POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME (POTS):

AN EVALUATION OF DAILY BARRIERS IN THE HOME ENVIRONMENT

By

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Title of Study: POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME (POTS): AN EVALUATION OF DAILY BARRIERS IN THE HOME ENVIRONMENT

Major Field: DESIGN, HOUSING, & MERCHANDISING

Abstract: This study focuses on the relationship between Postural Orthostatic Tachycardia Syndrome (POTS) and the home environment. Since starting this study, numbers on how many people have POTS have risen from 2015 from an estimated 500,000 people in the United States to between 1 million to 3 million people (Caceres, 2022; Sheldon, 2015). While new research has been conducted on the impact of POTS on daily life, there is a lack of specific understanding of the experience of those living with the condition and the impact of the home environment. The purpose of this study was to identify how the home environment influences individuals living with POTS physiological and cognitive responses. The study also addresses how the inclusion of environmental adaptations affect those relationships. A mixed-methods exploratory methodology was used with two phases, which included a Phase I Survey and a Phase II Focus Group. Conclusions based on this paper were used to develop a fact sheet for the general public to better understand the experience of living with POTS at home.

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CHAPTER I

INTRODUCTION

How does the home environment create barriers for people living with Postural Orthostatic Tachycardia Syndrome (POTS) and what are their physiological and cognitive responses to those barriers? POTS is a condition that can cause symptoms such as rapid heart rate, pain, fatigue, lightheadedness and fainting, nausea and vomiting, headaches, and brain fog (Theiben, et al, 2007). Simple movements such as sitting up, standing, and walking trigger POTS symptoms (Ashangari, 2015; Kavi, 2012; Low, 2009; Olshansky, 2020). While it is known that these activities can cause difficulties, extensive research has not been done on using environmental aids in the home to combat the symptoms (Dochod, 2022; Hollingsworth, 2022; Levine, 2021; Rich, 2020).

Since starting this study, numbers on how many people have POTS have risen from 2015 from an estimated 500,000 people in the United States to between 1 million to 3 million people (Caceres, 2022; Sheldon, 2015). Many are wheelchair-bound or even bed-bound, meaning that these individuals may spend most of their time in a home environment (Grubb, 2006; Sheldon, 2015). While new research has been conducted on the impact of POTS on daily life, there is a lack of specific understanding of the experience of those living with POTS and the impact of the home environment, specifically (Dochod, 2022; Herrara, 2022; Hollingsworth, 2022; Levine, 2021; Mike, 2021; Rich, 2022).

As individuals with POTS may spend much of their time in the home environment (Grubb, 2006), this is an important area of study because it is unknown how, specifically, the home environment affects POTS individual symptoms and their competencies. In addition, the experience of daily life changed during COVID-19 quarantines (Muscogiuri, 2020; Raj, 2021) and recent studies have begun to make connections between POTS and long-COVID symptoms (Goldstein, 2020; Li, 2014; Miglis, 2022; Raj, 2021; Rull, 2020).

The principle *research question* for this study therefore was:

- In what ways does the home environment create supports or barriers to the competencies of individuals living with POTS? In addition, other questions include:
    - What are the principal physical barriers for people with POTS when navigating a home environment?
    - How are individuals with POTS impacted emotionally when completing activities of daily living?
    - In what ways are individuals with POTS impacted physically when completing activities of daily living?

Definitions

Postural Orthostatic Tachycardia Syndrome (POTS)

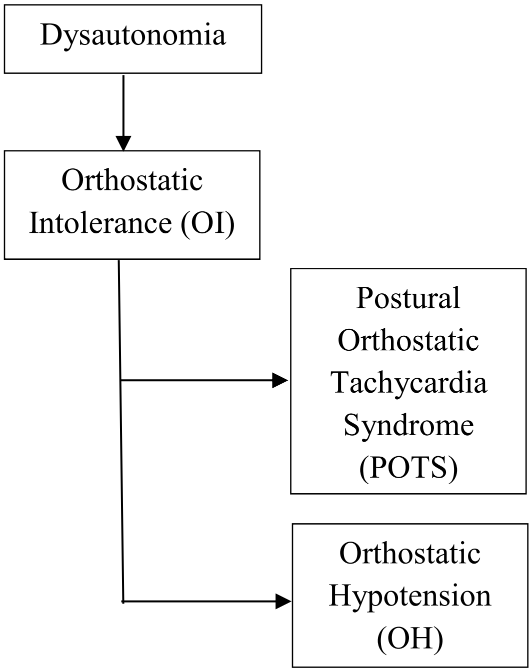
Postural Orthostatic Tachycardia Syndrome (POTS) is an autonomic nervous system disorder, which can cause a range of symptoms such as heart palpitations, tachycardia, headaches, lower back pain, chest pains, shortness of breath, overactive or underactive sweating, exercise intolerance, fatigue, lightheadedness, fainting, nausea and vomiting, and brain fog (Mar, 2020; Shaw, 2019; Stewart, 2012; Thieben, 2007). These symptoms can be caused by any orthostatic activity, such as sitting up, standing up, walking, or any other activities that require upright posture. POTS is not considered rare, but is commonly misunderstood or misdiagnosed as knowledge of the condition has only recently arisen (Kavi, 2012; Mar, 2020). Many individuals who have POTS have reported being misdiagnosed as having severe anxiety or a panic disorder (Shaw, 2019).

POTS was defined in 2009 as "The development of orthostatic symptoms associated with a heart rate (HR) increment ≥30, usually to ≥120 bpm without orthostatic hypotension" (Low, 2009). More simply, it can be described as intolerance to vertical activities. POTS is considered a syndrome rather than a disease. Diagnosis criteria for POTS is a heart rate increase of 30 beats per minute (bpm) or more, or over 120 beats per minute within the first ten minutes of standing not associated with other chronic debilitating conditions or increase in blood pressure (Mack, 2010).

POTS falls under the category of dysautonomia, or the failure of proper regulation of the autonomic nervous system. Many symptoms of POTS are attributed to the individual's orthostatic intolerance, or intolerance to standing (Mack, 2010; Parsaik, 2012; Stewart, 2012). Orthostatic intolerance is usually seen as caused by orthostatic hypotension or a drop in blood pressure upon standing up (Mack 2010; Stewart, 2012). However, individuals with POTS do not have that associated drop in blood pressure (Thieben, 2007). While POTS is not considered a form of orthostatic hypotension, these conditions share similar symptoms and are seemingly brought on by orthostatic activity. Where POTS lacks research, orthostatic hypotension often fills in the gaps. This is because there are already many studies on orthostatic hypertension while there is limited research on pots. The similarities between the two conditions are seen in Figure 1.

Figure 1

Relationship between Conditions



In more recent years, research related to POTS has increased (Agarwal, 2007); however, there is still no cure, and treatment options often do not work well for all those affected (Grubb, 2008).

Built Environment

The built environment can be considered as any man-made structures, facilities, furniture, and spaces that provide a setting for human activities in which people either live or work. For this study, the built environment was limited to the home setting. This was done to narrow the scope and focus on the main areas where potential participants spend their time on a daily basis.

Motivations for Study

While many studies on POTS have looked at prolonged standing (Parsaik, 2012; Theiben, 2007) and tolerance to temperature (Thieben, 2007), only a few recent studies look at how symptoms are affected by day-to-day interactions with individual's built environments (Dochod, 2022; Herrara, 2021; Levine, 2022; Mike, 2021; Rich, 2020). For instance, it is widely known that individuals with POTS may have a difficult time taking a shower or completing housework, as they may have heat or orthostatic intolerance, but there have not been any documented studies of this actual interaction (Raj, 2006). There is a critical need to investigate how the built environment—specifically home environments—affects individuals with POTS, as major symptoms are amplified with certain daily activities in the home. Two important components of this study are activities of daily living and instrumental activities of daily living. Activities of daily living are any tasks or activities that are crucial to everyday life. These include five basic categories: personal hygiene, dressing, eating, maintaining continence, and mobility (Oxford, 2015). Instrumental activities of daily living are any other activities that are a part of common everyday life such as communicating, transportation, meal preparation, shopping, housework, managing medications, and managing personal finances (Oxford, 2015).

Almost all related research has looked at pharmacological and non-pharmacological ways to treat symptoms. Medications used for other heart conditions have been tested with POTS individuals to see if they will relieve symptoms (Grubb, 2008). Non-pharmacological treatments suggested for POTS individuals include increasing in water and salt intake (Low, 2012), adding daily usage of compression stockings and abdominal binders (Mar, 2020), recondition exercise (Grubb, 2008), and avoiding triggers (Oldenburg, 2002). This work aims to analyze the relationship between those living with POTS and the barriers of the built environment to better understand potential design solutions to improve activities of daily living and instrumental activities of daily living and the connection between current accommodations in the home.

COVID-19 and POTS

In addition to the growing numbers of individuals living with POTS, there is now research that connects long-COVID and POTS (Blitshteyn 2021; Goldstein 2020; Kanjwal 2020; Miglis 2022; Raj 2021). There are still many unknowns related to long-COVID and POTS as data on this connection is still in its early stages, but the increase in a POTS diagnosis potentially caused by COVID infection has been documented (Blitshteyn 2021; Goldstein 2020; Kanjwal 2020; Miglis 2022; Raj 2021). This connection can be seen in individuals with long-COVID experiencing POTS symptoms such as shortness of breath, palpitations, chest pain, fatigue, orthostatic intolerance, and sustained orthostatic tachycardia upon standing (Kanjwak 2020; Miglis 2022; Raj 2021). With an increase in those diagnosed, it becomes even more necessary to identify triggers and ways to reduce POTS symptoms.

Relationship to Interior Design

This study relates to the field of interior design because in order to properly create a space for someone with POTS, it is necessary to understand how the environment may impact them negatively. Environmental barriers must be identified to be addressed properly As this condition is not considered rare, the built environment is an important area of study. While research related to POTS is being conducted, in general, there remains a focus on medical solutions instead of understanding how this condition could be managed by changing existing environmental factors (Low, 2012).

Pharmacological Treatments for POTS

As stated, current treatments for POTS includes pharmacological and non-pharmacological methods. This study, focuses on the non-pharmacological treatments as researchers have conflicting findings on POTS individuals' ability to "recover." Researchers define a POTS recovery as the absence of related symptoms to a point that allows individuals the ability to perform activities of daily living with few limitations (Grubb, 2008). Some professionals have taken this statement out of context and have determined that treatment can cure the condition, which is inaccurate (Shaw, 2019). Currently, there is no medicinal treatment that has been approved by the U.S. Food and Drug Administration for POTS. For example, some medications have been seen to improve symptoms, but many of the medications have side effects that are similar to current symptoms (Grubb, 2008). It is uncertain what the long-term effects of these drugs have on POTS individuals specifically, as related research has only started to emerge (Low, 2012). Some treatments do not work well, if at all, for individuals (Mar, 2020). Even with a mixture of pharmacological and non-pharmacological treatments, all solutions have some sort of connected issues (Grubb, 2008).

Pharmacological treatments currently being used for POTS are methods meant for other heart or neurological conditions (Grubb, 2008; Mar, 2020). Often, these treatments can cause side effects that are already seen as symptoms of POTS such as nausea, headaches, insomnia or sleep disturbances, fatigue, and lack of appetite, along with a long list of even more symptoms that could be considered worsened symptoms of current conditions like agitation, irritation, blurred vision, or tremors (Grubb, 2008). Even more, problems could arise due to these treatments, such as pain at injection sites, dry mouth, sexual issues, edema or swelling, or itchy scalp (Grubb, 2008). Issues related to pharmacological treatments may lead some individuals to look for alternative solutions or non-pharmacological treatments.

Non-pharmacological Treatments for POTS

The principle non-pharmacological treatments for POTS focus on addressing underlying symptoms. Compression stockings and abdominal binders are used to decrease blood pooling (Mar, 2020). Reconditioning through physical exercise is used to help regulate aerobic activity (Grubb 2008). An increase in water and salt intake is suggested for almost all individuals, as it can briefly lower or resolve certain symptoms (Low, 2012). It is suggested to avoid triggers of symptoms, such as standing up for long periods, hot baths or showers, and ingestion of alcohol, ingestion of caffeine, and any other personal triggers that varies person-to person (Oldenburg, 2002). However, it is impossible to avoid all triggers completely if individuals wish to live a relatively normal lifestyle.

Expected Contributions to Literature

This study will add to the previous body of literature in several fundamental ways. The results of this study will address the gap in the current literature on the relationship between the home environment and people with POTS to create baseline information for future research. Currently, there is no literature on how specifically the home environment impacts those with POTS (Dochod, 2022; Hollingsworth, 2022; Levine, 2021 Rich, 2020). This study identifies barriers within the home and symptoms affected by those problem areas. By identifying those areas, recommendations can be brought to light which add to the knowledge of the condition itself, as well as how to manage the condition with non-pharmacological adaptations.

In addition, after the research was completed, a draft of an Oklahoma State University Extension fact sheet was created that included study results and recommendations for environmental adaptations for people with POTS. While the fact sheet was not published during the duration of this study, the researcher has further goals of publication post-thesis submission. If published, this fact sheet can be widely distributed to individuals through the OSU Extension website and social media.

CHAPTER II

REVIEW OF LITERATURE

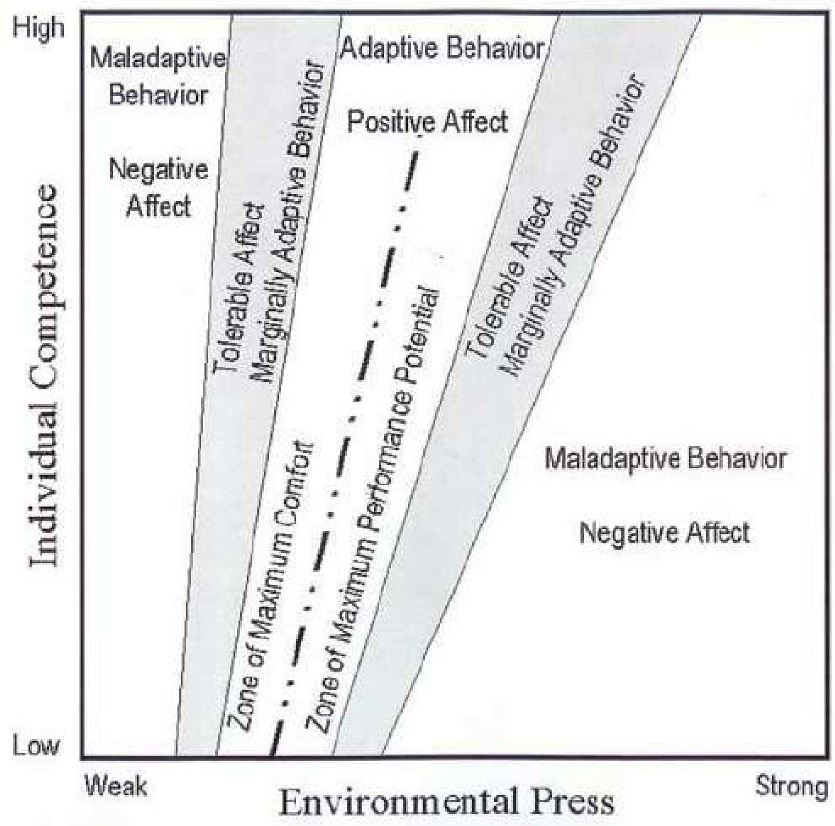
Ecological Press Model

The Ecological Press Model, also known as the Competence-Press Model, was developed by M. Powell Lawton, the U.S.'s first environmental gerontologist (Lawton, 1980). This model was first created in 1973 with the publishing of Lawton and Nahemow's explanation of *Ecology and the Aging Process.* The Environmental Press Theory is a further description of that model (Lawton, 1998). Figure 2 was designed by Lawton & Nahemow to express the Ecological Model of Aging. Figure 3 is based on the Ecological Model of Aging combined with the description of the Environmental Press Theory as a visual Theoretical Framework. Environmental Press Theory uses the constructs of environmental press and personal competence. Environmental press is any catalyst in a person's physical and social environment that puts demands on that individual (Lawton, 1973). Competency is defined by Merriam-Webster as "the possession of sufficient knowledge or skill" (Merriam-Webster, n.d.). While this is a good base definition, Lawton suggests that, when looking at an individual's set of competencies, more than just mental or learned abilities can affect an individual's competencies. Therefore, a person's physical and mental capacities should be identified.

Lawton suggests that, based on environmental factors, a person will have varying degrees of potential for performance. For instance, if a study room is not well lit, then the students may not be able to read documents well. This study will be guided by the conceptual model developed by Lawton in 1973, and previous evidence that POTS affects individual competencies within the environment, which can lead to either positive or negative effects.

Figure 2

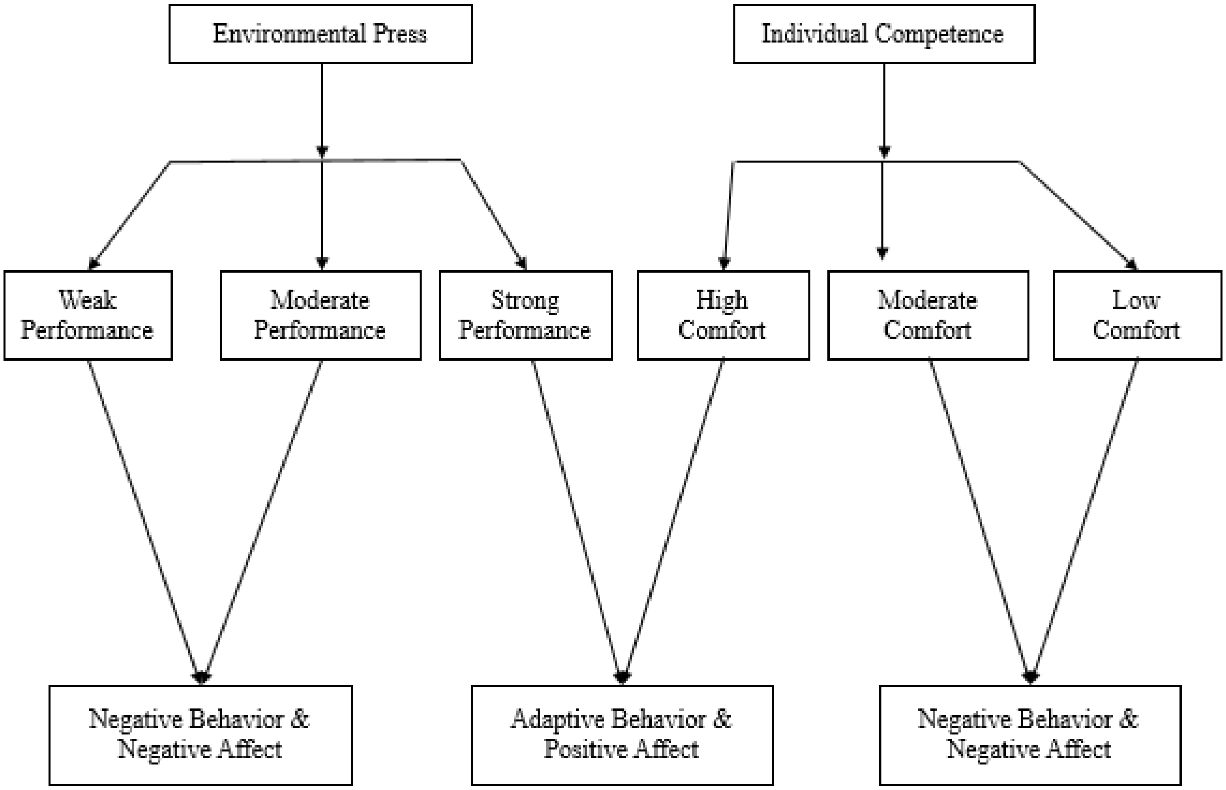
Ecological Model of Aging (Lawton, 1973)



This theory was used as it allowed the ability to analyze the stress or barriers an environment can place on individuals with pots and the individual's abilities to meet those demands with their personal physical and cognitive abilities. This is a very flexible and enlightening framework as it provides guidelines to find the intersection of the environment and how it influences people's competencies in this case people with POTS abilities to perform daily activities.

Figure 3

Ecological Press Model Theoretical Framework



Note. Based on Lawton & Nahemow's Ecological Model of Aging

Barriers due to POTS

Individuals living with POTS have a lower health-related quality of life, which can lead to a higher risk of suicide (Pederson, 2017). In a study of 624 people who have

POTS, almost half of the individuals reported being at a higher risk of suicide (Pederson, 2017). Those with POTS have higher scores for severity of pain, while reporting feeling as if they have less control over their life than control subjects. People who have POTS have reported feeling unsafe and unstable within their home environments (Anderson, 2014). As those with POTS are prone to fainting, they may be considered a fall risk according to their level of the condition and symptoms (Tinetti, 1986).

By identifying what specific environmental barriers there are in the home environment, interior designers can work to adjust or design spaces to support individuals living with POTS. However, current knowledge of these barriers is limited. For example, prolonged standing can be a trigger for POTS, as it is known to cause an increase in symptoms (Stewart, 2012). Exaggerated heat or cold can also trigger symptoms (Low, 2012), so it is suggested to use lukewarm water when bathing, even for showering. Additionally, it is recommended to use a shower chair to avoid long periods of standing. Symptoms of POTS when standing may be so intense for individuals that it limits their overall mobility, forcing some individuals to be wheelchair- or even bed-bound (Grubb, 2006). While these suggestions have been made, no studies have been conducted on the effectiveness of avoidance or implementation of environmental aids with POTS. More research is needed to determine what the principle barriers are for most individuals living with pots and how to reduce these barriers in the home environment.

Empirical Literature

POTS

The term “POTS” originated from Dr. Phillip Low in 1993 when a team of researchers at the Mayo Clinic were studying individuals who presented tachycardia during a head-up tilt test. Before its new term and eventual definition, POTS was called many different things: Soldier's Heart, DaCosta's Syndrome, Mitral Valve Prolapse Syndrome, Neurocirculatory Asthenia, Chronic Orthostatic Intolerance, and Orthostatic Tachycardia (Raj, 2006). Research related to POTS started soon after this identification, but an official definition was not made until 2009 (Low, 2009). Initially, researchers tried to understand and define what the condition consisted of and how to diagnose it more effectively (Thieben, 2007). The goal of these studies was to find the impact of POTS, through understanding it in its earliest stages of development (Grubb, 2008). Demographics and main symptoms were identified in previous studies, but the information remains speculative, especially as it relates to treatments. It took more than fifteen years just to define the condition, and studies have mainly concentrated on pinpointing the most common demographics and treatments for symptoms.

The most consistent findings of these studies are that most of the individuals were predominantly young, white, and female (Boris, 2018; Shaw, 2019; Thieben, 2007), which had been a predominant finding throughout the development of studies (Shaw, 2019). Thieben et al. (2007) first revealed statistics in a study of 152 individuals with POTS. The average increase in heart rate upon standing was 44 beats per minute. Of the individuals tested, 34.9 percent were identified as having a major adrenergic impairment, or dysfunction to the nerve cells controlling adrenaline, noradrenaline, or similar brain chemicals that act as neurotransmitters. This means that about half of individuals had a connection to neuropathy. With this added information, the condition began being considered a neurological defect along with cardiological. Common triggers of symptoms were identified as standing up, standing still, exercising, food or alcohol consumption, and exposure to heat (Thieben, 2007).

It remains difficult to generalize information on treatments, as each case varies on an individual level; information about POTS has continued to evolve since its definition (Raj, 2018). Recentl, people with the condition, caregivers of individuals, and even medical providers have felt a need to bring more awareness to the condition to encourage solutions to these problems (Shaw, 2019). With the aid of individual advocacy groups and social media, research related to the condition has grown immensely.

The main reason for the surge in studies can be attributed to individual advocacy groups and social media, which have a mission to provide education to individuals with POTS (Raj, 2018). Dysautonomia International, one of the first groups formed in 2012, is a group of parents and individuals who wanted to “make a difference” in the lives of people with related conditions. Another advocacy group, Standing Up to POTS, was founded in 2014 with a commitment to bringing awareness to the condition. These groups created social media accounts to reach POTS individuals looking for answers. These social media platforms have been able to bring POTS individuals and researchers together to further progress research. These platforms have even become a tool for researchers to recruit subjects. Some researchers have taken advantage of these groups to find subjects for larger, more generalized studies (Shaw, 2019; Ross, 2013; Wise, 2017).

When looking at the Dysautonomia International website, there is a dedicated tab for “Research,” (Dysautonomia International, 2019). There are sub-tabs under this heading where people can donate to the POTS research fund, look at and even participate in current research studies, sign up for the POTS Research Registry with ResearchMatch, and a compilation of tips and information for current researchers. From the individual side, people can find information on how to participate in current studies if they choose to pursue being a subject. There are links to several ongoing studies that are stated as either IRB approved or exempt and approved to be posted to the page by the Dysautonomia International board. Dysautonomia International worked with Research Match, a database that helps connect individuals with researchers who are studying medical conditions, to create the POTS Research Registry. Informational tips are given for researchers on how to acquire funding, recruit individuals, collaborate with other researchers, and the website even explains how to enter the group's annual conference.

As there is little current research on POTS and the built environment, this study will be exploratory with a focus on determining baseline information on the condition and interactions with the home environment. The purpose of this study is to gain more knowledge on how the home environment affects those with POTS through the use of activities of daily living and instrumental activities of daily living, such as sitting up, standing up, and walking. This research will investigate what activities increase POTS symptoms and how this impacts the patients. Results from this study will provide insight into POTS and environmental factors. From this study, further research can be broadened to determine what environmental accommodations may be recommended for the condition, and evidence-based design aids can be developed.

Dysautonomia

Dysautonomia is defined by the National Institute of Neurological Disorders and Stroke as "a disorder of autonomic nervous system (ANS) function that generally involves failure of the sympathetic or parasympathetic components of the ANS, but

Dysautonomia involving excessive or overactive ANS actions also can occur" (National Institute, 2019). The autonomic nervous system is in control of the automatic functions of the body, or anything that we do not consciously think about, such as heart rate, blood pressure, kidney function, and temperature control (Dysautonomia International, 2019). POTS falls under the category of dysautonomia, which is an umbrella term used for numerous medical conditions that cause a failure of the autonomic nervous system. People who have conditions that fall under this category have unconscious difficulty regulating these systems, which can lead to symptoms seen in POTS, such as lightheadedness, fainting, unstable blood pressure, and heart rate palpitations (National Institute, 2019).

Orthostatic Intolerance

Orthostatic intolerance is defined as "the development of symptoms of cerebral hypoperfusion or sympathetic activation while standing that is relieved by recumbency" (Low, 2009). In more general terms, orthostatic intolerance is the creation of symptoms—such as lightheadedness or dizziness—by upright activity that are relieved by reclining or horizontal positions (Stewart, 2012; Table 1). Most people can feel orthostatic intolerance when standing up too quickly or if they are currently ill (Stewart, 2012). Minimal orthostatic intolerance is normal for people to experience. However, when continually experienced, it can be incredibly debilitating to activities of daily living (Parsaik, 2012). The main symptoms associated with chronic orthostatic intolerance are syncope or fainting, memory loss, difficulty concentrating, vision impairment, lightheadedness, headaches, fatigue, nausea, sweating, abdominal pain, chest pain, and difficulty breathing (Mack, 2010; Stewart, 2012). As these are many of the symptoms of

POTS, it can be concluded that most symptoms of POTS are caused by, or are at least related to, orthostatic intolerance. The exact cause of orthostatic intolerance in POTS is unknown, as it can differ on an individual basis (Stewart, 2012).

Orthostatic Hypotension

The medical definition of orthostatic hypotension was determined by a Consensus Statement in 1996 as “Sustained reduction of systolic blood pressure of at least 20 mmHg or diastolic blood pressure of 10 mmHg within 3 min of standing or head-up tilt to at least 60 on a tilt table. Orthostatic hypotension is a clinical sign and may be symptomatic or asymptomatic” (Freeman, 2011). Orthostatic hypotension is a form of orthostatic intolerance that is defined by a fall in blood pressure after moving to an upright position (Oldenburg, 2002). POTS is characterized by the presence of orthostatic intolerance with a lack of orthostatic hypotension (Raj, 2006). Though those with POTS have orthostatic intolerance, they do not experience a drop in blood pressure. Even though POTS individuals do not usually have orthostatic hypotension tendencies, those with POTS do have similar symptoms of dizziness, blurred vision, headaches, lower back pain, nausea, and syncope (Oldenburg, 2002). Similar to POTS, orthostatic hypotension symptoms are seen to develop with upright activity and seem to resolve when lying down (Oldenburg, 2002).

Orthostatic hypotension is characterized as a large drop in blood pressure when an afflicted individual stands up (Maclean & Allen, 1940). If the individual lies back down, then the blood pressure will return to a more normal level. When an individual with orthostatic hypotension stands for too long, and their blood pressure drops to a very low level, then it is very likely that the individual will faint. Maclean & Allen (1940) studied how individuals that slept on a “head-up” bed can help relieve symptoms of orthostatic hypotension. The researchers looked at how the Mayo Clinic implemented a strategy of treatment for four different individuals with orthostatic hypotension and orthostatic tachycardia. The study showed that individuals who slept on a bed angled at 18 degrees improved symptoms of their conditions. However, there were only four individuals studied, and it is unknown if the doctors prescribed other treatments or medicine. Further studies on orthostatic hypotension individuals and the efficiency of head-up beds as treatment should account for this factor, as it could affect the validity of the results.

White (1980) studied the heart-rate changes of elderly individuals when standing. Sixteen of the subjects recruited had orthostatic hypotension, while 20 elderly subjects who did not were chosen as controls. The pulse rates of the subjects were recorded at one-minute intervals as the individuals laid down in bed and then stood up. The results of this study found that subjects with orthostatic hypotension had a lowered heart rate when standing. While White recorded the heart rate continuously, he should have broken up the act of standing up into more parts than just one, as there are several postural movements made in the process. For example, further research could have individuals relax in bed, then sit up vertically, then stand up, and lastly, continue to stand for a specific amount of time. A separate measurement of the heart rate could be made at each activity.

Orthostatic hypotension has been considered a risk factor for falls, but previous studies have failed to make a clear connection (McDonald, 2016). In McDonald’s study, beat-to-beat blood pressure monitoring techniques were used to compare levels of orthostatic hypotension using the standard and revised criteria for diagnosis to determine which method is more efficient in predicting future falls. Two hundred ninety-seven

(297) people older than sixty-five years of age were recruited for the experiment. A hundred of the participants were asked to write in a diary for a year describing and recording their falls. The study found that beat-to-beat monitoring and the 2011 criteria for orthostatic hypotension are the most useful tools in creating a clinical assessment of older fallers. Future studies on orthostatic hypotension should use the methods suggested by the McDonald study to help determine symptoms or do their analysis of the methods they use before the start of their experiments.

Smit et al. (1997) found that portable folding chairs helped improve blood pressure and reduced symptoms associated with orthostatic hypotension. The researchers noticed that people with orthostatic hypotension had difficulties in daily life due to their symptoms. They theorized that those with orthostatic hypotension could use portable folding chairs to relieve their symptoms. They recruited eight subjects who had been diagnosed with orthostatic hypotension. Even though some individuals had pharmacological treatments, they all still used some physical aide or maneuvers to reduce their symptoms in their daily life. The methods of the study were to have the different individuals try nine different maneuvers, with four different chairs. The maneuvers were done twice, and subjects were asked to do them in random order. The study found that subjects' symptoms were reduced when crossing their legs, regardless of sitting or standing up. The researchers suggest that individuals use a portable folding chair for their daily living. However, the study only looked at four types of folding chairs and did not ask how the individuals were feeling throughout the experiment. The researchers relied on measuring blood pressure and asking questions after the fact. Future studies on environmental factors should use a tactic that asks qualitative questions of the subjects throughout the tasks.

Smit et al. (1999) furthered Smit's previous research by identifying the favored choice of portable folding chairs by individuals who have orthostatic hypotension. The study attempted to create a generalization. However, the study only had 13 confirmed individuals with orthostatic hypertension as its subjects. The researchers asked the individuals to try out three different types of portable chairs that had sitting heights between 38-48 cm above the ground. These chairs were picked as they are commercially available and theoretically available for all individuals to purchase themselves. The individuals were asked to sit in the chairs without crossing their legs, maneuver about in them, then fold and unfold the chairs. They were then asked to walk with the chair. After all of this, the subjects were asked to respond to a survey. The study found that the best portable folding chair for individuals with orthostatic hypotension is typically a folding chair. To get more in-depth answers, individuals should be asked to describe their symptoms at the time of the activity, instead of after the fact. With a slight change in protocol, the subjects can best relay their most reliable answers and do not have time or other factors to influence the rest of the activities.

A study examining the effects of higher temperature months on individuals with orthostatic hypotension found that those afflicted have worsened symptoms and are at a higher risk for the condition to create more negative effects (Pathak, 2005). The researchers recruited 31 individuals with autonomic failure that were pharmacologically treating orthostatic hypotension. The amount of times individuals dealt with clinical events and the severity of their condition was tracked during August 2003 and the summer of 2004. It is unknown if researchers tracked the day-to-day temperatures; however, subjects were chosen on the basis that they lived in an area that would remain above 95°F during those months. The researchers conducted in-depth interviews with the individuals either during the clinical event or over the phone with the general practitioner after the fact. The individuals were asked to rank the level of severity of their attack on a scale from zero to three. While it was already known that high ambient temperatures can increase morbidity and mortality, this study demonstrated that individuals with orthostatic hypotension are at an even higher risk of those effects. This study had many limitations that mainly manifested in how the study was set up; it was difficult to control for external variables such as visits to hospitals for broken bones or otherwise.

Individuals with orthostatic hypotension and individuals with POTS tend to have an intolerance to heat, so taking extremely hot baths may cause negative reactions. A study done by Horvath & Botelho in 1949 looked at the physical responses of twenty-two subjects who were in seemingly good physical condition to extreme hot or cold baths. The researchers used 77°F temperature bath water for a control and had the subjects submerge themselves in the water for thirty minutes before conducting the warm temperature procedure. The water was then increased to 104°F and the individuals were asked to stay in the water for twenty minutes, after which the subjects were asked to lie facing upward and then sit upright. The subject’s heart rate and blood pressure levels were monitored at one-minute intervals during each position. The controlled temperature would then be introduced for another thirty minutes and then the same experiment would be repeated but with 64.4°F temperature water. The study found that eight of the individuals had abnormal responses to the activities in the extremely hot water.

Furthermore, four individuals experienced passing out, and the heart rates of individuals were reportedly up to the moments of fainting or extreme dizziness. Unlike the hot water activities, cold water did not produce any syncope or fainting in subjects, and there was only one abnormal response. As this study only recruited twenty-two subjects, it is difficult to generalize information. However, this study shows how those with orthostatic hypotension or POTS may react to a hot bath or shower.

The last study reviewed analyzed whether measuring with a composite autonomic severity score or a brief self-reported scale would show similar results of harshness for symptoms of orthostatic hypotension (Schrezenmaier, 2005). The study had a sample size of 145 individuals. Of those recruited, only 97 had orthostatic hypotension, which is just over half the subjects. Individuals were recruited over an inconsistent period, between August to October 2002 and then again in April 2004. Almost two years had passed before the second group of individuals was recruited. Much could have happened over that period to affect the individual's perception during that time versus if they took the experiment during the first trial. The survey for self-reporting had a section that asked if subjects experienced symptoms during exposure to heat, e.g. hot day, hot shower, hot bath. Another section looked for the level that which symptoms affect their activities of daily living.

There have been qualitative studies on individuals' choice of portable folding chairs for the use of relieving orthostatic hypotension (Smit, 1997; Smit, 1999). These studies looked at the effects of different portable folding chairs e.g. foot stools, fishing chairs, cane chairs, and derby chairs (Smit, 1997; Smit, 1999). The first study done by Smit et. al 1997 proved that using any type of portable chair could relieve symptoms of orthostatic hypotension. Subjects reported having lower symptoms when using the chairs, but still complained of comfort issues (Smit, 1997). The study concluded that the fishing chair was the most useful for individuals (Smit, 1997). Further research was done to find the exact preference of portable chairs for individuals, which concluded that folding chairs were the best option (Smit, 1999). Even though these studies have been cited subsequently to being published, none have dug deeper into environmental factors.

Like treatment for POTS, most treatments suggested for individuals with orthostatic hypotension are to avoid triggers of symptoms (Oldenburg, 2002). Those triggers may be similar to triggers for POTS, such as sudden changes in upright activity, e.g. head-up from a horizontal position or standing up, alcohol intake, and extensive exercise (Oldenburg, 2002). Treatments that have been suggested for both orthostatic hypotension and POTS symptoms are increasing the amount of water and salt in the diet, use of compression clothing, moderate reconditioning exercise, and implementing physical counter maneuvers (Grubb 2008; Low, 2012; Mar, 2020; Oldenburg, 2002). Further successful treatment that works for orthostatic hypotension such as sleeping in a head-up tilted bed (Oldenburg, 2002), or environmental aides like portable folding chairs (Smit, 1997; Smit, 1999) could be applied as a treatment for POTS, but more research would need to be conducted to prove this.

Conclusions Based on Literature

While there is little research on POTS and environmental adaptations, especially in the home environment, from research related to other similar conditions it can be concluded that with the addition of environmental aids or adaptations symptoms can be better managed and reduced. There may be beneficial aspects of chairs, stools, and shower chairs for those with POTS if applied appropriately. While current designs of environmental aids are a step toward helping resolve symptoms, there is a need for more research on how designers can create furniture and environments to help aid those living with POTS.

CHAPTER III

METHODOLOGY

This exploratory research study applies both quantitative and qualitative research methods to determine the impact of the home environment on individuals living with POTS. As most of the previous research related to POTS has been quantitative, the qualitative approach allowed research participants with POTS to share their experiences and the mixed methods approach allowed for comparisons in the qualitative and quantitative responses (Wisdom, 2013). The principle research question is in what ways does the home environment create supports or barriers to the competencies of individuals living with POTS? In addition,

- What are the principal physical barriers for people with POTS when navigating a home environment?
- How are individuals with POTS impacted emotionally when completing activities of daily living?
- In what ways are individuals with POTS impacted physically when completing activities of daily living?

The goal of the research was to determine the areas of home environments that are the most difficult to navigate for people with POTS, and what types of aids would be most helpful. To gain this information the research took place in two parts: Phase I was an online survey meant to identify common barriers for individuals with POTS in the home environment. Phase II was a focus group conducted with more probing questions about the impact of the environment on POTS individuals' mental and physical wellbeing. By breaking up the research into two phases within a mixed-method framework, the study was focused on gathering rich data for current and future analysis to help further understand the POTS experience at home.

IRB Procedures

As this study included the use of human participants by using data collected from voice recordings and employed a survey and focus group, this study was considered expedited but not exempt from the Intuitional Review Board (IRB). The researcher received approval in March of 2021 from the Oklahoma State University (OSU) IRB to conduct the study before proceeding with any phases of the study (see Appendix). The application contained required documents including the Phase I and II requirement flyer, the Phase I and II consent forms, Phase I survey questions, and Phase II focus group questions (see Appendix).

Phase I Online Survey

Participants for the Phase I online survey were recruited in April 2021 by direct messaging members of the private Facebook groups called “POTS,” “Dysautonomia International - Oklahoma Support Group,” and “Dysautonomia International College Student Support Group.” These Facebook groups each required verification from the group member of their condition before approval into the community. Individuals from these groups who showed interest in participating were sent a direct link to the survey.

The inclusion criteria for the online survey were that participants must have been diagnosed with POTS and were 18 years or older. To verify that participants did have POTS, the informed consent section of the survey stated that by participating in the survey participants agreed that to their best knowledge they had the condition. Responses from people under the age of 18 years old were not collected or stored.

As the survey was sent to three entire Facebook Groups' members which made up about 41,400 people, the researcher hoped to receive at least 200 responses. Instead, the researcher received 42 fully completed surveys.

Phase I Reasoning

There were advantages to engaging participants with an online survey during this time, which the researcher took into consideration. Some advantages were that respondents would be from around the country and the online data collection reduced the potential amount of errors as compared to a compilation of results from a hard copy of the survey. Additionally, no physical contact was needed to conduct the research (Owens, 2002). This was especially important as guidelines for conducting research during COVID-19 were more stringent and it was difficult to avoid risk factors (Boni, 2020). There were also disadvantages to conducting an online survey. For instance, not every person has internet access in their home or owns a computer, which may have reduced the number of responses from underrepresented populations (Owens, 2002). The advantages of using an online format outweighed the disadvantages for this research. The risk of in-person research was too high to ignore, especially for those with health conditions (Boni, 2020).

Phase I Survey Implementation

The Phase I survey was delivered online with Qualtrics and distributed to the group of individuals who have POTS and fit the inclusion criteria. The survey did not record information if the respondent was under the age of 18. The researcher hoped to get an equal 50:50 balanced ratio of male to female respondents, but expected that, since previous demographics showed that the condition is predominantly seen in women, it would be difficult to obtain the desired ratio (Boris, 2018; Shaw, 2019; Thieben, 2007). The survey had 45 questions with an approximate completion time of 30 minutes. Participants were asked to respond to as many questions as possible, however, they were given the option to opt-out of any question they did not feel comfortable with answering by choosing to not respond. The survey was set to automatically close after five weeks.

The survey included multiple-choice, Likert scale, and long answer questions. The questions focused on providing information on the individuals' demographics, activities of daily living, and environmental barriers or aids. See Table 2 for sample questions. Multiple choice questions gave respondents answer choices that are considered the easiest for subjects to answer and are also the easiest types of questions for researchers to analyze (Treadwell, 2019). Likert scale questions allowed the researcher to measure the subjects' opinions according to a scale (Hartley, 2014). There were also five open-ended questions within the survey. Having opportunities for open-ended, long answer questions elicited an emotional response from participants, which enabled the researcher to gain a better insight of knowledge of what they may know or how they feel

(Allen, 2017). Having mixed-use questions allowed the researcher to see a more holistic picture provided by the data (Hartley, 2014). The survey results were collected and stored on a secure online database. Follow-up questions asked if the respondents would be willing to participate in a virtual focus group. The follow-up questions helped determine the focus group participants, as those who indicated they would be willing were directly recruited for the Phase II focus group.

Phase I Data Analysis

The quantitative responses from the Qualtrics survey were collected, and numerical data was provided on demographics, the subjects' background information, and the Likert scale questions. Descriptive statistics were identified by using the online software SPSS Statistics. From the multiple-choice questions and the Likert scale questions, the mode percentages were gained from how many people answered a certain way; this identified the most frequently responded answers. The mean and standard deviation of the Likert scale questions were determined to find the average score and the spread of those scores. As this was exploratory research, T-tests and ANOVA were not conducted.

Phase II Focus Group

Using participants who agreed to participate in the follow-up focus group, Phase II of this study was a virtual focus group that took place two weeks following the Phase I survey closing date, which allowed time for the researcher to analyze the survey data. It was a virtual group in that it was conducted via Zoom, however, unlike many Zoom conferences and calls, the participants were requested to keep their cameras off while keeping their microphones on to maintain confidentiality.

Phase II Reasoning

To expand the information gathered from the survey, the focus group created an opportunity for more in-depth responses from the participants. Many people with POTS have reported feeling as if they are invisible, or as if their voice is not heard; the main purpose of the focus group was to hear that voice and analyze the responses collected (Anderson, 2014). As most of the research done on health, especially POTS, is quantitative, the qualitative responses allowed the researcher to identify the complexity of the issues surrounding POTS, rather than only highlighting the numerical data (Freeman, 2011; Powell, 1996).

Phase II Focus Group Implementation

The focus group was conducted over Zoom Videoconferencing to avoid any in-person contact risks associated with COVID-19. There were many positives to using Zoom for the focus group: it permitted the researcher to set up the focus group meeting virtually instead of physically, allowed participants to join regardless of geographical location, was easily able to record and save the entire focus group recording securely, and overall, the format may have been more appealing to participants (Archibald, 2019). The researcher was aware of potential problem issues with using the videoconferencing system, such as poor internet connectivity causing dropped calls and pauses, or a challenging time connecting to nonverbal cues (Archibald, 2019). However, while those issues were considered and prepared for beforehand, they did not arise during this focus group.

The number of focus groups was determined by the number of subjects recruited, but the researcher hoped to gather two groups of between four to eight people, or 16 individuals total. Based on availability, only four individuals were recruited for one focus group. However, a rich data set was still collected from those four individuals. The focus group was conducted over a secured, private Zoom call that was recorded and later transcribed and coded. The Zoom call was protected by using a password that was only given to the subjects and was distributed over email. The focus group questions were based on the survey findings, with the topics of the questions focused on finding specifics of trigger activities, aids that are currently used, ease of use of current aids, and an open discussion on what participants would like to see in the future regarding environmental aids (see Appendix). The focus group meeting lasted approximately one and a half hours.

Phase II Data Analysis

The focus group audio transcription was conducted manually to avoid any confidentiality risks from online automated transcription services. Content analysis then took place with the transcriptions in the following manner: when the data was fully transcribed, the researcher read all the responses from the focus group three times in total. During the second read-over, the researcher made memos about the transcriptions, noting two or three similar topics or ideas that emerged, all while highlighting quotations that stood out (Breen, 2007 & Krueger, 2014). Once that was completed, the researcher then went back through and reread the transcription to identify five to six total themes that emerged the most often; based on those themes and the quotations noted, a few sub-themes emerged. Throughout this coding process, the researcher highlighted and noted actual quotations from the focus group to determine the themes and then discuss them in the write-up (Breen, 2007). Then, the researcher placed the quotations under each theme and sub-theme that was most appropriate. During the third read-through, the researcher looked at both the transcript and the themes to ensure that the quotations were aligned with the themes and subthemes.

Fact Sheet Development

When both phases were completed, the results and analysis resulted in the preparation of a preliminary Oklahoma State University Extension fact sheet on recommendations for environmental adaptions for individuals living with POTS. Fact sheets are short documents that are meant to be easy to read and visually appealing (Kent State University Center for Teaching and Learning, 2019 & Dellett, 2018). They are typically only a few pages long, between one to two total, and present key information on a specific topic. They differ from an abstract in that they are not a completely text-based summary, and they provide more in-depth details on the results and analysis (Kent State University Center for Teaching and Learning, 2019 & Dellett, 2018). They are composed of bullet points and graphics to keep them short and to avoid long-winded sentences. The information presented comes from a study(s) or specialized professional to provide facts to the public on a specific topic (Kent State University Center for Teaching and Learning, 2019). These documents are meant to educate the public or a community about certain issues or areas of interest (Dellett, 2018). Besides educating people, the purpose of these documents is to make an argument for reasoning or a plan.

The content in the fact sheet used evidence found in the study in an easily read and comprehended format. The clearer and more concise the document, the easier it will be for someone with any level of education or understanding to comprehend the information presented (Kent State University Center for Teaching and Learning, 2019).

Since anyone interested in POTS must be able to access this information, providing a fact sheet is the most appropriate way of presenting recommendations.

The fact sheet drafted from this study shows only the essential information with bullet points. The researchers included two short quotations from the focus groups to include the voice of the participants. The fact sheet provides brief information on the literature review, common environmental triggers and symptoms, statistics and quotations from the study, and recommendations based on the findings. While the researcher produced the fact sheet within the duration of this study, it will not be put through the publication process until after the thesis completion.

CHAPTER IV

RESULTS & DISCUSSION

In this research, the use of both quantitative and qualitative data allowed for the identification of symptoms, triggers, barriers within the home, and an understanding of the need for environmental aids in the daily management of POTS. The descriptive statistics from the survey in Phase I focused on determining the types of homes participants live in, barrier in the home, and resulting symptoms of POTS. The focus group in Phase II allowed for a small group of participants to expand and elaborate on those areas. Phase I centered on the range of responses to needs in the home, while Phase II focused on the specifics of physiological and cognitive symptoms of POTS and how environmental adaptations at home may impact day-to-day life.

Phase I Survey

The Phase I Survey was developed with 45 questions that focused on the experiences of POTS within the home. There were five open-ended questions where participants had the opportunity to describe their experience with a text answer. Participants were asked to respond to all questions, but were not required to answer them if they did not feel comfortable. Each question may have a different sample size due to this fact.

Demographics

In the Phase I Survey, the total sample size was 42 individuals; however, since participants were allowed to choose to respond to questions each question may have a

Table 1

Phase I Survey Demographics

Sample Characteristics	*n*
Gender	40
Female	39
Non-Binary	1
Male	0
Age	42
19-25	24
26-30	3
31-35	3
36-40	3
41-45	4
50-55	2
56-60	1
61-65	0
66-70	2
Ethnicity	41
Caucasian	35
Other	4
African American	1
Middle Eastern/Arabic	1

Note. As participants were not required to respond to all questions $n \neq 42$ for each question.

varying sample size. The participants ranged from 19-70 years old with a mode age of 23 and median age of 24. Thirty-nine of the participants were female, while one identified as non-binary. There were no male participants. This was expected as POTS is female dominated. In Shaw's study of 4835 participants, 94 percent were female (Shaw, 2019). This prevalence is seen throughout previous research (Boris, 2018; Shaw, 2019; Thieben, 2007). 85.37 percent of 41 participants identified as Caucasian. Table 1 shows the survey demographics. 100 percent, or 40 responses, stated that participants lived in North America. Participants had been diagnosed with the condition from between one month to ten years; prior to diagnosis individuals had gone undiagnosed for as long as 42 years. Before diagnosis, participants reported living with symptoms undiagnosed at 99.05 ± 148.28 months.

Quantitative Findings

With a n= 40, perceived health was placed on a scale for Bad 1, Fair 2, Neutral 3, Good 4, and Excellent or Very Good 5. No individuals reported having excellent or very good perceived health. It was found that perceived health's mean and the mode was described as fair with a mean of 1.88 and a standard deviation of 0.97. Most survey participants lived in single-family homes at 62.5 percent, while 32.5 percent lived in apartments, condominiums, or duplex homes, and 5% lived in a home described as "other." Of 32 responses 23, or 71.88 percent, reported having stairs in their home while 9, or 28.12 percent, reported they did not.

When asked how often they felt symptomatic when sitting up, standing up, or walking, 76.32 percent responded multiple times a day. Table 2 shows what areas of the home participants struggle. More than half of the participants reported having symptoms in the bathroom, bedroom, kitchen, and laundry room. While Table 3 shows what general activities in the home they feel symptomatic from, more than half of the participants reported having symptoms when cleaning,

Table 2

Problematic Areas within the Home

Areas of Home	*n*	Percent
Laundry Room	30	71.43
Bathroom	29	69.08
Kitchen	29	69.08
Bedroom	24	57.14
Living Room	15	35.71
Dining Room	14	33.33

Note. n = 42

Table 3

Problematic Activities within the Home

Activities	*n*	Percent
Cleaning	34	80.95
Standing	33	78.57
Vacuuming	32	76.19
Climbing stairs	30	71.43
Getting up or going to bed	28	66.67
Walking	23	54.76
Getting up or down from a chair	22	52.38
Sitting up	20	47.62
Sleeping or napping	16	38.1

Going up or down a ramp	7	16.67
Adjusting the a/c or heating controls	6	14.29
Locking or securing home	4	9.52

Note. $n = 42$

climbing stairs, getting up or down from a chair, getting up or going to bed, standing, vacuuming, and walking.

The next questions were more focused on specific areas of the home and activities that created symptoms. The main activities with issues within the kitchen showed that 50 percent or more of participants had symptoms while cleaning dishes while standing, cooking at a stove while standing, eating while standing, preparing food while standing, and putting away dishes or groceries while standing. The most reported activity with difficulty in the kitchen/dining room was putting away dishes or groceries while standing. 32 participants, or 76.19 percent, reported having symptoms from putting away dishes or groceries while standing. This was followed closely by 31 participants, or 73.81 percent, reporting symptoms occurring while preparing food while standing. Within the living room, at least half of the participants reported needing assistance or feeling symptoms when getting up from a chair or sofa and having someone else bring items to them. Twenty-four participants stated having symptoms or requiring assistance when getting up from a chair or sofa. Within the bedroom half or more participants responded having symptoms while getting up from the bed, making the bed, and retrieving clothing. Making the bed had the highest percentage at 66.67 percent, or 28 participants. Almost half or more of the participants had symptoms when showering, bathing, and shaving. 33 participants said they had symptoms while showering, while 26, or 61.90 percent, had symptoms while bathing. At least half of the participants reported having symptoms when loading/unloading both the washer and dryer, and folding clothes.

Table 4

Recovery Time after an Episode

Quantitative Test	Time in Minutes	Time in Hours
Mean	126.83	2.11
Median	10	0.17
Mode	10	0.17
Range Min	0	0
Range Max	1440	24
Std. Dev.	376.6	6.28

Note. *n* = 42. Recovery Time is 126.83 ± 376.59 minutes.

The time it takes to recover from an episode was seen as 126.83 ± 376.59 minutes in Table 4, with a mean of 126.83 minutes and a median and mode of both 10 minutes. The range of duration is anywhere between 0 minutes to 1440 minutes or 24 hours.

The next questions were more generalized on POTS and home activities. Of the participants, 64.87 percent reported avoiding activities about half of the time to most of the time. No participants reported never avoiding activities. 89.18 percent of participants report that POTS impacts freedom at home from a moderate amount to a great deal. Half of the participants reported using a shower chair or stool. 54.05 percent of participants reported that none or very little information is available on environmental aids. 35.14 percent of participants stated that there was some information available on environmental aids but could use more. 89.19 percent of participants somewhat agree to strongly agree with the phrase “Environmental aids or technology are too expensive to be accessible.”

Survey Summary

This study's demographics were predominately younger, Caucasian females. The survey showed that more than half of the participants (71.42 percent) were between the ages of 19 and 25. When looking at the quality of life for those with POTS, individuals self-reported that they fell on the lower side of the spectrum and none believed they were in good or excellent health. It was found that most individuals with POTS feel symptoms multiple times per day, if not constantly. Additionally, the average time it can take to recover from symptoms is two hours and 11 minutes. Most respondents with POTS had difficulties or experienced symptoms with the following activities: cleaning, climbing stairs, getting up or down from a chair, getting up or down to a bed, standing, vacuuming, and walking. The main areas of the home where respondents experienced symptoms related to POTS were the bathroom, bedroom, kitchen, and laundry room. Survey data showed that within the bathroom individuals had symptoms when bathing or showering. In the bedroom, many had symptoms from getting up from a bed, making a bed, and retrieving clothing. It was brought to light that in the kitchen the most prominent bothersome activities were standing while cleaning dishes, cooking on a stovetop, preparing food, and putting away dishes or groceries. In the laundry room, many people with POTS had issues with loading or unloading the washer and dryers, and folding clothing.

Phase II Focus Group

Analysis of the Phase II focus group data results in the principal themes of triggers, physiological responses, cognitive responses, and environmental adaptations. The subthemes for triggers were standing, bending, daily tasks, and heat intolerance.

Physiological response~~s~~ subthemes were blood flow/blood pooling and aching/pain. The subthemes for cognitive responses were depression, anger, and brain fog. Stools/chairs, shower chairs, mobility devices, and assistive technology were the subthemes for environmental adaptations.

Table 5

Phase II Focus Group Demographics

Coded Name	Gender	Age
P1	Female	68
P2	Female	42
P3	Female	23
P4	Female	35

Demographics

There were four participants in the Phase II focus group. All participants were female and ranged in age from 23-68. Table 5 shows the demographic data for the Phase II focus group. Focus group participants were recruited from the survey. The last question asked in the survey was whether participants would be willing to participate in the focus group. If they were willing, they left contact information that the researcher used to contact them.

Themes

The principle themes of the Phase II Focus Group were triggers, physiological responses, cognitive responses, and environmental adaptations. The principle themes and their subthemes can be seen in Table 6.

Table 6

Qualitative Themes

Theme	Definitions	Example	Subthemes
Triggers	Are activities that lead to negative symptoms for POTS	"I know for me, the home office is a difficult place for me. You know, just sitting up for long periods of time at a computer it's uncomfortable."	standing, bending, daily tasks, heat intolerance
Physiological Responses	Are the effects of triggers that are related to the physical body	"The blood just pools away from the brain."	lack of blood flow/blood pooling, aching/pain
Cognitive Responses	Are the effects of triggers that are related to the emotional state	"I think the executive tasks I try to get done in the earliest part of my day. It's very hard, I started thinking I was getting dementia or something."	brain fog, anger, depression
Environmental Adaptations	Are an environmental aid that can be added to the home to lessen the frequency of triggers	"I often have to sit down on a stool to recover after a certain amount of time."	stools/chairs, shower chairs, mobility devices, assistive technology

Triggers

The focus group participants described triggers as “activities that bring on symptoms that can be debilitating.” A trigger for someone living with POTS can lead to several potentially negative and varied outcomes. Triggers differ from symptoms, as symptoms are the reaction(s) that occur~~s~~ after the trigger. Triggers can be seen as the cause, while symptoms are seen as the effect. A trigger can be one or multiple events or actions which result in the symptom. Multiple triggers may result in compound reactions or symptoms.

Triggers can be simple activities, such as just getting up from a seated position. That can mean that individuals with POTS are constantly having to adjust their lives to minimize their symptoms. This can be exhausting, as individuals with POTS are forced to prepare for small tasks. While this preparedness can become routine, and routine can become sub-conscious, not all activities are done each day so routines need to be maintained or they have to be continually relearned. Triggers can include anything that can be considered regular activities of daily living such as walking, standing, sitting for prolonged periods, climbing, or descending stairs, bending, reaching, cleaning, cooking, and gardening. Heat intolerance is another trigger that can arise at any time (Goodman, 2018).

Triggers were the main topic spoken of by participants throughout the focus group and a variety of topics within this theme were communicated during the focus group. In general, experiences with triggers were based on each individual's experiences, however, most participants had had similar experiences and were able to relate to each other’s comments. The principal triggers that were described were standing, bending, reaching, and daily tasks which require these actions such as cleaning and gardening. The likelihood that a trigger would cause a negative symptom tended to increase with further activities such as climbing stairs, not having enough electrolytes in the body, and experiencing a menstrual cycle.

Standing. POTS patients have orthostatic intolerance, or intolerance to standing (Low, 2009), therefore it is not surprising that standing is a major trigger for most individuals with POTS. Standing was one of the first triggers discussed within the focus group. For a person with POTS, this simple task can become very strenuous. Any activities that require standing for an extended period, or getting up and down from a seated position were seen as difficult to the individuals with POTS. Other triggers compounded with standing can cause physical and cognitive responses (Olshansky, 2020). As an unavoidable activity, standing can cause rapid heart rate, muscle pain, and even fainting. This may be the most difficult to handle trigger as it typically caused the most dangerous physical responses of all the recognized triggers.

Standing was a recurring trigger discussed by all the participants and they talked about how prolonged standing can also cause a plethora of symptoms. Those symptoms can include but are not limited to blood pooling, aching or pain, and even syncope or fainting. Blood pooling is defined as when the blood is unable to pump back up to your heart, and pools or collects in your legs, ankles, and/or feet (Vayuvegula, 2022). For the participants, it was described as “aching or numbness in the legs or feet.” Many participants explained that the majority of the time that they were standing was in the kitchen. All four participants thought standing in the kitchen could be a major trigger for them. P3 explained, “[The] kitchen is a big trigger for me, cutting vegetables, washing dishes, and any prolonged standing." She went on to summarize the multiple symptoms which can result from standing, "A big challenge when I am standing up in the kitchen is not only the blood pooling in my feet but the muscle aches start kicking in and I get a lot of back and shoulder pain."

Another problematic area of the home was the bathroom. This is because the amount of standing that needs to be done to complete any hygiene activity requires a lengthy period, such as brushing teeth, shaving, brushing hair, makeup application, etc. A third area of the home that was discussed was the bedroom. Participants explained that simply getting out of bed in the morning, from lying down to a standing position, could be a trigger that led to symptoms.

When discussing these three areas: the kitchen, bathroom, and bedroom, participants described having regular symptoms and having to use at least one or more environmental aids, such as chairs or stools, to combat the symptoms due to triggers. There was shared frustration that standing within the home is such a taxing activity. Participants indicated that the kitchen, the bathroom, and the bedroom need more environmental aids or intentionally designed furniture/technology that allows individuals to get relief from their symptoms.

Bending. Bending is another trigger; it can be any movement from an upward position to a downward position, or vice versa. Bending activities could include putting shoes on, putting groceries away, putting dishes away, gardening, and many other activities of daily living. Bending is unavoidable, as there are not many current environmental adaptions that can aid in completing the tasks that require it. Additionally, bending is more difficult to incorporate into a routine, so it becomes more difficult to prepare for. Individuals partake in bending tasks multiple times a day (To, 2019), therefore this can mean individuals with POTS are experiencing symptoms that are debilitating multiple times a day.

Bending can cause symptoms such as balance issues, dizziness, and fainting. While symptoms may not be as serious or dangerous as prolonged standing, they do cause unavoidable symptoms. P2 described her experience in the following way, “I think, like bending, getting pots and pans from the lower cupboard, putting things away or getting things out of the dishwasher. Any kind of up-down, up-down in the kitchen I know is rough for me.”

Participants explained that a symptom episode can last after a bending trigger anywhere from a few seconds to several minutes. P2 described those symptoms in this way:

> [The recovery time] depends on how fast I can sit down, or lay down, or get salt into me, I’d probably say five-ten minutes. It’s kind of hard to say because there are different levels of episodes. I have kind of minor episodes where I stand up from bending over and that lasts maybe five seconds. Then, there are more serious episodes where I have to stop what I am doing, lay down, get water, get Gatorade and salt food, and those last maybe 5-10 minutes.

The other participants agreed and spoke of how often the only way to recuperate is to stop, lie down, drink water or Gatorade, and wait for the symptoms to subside.

These triggers can be brought on at any point, as most individuals do not have a routine that can avoid bending, thus, preparing for bending cannot always be planned out. Even with environmental aids, leaning over and coming back up to the upright position cannot be avoided, as many activities must be done with this motion. Participants found it difficult to prepare for bending, as it can be done unexpectedly such as if they are walking and have something fall from their hand, which causes them to automatically bend down to pick it back up.

Daily Tasks. This trigger sub-theme is more generalized in that it covers house cleaning, gardening, and preparing meals, which can all be daily tasks. All participants discussed how house cleaning can be a trigger and agreed that they often made efforts to completely avoid these tasks, or have had to change or alter the method of completing cleaning tasks to avoid triggers and symptoms.

Often there were times daily task activities were put off by the participants or avoided until the last minute, as they contribute to common areas of discomfort. Other times participants spoke about completing these activities sporadically to lessen the overall time of the trigger or having to take breaks to fully complete these tasks. While two participants shared that they hired a cleaning company to do the majority of their housework, the other two participants stated that this was not a cost-effective or affordable option for their lifestyle.

Heat Intolerance. The symptoms participants spoke of due to heat intolerance were extreme and often occurred in the kitchen while cooking. Oftentimes, activities that create heat can cause multiple triggers. For example when cooking, individuals not only experience heat from the stove, but they are also standing to prepare the food.

When discussing heat intolerance or feeling overheated, the participants described the different symptoms triggered by heat. These symptoms could be a racing heart, feeling faint or heavy sweating. A minor episode can be addressed by waiting to do any additional activity for a few minutes with something cold against the body. Other more dramatic episodes can cause participants to have to change clothes, lie down, aim a fan directly at them, or turn the temperature down in the house and drink a lot of electrolytes.

The bathroom is another area where heat intolerance from showering can trigger symptoms. One person articulated that they can no longer take showers since the heat creates so many uncomfortable symptoms that they completely avoid the activity. She explained,

> There are a lot of things I just can't do anymore and I just have to accept that. I can't shower anymore, even with a shower chair, because it is too upright. So I have to take baths. That usually takes my credits for the day. I know I usually can't complete any other activities the rest of the day. That stops me from completing any other activities around the house, especially if I wash my hair, no matter how much I prepared for it.

It is important to note that most people stand to take a shower unless they have a shower chair. Not all people with POTS are aware of environmental aids, so they may not have a shower chair. In addition, if someone is taking a bath rather than a shower, they must bend and reach, which are other tasks that can trigger symptoms.

The participants agreed that heat intolerance along with standing can trigger a cluster of symptoms. One participant explained her difficulty traveling due to not being able to control the temperature. This problem can occur daily when moving from an indoor temperature that can be monitored to outside, where temperatures cannot be monitored. The same participant also shared that she is no longer able to travel outside of the country at all because many other countries outside of the United States do not have air conditioning. She described her experiences in this way:

> I spend a lot of time wearing cooling towels, even in the house. Keeping cool, fans everywhere. Or just staying cold all winter with just shorts on. I don't sleep with sheets or blankets on either, typically. I don't have a problem with getting too cold usually. That sort of knocks out traveling though, because there are too

> many places without air conditioning in cars and buildings, especially in other countries.

All the participants agreed that losing consciousness or fainting was the main symptom of any activity that can be caused by heat intolerance and that once they reach a certain level of heat within their body, it is difficult to cool their body temperature back down. The participants spoke of how it can take up to 20 to 30 minutes to recover from these episodes and it can often lead to a difficult recovery, which often has to be helped with medical attention.

Heat intolerance can be one of the most dangerous triggers of POTS symptoms and can be potentially life-threatening, as the episode is often longer than other symptoms. While no one with POTS is known to have died of the actual condition, the symptoms of heat intolerance could potentially put them in such danger (Wells, 2017). Symptoms of heat intolerance often include fainting, which can put participants in danger of bodily harm, such as head injuries or other injuries (Low, 2009). This is particularly dangerous in settings such as the shower or bath where water and condensation can create an unstable situation where individuals could slip and fall when passing out (Stevens, 2011).

Physiological Responses

Physiological responses are normal functioning responses of the human body that automatically occur. An example of physiological responses for POTS patients is an increased and maintained heart rate without a change in blood pressure upon standing up (Olshansky, 2020). For those living with POTS, blood pooling, aching/pain, and dizziness can cause discomfort and potential trauma.

Lack of Blood Flow/Blood Pooling. One physiological response noted by many of the participants was either lack of blood flow or blood pooling. A lack of blood flow was experienced as dizziness, numbness, and tingling, which typically went on in the lower body, specifically the feet. Participants explained that blood pooling was often followed by other negative symptoms, such as brain fog, dizziness, and muscle aches. Brain fog was described as the inability to think clearly for a defined amount of time. Within the focus group, the participants pinpointed the causes of brain fog as standing for too long, sitting in one position for too long, or any stressful activities. Stressful activities are described by P4 in the following way:

> Doing any kind of thinking, trying to remember, the process of looking at an email, and thinking "Oh, I have to send a file to somebody" and then finally getting that file to somebody. It just has so many steps in there that my brain goes off the track so many times for something that should be a simple task.

Blood pooling was often paired with other responses, whether that be physiological or mental. Blood pooling, because of standing, can cause brain fog or confusion. This can be disorientating for people with POTS and that can disrupt their entire day. While direct recovery could be as soon as 30 minutes, often the rest of the day has to be dedicated to recuperating. As the simple act of standing can cause blood pooling for people with POTS, this act, when prolonged, can prevent people with POTS from having a normal day.

Aching/Pain. When participants mentioned pain as a symptom of POTS, it was often in several areas of their body, depending on the activity, and muscle aches were often experienced. The pain was more defined as "sharp and instant," whereas aching came on overtime and was described more as "soreness." As mentioned before, blood pooling is often experienced with pain. Prolonged activities like standing can cause blood pooling, which creates muscle fatigue, which causes pain. A simple task was often seen to create a domino effect. P3 explained her experience:

> I'd say for me, a big challenge when I am standing up in the kitchen is not only the blood pooling in my feet, but the muscle aches start kicking in. I get a lot of back and shoulder pain, then I start getting a lot of muscle fatigue and I start getting swelling in my feet because of the blood. After a while, this gets to be really uncomfortable.

The symptoms often compounded, leading to multiple issues at once. By standing up for a few minutes, blood begins to pool in the feet, which then leads to muscle fatigue, which then leads to swelling, aching, and further pain. Regular activities throughout each day, such as standing, can create a lot of discomfort for someone with POTS. Once the pain is onset, it can often take 30 to 45 minutes to recover. Physiological responses cannot be adjusted, only reduced with the use of environmental aids, medication, or alternative methods.

Cognitive Responses

In addition to physiological responses to POTS, there are also cognitive responses. For this study, cognitive responses are mental reactions to triggers, symptoms, or the condition itself. Unlike physiological responses, participants felt that they had a little more control over their cognitive responses and behaviors.

Brain Fog. One cognitive response that seems to be a reoccurring theme for all participants is brain fog. Brain fog was described as making it difficult to do any activity that required thinking or remembering or drawing from the mental capacities of the brain. Participants disclosed that brain fog was experienced less at the beginning of the day, however, by the end of the day, participants often had a hard time thinking clearly due to the accrued triggers and symptoms. Participants explained that they consciously tried to do activities that required more mental capacities in the morning. As PI stated:

> I think the executive tasks I try to get done in the earliest part of my day. It's very hard, I started thinking I was getting dementia or something. It's just a fatigued brain, and it does get worse by 5:00 or 6:00. I don't try to do all my thinking late at night.

Some participants described being unable to avoid or accommodate their brain fog. This meant that they had to work through daily tasks much more slowly than normal. A task, such as sending an email, which normally only takes a few minutes can take much longer due to brain fog.

Anger. All of the participants described experiencing feelings of anger due to POTS. Their anger is usually caused by the current frustration they must deal with. P2 shared her experiences which caused anger due to the time and effort to get a validation of her symptoms:

> It took me a year to get into the POTS specialist, so it is a lot of waiting. I have been seeing my cardiologist since 2015, but he is an old-school cardiologist. When I told him I think I have POTS he said, "Oh there is nothing I can do about that, so just carry on."

One participant described her anger at being completely ignored by their contractor when asking for handicap accessories that would be beneficial to reducing her symptoms. Several participants disclosed they held anger with their family members who did not understand what they were going through with POTS, and with their medical professionals as they were often undiagnosed and ignored by the medical community.

Depression. Depression can include several symptoms such as sadness, loneliness, or feelings of being out of control (Anderson, 2014). Several participants mentioned feeling alone or sad as they often do not feel seen or heard when it comes to their condition. While their symptoms may not be terminal, they are extreme, yet they felt when they communicated their feelings to family and medical professionals that they were ignored. The general public is typically uneducated or unaware of the subject of POTS and the condition is often misdiagnosed (Kavi, 2012; Mar, 2020). Participants have been misdiagnosed by doctors with general anxiety disorder, which can add to depression as the impact of POTS on their life is downplayed. P2 explained general reactions to her POTS in this way, “Yes, when you are not dying there is a different response, 100%. You are not acute, so (some think) ‘what’s the problem?’” POTS can cause many difficulties in daily living and individuals need support, yet they feel ignored by their friends, family, and the medical community. P1 spoke about her experiences in this way:

> I am kind of left alone to a certain point. You have your doctors, but half of them don’t care either. I can’t be responsible for all these people’s ignorance. On top of trying to get better myself, I can fix some things and improve others, but it is a very steep curve. I tend to fix things or help myself, I don’t think I can rely on anyone else.

Participants strongly agreed that doctors did not appear to understand nor properly treat the condition, and that with a diagnosis of POTS they are still unrecognized and unseen. PI explained:

> Thankfully my doctor knows a lot about POTS, but even she will fall back on “Well why can’t you just exercise and walk?” I told her there is no way I could do that because that’s a lot of walking. I am not going to walk that much. As a cardiologist, that is their main thing. “Get exercise, get out there, and move!” That is just not something I can do. Sometimes my doctor just forgets. She is usually good, but I think her training just seeps in sometimes. I don’t feel sorry for her though, they should all be up to speed as doctors. It’s hard to find someone who follows what we need well.

Treatments for POTS do not align well with the diagnosis, oftentimes leading to feelings of isolation and depression. As there is no official pharmacological treatment that has been approved by the US Food and Drug Administration (USDA) for POTS, recommendations made by doctors are based on trial and error, and the little known research done in the recent past (Grubb, 2008). Some treatments do not work at all for patients, and when treatments do work they often produce side effects similar to already-presenting symptoms of the conditions (Mar, 2020). When going to the doctor, POTS patients wish for answers, not more unknowns. Patients expect their doctors to know how to help solve their health problems, they wish for answers, not more unknowns. this can lead to a lost feeling and further depression, as they are unsure who and where to turn to next.

Environmental Adaptations

Stools, chairs, shower chairs, and mobility devices are all known to help support people with disabilities. It is possible to relieve symptoms of orthostatic hypotension related to POTS through the use of portable folding chairs, as their use can help improve blood flow (Smit, 1997). Shower chairs or seats are recommended, as they can reduce symptoms, lower efforts related to hygiene practices, and reduce the energy needed to stand while in the shower. Seated showering is done to help preserve energy that can be used on other more significant activities (Yaghobian, 2015). Wheelchairs have been found to help limit orthostatic symptoms for those with POTS (Inskip, 2017).

Stools/Chairs. Many participants use stools throughout their homes to complete tasks because they are taller than household chairs, therefore making some tasks easier. Stools also are easier to move around than traditional chairs, as they are lightweight. Participants explained that by using stools they can alter the rigor of tasks and are better able to complete them. Two places this can be seen are in the kitchen and the bathroom. In the kitchen, stools are pulled around to sit on while loading and unloading the dishwasher, preparing food, putting away groceries, and any other activities that are common within the kitchen. For other activities—such as putting dishes away, organizing, or folding dishtowels—that need to be done closer to the floor, participants either squat or sit down fully on the ground. Within the bathroom, participants explained that it is easiest to complete hygiene routines while sitting. This can be anything from brushing teeth, washing the face, brushing hair, and putting on makeup. Participants each spoke of adapting their activities within the bathroom by using stools.

The participants agreed that even though stools are helpful and convenient, they bring a new set of difficulties. Often it was necessary to try several different options to fit their needs. Some stools can be too high, while others can be too low to reach the countertops. Some stools can be uncomfortable to sit in for too long without a cushion or are too small. Some stools can have too much of a cushion and make it difficult to complete activities because they are imbalanced, while others are too big for the space and make it difficult to navigate when standing.

Shower Chairs. Shower chairs are different than stools, as they are specifically used within the bathtub or shower. All but one participant described using a shower chair, the other participant only used the bathtub rather than the shower. As previously discussed, standing for prolonged periods and heat intolerance are both triggers brought on by the activity of showering. Using a shower chair appeared to help participants complete the task while reducing the number of symptoms. As P4 put it, “I use a shower chair. It has been life-changing using a shower chair.”

While these aids do help with symptoms they still have negative aspects. They generally are not appealing aesthetically, they are difficult to clean, they are unbalanced and bulky, and they can skid on the slick surface. People with POTS need to have both an environmental aid that reduces their symptoms and is aesthetically pleasing. As P2 explained,

> Personally, I like that they are effective but they don't look so cute. You have this beautiful bathroom, you work to keep it nice, and then you just have this "old lady" shower chair in my shower. How it looks, I wish there were things that were cute and looked nice but are medical grade. Because, when I looked to see what kind of shower chairs I could get, I could get the really grippy sturdy medical one or there was one that looked really pretty but I am sure would like to skid all over the place. So, I had to make a choice between function and looking cute. I wish there was the option to be cute and functional at the same time.

Environmental aids such as shower chairs have a stigma, both due to the need to use them and their aesthetics, which impact the user. Participants described not only wanting to minimize symptoms with these aids but also to feel good about themselves doing so, therefore both form and function should be considered in these environmental aids.

Mobility Devices. A few of the participants expressed that they like to use a walker or cane. This helps them adapt to their environment, whether that be within the home or outside of the home. The topic of this study was to explore the home environment, but participants often discussed experiences outside of the home, as well. Walkers and canes were found to help participants navigate space and alleviated symptoms momentarily. One participant described feeling that these aids bring more visibility to their condition, as without an aid most people do not notice that they have a disability. The perception of a disability often leads others to be more supportive and willing to be helpful. As P1 explained,

> I will say, using a walker, it kind of broadcasts you have a handicap. I don't look like I am disabled, but as soon as I have a walker or cane even, everyone is open doors. You get to go to the front of the line.

The cue of using a mobility device conveys that people with POTS may need additional help.

None of the participants used a wheelchair regularly, but several did mention that it would be helpful if they had an automated one. They saw them as more comfortable and easier to use than a cane because they would not have to get up and down from a seated position. However, they did mention that wheelchairs take up a lot more space than a walker or cane and are difficult to maneuver within the home. There is often not sufficient space to accommodate wheelchairs, particularly in the bathroom.

Walkers and canes were also discussed as being very beneficial within the home. Instead of using a stool, a walker or cane could be used as an aid for short-term mobility navigation or leaned on to help alleviate symptoms from standing for prolonged periods. Walkers with seats are another mobility alternative and are typically reasonably comfortable. P1 explained, "The seated [walkers] really are helpful. They're pretty comfortable... Even on my good days I just bring it with me, because I don't want to get stuck in a long 45-minute line somewhere." While a piece of furniture like a stool fits within the home's aesthetics, a walker or cane has more flexibility and is less heavy and more mobile.

Assistive Technology. Assistive technology is any technology that can help people living with POTS ease their symptoms. Assistive technology was used by participants in many ways. Several participants acknowledged having an Apple Watch or Fitbit to track their heart rate, oxygen levels, or even their sleep patterns to help prevent drastic symptoms. Many had used automated electronic notifications, so they did not have to actively watch their heart rate. In the event that they received notification that their heart rate was spiking, they knew that other symptoms, such as dizziness or fainting, were soon to follow. Participants said that they were able to adapt and prepare for those subsequent symptoms by sitting down, drinking water, or other actions depending on the situation. Prior notification of oncoming symptoms allowed time to prepare and prevent further discomfort.

Apple Watches can detect falls, drops or rises in heart rate, and monitor heart pulse patterns (Time, 2019). One study that partnered with Apple found that the Apple Watch notifications are reliable, as 84 percent of the time they matched with Electrocardiogram (ECG) readings (Perez, 2019). This Perez study concluded that users of Apple Watches could correctly use technology to identify atrial fibrillation or an irregular or rapid heart rhythm (Perez, 2019). One paper suggests that AI technology could help doctors predict something is wrong with a patient many minutes before an episode (Mims, 2018). This can be translated to POTS patients, as easy-to-read notifications tell that their heart rate has already spiked (Time, 2019) at the moment, which means they need to go ahead and implement known methods to reduce their heart rate. Apps such as Heart, which are automatically downloaded to the system, record background data of heart rate throughout the day so POTS patients can monitor their fluctuations (Time, 2019). This could help pinpoint certain strenuous activities to avoid or prepare for in advance.

Besides an Apple Watch or Fitbit, other participants used technology in different ways. One participant used AirPods, which are a wireless headphone that connected to their phone to help with noise cancelation. This helped reduce their brain fog, as they were able to block out background noise, which helped with mental focus while minimizing varying noises. Another participant described using her computer to make phone calls, mitigating the steps needed to use a home or cell phone. This also meant that there is not a need to get up from rest to locate their phone, avoiding several triggers and minimizing the tasks involved, and reducing discomfort.

Focus Group Summary

The focus group data provided four main themes which included thirteen sub-themes. The first theme found was triggers with four sub-themes of standing, bending, daily tasks, and heat intolerance. The second theme identified was physiological responses, with two sub-themes of blood flow/blood pooling and aching/pain. Cognitive responses were the third theme, with three sub-themes of depression, anger, and brain fog. The last theme was environmental adaptions, with four sub-themes of stools/chairs, shower chairs, mobility devices, and assistive technology.

Phase I and Phase II Cross Analysis

Findings within the Phase I survey were not only seen in the Phase II focus group but also expanded on in further detail, validating the data collected from both. Demographics from the Phase I survey and Phase II focus group showed that POTS mainly affects females. Both the survey and focus group findings reflected that while the experience of POTS can vary person-to-person, all people with POTS must learn to manage their symptoms daily and the symptoms cannot be ignored. The survey provided a more general idea of problem areas of the home and activities within the home, while the focus group targeted the specific activities and responses to those activities. By looking at both the survey and focus group results it can be identified that the main problem areas of the home were the bathroom, bedroom, kitchen, and laundry room. Further, the results of both showed difficulties doing the following tasks:

bathing/showering, cleaning, bending, cooking, gardening, preparing food, putting away dishes or groceries, and standing.

Contributions

Using the Ecological Press Model and theoretical model inspired by it, the researcher answered the three research questions (1) What are the principle physical barriers for people with POTS when navigating a home environment?; (2) How are individuals with POTS impacted emotionally when completing activities of daily living?; and (3) In what ways are individuals with POTS impacted physically when completing activities of daily living? Guided by the Ecological Press Model, the Phase II Focus Group validated and grouped results from the Phase I survey. The laundry room, bathroom, and kitchen were found in the Phase I survey to be the main areas in the home that were problematic. Follow-up questions identified many problem activities that the Phase II focus group was able to group within the themes. The Phase I survey found that vacuuming, making the bed, cleaning dishes while standing, eating while standing, preparing food while standing, putting away dishes or groceries while standing, making the bed, retrieving clothing, loading/unloading both the washer and dryer, folding clothes were all problem activities that the Phase II focus group discussed as daily tasks. Similarly, problem activities of climbing stairs, getting up or down from a chair, and getting up or going to bed were identified in Phase I, and grouped as the trigger of bending in the Phase II focus group. Lastly, the Phase II focus group was able to connect heat intolerance to the Phase I problem areas of showering, bathing, and preparing food on a stovetop while standing. These tasks can lead to environmental press through the POTS symptoms as they all take place in the home environment and impact individual competencies.

Discussion

The Phase I survey data highlighted many issues that the Phase II focus group data explained in more detail. The Phase I survey identified that the majority of people with POTS felt symptomatic multiple times per day when sitting up, standing up, and walking. The Phase II focus group data described how these symptoms made the participants feel on daily basis. In the Phase I survey, perceived health was mostly described as “fair” while there were not any reports of having “excellent” or “very good” perceived health. Additionally, the Phase I survey found that 89.18 percent of respondents felt that POTS impacted their freedom at home from a moderate amount to a great deal. Further, more than half of individuals reported avoiding activities about half of the time to most of the time. The Phase II focus group data supported the Phase I survey data from the outlook of their health and daily experiences.

While the original Ecological Press Model describes the relationship between environmental press and an individual’s competencies, this research has resulted in the updated-framework that incorporates the experience of POTS within the home environment. Figure 4 shows how the framework will be including the roles of the home environment and POTS. Figure 5 expresses the experience of POTS in the home environment in the following way. An individual’s home environment can cause triggers for people with POTS, leading to environmental press. Those triggers influence symptoms of POTS, which plays a part in both their physiological and cognitive response, and affects their competencies. The research found that with the inclusion of environmental adaptations individuals are more likely to have stronger performance and higher comfort and competencies than without them. It is known that stronger performance and higher comfort allow for adaptive behavior and positive effects, while weak and moderate performance and comfort cause negative behavior and effects.

While a multiple-step framework, these factors are often happening simultaneously and there are different triggers and symptoms on a case-by-case basis. Using the example of an individual with POTS doing the dishes and then fainting, the home environment would be the setting and the environmental press would be the

Figure 4

Ecological Press Model Theoretical Framework with Study

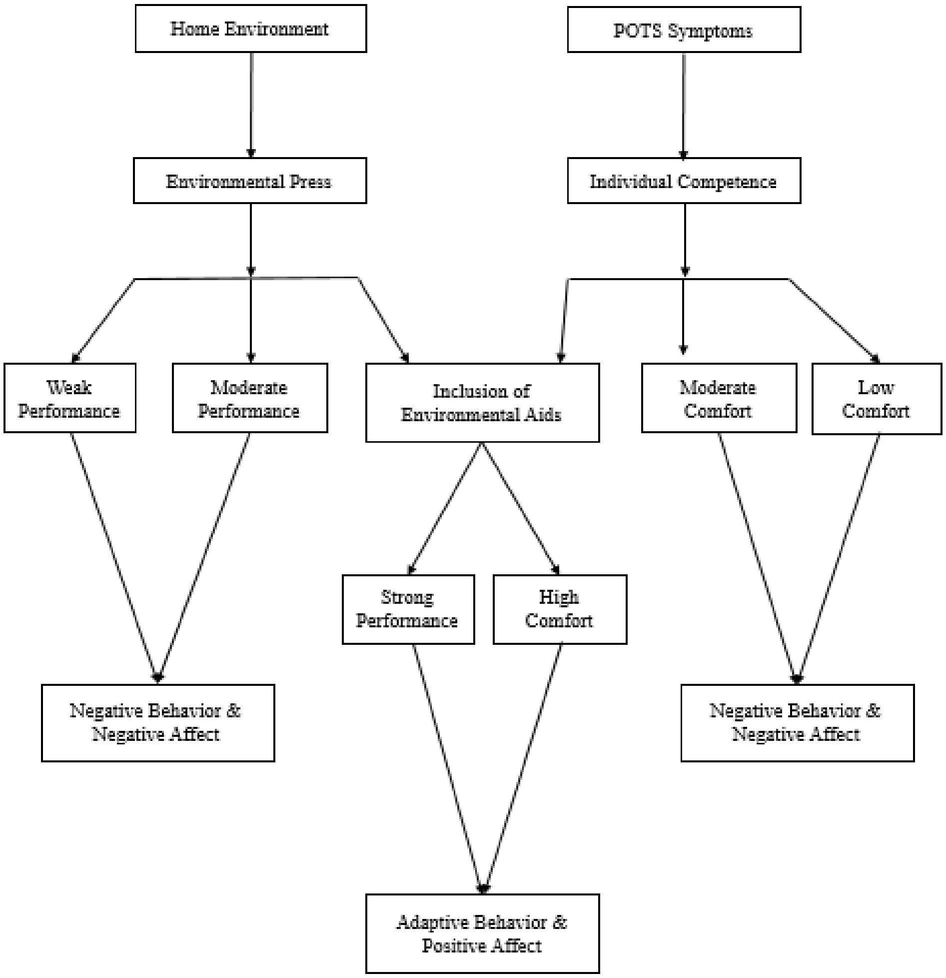
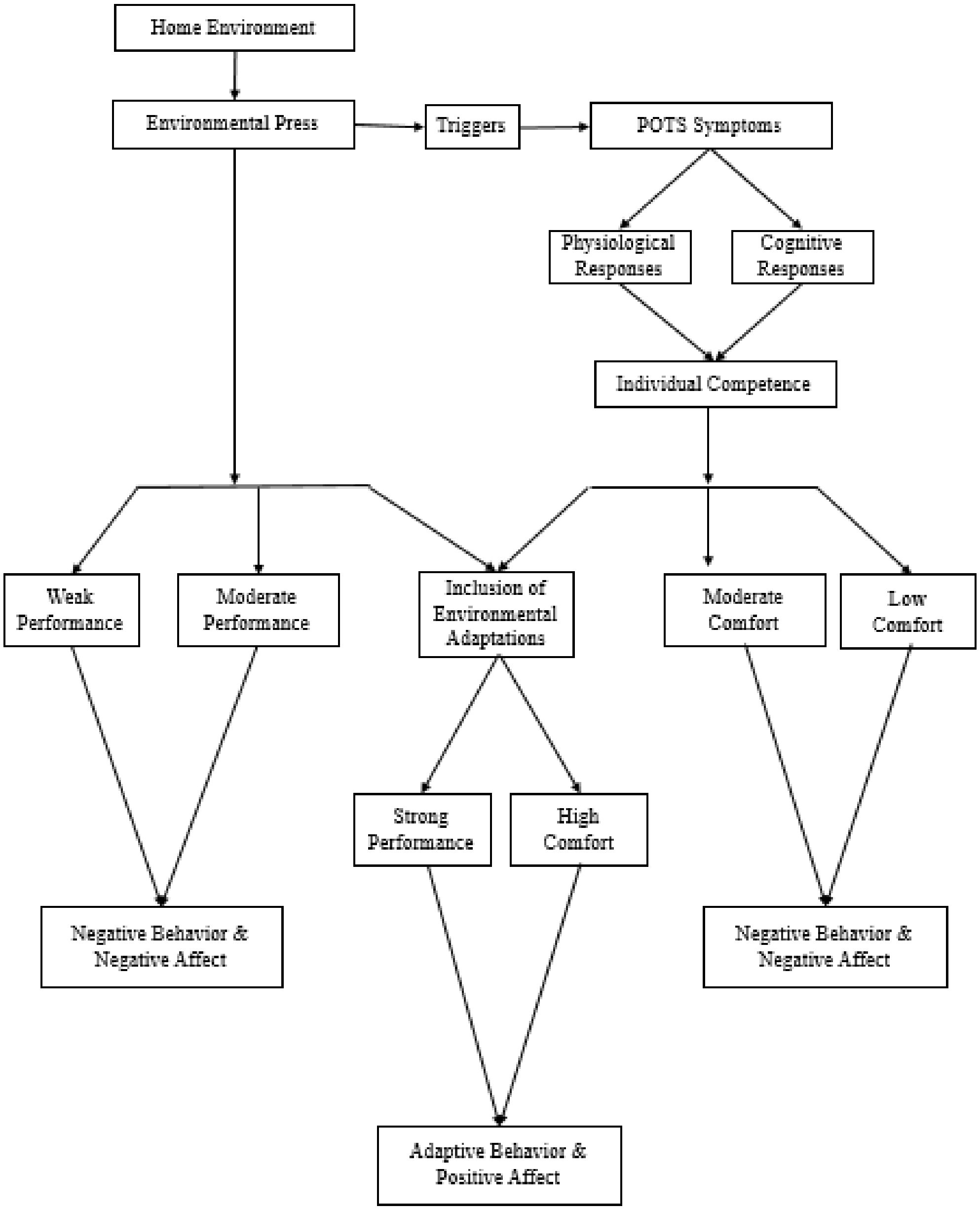


Figure 5

Diagram Summarizing Research Findings



situation. Leading up to the fainting, the individual would have blood pooling into their feet, with following dizziness and aching building up to more dramatic pain. This would all happen while the person would be standing in front of a sink with hot water. The individual might shift back and forth due to the discomfort in their feet and to avoid the direct stream and steam of water causing pain in their hands. The individual may become frustrated, as the task seems to go on for a longer time than normal and become progressively more uncomfortable. Once the individual finally gets the plate clean they may bend and reach over to put the dish inside the dishwasher. This particular action may then cause the individual to faint, and lay on the floor for a few moments disorientated and confused. When the individual finally sits up their frustration becomes anger because they feel that this should be a simple task. A family member may enter at this point with a look of disbelief and ask, “You can’t even do the dishes?” causing the individual with POTS even more stress. The fainting would be the physiological response to the symptoms, while their anger and sadness would be their cognitive response. Their experience of having POTS affecting this situation would be part of their competencies. By having both an environment that did not adjust for their POTS paired with having their condition, the person had a negative behavior and affect. While this is just one specific example of a task, people with POTS are continually going through these types of steps of the theoretical model. Almost all tasks of their day-to-day life could fit within this model as they interact with their home environment and battle their symptoms.

Environmental Factors

Before this study, it was unknown in literature what the principal physical barriers are within a home environment for people with POTS. The problematic areas home with barriers were identified as the laundry room, bathroom, and kitchen in the Phase I survey. Further, the Phase II focus group found that homes do not support those with POTS. People with POTS must add items to their homes, such as stools or chairs, to complete tasks and use mobility devices or technology to navigate their home space. Many do not know how useful environmental adaptions can be, as the survey found that more than half of participants know little, if any, information on environmental aids.

The lack of support from the environment can be distressing, but it can be even more of an issue if not supported by other people. This study found that being misunderstood or ignored by family members, designers, and medical professionals caused frustration, anger, and even depression in individuals. This increased their negative cognitive responses. Individuals may already be frustrated by these situations, and then having to handle having their condition downplayed by others only furthers that frustration and depression. Meanwhile, they are also dealing with their physiological responses, such as aching/pain.

Individual Competencies

This study adds to the literature by answering the question of how people with POTS are impacted physically and emotionally when completing activities of daily living. Triggers such as standing, bending, and dealing with heat intolerance are related daily tasks involved in activities of daily living. While heat intolerance may not occur daily, it typically arises during bathing or cooking. Some people do not bathe or cook every day, however many do several times a week, based on individual lifestyle. Standing and bending cannot be so easily avoidable. These trigger activities lead to physiological responses such as blood pooling or lack of blood flow and aching or pain. In turn, blood pooling or lack of blood flow and aching or pain can cause brain fog. Brain fog can be exhausting, as it can make unconscious activities become multi-step processes that need to be double-checked to ensure they are done correctly. Double-checking work to see if it may need to be redone to be completed correctly extends the overall time to finish the task. This can be frustrating for individuals, which may cause cognitive responses such as anger and depression. Having to deal with anger from brain fog continuously creates depression, as individuals with POTS would just like to be able to complete tasks with no symptoms in the first place.

Inclusion of Environmental Adaptations

Findings from this research suggest that including an environmental adaptation could help create a stronger performance and higher comfort which establishes the ability for adaptive behavior and positive affect. If in the prior example of the person with POTS cleaning dishes there had been a stool to sit on while completing the task, they would have been able to adapt to responses such as blood pooling into their feet, dizziness, aching, and pain. While they may not be able to fully avoid physiological and cognitive responses from triggers, they can have stronger performance and higher comfort by using an environmental adaption. For example, by using a stool while washing dishes there would be no reason to stand for long periods. They would still need to bend over and deal with heat intolerance, but fewer triggers would be activated, which would decrease symptoms and responses to them. Even if the individual still experiences several symptoms, having an environmental adaption such as a stool can increase their performance ability and promote a higher comfort by decreasing interactions with triggers and symptoms. Environmental adaptions allow individuals to do tasks for longer by avoiding triggers and adapting to their symptoms when avoidance is not possible. This provides higher competency to the individual and improved comfort due to reduced environmental press.

CHAPTER V

CONCLUSION

This study provides insight into the principal barriers for people with POTS when navigating a home environment. It identified triggers of POTS symptoms in the home environment, both the physiological and cognitive responses to those triggers, how those responses impact individual competencies of people with POTS, and how including environmental adaptions can ultimately improve performance and comfort, as well as the connections between all of these factors. These findings are important, as there is currently a lack of literature in all of these areas. While symptoms of POTS have already been identified (Theiben, 2007), it had been unknown how the home environment played a part in those symptoms and what types of environmental adaptions individuals with POTS could use. This study provides information which can be used by people with POTS, caregivers or support persons, designers, and medical professionals.

The fact sheet, which has been developed to align with this research, will provide easy to understand information on POTS. General education about the condition is important, as the general public's understanding of POTS can ultimately help alleviate the negative stigma around the condition. The study findings identified that a lack of support from laypersons and medical professionals feeds anger and depression in people with POTS. Increased awareness of the condition could also result in new treatments from the medical community and new environmental adaptations from the design community.

Limitations

There were several limitations to this research. A lack of prior research on POTS made this study difficult to prepare for and to conduct. The researcher had to refer to studies done on similar conditions rather than POTS specifically to prepare for the study. Another limitation of this study was the time constraints and COVID-19. Originally the study was to be an experimental design in a lab, but COVID restrictions did not allow for any in-person research. The research then moved forward with the exploratory design, but participant recruitment was still difficult during the pandemic. Additionally, when recruiting it was more difficult to get approval from the Facebook groups than the researcher expected. Many of the Facebook groups required approval to share the survey link by a committee and one group did not understand the purpose of the study so the study recruitment was denied. This led to a lower than expected response rate, as the researcher was hoping to get a sample of 200 for the Phase I survey. Similarly, the researcher wanted to gather two groups of between four to eight people with 16 individuals total for the focus group, and had one group of four people. While these small sample sizes restrict the generalizability of the data, information was gathered that can be used for future studies with larger numbers of participants.

Directions for Future Research

In the future, designers may look at how already used environmental adaptions such as chairs and stools could be adjusted to help alleviate multiple symptoms of POTS. While it could be helpful to design new innovative devices specifically for triggers, it would be more cost-effective to modify simple items like chairs and stools already being used for people with POTS. Chairs and stools would need to be easily adjustable to go from counter height to just barely above the ground to accommodate for the varying heights that both cleaning and gardening may require. This would help reduce the multiple stools or chairs cluttering the home environment for different activities.

Other future design options are the creation of a line of adaptive devices that are aligned with the user's aesthetics in the home. Working on developing more aesthetically pleasing devices such as shower chairs, stools, canes, and walkers would ensure that a younger generation of POTS patients would be encouraged to use them in the first place.

Final Observations

The relationships between triggers, physiological responses, and cognitive responses can be impacted with proper environmental adaptations for individuals living with POTS. The home environment, if not designed with environmental adaptations, can be the cause of great distress to individuals with POTS., as evidenced by the Phase 1 and Phase II results.

It is also important that environmental adaptations are accessible and affordable, as individuals in need come from multiple economic backgrounds. Environmental aids should be available to anyone with POTS, with more general information so that those with POTS can make more informed decisions on what works best for them. There is a direct need for more awareness and design focus from professionals for environmental adaptations such as stools, shower chairs, and mobility devices to be more suitable and beneficial to users with POTS.

POTS is a misunderstood and often misdiagnosed syndrome. While the home environment plays a significant role in the daily experience of an individual with POTS, the general population’s understanding of the syndrome needs to be strengthened to align with the number of individuals who are living with it. This includes educating family members, health professionals, and the design community. This research provides a general understanding of the experience of living with POTS which can be used for education and innovation, both now and in the future.

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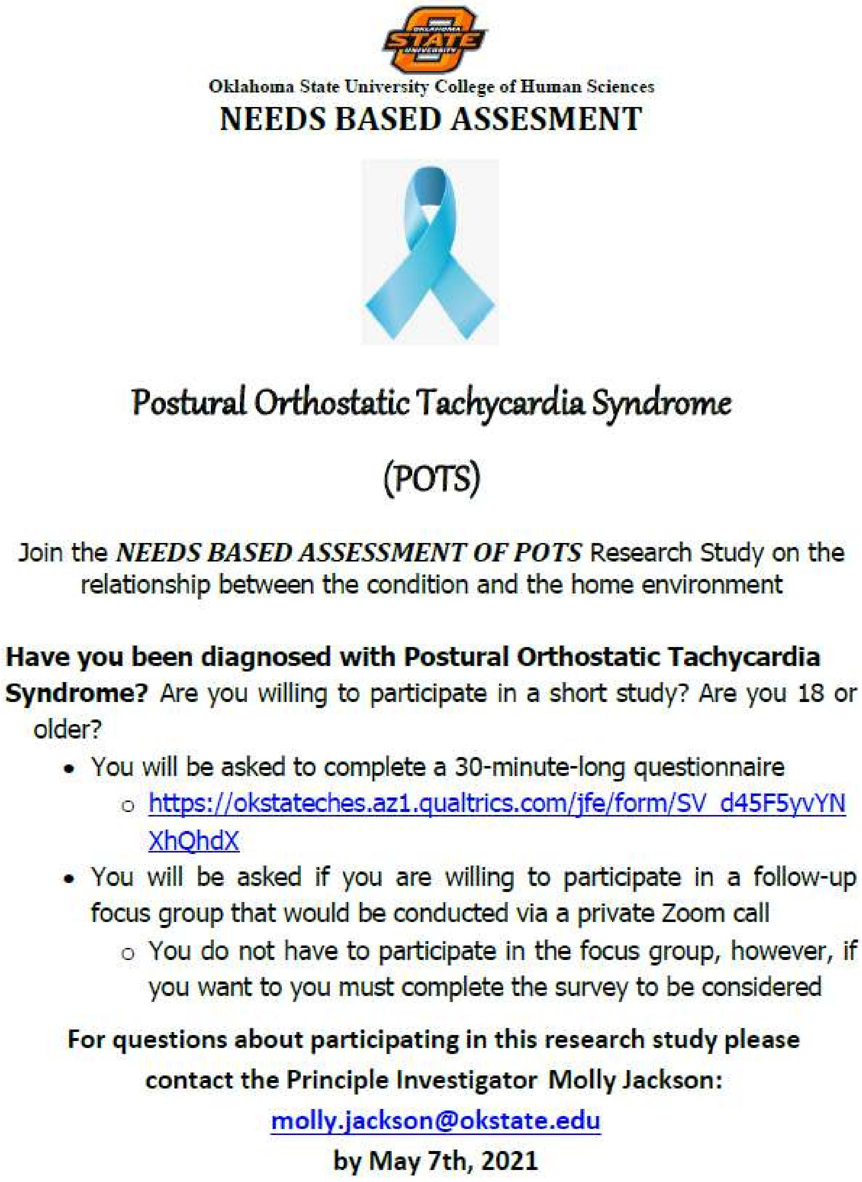
APPENDICES

Phase I and Phase II Recruitment Flyer



Oklahoma State University College of Human Sciences

NEEDS BASED ASSESMENT

Postural Orthostatic Tachycardia Syndrome

(POTS)

Join the ***NEEDS BASED ASSESSMENT OF POTS*** Research Study on the relationship between the condition and the home environment

Have you been diagnosed with Postural Orthostatic Tachycardia Syndrome? Are you willing to participate in a short study? Are you 18 or older?

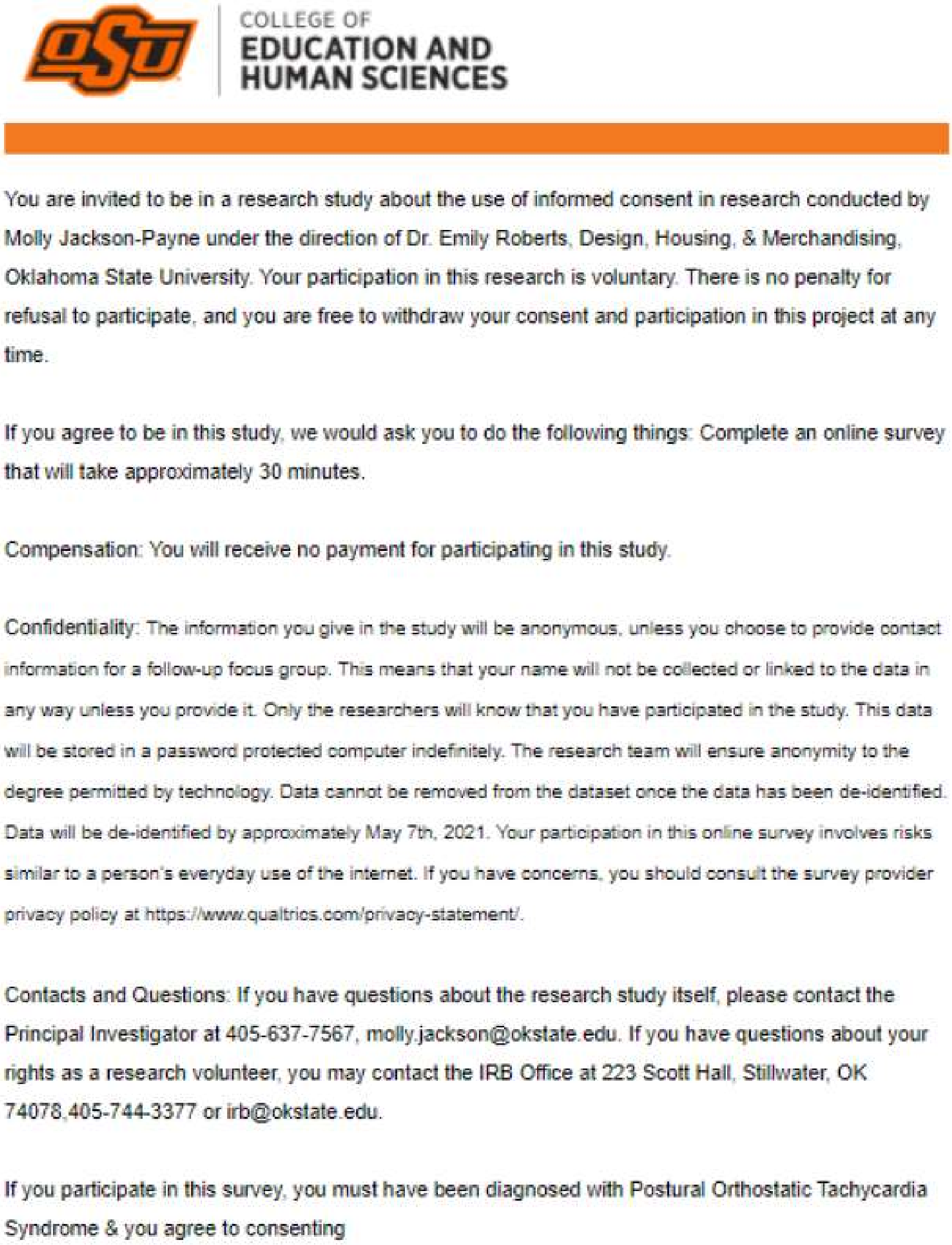
- You will be asked to complete a 30-minute-long questionnaire
    - https://okstateches.az1.qualtrics.com/jfe/form/SV_d45F5yvYNXhQhdX
- You will be asked if you are willing to participate in a follow-up focus group that would be conducted via a private Zoom call
    - You do not have to participate in the focus group, however, if you want to you must complete the survey to be considered

For questions about participating in this research study please contact the Principle Investigator Molly Jackson:

molly.jackson@okstate.edu

by May 7th, 2021

Phase I Survey Consent Form



COLLEGE OF
EDUCATION AND
HUMAN SCIENCES

You are invited to be in a research study about the use of informed consent in research conducted by Molly Jackson-Payne under the direction of Dr. Emily Roberts, Design, Housing, & Merchandising, Oklahoma State University. Your participation in this research is voluntary. There is no penalty for refusal to participate, and you are free to withdraw your consent and participation in this project at any time.

If you agree to be in this study, we would ask you to do the following things: Complete an online survey that will take approximately 30 minutes.

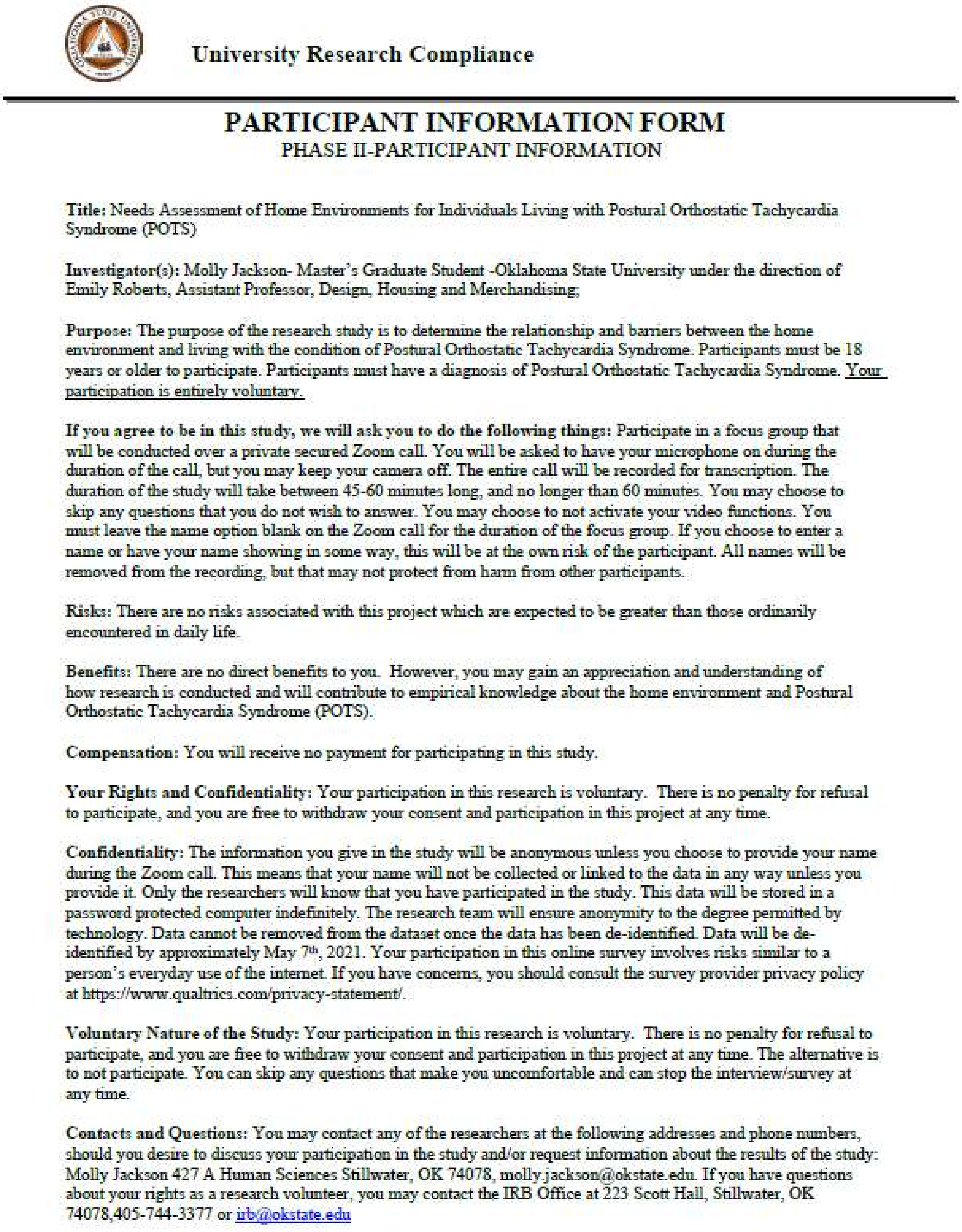
Compensation: You will receive no payment for participating in this study.

Confidentiality: The information you give in the study will be anonymous, unless you choose to provide contact information for a follow-up focus group. This means that your name will not be collected or linked to the data in any way unless you provide it. Only the researchers will know that you have participated in the study. This data will be stored in a password protected computer indefinitely. The research team will ensure anonymity to the degree permitted by technology. Data cannot be removed from the dataset once the data has been de-identified. Data will be de-identified by approximately May 7th, 2021. Your participation in this online survey involves risks similar to a person's everyday use of the internet. If you have concerns, you should consult the survey provider privacy policy at https://www.qualtrics.com/privacy-statement/.

Contacts and Questions: If you have questions about the research study itself, please contact the Principal Investigator at 405-637-7567, molly.jackson@okstate.edu. If you have questions about your rights as a research volunteer, you may contact the IRB Office at 223 Scott Hall, Stillwater, OK 74078,405-744-3377 or irb@okstate.edu.

If you participate in this survey, you must have been diagnosed with Postural Orthostatic Tachycardia Syndrome & you agree to consenting

Phase II Focus Group Consent Form



University Research Compliance

PARTICIPANT INFORMATION FORM

PHASE II-PARTICIPANT INFORMATION

Title: Needs Assessment of Home Environments for Individuals Living with Postural Orthostatic Tachycardia Syndrome (POTS)

Investigator(s): Molly Jackson- Master's Graduate Student -Oklahoma State University under the direction of Emily Roberts, Assistant Professor, Design, Housing and Merchandising;

Purpose: The purpose of the research study is to determine the relationship and barriers between the home environment and living with the condition of Postural Orthostatic Tachycardia Syndrome. Participants must be 18 years or older to participate. Participants must have a diagnosis of Postural Orthostatic Tachycardia Syndrome. Your participation is entirely voluntary.

If you agree to be in this study, we will ask you to do the following things: Participate in a focus group that will be conducted over a private secured Zoom call. You will be asked to have your microphone on during the duration of the call, but you may keep your camera off. The entire call will be recorded for transcription. The duration of the study will take between 45-60 minutes long, and no longer than 60 minutes. You may choose to skip any questions that you do not wish to answer. You may choose to not activate your video functions. You must leave the name option blank on the Zoom call for the duration of the focus group. If you choose to enter a name or have your name showing in some way, this will be at the own risk of the participant. All names will be removed from the recording, but that may not protect from harm from other participants.

Risks: There are no risks associated with this project which are expected to be greater than those ordinarily encountered in daily life.

Benefits: There are no direct benefits to you. However, you may gain an appreciation and understanding of how research is conducted and will contribute to empirical knowledge about the home environment and Postural Orthostatic Tachycardia Syndrome (POTS).

Compensation: You will receive no payment for participating in this study.

Your Rights and Confidentiality: Your participation in this research is voluntary. There is no penalty for refusal to participate, and you are free to withdraw your consent and participation in this project at any time.

Confidentiality: The information you give in the study will be anonymous unless you choose to provide your name during the Zoom call. This means that your name will not be collected or linked to the data in any way unless you provide it. Only the researchers will know that you have participated in the study. This data will be stored in a password protected computer indefinitely. The research team will ensure anonymity to the degree permitted by technology. Data cannot be removed from the dataset once the data has been de-identified. Data will be de-identified by approximately May 7th, 2021. Your participation in this online survey involves risks similar to a person's everyday use of the internet. If you have concerns, you should consult the survey provider privacy policy at https://www.qualtrics.com/privacy-statement/.

Voluntary Nature of the Study: Your participation in this research is voluntary. There is no penalty for refusal to participate, and you are free to withdraw your consent and participation in this project at any time. The alternative is to not participate. You can skip any questions that make you uncomfortable and can stop the interview/survey at any time.

Contacts and Questions: You may contact any of the researchers at the following addresses and phone numbers, should you desire to discuss your participation in the study and/or request information about the results of the study: Molly Jackson 427 A Human Sciences Stillwater, OK 74078, molly.jackson@okstate.edu. If you have questions about your rights as a research volunteer, you may contact the IRB Office at 223 Scott Hall, Stillwater, OK 74078,405-744-3377 or irb@okstate.edu

PARTICIPANT RIGHTS:
I understand that my participation is voluntary, that there is no penalty for refusal to participate, and that I am free to withdraw my consent and participation in this project at any time, without penalty.

CONSENT DOCUMENTATION:
I have been fully informed about the procedures listed here. I am aware of what I will be asked to do and of the benefits of my participation. I also understand the following statements:
I affirm that I am 18 years of age or older.

I have read and fully understand this consent form. I sign it freely and voluntarily. A copy of this form will be given to me. I hereby give permission for my participation in this study.

I give consent to be audiotaped during this study.
___Yes ___No

I give consent to be videotaped during this study:
___Yes ___No

I give consent for my data to be used in future research studies:
___Yes ___No

I give consent to be contacted for follow-up in this study or future similar studies:
___Yes ___No

By selecting "Yes" using any device, means or action, you consent to the terms and conditions of this Agreement. You further agree that your signature on this document (hereafter referred to as your "E-Signature") is as valid as if you signed the document in writing.

___Yes ___No _________
Date

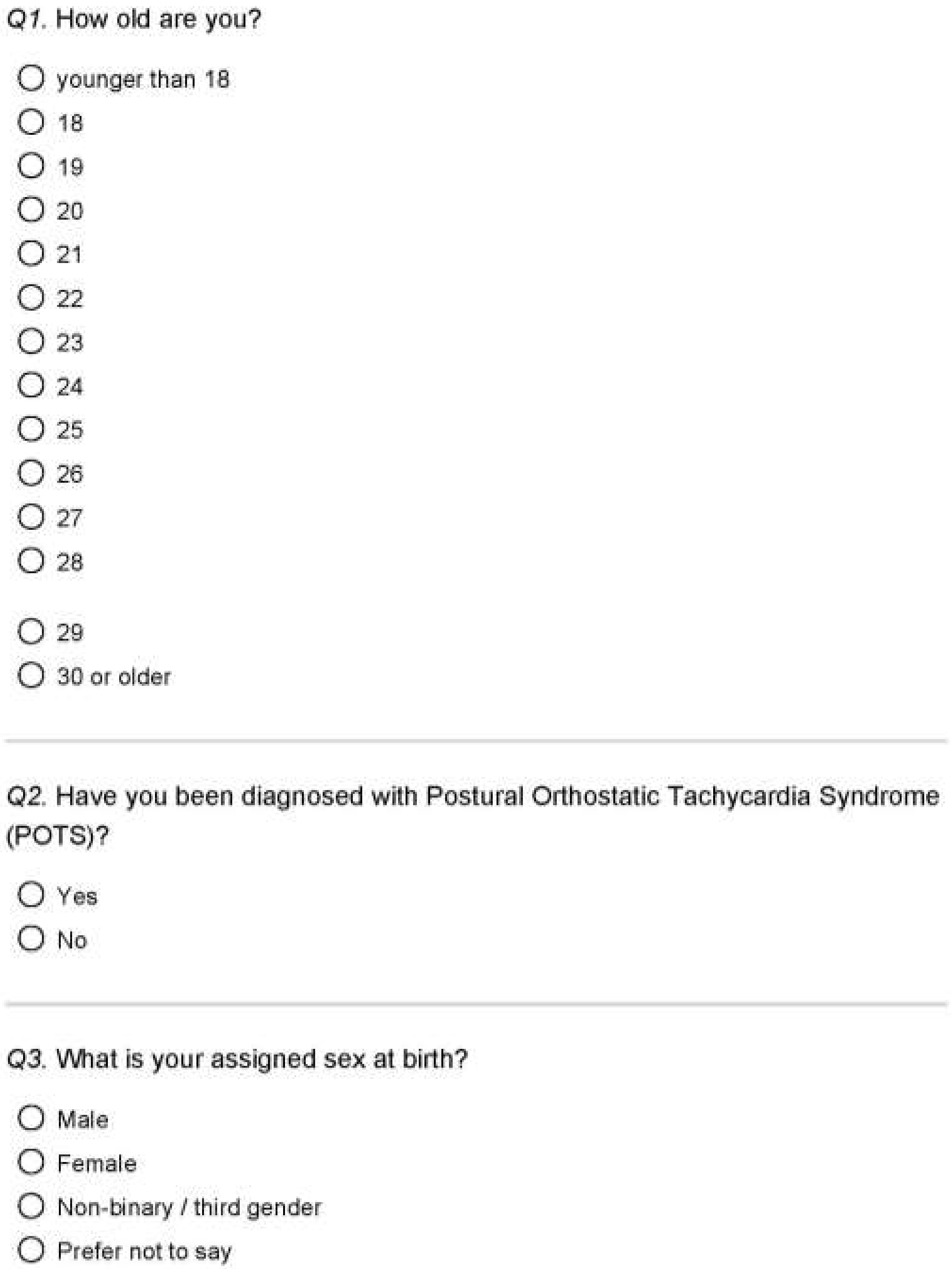
or

_____________________________________ ____________
Signature of Participant **Date**

I certify that I have personally explained this document before requesting that the participant sign it.

_____________________________________ _____________
Signature of Researcher **Date**

Phase I Survey Questions



Q1. How old are you?

○ younger than 18
○ 18
○ 19
○ 20
○ 21
○ 22
○ 23
○ 24
○ 25
○ 26
○ 27
○ 28

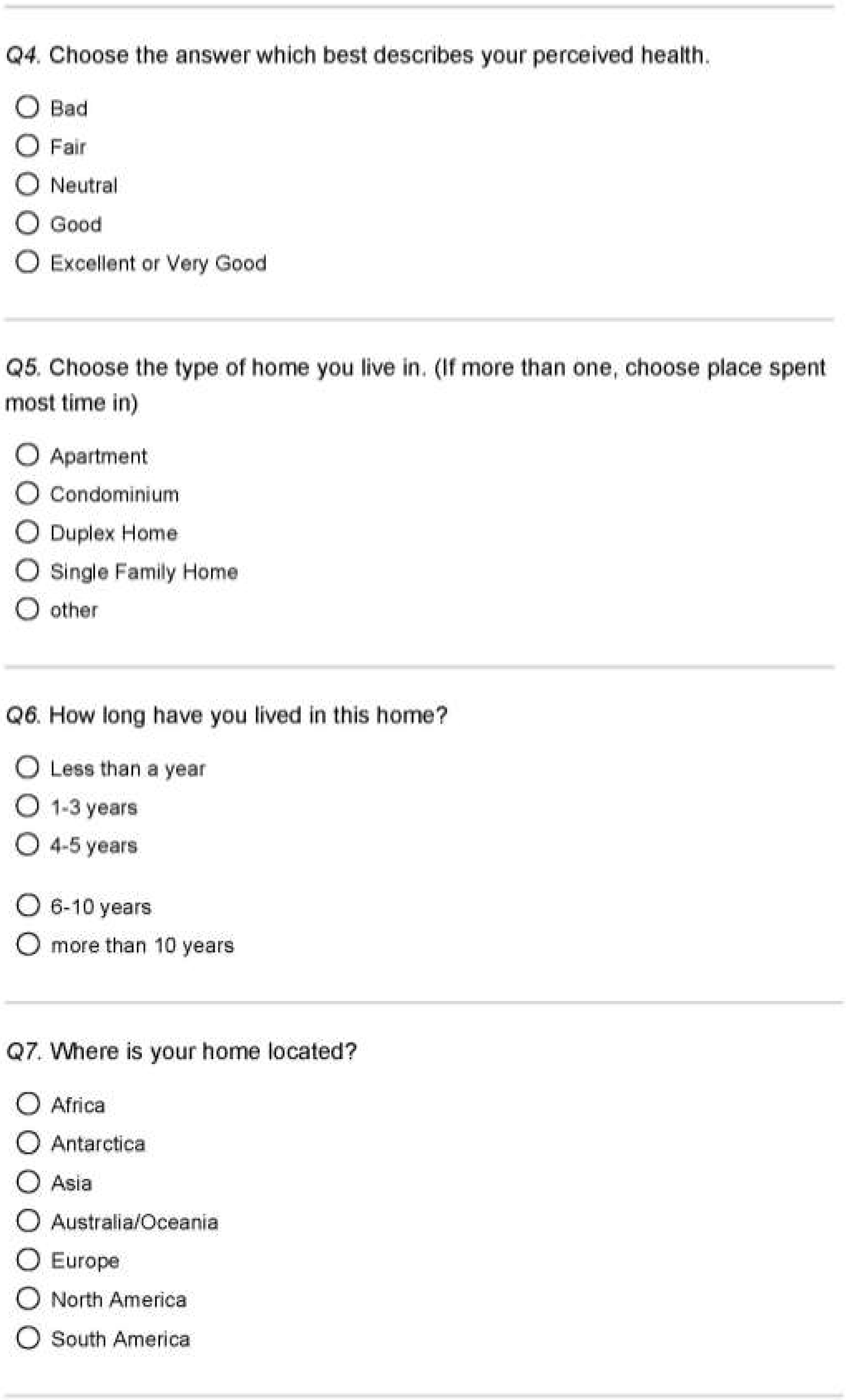
○ 29
○ 30 or older

Q2. Have you been diagnosed with Postural Orthostatic Tachycardia Syndrome (POTS)?

○ Yes
○ No

Q3. What is your assigned sex at birth?

○ Male
○ Female
○ Non-binary / third gender
○ Prefer not to say



Q4. Choose the answer which best describes your perceived health.

○ Bad
○ Fair
○ Neutral
○ Good
○ Excellent or Very Good

Q5. Choose the type of home you live in. (If more than one, choose place spent most time in)

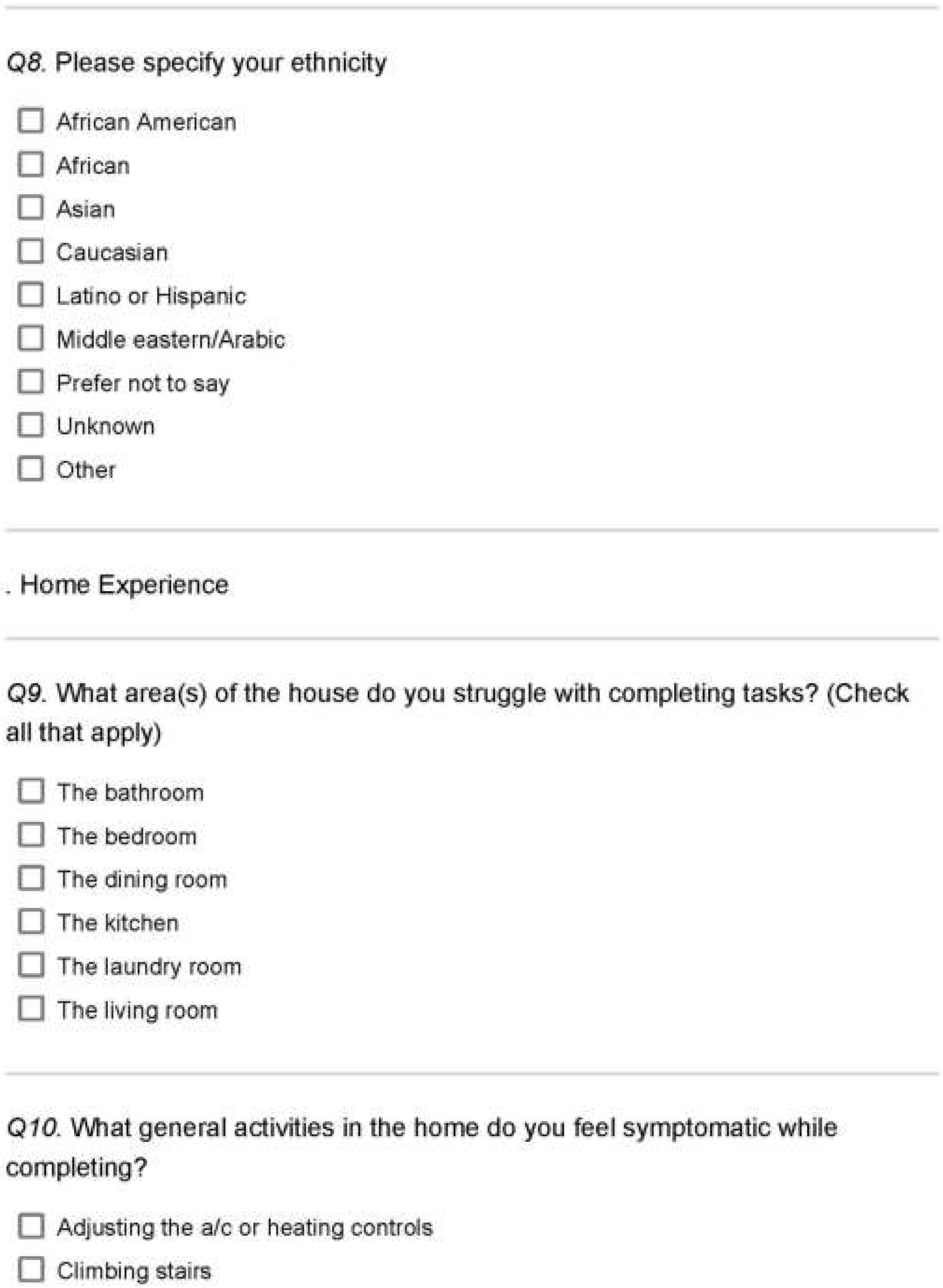
○ Apartment
○ Condominium
○ Duplex Home
○ Single Family Home
○ other

Q6. How long have you lived in this home?

○ Less than a year
○ 1-3 years
○ 4-5 years
○ 6-10 years
○ more than 10 years

Q7. Where is your home located?

○ Africa
○ Antarctica
○ Asia
○ Australia/Oceania
○ Europe
○ North America
○ South America



Q8. Please specify your ethnicity

☐ African American
☐ African
☐ Asian
☐ Caucasian
☐ Latino or Hispanic
☐ Middle eastern/Arabic
☐ Prefer not to say
☐ Unknown
☐ Other

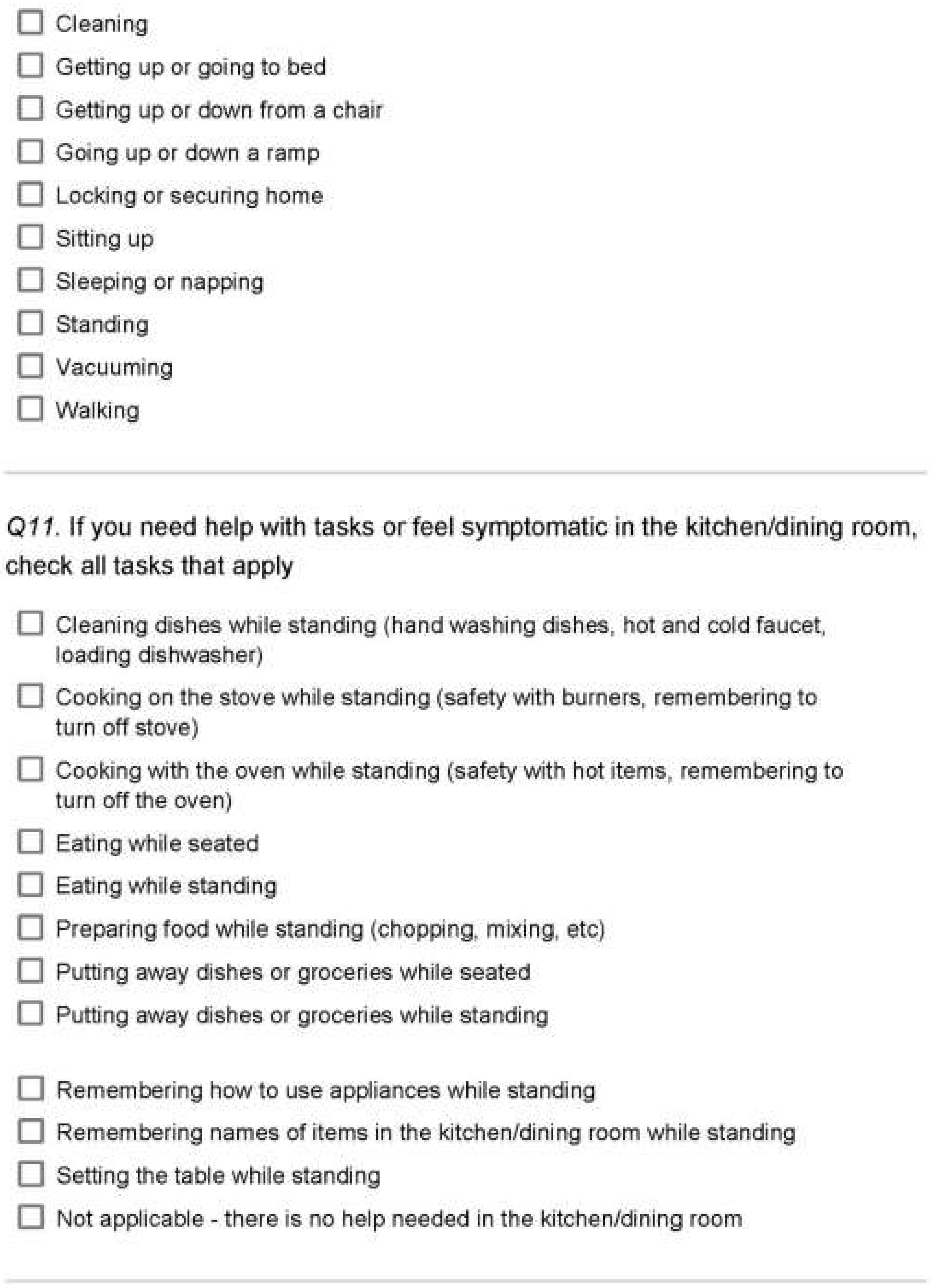
. Home Experience

Q9. What area(s) of the house do you struggle with completing tasks? (Check all that apply)

☐ The bathroom
☐ The bedroom
☐ The dining room
☐ The kitchen
☐ The laundry room
☐ The living room

Q10. What general activities in the home do you feel symptomatic while completing?

☐ Adjusting the a/c or heating controls
☐ Climbing stairs



☐ Cleaning

☐ Getting up or going to bed

☐ Getting up or down from a chair

☐ Going up or down a ramp

☐ Locking or securing home

☐ Sitting up

☐ Sleeping or napping

☐ Standing

☐ Vacuuming

☐ Walking

Q11. If you need help with tasks or feel symptomatic in the kitchen/dining room, check all tasks that apply

☐ Cleaning dishes while standing (hand washing dishes, hot and cold faucet, loading dishwasher)

☐ Cooking on the stove while standing (safety with burners, remembering to turn off stove)

☐ Cooking with the oven while standing (safety with hot items, remembering to turn off the oven)

☐ Eating while seated

☐ Eating while standing

☐ Preparing food while standing (chopping, mixing, etc)

☐ Putting away dishes or groceries while seated

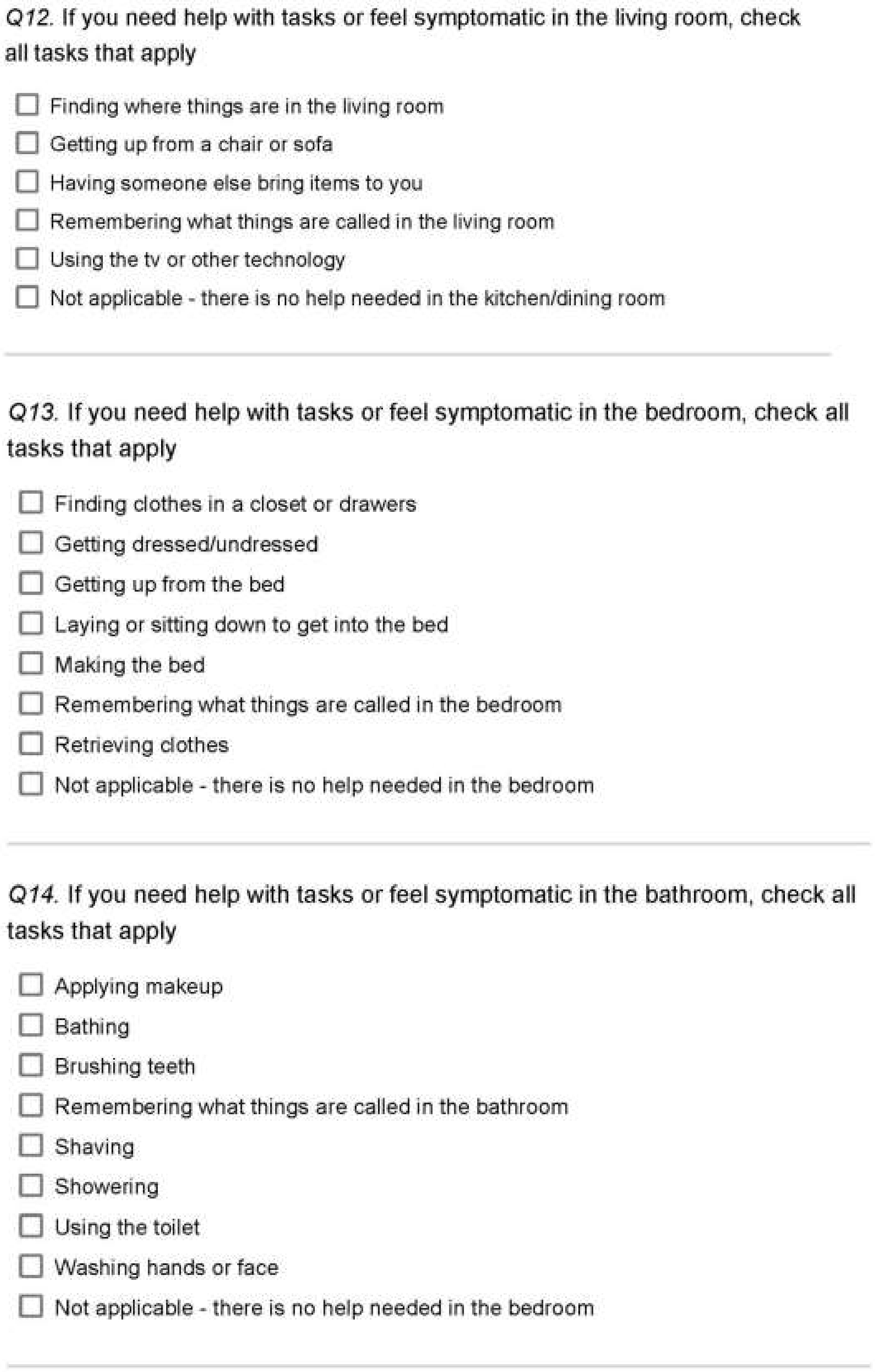
☐ Putting away dishes or groceries while standing

☐ Remembering how to use appliances while standing

☐ Remembering names of items in the kitchen/dining room while standing

☐ Setting the table while standing

☐ Not applicable - there is no help needed in the kitchen/dining room



Q12. If you need help with tasks or feel symptomatic in the living room, check all tasks that apply

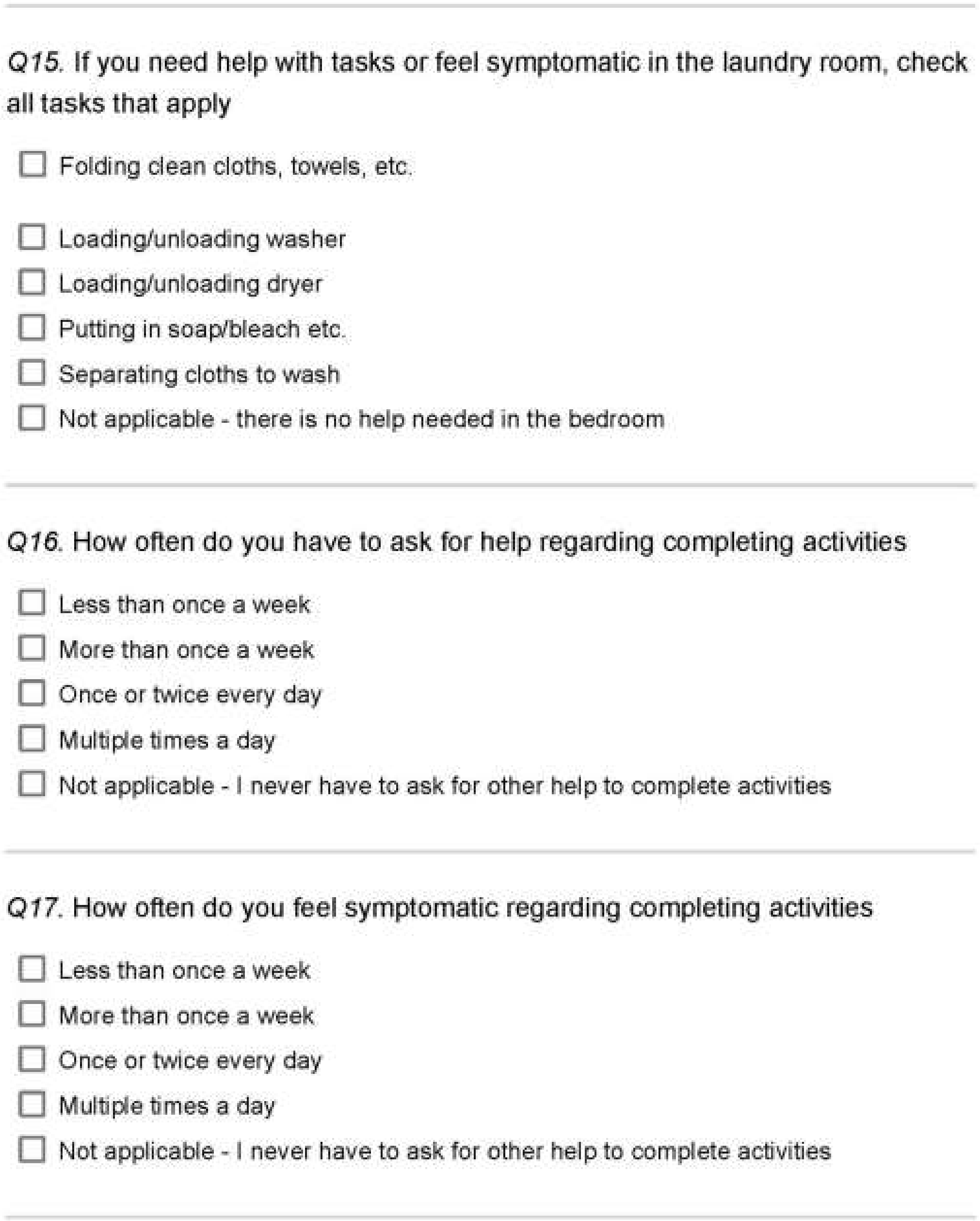
☐ Finding where things are in the living room
☐ Getting up from a chair or sofa
☐ Having someone else bring items to you
☐ Remembering what things are called in the living room
☐ Using the tv or other technology
☐ Not applicable - there is no help needed in the kitchen/dining room

Q13. If you need help with tasks or feel symptomatic in the bedroom, check all tasks that apply

☐ Finding clothes in a closet or drawers
☐ Getting dressed/undressed
☐ Getting up from the bed
☐ Laying or sitting down to get into the bed
☐ Making the bed
☐ Remembering what things are called in the bedroom
☐ Retrieving clothes
☐ Not applicable - there is no help needed in the bedroom

Q14. If you need help with tasks or feel symptomatic in the bathroom, check all tasks that apply

☐ Applying makeup
☐ Bathing
☐ Brushing teeth
☐ Remembering what things are called in the bathroom
☐ Shaving
☐ Showering
☐ Using the toilet
☐ Washing hands or face
☐ Not applicable - there is no help needed in the bedroom



Q15. If you need help with tasks or feel symptomatic in the laundry room, check all tasks that apply

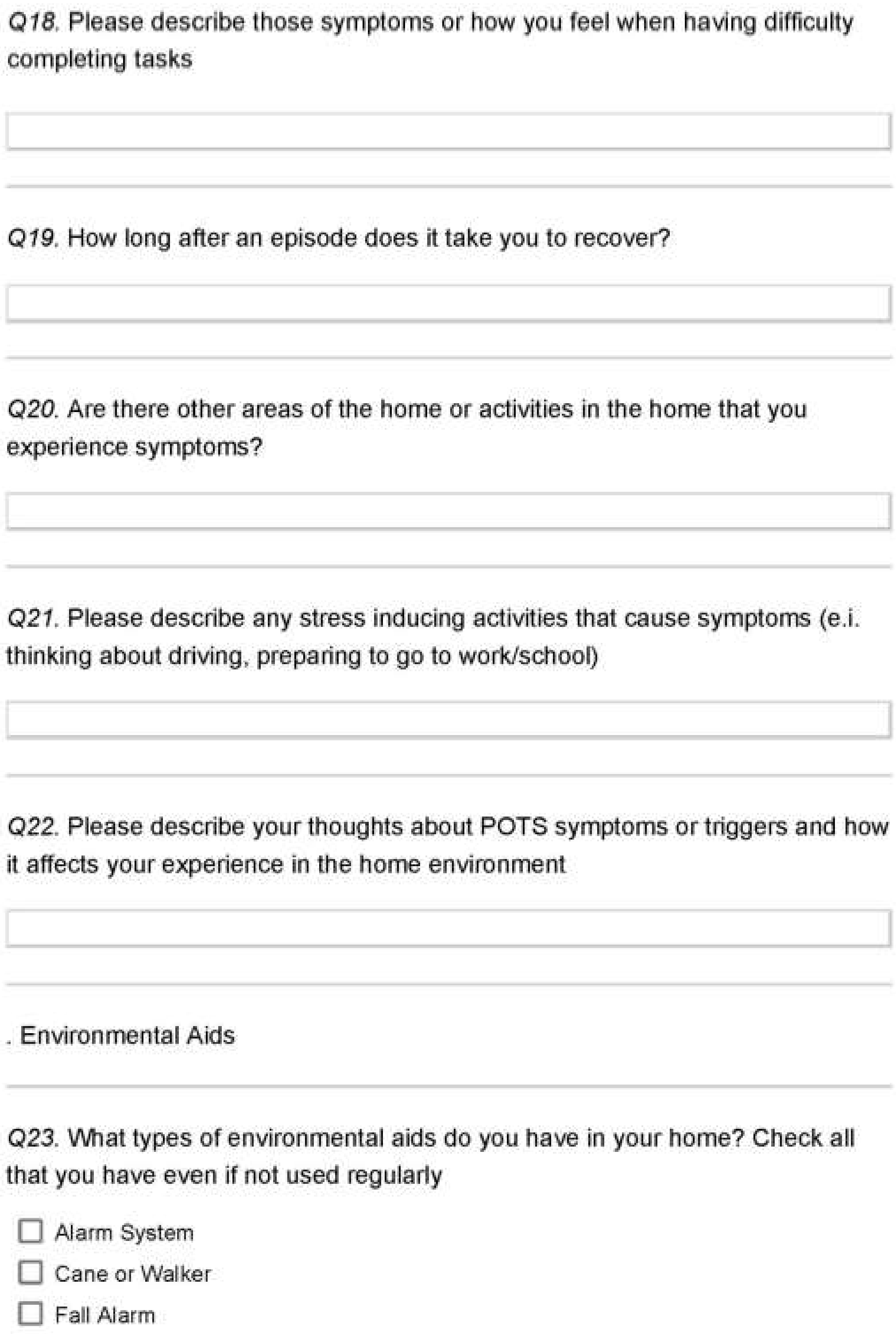
- ☐ Folding clean cloths, towels, etc.
- ☐ Loading/unloading washer
- ☐ Loading/unloading dryer
- ☐ Putting in soap/bleach etc.
- ☐ Separating cloths to wash
- ☐ Not applicable - there is no help needed in the bedroom

Q16. How often do you have to ask for help regarding completing activities

- ☐ Less than once a week
- ☐ More than once a week
- ☐ Once or twice every day
- ☐ Multiple times a day
- ☐ Not applicable - I never have to ask for other help to complete activities

Q17. How often do you feel symptomatic regarding completing activities

- ☐ Less than once a week
- ☐ More than once a week
- ☐ Once or twice every day
- ☐ Multiple times a day
- ☐ Not applicable - I never have to ask for other help to complete activities



Q18. Please describe those symptoms or how you feel when having difficulty completing tasks

Q19. How long after an episode does it take you to recover?

Q20. Are there other areas of the home or activities in the home that you experience symptoms?

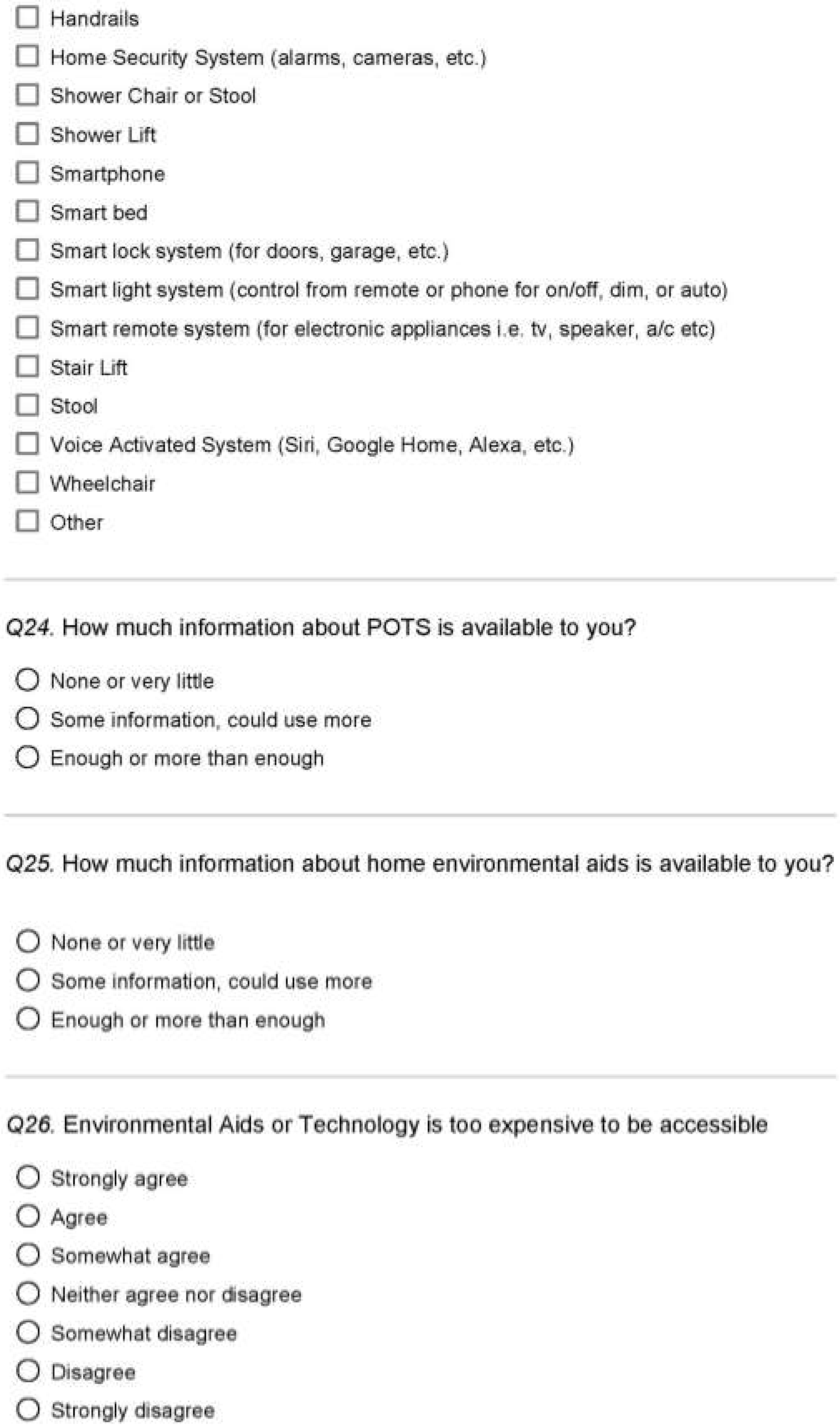
Q21. Please describe any stress inducing activities that cause symptoms (e.i. thinking about driving, preparing to go to work/school)

Q22. Please describe your thoughts about POTS symptoms or triggers and how it affects your experience in the home environment

. Environmental Aids

Q23. What types of environmental aids do you have in your home? Check all that you have even if not used regularly

☐ Alarm System
☐ Cane or Walker
☐ Fall Alarm



- ☐ Handrails
- ☐ Home Security System (alarms, cameras, etc.)
- ☐ Shower Chair or Stool
- ☐ Shower Lift
- ☐ Smartphone
- ☐ Smart bed
- ☐ Smart lock system (for doors, garage, etc.)
- ☐ Smart light system (control from remote or phone for on/off, dim, or auto)
- ☐ Smart remote system (for electronic appliances i.e. tv, speaker, a/c etc)
- ☐ Stair Lift
- ☐ Stool
- ☐ Voice Activated System (Siri, Google Home, Alexa, etc.)
- ☐ Wheelchair
- ☐ Other

Q24. How much information about POTS is available to you?

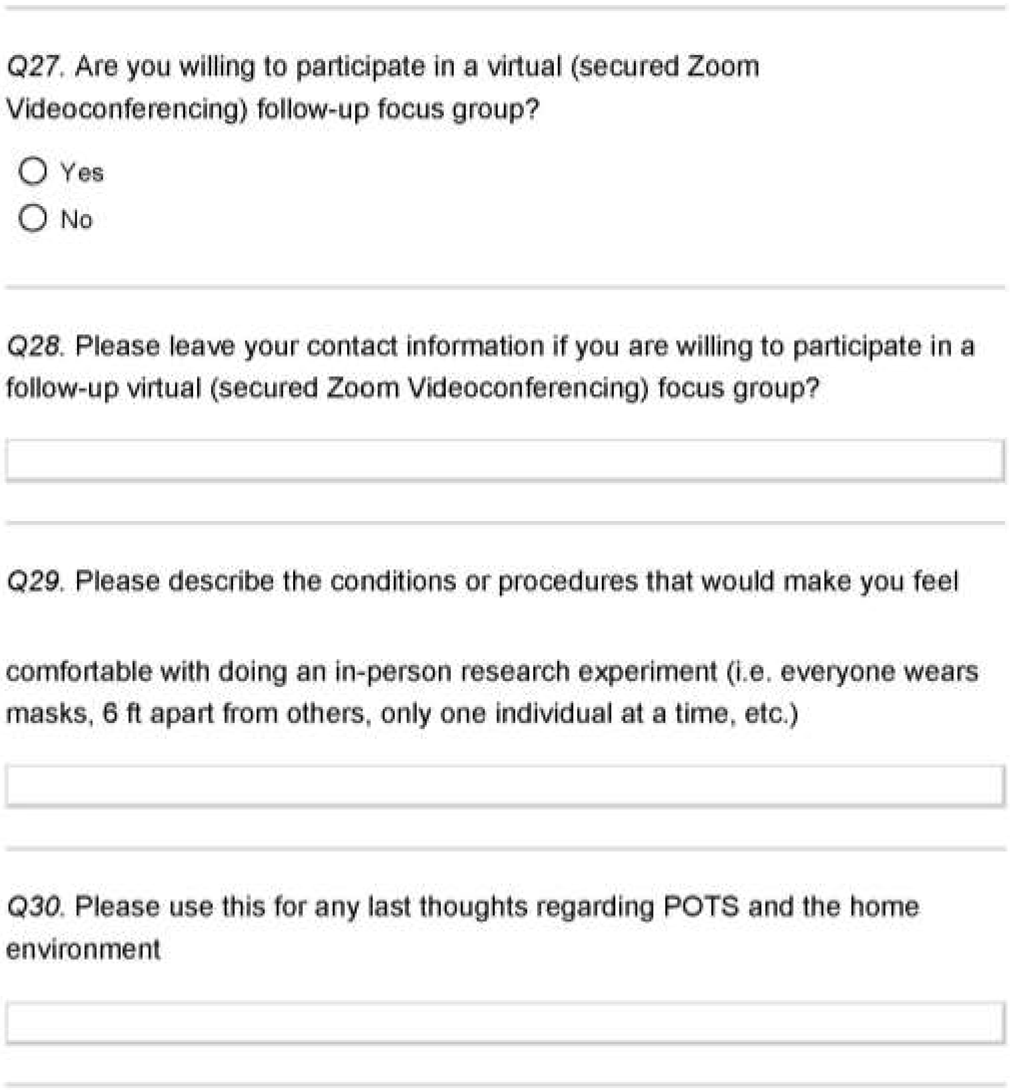
- ○ None or very little
- ○ Some information, could use more
- ○ Enough or more than enough

Q25. How much information about home environmental aids is available to you?

- ○ None or very little
- ○ Some information, could use more
- ○ Enough or more than enough

Q26. Environmental Aids or Technology is too expensive to be accessible

- ○ Strongly agree
- ○ Agree
- ○ Somewhat agree
- ○ Neither agree nor disagree
- ○ Somewhat disagree
- ○ Disagree
- ○ Strongly disagree



Q27. Are you willing to participate in a virtual (secured Zoom Videoconferencing) follow-up focus group?

○ Yes
○ No

Q28. Please leave your contact information if you are willing to participate in a follow-up virtual (secured Zoom Videoconferencing) focus group?

Q29. Please describe the conditions or procedures that would make you feel

comfortable with doing an in-person research experiment (i.e. everyone wears masks, 6 ft apart from others, only one individual at a time, etc.)

Q30. Please use this for any last thoughts regarding POTS and the home environment

Phase II Focus Group Questions

1. What kind(s) of activities in your own home would you consider a ‘trigger’ for symptoms of POTS?
2. What areas of the home do you have difficulty completing tasks?
3. How often do you feel symptomatic to the point of not being able to complete activities?
4. How long does an episode typically last?
5. What kind(s) of environmental aids (i.e. shower chair, stool, walker) do you use in your home to ease your symptoms of POTS?
6. What are your thoughts on the usefulness of home environmental aids?

Preliminary POTS Fact Sheet Draft

POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME (POTS): AN EVALUATION OF DAILY BARRIERS IN THE HOME ENVIRONMENT

Molly Jackson-Payne, B.S.,
Master's Student

POTS

Postural Orthostatic Tachycardia syndrome (POTS) can cause symptoms such as rapid heart rate, pain, fatigue, lightheadedness and fainting, nausea and vomiting, headaches, brain fog, and much more (Theiben, 2007). These symptoms can be caused by sitting up, standing up, walking, or any other activities that require upright posture. A "POTS recovery" is defined as the absence of related symptoms to a point that allows individuals the ability to perform activities with few limitations (Grubb, 2008). Some professionals have taken this statement out of context and have determined that the condition can be *cured* with treatment, which is not true (Shaw, 2019).

- Estimated 500,000 people have POTS in the United States (Sheldon, 2015).
- 1 in every 100 teens before they reach adulthood (Sheldon, 2015).
- Not considered rare, but is commonly misunderstood or misdiagnosed (Kavi, 2012; Mar, 2020).
- No medicinal treatment approved by the US Food and Drug Administration (US FDA)

Symptoms

The following issues are symptoms of POTS: Aching/Pain, Brain Fog, Fatigue, Headaches, Lightheadedness, Dizziness, and Fainting, Nausea and Vomiting, Tachycardia or Sudden Rapid Heart Rate. Not all individuals experience every single symptom, while others may feel all symptoms regularly. There are many more symptoms but these are the most frequently seen and life changing. Keep in mind these lists are in alphabetical order and not in order of frequency seen or damaging to abilities.

Triggers

Triggers are seen as activities or tasks that bring on symptoms. These are different from symptoms as symptoms are the reaction(s) that occurs that is caused by the trigger. Triggers can be seen as the cause, while symptoms are seen as the affect. One participant describes triggers, "A big challenge when I am standing up in the kitchen is not only the blood pooling in my feet but the muscle aches start kicking in and I get a lot of back and shoulder pain." This list does not include every single activity that causes symptoms of POTS, but include the main ones seen within the home.

- Bending
- Daily Tasks
- Heat Intolerance
- Standing

Problem Areas of the Home & Related Activities that are Triggers of Symptoms

The following have been identified as the main problem areas of the home for people with POTS. One participant discussed the kitchen area, "[The] kitchen is a big trigger for me, cutting vegetables, washing dishes, and any prolonged standing." Underneath each problem area lists the main trigger activities in those spaces.

- Bathroom
    - Bathing/Showering
- Bedroom
    - Getting Up From a Bed
    - Making Bed
    - Retrieving Clothing
- Kitchen
    - Cleaning Dishes

    - Cooking On a Stove Top
    - Preparing Food
    - Putting Away Dishes or Groceries
- Laundry Room
    - Loading/Unloading Washer/Dryer
    - Folding Clothes

Environmental Aids/Adaptations
Environmental Aids or Adaptions are any item that is either built into the home originally or added into the home to help people complete a task. The following list is specific for people with POTS to help decrease symptoms from triggers activities.

- Chairs/Stools
- Shower Chairs
- Mobility Devices
- Assistive Technology

Chairs/Stools
Chairs and stools can be used in multiple ways in different areas of the home. Stools are more flexible within the spaces as they are more lightweight and easier to move around the house. Stools with adjustable heights are more useful as you can use them for several activities instead of having to have several chairs or stools for different tasks. They can be used for sitting while:

- Applying Makeup
- Brushing Teeth
- Doing Dishes
- Folding Clothes
- Loading/Unloading Dishwasher
- Loading/Unloading Washer/Dryer
- Preparing Food
- Putting Away Groceries
- Washing Your Face

Shower Chairs
Shower chairs can be used in the bathtub or shower. Shower chairs can reduce long periods of standing needed to complete hygiene routines such as brushing teeth, shaving, or washing hair and body.

Mobility Devices
Some people with POTS may find support in using a cane, walker, or wheelchair. They can reduce symptoms of POTS making it easier to navigate spaces within the home. They all help lessen the amount of time people with POTS must be on their feet. They can be used like chairs or stools to complete tasks. Each device does come with some negative aspects though.

Canes

- Still Have to Stand Even if it is for Less Time

Walkers

- May Need to Get Up/Down from Seated Positions
- Still Have to Stand Even if it is for Less Time

Wheelchairs

- Difficult to Travel Throughout Home
- Take Up a Lot of Space

Assistive Technology
Technology like Apple Watches, Fitbits, and Noise Canceling Headphones can help prevent symptoms. Specific brands do not matter as long they can do the functions recommended.

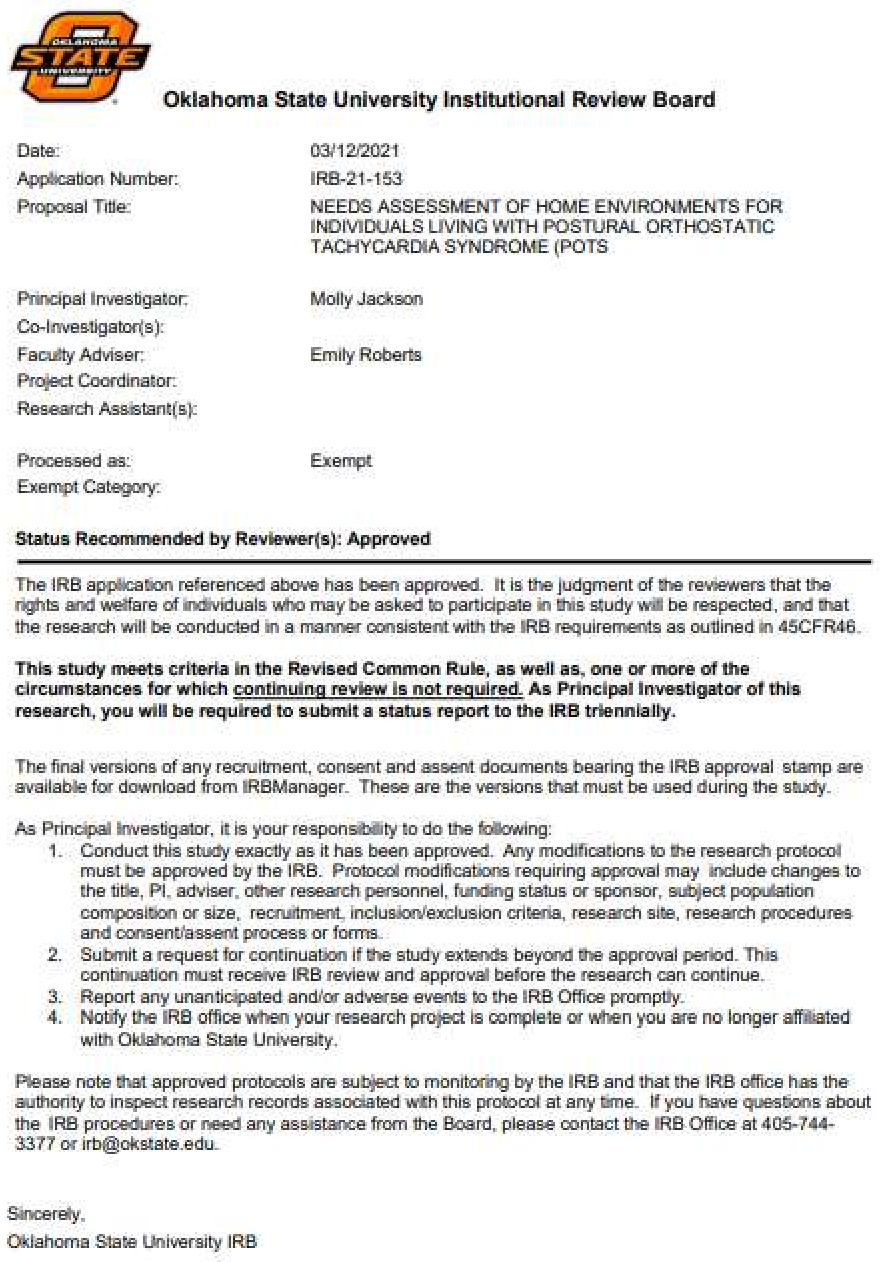
Apple Watch/Fitbits

- Can Track Heart Rate, Oxygen Levels and Sleep Patterns
    - Can Automatically Track Important Information for Medical Professionals
    - Can Notify User that Heart Rate is Spiking
    - Monitor Heart Rate to find what are Difficult Tasks for Each Person

Noise Canceling Headphones

- Block Background Noise to Reduce Distractions and Brain Fog

Institutional Review Board (IRB) Approval Page



Oklahoma State University Institutional Review Board

Date:	03/12/2021
Application Number:	IRB-21-153
Proposal Title:	NEEDS ASSESSMENT OF HOME ENVIRONMENTS FOR INDIVIDUALS LIVING WITH POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME (POTS
Principal Investigator:	Molly Jackson
Co-Investigator(s):	
Faculty Adviser:	Emily Roberts
Project Coordinator:	
Research Assistant(s):	
Processed as:	Exempt
Exempt Category:	

Status Recommended by Reviewer(s): Approved

The IRB application referenced above has been approved. It is the judgment of the reviewers that the rights and welfare of individuals who may be asked to participate in this study will be respected, and that the research will be conducted in a manner consistent with the IRB requirements as outlined in 45CFR46.

This study meets criteria in the Revised Common Rule, as well as, one or more of the circumstances for which continuing review is not required. As Principal Investigator of this research, you will be required to submit a status report to the IRB triennially.

The final versions of any recruitment, consent and assent documents bearing the IRB approval stamp are available for download from IRBManager. These are the versions that must be used during the study.

As Principal Investigator, it is your responsibility to do the following:

1. Conduct this study exactly as it has been approved. Any modifications to the research protocol must be approved by the IRB. Protocol modifications requiring approval may include changes to the title, PI, adviser, other research personnel, funding status or sponsor, subject population composition or size, recruitment, inclusion/exclusion criteria, research site, research procedures and consent/assent process or forms.
2. Submit a request for continuation if the study extends beyond the approval period. This continuation must receive IRB review and approval before the research can continue.
3. Report any unanticipated and/or adverse events to the IRB Office promptly.
4. Notify the IRB office when your research project is complete or when you are no longer affiliated with Oklahoma State University.

Please note that approved protocols are subject to monitoring by the IRB and that the IRB office has the authority to inspect research records associated with this protocol at any time. If you have questions about the IRB procedures or need any assistance from the Board, please contact the IRB Office at 405-744-3377 or irb@okstate.edu.

Sincerely,
Oklahoma State University IRB

VITA

Molly Jackson

Candidate for the Degree of

Master of Science

Thesis: POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME (POTS): A HOME EVALUATION

Major Field: Design, Housing, & Merchandising

Biographical:

Education:

Completed the requirements for the Master of Science in Interior Design at Oklahoma State University, Stillwater, Oklahoma in July, 2022.

Completed the requirements for the Bachelor of Science in Interior Design at Oklahoma State University, Stillwater, Oklahoma in 2020.

Experience:

Graduate Teaching Assistant, Department of Design, Housing, and Merchandising, Oklahoma State University, August 2020-May 2021. Responsibilities included grading work of more than 150 students at a time, entering grades into a database system, having office hours for students, providing guidance on projects, and giving feedback on sketches.

Undergraduate Research Assistant, Department of Design, Housing, and Merchandising, Oklahoma State University, August 2019 – December 2019. Responsibilities included analyzing readings, creating annotations from readings, and making summaries of those readings.