of emerging adults with chronic illness. How to best support fathers through the experience of an illness with no cure is an important clinical topic for further study.

Parent-child reparation. Parent-child relationship reparation during emerging adulthood was one family science research topic skimmed in this study that could become its own research direction. Arnett (2004, 2014) postulated that emerging adulthood was a time in life when parent-child relationships generally improve as adult children experience a release from parental control and gain life experience that expands their empathy and understanding for their parents' as complex individuals rather than their caretakers. Our participants' descriptions of their parent-child power struggles over health and illness and related functional limitations mirrored this growth and development pattern, with both parents and emerging adults generally reporting improved relationships during adulthood compared to adolescents. Our participants credited increased parental trust in the emerging adult and decreased "pushing" the emerging adult

as well as emerging adult increased appreciation for the parent. Emerging adults also noted having deeper conversations with their parents as something they enjoyed in their mature stage of parent-child relationship. One participant noted that growing up gave her and her parents a release from parental blame for not being able to “fix it” in regard to health problems. Increased parent-child open communication, appreciation, mutual understanding and empathy seem to make emerging adulthood an ideal window of time for relationship reparation; however, further research is needed.

Sexuality. Sexuality differences with POTS was one surprising finding that would require a different study approach to explore further. Because the autonomic nervous system is involved in both POTS and sexual response and functioning, it would be useful for a more medical perspective to explore this phenomenon of sexual orientation ambiguity and absence of desire, which some of the participants in this study found distressing and attributed to their illness experience.

Family-provider conflict. Parent-provider conflict prevention and resolution might be one medical family therapy theme to explore further within the POTS community. Several studies have documented negative experiences with the medical system among families seeking help for POTS (Mohr, 2017; Stiles et al., 2018).

Adjustment and coping. Participants described about a two-year period of adjustment to the disorder. Effective coping strategies that improving quality of life are an important factor in health and wellness in the context of chronic illness (Benedetto, 2014; Ventegodt, 2011). A recent study by Cuttita, Self, and de la Uz (2019) listed 15 helpful behavioral strategies to cope with POTS during teens. An expanded focus on coping through collaborative study methods, perhaps a focus group conducted online,

might be illuminating and helpful to the POTS community to facilitate adjustment to the complexities of symptom-reducing coping strategies as well as development of positive emotional coping strategies for parents and youth. Examining coping at the launching stage of the family life cycle, with strategies in regard to self-advocacy at the workplace and how to manage living alone and romantic partnership for example, may also be fruitful.

Etiology, mechanisms, and treatment of POTS. Participants of this study unanimously hoped for further medical research into the causes and treatments for POTS, as one emerging adult stated, “More research needs to be done. And I do wish that they would find a medication or treatment method that was actually effective.”

Conclusion

This transcendental phenomenological study described the shared lived experience of seven parent-child dyads coping with a chronic illness called Postural Orthostatic Tachycardia Syndrome (POTS) during the launching stage of the family life cycle. Three overarching themes—parent-child dyadic illness experience in daily life, in the world, and with agency over POTS—and eight subthemes emerged from in-depth interviews: a) reduced quality of life and related functional limitations, b) parents’ shared emotions, c) invisibility of POTS, d) social life changes, e) medical system frustrations, f), family gains, g) effective coping, and h) developmental dynamics. In discussing our results, we suggested that family systems-illness (FSI) model provides constructs that would be helpful in family therapy with persons with POTS.

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Appendix A: Interview Protocol

Introductory Script

Thank you very much for your time and openness to participating in this study about how parents and emerging adult children experience living with POTS during the launching stage of the family life cycle. Emerging adulthood is a time in the family life cycle when parents and their young adult child typically start looking for ways for that youth to take their place in the world, and the youth starts experimenting with personal identities and values in love, work, ideologies, and more. Hopefully your participation will help us help professionals better understand the experience of living with POTS at this stage of life. What you share might also help others who are living with similar chronic illnesses or invisible disabilities. Your participation is voluntary. Discussing your family's experiences with POTS may provoke strong emotions. Please let me know if you start to feel overwhelmed. If at any time you feel uncomfortable answering a question, you can pass on any question. Also, if you would like to end the interview at any time for any reason, please let me know and we will stop. If you feel overly tired during the interview, also please let me know. We can potentially split the interview into two appointments if that works better for health reasons. Your responses will be audio recorded, transcribed, and analyzed. Portions of your statements might be shared verbatim in the final study report, which I will distribute to you and other participants as well as potentially publish. However, your real name will not be shared with other than primary investigators of the study, that is myself and my thesis committee.

Oral Confirmation of Consent

Before we get started with the survey and interview, I'd like to make sure you have received the consent form sent to you by email. Do you confirm that you have reviewed the Consent Form and conditions of this project. Do you have any questions about the consent form? Do you hereby give your voluntary consent? And just for clarity, could you please spell your first name and your child/parent's first name for our recording, please.

Demographics, Medical History, Family Constellation Survey

Before we get started with interview questions about your experience living with POTS as a parent-child dyad, I'd like to find out some basic information about your life and medical history. This part of our conversation should take only about 5-10 minutes. (See Appendix D for survey questions.)

If you are comfortable proceeding with the interview questions about living with POTS now, I'd like to begin with a few very broad questions.

Grand Tour Questions

1. "What has been your experience of living with POTS during emerging adulthood?"

2. “What contexts or situations have typically influenced or affected your experiences of living with POTS during emerging adulthood?”
3. “How has living with POTS impacted your parent-child relationship?”

Transition script: Now I have some questions that are pretty specific to your experience managing life with the illness as a family.

Follow-Up Questions on Chronic Illness Experience Using FSI

1. “What has changed for you since living with POTS?” [loss and adaptation]
2. “How did family members initially react to your/their change in health?” [pre-dx reaction and toward adaptation; denial v acceptance shared themes]
3. “In your experience living with POTS, what gives you hope and courage, relief and renewal?” [resilience; shared emotional themes]
4. “What makes you feel angry or sad?” [shared emotional themes]
5. “How have you navigated uncertainties in living with POTS?” [uncertainty] /Alt probe: “What has it been like shifting between different levels of functioning with fluctuating symptom severity?” [relapsing-remitting pattern]
6. “Tell me about your experience living in the world with POTS in respect to social reactions.” /Simplified alt probe: “Have you ever felt misunderstood due to POTS?” /Explanatory alt probe: “Sometimes invisible disability is misunderstood by family, friends, doctors and others. Literature on invisible disability talks about a wide range of social themes such as stigmatization versus support, access to competent medical care, patronization versus respectful compassion..” [social reactions]
7. “How has POTS impacted relationships within the family?” [family relationships]
8. “How has POTS impacted relationships outside the family, for example with extended family, friends, neighbors, and others in your social circle?” [social relationships; social support]
9. “What significant lessons, meanings, or values do you feel your family has gained from its health experience with POTS?” [meaning-making; gains of disability; resilience]

Transition script: These next questions have to do with features of emerging adulthood and the family life cycle stage of launching a young adult child into the world.

Follow-Up Questions on Emerging Adulthood Features

1. Emerging adult: “Many people your age are exploring their identity, asking themselves questions like, ‘*What kind of person am I? What kind of person would best suit me as a partner in life?*’ And ‘*What kind of work am I good at? What do I believe about the world?*’ How have you navigated exploring your identity while living with POTS?” [identity exploration in love]
2. “What are some ways living with POTS has impacted your romantic life?” [identity exploration in love]
3. “What are some ways living with POTS has impacted your financial life?” [becoming financially independent]

4. Emerging adult: “Tell me about your experience learning to take care of yourself or to pro-actively enlist support you need as an emerging adult living with POTS.”
5. Parent: “Tell me about your experience as a parent as your emerging adult child learns to take over their self-care or proactively enlist the help they need while living with POTS.” [accepting responsibility for yourself]
6. “Please describe your relationship with your parent(s)/child during this stage of life compared to adolescence or childhood?” [changes in parent-child relationship toward friendship, less subordination/near-equals, less fighting]

Transition: Thanks for answering my questions about illness experience and life stage. I have just a couple open questions left.

Closing Questions

1. “Is there anything else you would like health professionals, such as family therapists or medical counselors, to know about the experience of living with POTS from your perspective?”
2. “Is there anything else I haven’t asked you about that you think that I should know?”

Pseudonym

My final question might be a fun one. For confidentiality, your real name will not be used in the study report. Instead, we’ll use fake names, pseudonyms. I’d like participants to choose their own pseudonyms. What would you like to be called in the study report?

Closure

Thank you very much again for your time, openness, and energy! I know I took some spoons from your day, and I really appreciate your willingness to contribute your voice to this research. I will do my best on my part to analyze your statements along with other participants’. Expect a short version of a results draft to be sent to you by email in a few weeks to months, after all the interviews have been conducted and analyzed. Those initial results will be sent to you for member-checking, so you can see if we got it right in the way we describe the parent-child dyadic experience of living with POTS during emerging adulthood. I’ll be looking forward to sharing that with you and hearing your feedback. Later, when the polished version is ready, I will send you our final conclusions. Thank you so much again for helping in this study!

General Follow-Up Expansion, Clarity, and Focus Prompts

Can you tell me more about...?

When you say..., what would that look like to me if I was a fly on the wall watching it happen?

What does...look like in your family?

What do you mean by...?

What has that been like for you?

Please describe that for me more in a bit more detail.

That sounds meaningful and important. Please talk more about that.
I'd like to hear more about that, if you don't mind elaborating.
Tell me more about what that was like for your family.
If you don't mind, please explain that in more detail.
Please describe that experience more.
I'd like to understand that better. Please give me an example.
Take me inside that experience/feeling/moment/ "...".
What did that mean for you/your relationship/your family?
For a person who has no idea what POTS is or what it is like to live with it, please explain what you mean by "...".

Appendix B: Informed Consent Form

VIRGINIA POLYTECHNIC INSTITUTE AND STATE UNIVERSITY
Informed Consent for Participants
in Research Projects Involving Human Subjects

Title of Project:

Parent-Child Dyadic Experiences Living with Postural Orthostatic Tachycardia Syndrome (POTS) during Emerging Adulthood

Investigator(s):

Dr. Carolyn Shivers

shivercm@vt.edu

(540)231-5434

Masumeh Farchtchi

masumeh@vt.edu

(703)298-9303

I. Purpose of this Research Project

You are being asked to participate in a research study with Virginia Tech. The study will gather information about families with a young adult (age 18-29) living with Postural Orthostatic Tachycardia Syndrome (POTS). Your family will be one of 8-10 families in this research. Results of this study may be published to increase knowledge about how families cope with POTS.

II. Procedures

If you agree to participate, you will be interviewed by phone. The interviewer will ask questions about your family experience with POTS. Interviews will last about 90 minutes. Young adults and their parent will be interviewed separately. You will have a chance to read and comment on researcher findings before publication.

III. Risks

It may be upsetting to talk about your family experience with chronic illness. Emotions of grief and anger may come up during the interview. The interviewer may ask how you are feeling. The interviewer may suggest a break or end the interview if you seem upset at any point.

The study is not a form of psychological help or counseling. Researchers and interviewers cannot provide you with counseling.

Researchers may provide a list of care resources. You will be responsible for paying for any treatment. Treatment is not the responsibility of the research project, team, or Virginia Tech.

Some individuals with POTS have limited daily energy. You may find a 90-minute interview tiring.

IV. Benefits

Talking about POTS may help you understand its role your life. Your responses may highlight family strengths like togetherness, love, and patience. Your family may realize new ways to cope in the future. Becoming more aware of your experience may produce emotional and mental benefits to you and your family.

If you agree to participate, you will be helping to move understanding of POTS forward in family science research. This may give you feelings of accomplishment and contribution.

No promise or guarantee of benefits has been made to encourage you to participate.

V. Extent of Anonymity and Confidentiality

The Virginia Tech (VT) Institutional Review Board (IRB) may view the study's data for auditing purposes. The IRB is responsible for protection of human subjects involved in research.

If you agree to participate in this study, you will be asked to provide your name and contact information. Your real name and contact information will be kept confidential. You will choose a fake name for published results. At no time will the researchers give your real name or contact information to anyone other than individuals working on the project without your written consent. Your real name and phone number will be stored on a coded list. Only the researchers will have access to that list.

Things you say in interviews will not be revealed to your family members. However, you may be quoted in finding reports. There is a chance that your family members or others may recognize your style of speech from quotes. Quotes may reveal thoughts and feelings that you may not have discussed with others.

Note: in some situations, it may be necessary for an investigator to break confidentiality. If the researcher suspects that someone may be in immediate harm, the researcher is required by Virginia State law to tell the authorities.

VI. Compensation

No compensation will be provided.

VII. Freedom to Withdraw

You are free to withdraw from this study at any time without penalty. You can choose to skip or not answer any questions for any reason.

Sometimes, the researcher may decide that it is best for an interview to end early.

VIII. Questions or Concerns

If you have any questions about this study, you may contact one of the research investigators. Researcher contact information is included at the beginning of this document.

If you have any questions or concerns about the study's conduct or your rights as a research subject, or need to report a research-related injury or event, you may contact the Virginia Tech Institutional Review Board at irb@vt.edu or (540) 231-3732.

IX. Subject's Consent


I have read the Consent Form and conditions of this project. I have had all my questions answered. I agree with the information in this document and give my consent:

You will be asked to give your consent on a sound recording at the beginning of the phone conversation.

Appendix C: Recruitment Communication

Ad

What is it like living with POTS during emerging adulthood?



Virginia Tech wants to know.
If you are interested in joining a family science study on POTS, please contact: Masumeh@vt.edu.

*Participants must be 18-29 years old, diagnosed with POTS. This is parent-child study, so both must be willing to participate. Participants must reside in the U.S.

Email

Subject line: POTS research

Dear Prospective Participant,

Thank you for your interest in participating in the study “Parent-Child Dyadic Experiences Living with Postural Orthostatic Tachycardia Syndrome (POTS) during Emerging Adulthood”! This study has been approved by the internal review board (IRB) of Virginia Polytechnic Institute and State University.

To qualify for participation in this study, emerging adult participants must currently be age 18-29 years old and diagnosed with Postural Orthostatic Tachycardia Syndrome (POTS) by a licensed physician. One parent must be willing to participate as well. The

participating parent may be any person whom the emerging adult participant views as their caregiver/parent, which may include biological grandparents, other extended family, adoptive parents or others. Both emerging adult and participating parent must currently reside in the U.S. and be conversant in English. Both emerging adult and participating parent must be cognitively able to give consent for participation.

The purpose of the study is to describe what it is like for parents and emerging adults to live with POTS. I hope this study will help fill a gap in family science literature in order to better service families of emerging adults with POTS in the future.

Participation involves two main tasks: being interviewed for about 90 minutes, and reviewing study results (2-3 pages) before publication. For privacy, parents and emerging adults will be interviewed separately.

If you qualify for the above-mentioned criteria (i.e., diagnosis, age range, parent-child dyad) and would like to become a member of this study, please read the attached informed consent document. Please confirm your participation interest and availability by email, and we will move on to scheduling your and your parent/child's phone interview at your earliest convenience.

NOTE: The attached informed consent document outlines expectations for participation. During the interview, researchers will remind participants of their rights outlined in the informed consent and audio record consent confirmation. Please read the attached informed consent document and email any questions you may have concerning conditions of participation in advance of the scheduled phone interview.

Kind regards,

Masumeh Farchtchi

Masumeh@vt.edu
(703)298-9303

Appendix D: Demographic Survey and Medical History

Demographics, medical history, and family constellation information will be surveyed orally by phone before the interview commences with both emerging adults and their parent.

FAMILY INFORMATION

Parents' relationship status:

Emerging adult relationship status:

Members of household (living with emerging adult):

Children (of emerging adult):

SURVEY RESPONDENT PERSONAL INFORMATION

Age:

Highest level of education attained:

Household income:

[Options: <\$25,000/year; 25-34,999/year; 35,000-64,999; 65,000-100,000;
>100,000/year]

Occupation/ work status:

State of residence:

Gender assigned at birth:

Gender identification/ preferred pronouns:

Racial-ethnic identification:

Spiritual/religious identification:

RELEVANT MEDICAL HISTORY (OF EMERGING ADULT)

Type of illness onset:

[Options: sudden; gradual; not sure]

Estimated year of onset:

Year of diagnosis:

Diagnosing physician's specialization:

Diagnostic testing done:

[Options: Tilt Table Test (TTT); Poor Man's Tilt; Echocardiogram (ECG); Electrocardiogram (EKG); Holter Monitor; Cardiac Stress Test; Electroencephalogram (EEG); Nerve Conduction Test; Autonomic Function Testing (such as QSART); Catecholamine Blood Test; other/s]

Subtyping:

[Options: None; Hyperadrenergic; Hypovolemic; Neuropathic; Dysautonomic; Cardiac Origin; Autoimmune; other]

Symptoms experienced (currently or in the past in association with POTS):

[Options: dizziness; palpitations; headache; nausea; vomiting; chronic fatigue; shortness of breath; bladder problems; digestive problems such as constipation/diarrhea or dysmotility; trouble swallowing; sleep disorder (trouble falling asleep, staying asleep, or quality of sleep); exercise intolerance; anxiety; depression; obsessive compulsive disorder; suicidal ideation; self-harming behavior; panic disorder; infertility; sexual difficulties such as impotence or loss of libido; menstrual/gynecological problems; chemical sensitivity; seizures; syncope (fainting); pre-fainting episodes; loss of appetite; weight gain or loss; heat intolerance; photosensitivity; sound sensitivity; cognitive difficulty; visual disturbance; hearing problems; other sensory deficit (e.g., loss of feeling or smell); muscle atrophy and difficulty building muscle tone; brain fog; cold extremities (e.g., hands, feet, nose); chest pain; muscle spasms]

Course of illness experienced:

[Options: remitting-relapsing; worsening over time; improving over time; full recovery; fluctuating severity of symptoms; not sure]

Comorbid, meaning other diagnosed illnesses present (including psychiatric diagnoses):

Appendix E: Resources for Participants

Participants may benefit from the following references to national resources for mental health support, which will be on hand during interviews and emailed to participants on request:

National Suicide Prevention Lifeline
1-800-273-8255

National Alliance for Mental Illness
800-950-6264

POTS Physician's List from Dysautonomia Information Network
www.dinet.org/physicians/

Family Therapists List from American Association of Marriage and Family Therapists (AAMFT), Psychology Today, American Family Therapy Association (AFTA), American Psychology Association
www.psychologytoday.com/us/therapists/family-marital
www.therapistlocator.net
afta.org/afta-therapist-search/
locator.apa.org/

Appendix F: Data Analysis Notes to Validate Invariant Description

Table 3

Dyadic Validation

Child-Parent Dyad	1	2	3	4	5	6	7	Notes on meanings and exceptions (constituent descriptions and interpretations)
“All in head”	✓	✓	✓	✓	✓	✓	✓	From doctors, teachers, friends and extended family, parents and siblings, coworkers and bosses
“Everything” context	✓	✓	✓	✓	✓	✓	✓	Every context was affected, some to the degree that they were not in the person’s life at all (e.g. no romantic experience or idea of sexual orientation, no work experience, no friendships). Some only left home for doctor appointments.
Never know/ fluctuation	✓	✓	✓	✓	✓	✓	✓	Not knowing how they will feel/function waking up the next morning, five minutes later, long-term future.
“Push” fine line	✓	✓	✓	✓	✓	✓	✓	Symptoms were difficulty to push through and made engaging in preferred activities difficult. Not pushing through symptoms and remaining inactive caused further worsening gradually. Pushing too hard, doing too much too fast, caused total collapse and sudden symptom flare-up or relapse described as days bedridden.
Hard to be understood	✓	✓	✓	✓	✓	✓	✓	Difficulty explaining POTS to others, that it cannot be understood except through personal experience, and the social reaction that people just cannot understand POTS was reiterated many times.
Invisibility issues	✓	✓	✓	✓	✓	✓	✓	All settings: home/family, friendships, work, study, medical care, random strangers in public places.
\$\$\$ impact	✓	✓	✓	✓	✓	✓	✓	Travel for treatment, out-of-pocket treatments, treatments not covered by insurance due to being off-label or lack of research supporting their use with POTS, supplemental and complementary treatments, cost of lifestyle to accommodate disability (e.g. bathroom modifications, service animal, compression clothing)
Medical care frustrations	✓	✓	✓	✓	✓	✓	✓	Medical professionals incompetent to deliver supportive care due to lack of knowledge about POTS and no experience treating it successfully was experienced as angering, disheartening, frustrating, dehumanizing.
Plans problem	✓	✓	✓	✓		✓	✓	Parents and emerging adults repeatedly expressed frustration and coping strategies around planning, canceling, rescheduling family functions, social engagements, and work commitments.
Dreams change		✓	✓	✓	✓	✓	✓	Astronaut, opera singer, air force pilot, world traveler/historian, competitive distance swimmer

Friendship loss and filter	✓	✓	✓	✓	✓	✓	✓	One described difficulty making new friends (shared theme) but no loss of old friends. Most described loss of friends with meaning-making that “true” or “real” friends stayed. One described a total loss of all friends. Parents also lost friendships and communities but felt that remaining friendships were more supportive and meaningful.
Optimism future (EA)	✓	✓		✓	✓	✓	✓	Emerging adults expressed hope in their futures through hoping for medical recovery, discoveries that would lead to more treatment options, and also reasonable hope that they would reclaim some of their lost dreams.
Feeling closer	✓	✓	✓	✓			✓	The 2 dyads who did not report the illness made them closer, reported already being extremely close pre-illness.
Sexuality impact (EA)		✓	✓	✓			✓	Fewer romantic and sexual experiences, low libido, no drive, ambiguity about their orientation (no arousal), problems engaging in sexual activity with partner due to symptoms (pain, fatigue). Less interest in romantic coupling (doubt about finding a partner who can accommodate to daily limitations).
Learning to accept help (EA)	✓		✓	✓	✓		✓	Some self-reported “independent” personalities; others were more comfortable accepting help and did not identify as independent.
Support in POTS community		✓	✓				✓	Social media and clinics provided communities where participants connected with others with POTS for information and emotional support. Several also helped friends identify their POTS when it developed.
Early maturity (EA)	✓		✓	✓	✓			For better or worse, emerging adults seemed to have skipped some of the spontaneity, adventure, irresponsibility and carefree nature of youth. Growing up fast/early, knowing themselves early, and feeling more mature than peers. Also feeling elderly in terms of fatigue, incapacitation and accommodations.
Each other’s heroes	✓	✓		✓				Hope, courage, comfort, motivation, daily coping support. Parent-child dyads expressed not only closeness but deep appreciation and even awe for each other.

Note. Researcher altered identification from pseudonyms to random numbers for confidentiality of participant matching their pseudonym with their parent’s or child’s.

Table 4

Individual Validation with Constituents

Participant	1	2	3	4	5	6	7	8	9	10	11	12	13	14
“It’s all in her head” mislabel		✓ “Oh, it’s all in her head”	✓ “It’s all in your head. It’s a mental	✓	✓ “The word ‘somatic’ was thrown	✓ “a lot of people thought that I was faking or	✓ “anxiety”	✓		✓ “Even with doctors, they just thought,		✓	✓ “discounted it as psychiatric” “told	✓

			thing. We've heard that so many times."		around" "you're being told that maybe a lot of this is in your child's head"	that it was all in my head"				there was like, "Maybe your child is stressed or anxious"			several times by both psychological and medical professionals, 'what happened to her didn't happen.'"	
"Everything" affected contexts	✓ "they help compromise every situation with me"	✓	✓	✓ "it makes everything a lot harder" "The world revolves around my POTS... you have to modify everything and change your beliefs about a lot of things."	✓ "Everything literally changed"	✓ "a severe wrench"		✓	✓ "Everything has changed"		✓ "Everything!" "I really can't think of anything that's not really affected at all."	✓	✓	✓
Impossible planning		✓ "Planning things, as simple as planning a meal, you can't do it."			✓ "Plans are more suggestions than reality"	✓	✓					✓	✓	✓

Each other's heroes, courage, hope		✓	✓ "What gives me courage? She does!"					✓ "What gives me hope? Well, her! Just the phenomenal way she handles these challenges."						
Anticipatory loss		✓			✓ "She lost everything." "Life was reduced to a recliner"	✓ "interrupted my life plans"	✓		✓ "I've had to change my career ideas."	✓ "watching my child give up the dreams..."	✓ "Thinking about the future is the hardest to deal with. I don't know what I'll be able to do."	✓ "she wanted to be a pilot... that option is gone!"		✓
Overachiever		✓ "overachiever" "straight As"	✓ "definitely above average"					✓ "extremely intelligent"		✓ "gifted"	✓ "I'm an overachiever"			
Feeling closer	✓ "we've all grown closer" "we've realized that there are a lot of issues in life, and the best way to help"	✓ "it made us closer"	✓ "it can also make us closer"	✓			✓ (in EA)	✓ (EA) "She's very appreciative"	✓ "Extremely close" "And she has become everything to me." "It helps that I don't live with her."		✓ "it's made us grow closer"			✓

	each other is to just be there for each other.”													
Medical lack/care			<p>✓ “extremely dismissive” “You really have to keep fighting until you get a diagnosis” “So it’s almost like we diagnosed her and made them perform the tests and look into it.”</p>	<p>✓ “so little medical information” “It’s really getting a weird diagnosis for something that nobody knows about and having to deal with it by yourself</p>	<p>✓ “a medical professional should not be part of the problem”</p>	✓	<p>✓ “If I go to an appointment knowing more about POTS than they do...” “It’s not fun to be treated like not a human.” “Very angry at the doctors”</p>	✓		<p>✓ “I’m most frustrated with the medical system”</p>	<p>✓ “It’s kind of a big mess.”</p>	<p>✓ “The situation is we can’t figure out what’s going on and fix it.”</p>	<p>✓ “up against the medical establishment” “He did that grudgingly, and in the diagnosis, he wrote ‘hovering mother.’” “We’ve traveled there for 3 years...not in her age bracket”</p>	
Invisibility	<p>✓ “Mine’s is a hidden illness... They think I’m lazy.”</p>	<p>✓ “she looks so normal”</p>	<p>✓ “she’s been ignored, and she’s had a chronic illness ever since she can remember”</p>	<p>✓ “You can’t see if somebody has POTS”</p>	✓		✓		<p>✓ “he said, ‘she looks fine to me.’”</p>	<p>✓ “they see a healthy-looking young person, and they don’t understand the limitations they</p>	<p>✓ “People don’t want to hear that you’re sick.”</p>		<p>✓ “It’s invisible. You look normal, mostly.”</p>	

										have.”				
“People can’t understand”	✓“Most people don’t get it.”	✓“society’s not going to understand”		✓			✓“Unfortunately, it’s hard to tell people”				✓	✓	✓“People really don’t understand what it is.”	✓“It’s hard to explain to people”
Old beyond years	“I’ve definitely grown up fast because I had to learn how to manage this by myself”	✓“They’re supposed to be little adults, before they’re adults.”			✓“modifications best suited to the elderly” “Takes adults decades ...”		✓“I had to grow up and learn a lot of stuff myself and grow up that much earlier.”	✓	✓“I feel like I’m 80 years old sometimes.” “I’ve had to really grow up and be able to take care of myself”					
Trusting, letting go			✓“I just learned to trust her judgment.” “I had to step back and leave it up to her.”		✓“Trusting her to define what is happening within her body”		✓“you don’t need to push them”	✓“we grapple with that every day...the issue of respect”	✓“learning to listen when I am saying I need help or I don’t need help, really listening and not overstepping that but also giving enough help.”	✓“It’s hard. To allow them to make that choice for themselves. It’s important.”		✓		

Sexuality impacted	Romantic impact: "It's hard to find someone that's understanding enough...it's not just one accommodation, it's like 20."		✓ "She doesn't really know what she is." (ambiguous sexual orientation; "no desire")	✓	✓	✓ "I don't even know what physical stuff I could do."	✓ "I don't plan on ever having kids"		✓ "Sex is a big thing" "Sometimes I'm in so much pain, I can't be touched."		✓ "I don't have a romantic life"		✓ "She's never been sexually active" "She's never had dating experience"	
Learning to accept help	✓ "I've always been a really independent person."					✓ "The biggest thing is learning how to ask for help"			✓ "Understanding that sometimes I need people to help me. This is a big one because I don't like to accept help."		✓ "I have just decided that not asking for help is going to hurt me. It's not, pride is not worth that."			"It can be pretty annoying to not be able to do everything on my own. Frustrating."
True friends filter	✓ "it helped me realize who my true friends are and who stood by me the whole time"			✓ "it helps you weed out the bad ones" "I was able to say, these are my real friends , the good friends who listen to		✓ "those friends that stick with you."			✓ "I kind of lost all of my friends because of POTS"	✓ "I had to let go of some of them because they still are not understanding. And then other relationships, like new relationships	✓		"She's lost social interaction . That's probably distressing to her more than anything."	

				what I say and believe me without me having to go and get like a diagram”						ips have developed around people who do understand and are supportive.”				
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Shared Lived Experience Description

We interviewed 7 parent-child dyads, a total of 14 individual interviews. Transcriptions averaged near 10,000 words per interview. Emerging adult ages ranged from 18-27. Six mothers and one father participated. Participants in this study tended to represent the more severe end of the POTS spectrum. Overwhelmingly, parents and emerging adults described a pervasive impact of symptoms on the emerging adult's life.

Analysis identified nine themes related to the experience of living with POTS during the launching stage of the family life cycle. In addition to these nine core themes, we listed effective coping strategies. The themes and coping strategies are compiled below in Table 1 and Table 2. A brief narrative description follows.

Table 1

Thematic Clusters of Meaning (Member Checking Version)

9 Thematic Clusters of Meaning		
<p>Emerging Adult's Difficulty Functioning due to Symptoms</p> <ul style="list-style-type: none"> • Loss of role and identity (mostly anticipatory loss) <ul style="list-style-type: none"> ○ Wanting to help others ○ Work/career dreams ○ Education ambitions and competitive status ○ Travel and experiencing the world • Disrupted daily plans (EA and parents if living together) • Household chores • Self-care • Fun with loved ones • Sexuality 	<p>Emerging Adult's Quality of Life Related to Illness</p> <ul style="list-style-type: none"> • Narrowed horizons and possibilities • Unpleasant symptoms (e.g. dizziness, pain, fatigue, nausea) • Mental health breakdown (clinical/subclinical depression, anxiety, OCD) • Suicidality and self-harm behaviors (life worth living) • Uncertainty about the future (waking up, 5 minutes, long-term) 	<p>Social Life</p> <ul style="list-style-type: none"> • Loss of friendships • "True friends" filter • POTS community support • Hard to make new friends • Difficult to explain/ People can't understand • Invisibility in public • Pressure not to be/appear sick (lack of acceptance) • Limited social stamina
<p>Parent Shared Emotional Themes</p> <ul style="list-style-type: none"> • Powerlessness • Sadness/grief • Worry (about EA's financial future, health, wellbeing) • Anger (at medical system/ public) • Pride in child • Self-sacrifice • Inspired by child (hope, courage) 	<p>Family Gains</p> <ul style="list-style-type: none"> • Appreciation (time, people, life) • Celebrating small victories • Family cohesion <ul style="list-style-type: none"> ○ Coming together to solve problems ○ Showing more kindness ○ Talking/listening more ○ Feeling "there" for each other • Understanding (disablement, other people, illness) • Compassion/empathy • Feeling "stronger" (mental/emotional fortitude) 	<p>Medical System Frustrations</p> <ul style="list-style-type: none"> • Lack of information about the disease • Lack of effective treatment options • Lack of medical support • Delayed diagnosis • Misdiagnosis • Mislabeling of EAs (psychosomatic, malingering) • Mislabeling of parents (hovering) • Expenses not covered by insurance • Accessibility (travel for competent care) • Fear about future healthcare coverage • Feeling "up against the system" (fighting for care)

<p>Invisibility</p> <ul style="list-style-type: none"> • “All in their head” mislabel • Interference with acceptance process for family • Role of variability of symptoms • Role of being young and looking “normal” • Appearing malingering (ongoing fear, accusations) 	<p>Development Dynamics</p> <ul style="list-style-type: none"> • Parental letting go and trusting the child • Feeling stalled/ in limbo • Dependency in care and economics • EA leadership, decision-making • EA early maturity in self-management, willpower, values • Parent’s stage of rest/retirement forestalled • Becoming near-equals (parent-child relationship) 	<p>Optimism and Hope in the Future</p> <ul style="list-style-type: none"> • Part of dreams • Medical discoveries • Some recovery • Adjusted expectations (confronting meritocracy myth)
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TABLE 1: Nine Thematic Clusters of Meaning

Table 6

Effective Coping Strategies (Member Checking Version)

Effective Coping Strategies	
<p>Physical Coping (Symptom-Reducing)</p> <ul style="list-style-type: none"> • Hydration diligence • Taking breaks • Finding the fine line for “pushing” but not too far • Body awareness (tracking needs minute-to-minute) • Exercise • Compression socks • Mobility aids (wheelchair) • Service dog (alerts to symptoms) • Slowing the pace (e.g. going part-time) • Keep moving when tired paradox • Strict daily schedule (sleep/wake, meals, exercise) • Personalization (individual differences, what works for you) • Utilizing work/study from home options (more control over schedule) 	<p>Emotional Coping</p> <ul style="list-style-type: none"> • Optimism • Being proactive (agency) • Taking time for grief • Talking about it with friends (especially others with POTS) • Focusing on the present (to deal with uncertainty) • Not comparing to pre-illness (expectations of self) • Making peace with the unchangeable • Perseverance • Acceptance (of limitations, self, situation) • Self-compassion • Flexibility • One day at a time • “Part”, “somehow”, “maybe tomorrow” adaptations (reasonable hope) • Coming together as a family • Humor

TABLE 2: Effective Coping Strategies

Daily Functioning, Quality of Life, and Invisibility

All participants described limitations in functioning imposed by POTS symptoms and associated problems in quality of life. One parent described, “Life was reduced to a recliner.” Symptoms fluctuated day-to-day and even minute-to-minute. Course of illness differed from person to person, with some participants experiencing a long-term trend of partial recovery, some remitting and relapsing, and some worsening over the past several years. Fatigue, nausea, dizziness with or without fainting, and cognitive difficulties interfered with preferred activities across multiple settings, including domestic chores, self-care, work/career and education, social life, and romantic partnerships. Participants described processes of loss and adaptation in response to the stressor of POTS, in which

they learned to accept limitations and push through difficult and confusing symptoms with insufficient medical information or support.

Invisibility and fluidity of disability status contributed to an *'all in their head'* mislabel that in turn created conflict and distancing among important support relationships, delayed healthcare delivery, reduced self-esteem, and disrupted parental resolution processes around accepting a life-altering diagnosis. Social invisibility of POTS-related impairment seemed to provoke blaming and denial responses that were not supportive of emerging adults with POTS and their families instead of empathy, informed care and appropriate accommodation generally afforded better-recognized illness experiences. One mother stated, "They see a healthy-looking young person, and they don't understand the limitations they have." Emerging adults interviewed tended to express lingering fears that others perceive them as lazy, faking or malingering rather than chronically ill.

Shared Parental Emotions

Parents expressed similar emotional themes. Several parents expressed feelings of powerlessness, such as "Your child is struggling and you can't do anything about it." Parents felt sad about their child's losses and daily discomfort. They worried about their child's future financial life and overall wellbeing. They also expressed pride in their child's will and perseverance. In fact, parents seemed deeply awed by their child's courage, "What gives me hope? Well, her! Just the phenomenal way she handles these challenges." All the parents had made sacrifices in time, energy, and family finances in order to prioritize their child's care. Several stated feeling focused on the child with POTS, "My life revolves mostly around her." Two described managing their child's healthcare as "a full-time job" in addition to their actual full-time job.

Emerging adults perceived their parents' stress and sacrifices around coping with POTS, as well as that of siblings in many cases, and reported feeling closer and more appreciative of parents. These parents and emerging adults seemed in many ways to be each others' heroes, giving each other comfort, courage, and motivation in their daily coping. Not all parent-child relationships were as positive, however. Some participants reported parent-child conflict and cutoff, explaining that the distanced parent had trouble accepting or coping with POTS.

Family Gains, Developmental Themes, and Persistent Hope in the Future

Participants described family gains in response to the stressor of living with POTS, including increased appreciation of people, time together as a family, and life, echoing the sentiment, "Life is precious," and, "You can't take anything for granted." They described increased family cohesion through joint problem-solving, talking/listening more, and feeling "there" for each other. Personal fortitude was another gain recurrently expressed by both emerging adult and parent participants. They reported family growth in understanding, compassion and empathy not only for each other but for others living with disability.

Although most dyads described increased parental involvement in healthcare and financial support as compared to their expectations of emerging adulthood without health problems, they expressed many salient themes of successful development. In fact, parents described emerging adults as old beyond their years, and emerging adults reported feeling more mature than peers, such as, "I've definitely grown up fast because I

had to learn how to manage this by myself.” Sometimes this maturation was ascribed negative aging terms, such as needing “modifications best suited to the elderly,” and “I feel like I’m 80 years old sometimes.” Emerging adults utilized appropriate assistance from parents and others but most often occupied decision-making roles and followed up their own well-disciplined self-care. Parents described parallel processes of learning to let go and trust their child.

Parent-child dyads expressed typical emerging adulthood themes of becoming near-equals, but with some added closeness and adaptive child dependencies. Typical of psychological trends of emerging adulthood and in spite of uncertain prognosis and sometimes worsening course of illness, participants expressed persistent hope in their futures. Although they also expressed fear and uncertainty in regard to their future physical ability and health, many articulated adaptations of their pre-illness aspirations for their futures. They believed they would accomplish their dreams somehow, in part, or on a slowed timeline, showing resilient integration of anticipatory loss and reasonable hope. Due to slowed pace of work/study and economic barriers of disablement as well as complexity of medical care, many dyads also reported feeling “in limbo” and unable to move fully into adulthood and independence from parental help. Though feeling in-between childhood and adulthood is again a typical theme of emerging adulthood, medical complexity was involved for these dyads. The central theme of emerging adulthood that was not confirmed in this study for participants was Instability. They coped with illness and symptom uncertainty partly by rigidity of scheduling and more closed social networking and therefore did not tend to move from place to place or relationship to relationship as typically occurs in exploration of identities during emerging adulthood.

Romantic pairing was impacted by POTS in significant ways. All participants reported fewer emerging adult romantic and sexual experiences. Many reported low libido or no desire, ambiguity about their orientation associated with absent arousal, and problems engaging in sexual activity with their romantic partner due to symptoms like fatigue and pain. None of the emerging adult participants had children or had tried to conceive. One participant commented, “It’s hard to find someone that’s understanding enough... It’s not just one accommodation, it’s like 20.” However, two of the seven participating emerging adults were in stable romantic relationships and reported that their partners were extremely understanding and provided emotional and instrumental support.

Medical System Frustrations and Effective Coping Strategies

Participants expressed frustration with medical care, and for some, this was the most angering part of their illness experience. One participant summarized medical support for POTS, saying, “It’s kind of a big mess.” All participating dyads reported stressful encounters with doctors and other healthcare workers who were misinformed or uninformed about POTS, stating they often knew more about POTS than their doctors. Although some doctors were supportive and competent, others were dismissive and unwilling to learn or collaborate. One participant described, “A medical professional should not be part of the problem,” and another reported, “It’s not fun to be treated like not a human being.” Participants also mentioned feeling frustrated with the paucity of research, effective treatment options, and understanding about how or why POTS happened. They reported problems accessing competent medical care for POTS as well

as short and long-term financial burden from helpful treatments not covered by insurance. Many had fears about continuity of healthcare access as the emerging adult ages out of family care plans, gains employment insufficient to cover the cost of living but enough to disqualify medicaid, or becomes otherwise ineligible for current coverage.

Dyads reported joint and individual stress management and coping around POTS, both problem-focused and emotion-focused, with associated gains in family cohesion and reduced mental health strain. One participant described their parent-child dyadic coping, saying, “A lot of hugging. A lot of just saying that everything’s going to be okay. Very reassuring.” Several participants described an about two-year-long adjustment process, in which they became familiar with physical limitations and learned effective coping strategies through trial and error, online research, medical support, and networking within the POTS community. Symptom-reducing strategies included compression socks, wheelchairs, body awareness, hydration diligence, and maintaining a strict schedule in regard to sleep/wake, meals, and exercise. Dyads reported resilient emotional coping strategies, such as optimism, “I hope for the best,” and perseverance, “Sometimes you’ll take two steps back and sometimes you’ll take three steps forward. But you just got to keep on walking, no matter what life deals you.” Other emotional coping strategies included taking time to grieve losses, talking with friends, focusing on the present to reduce stress over uncertainty, not comparing oneself now to pre-illness abilities or peers who are not coping with chronic illness, giving oneself a break and being easy on oneself, pivoting with symptom fluctuation in a flexible manner as a family, and taking things one day at a time.

Acceptance was an ongoing process complicated by uncertainty. One participant described, “Not having expectations when you wake up in the morning, and accepting how the day is going to be.” Some participants described grappling with social stigmatization around disability and illness, including meritocracy myths, producer-consumerism, and pressure to be or appear recovered. One participant expressed feeling social messages, “Like if I don’t get better, I will have failed.” Another participant articulated her shift in mindset replacing the social myth “You can do anything you put your mind to,” with a more realistic and self-accepting, “I can do anything I can do.” One participant described feeling isolated in coping with POTS as a socially stigmatized stressor, stating, “The general public doesn’t deal with disability very well. And so when you are in a family with disability, you’re kind of on your own.” Dyads learned not only self-acceptance but advocacy to cope with their illness experience.