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## Abstract

FROZEN BY WORRY AND FATIGUE? A MIXED METHODS APPROACH TO  
UNDERSTANDING THE LIVED EXPERIENCES OF FREEZING OF GAIT

By Sarah M. Ghose, M.A.

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of  
Philosophy at Virginia Commonwealth University

Virginia Commonwealth University, 2024

Major Director: Natalie D. Dautovich, Ph.D., Professor, Department of Psychology

This study utilized a mixed methods emergent, phenomenological approach to (1) understanding the lived experience of freezing of gait for individuals diagnosed with Parkinson's Disease and (2) determining the role of anxiety and sleep in freezing of gait outcomes. Participants included 13 adults diagnosed with Parkinson's Disease ( $N=14$  for qualitative data,  $N=13$  for quantitative data; 23.1% female-identifying, 76.9% male-identifying) who were predominantly white (92.3%) with an average age of 69 years ( $SD = 6.73$  years). Data collection consisted of semi-structured interviews, self-report measures, actigraphic sleep data, and salivary alpha amylase biomarker collection. Results are organized into key components including: anxiety and affectivity, sleep, coping, support, and living with Parkinson's Disease and freezing of gait. A combination of direct quotes from participant interviews and quantitative data visualizations are utilized to present mixed-methods results. Results are then discussed in the context of the proposed theoretical framework, positing anxiety and sleep as potential contributing factors to the coupling model of freezing of gait adapted from Ehgoetz Martens et al. (2018) and Vandenbossche et al. (2013). This investigation is a first important step in positioning this coupling model, with the addition of sleep and anxiety as contributing mechanisms, as a framework for better understanding psychosocial factors and their

contributions to freezing of gait broadly. The context of results in relation to the larger body of literature, strengths and weaknesses of the present study, implications, and suggestions for future research are discussed.

Keywords: *Parkinson's Disease, freezing of gait, sleep, anxiety, phenomenology, mixed methods*

**Vita**

Sarah M. Ghose (they/she) was born on April 21, 1994 in Cleveland, OH. She worked for Cleveland State University as a research assistant in the Mood and Emotion Regulation (MER) Lab from August 2016 to May 2018. She currently works for Virginia Commonwealth University as a researcher on a project for which she received NINDS diversity supplement funding (PIs: Ingrid Pretzer-Aboff, Ph.D., RN, FGSA and Leslie Cloud, M.D.), SCH: Context Aware Freezing of Gait in Real World Settings study for individuals living with Parkinson's disease. Sarah received their Bachelor of Arts degree in Psychology and Philosophy from Bowling Green State University in 2015 and their Master of Arts in Clinical Psychology from Cleveland State University in 2018. They will be completing their predoctoral internship in the Behavioral Medicine service at Yale School of Medicine from the Summer of 2023 to the Summer of 2024 and completing a postdoctoral health psychology fellowship at the Cleveland Clinic from Fall 2024 to Fall 2025.

## Chapter 1: Literature Review

### Overview of the Literature Review

Parkinson's Disease (PD) is a chronic neurodegenerative disorder that is becoming more and more common within our increasingly aging population. Approximately 60,000 individuals are newly diagnosed with PD in the United States each year, equivalent to someone being diagnosed every 9 minutes (Parkinson's Foundation, 2022). PD is a disease characterized by several debilitating non-motor and motor symptoms, including tremors, changes in speech, altered posture, and freezing of gait (FoG). FoG, characterized by an inability to engage in voluntary walking despite the desire to, is arguably one of the most distressing symptoms for diagnosed individuals. More than half of individuals diagnosed with PD experience FoG and the occurrence of FoG increases as the disease progresses. FoG has been documented to severely impact quality of life across biopsychosocial domains. Indeed, individuals with FoG may experience increased falls and decreased balance (biological; Jankovic, 2008), fears of falling or freezing when going out in public (psychological; Broen et al., 2016), and may feel like a burden to those who have to care for and assist them in daily activities (social; Schrag et al., 2006).

Although much is known about the neurobiological underpinnings of FoG, there is increased interest in understanding psychosocial correlates of FoG, such as sleep and anxiety. Sleep disturbances and anxiety disorders have a high prevalence among those living with PD (Broen et al., 2016; Goetz et al., 2005). However, research increasingly suggests that sleep and anxiety may not only be the result of living with PD, but may also play a role in symptom expression, including FoG. Indeed, higher levels of anxiety and poor sleep predict FoG outcomes among individuals diagnosed with PD across self-report and experimental paradigms (de Almeida et al., 2021; Ehgoetz Martens et al., 2016; Witt et al., 2019). However, only a small

body of research has examined these associations to date, and even fewer studies have examined these mechanisms together and/or qualitatively.

This review of the literature begins by defining PD broadly and FoG more specifically. Prevalence, etiology, and symptomatology of PD are briefly summarized before discussing FoG. Models of FoG are presented, followed by discussion of potential psychosocial contributors to FoG symptomatology. In particular, the coupling model of FoG proposed by Eghoetz Martens and colleagues (2018) will be introduced. This model describes how cognitive and limbic systems become inappropriately integrated (coupled), resulting in cognitive resource overload, and inhibited forward movement (FoG) in individuals with PD. The current study will expand on this model and provide a brief review on the literature of anxiety and sleep as potential contributors to FoG, ultimately making a case for the inclusion of these two psychosocial factors in the aforementioned coupling model. Finally, this review of literature will be integrated to describe the purpose of the present study alongside study aims and research questions. Overall, the current study aims to use a mixed methods approach to integrate both qualitative and quantitative information about sleep, anxiety, and FoG to supplement existing research on neurobiological FoG mechanisms and to better understand and highlight the lived experiences of FoG among individuals diagnosed with PD.

### **Parkinson's Disease**

Parkinson's disease (PD) is a chronic and progressive neurodegenerative movement disorder that affects approximately 1 million individuals in North America (Marras et al., 2018). In particular, PD impacts 1 to 2 persons out of every 1,000 at any given time, with prevalence increasing with age. PD is known to affect 1% of the population aged 60 years or older, with less than 5% of cases experiencing disease onset before the age of 40 (Tysnes & Storstein, 2017). As

such, PD is the fastest growing neurological disorder, due in part to an aging population. The older adult population is expected to grow at least 20% by 2050 in the United States (Ortman & Velkoff, 2014). Further, the prevalence of PD within the US and other countries with fast-growing populations is expected to at least double by 2030 (Dorsey et al., 2007; Rossi et al., 2018).

Although more and more has been uncovered in the last decade about potential causes of PD, the reality is that the cause of PD onset is often unknown for most diagnosed individuals (Tysnes & Storstein, 2017). Genetic factors (e.g., gene mutations), biological sex (males are slightly more likely to be diagnosed than females), and environmental factors (e.g., pollution, cigarette smoke, and overexposure to Vitamin D) have all been identified as factors that may contribute to PD onset in approximately 5 to 10% of cases, more depending on individual and regional factors (Kalia & Lang, 2016; Tysnes & Storstein, 2017). Although many questions remain unanswered regarding PD's etiology, there is consensus surrounding the mechanisms that maintain and contribute to cell death and, ultimately, neuronal loss in PD (e.g., oxidative stress, mitochondrial dysfunction, and inflammatory changes; Schapira & Jenner, 2011). Despite all that has been and continues to be uncovered pertaining to etiology and brain-level changes associated with PD, aging remains the most significant risk factor for PD (Schapira & Jenner, 2011; Tysnes & Storstein, 2017)

The symptoms of PD are multifaceted and can be divided into motor and non-motor categories. Motor symptoms can include: reduced speed in initiating voluntary movements such as walking (bradykinesia); resting tremor; muscle rigidity; inability to move the feet upon attempts to walk (freezing of gait); muscle spasms or abnormal posture (dystonia); uncontrolled and involuntary movement (dyskinesia); speech disturbances; and postural instability. Non-

motor symptoms can include: excessive daytime sleepiness; mood disturbance; decreased emotionality; constipation; and memory complaints (Sveinbjornsdottir, 2016). Notably, non-motor symptoms can appear up to more than 10 years prior to motor symptom onset (Pont-Sunyer et al., 2015). The Hoehn and Yahr (H&Y; 1967) scale is one of the most commonly used scales to determine individuals' PD severity. The original scale, a 5-point scale, evaluates PD severity attending specifically to bilateral motor involvement, gait, and balance. The original scale includes 5 stages of PD, with the least severity at Stage I marked by symptoms such as tremor, rigidity, and slowed movement or impaired expression(s) on one side of the body. Stage II, still characterized as earlier in PD disease progression, may be characterized by symptoms on both sides, rather than solely one side, of the body without impaired balance. Symptoms at Stage II may also include decreased facial expression on both sides, decreased blinking, and speech changes (e.g., softening or monotone voice). It is important to note that a patient may be misdiagnosed or underdiagnosed at Stages I and II as symptoms may be misinterpreted as "normal aging." At Stage III, the middle stage of disease progression, diagnosed individuals start to experience balance loss. Falls also become more common at Stage III. Stage IV of disease progression is characterized by an increased need for assistance with activities of daily living (e.g., getting in and out of bed, getting up from sitting in a chair, walking from place to place) and reliance on mobility aids (e.g., canes, walkers). Stage V indicates the most severe stage characterized by required use of a wheelchair or bed confinement and needing daily and/or hourly assistance with ADLs alongside freezing or stumbling while walking. The H&Y scale has since been modified to a 7-point scale including two additional stages, 1.5 and 2.5. Notably, PD disease progression and staging can vary from individual to individual, with some patients never reaching Stage V (Editorial Team, 2017; Hoehn & Yahr, 1967; Zhao et al., 2010).

The day-to-day impact of PD on health-related quality of life is multifaceted. Quality of life has been shown to deteriorate, or worsen, with increasing disease stages. As aforementioned, higher stages of PD are associated with decreased independence and increased reliance on others to perform hourly and daily tasks. Between 40 and 55% of individuals diagnosed with PD experience anxious symptoms or are diagnosed with an anxiety disorder (Broen et al., 2016) and approximately 40 to 50% of individuals diagnosed with PD experience depression (Cong et al., 2022). In a study of individuals diagnosed with PD from Finland, H&Y stage, gender, and depression showed significant associations with quality of life. Specifically, more advanced disease stages were associated with decreased physical functioning and increased physical limitations. Further, women were more likely than men to rate their quality of life lower and their depression levels higher. Lastly, depression was significantly associated with increased bodily pain and the emotional impact of role limitations associated with PD. Other factors directly related to living with PD including daytime sleepiness/fatigue, apathy, and the impact of motor symptoms on one's ability to engage in daily activities also contribute to worsened perceptions of quality of life among diagnosed individuals (Kuhlman, 2019).

### **Freezing of Gait**

Although the experience of PD is multifaceted, one of the most distressing symptoms experienced by individuals living with PD is freezing of gait (FoG). FoG is a paroxysmal gait abnormality that is characterized by a periodic inability to either initiate or continue normal heel-to-toe walking (Giladi et al., 2001). It can also be defined as a “brief, episodic absence or marked reduction of forward progression of the feet, despite the intention to walk” (Giladi & Nieuwboer, 2008). FoG affects over 50% of individuals living with PD, and up to 81% in later stages of the disease (Giladi & Hausdorff, 2006; Hely et al., 2008). General gait abnormalities in PD can



manifest as poor step scaling (length) and rhythm (timing), shuffling of the feet, abnormal posture, and/or impaired balance (Jankovic, 2008; Sveinbjornsdottir, 2016). During a FoG episode, individuals experience an inability to move despite the desire to. Many individuals have reported that an episode of freezing feels like having their feet glued to the ground. These episodes can last between 30 seconds and several minutes (Gao et al., 2020).

FoG is a common and devastating manifestation of PD for which there is currently no cure or adequate medical or surgical treatment. FoG is most frequently triggered by turning, dual-tasking (e.g., engaging in cognitive tasks while walking), environmental stimuli and/or challenges, navigating doorways, and approaching a target destination (Gilat et al., 2021). The distress and burden associated with FoG compounds upon difficulties already experienced by those living with PD. Part of what makes FoG so devastating, aside from the experience of being unable to move despite intention to do so, is the potential for FoG to greatly reduce an individual's ability to be independent due to increasing risk and occurrence of falls (Gao et al., 2020; Schaafsma et al., 2003).

FoG is identified as the strongest predictor of worsened health-related quality of life among individuals in H&Y stages I to III. Specifically, FoG has been shown to poorly impact quality of life beyond depression, anxiety, and sleep disturbance among individuals diagnosed with PD (Walton et al., 2015). Walton and colleagues (2015) suggest that the reason for FoG's large contribution to quality of life beyond several other contributors may be tied to decreased sense of safety, fear of falling, and feelings of decreased independence associated with freezing episodes over time. Notably, these episodes, beyond implications for safety, can make an individual feel embarrassed, frustrated, and more like a burden to important others in their lives (Schrag et al., 2006; Walton et al., 2015). Although promising treatment options exist for many

other symptom presentations in PD, levodopa (Schaafsma et al., 2003), deep brain stimulation (Davis et al., 2006), and environmental cueing interventions (Nieuwboer et al., 2007) have shown poor to modest FoG treatment outcomes (Lewis & Barker, 2009).

Part of the reason for inconsistent treatment response to these intervention modalities is that FoG is complex and heterogeneous (Ehgoetz Martens et al., 2018). Importantly, among diagnosed individuals and caregivers, PD is known as a “snowflake disease,” meaning that just as no two snowflakes are alike, no two individuals living with PD have the same disease presentations or experiences. As such, it is important to identify any possible commonalities underlying FoG that may exist from individual to individual to inform and improve treatment. Toward this aim, research has increasingly sought psychosocial contributors for FoG to supplement our understanding of neurobiological underpinnings.

### **Models of Freezing of Gait**

The primary models of FoG fall broadly into four main categories, including threshold, crosstalk/interference, cognitive, and decoupling/coupling (Nieuwboer & Giladi, 2013). Each of these models broadly builds off of the assumption that FoG occurs as a result of abnormal cortical functioning within the networks and structures responsible for voluntary movement control: the basal ganglia overall (group of subcortical nuclei responsible for motor control and learning among other functions), the subthalamic nucleus (responsible for movement regulation), and the striatum (the input nodule/neuronal circuit for the basal ganglia necessary for voluntary movement; Shine et al., 2013).

The *threshold model* of FoG suggests that motor deficits (e.g., poor step scaling, rhythm control, and gait coordination) accumulate to the point that the already abnormally functioning system for voluntary movement control is ultimately overloaded, leading to freezing of gait

(Plotnik et al., 2012). The *interference*, or *crosstalk*, model of gait freezing posits that neural pathways that are normally parallel to and segregated from one another as they pass through the basal ganglia become abnormally integrated (Ehgoetz Martens et al., 2018), resulting in crosstalk among competing inputs derived from motor, cognitive, and limbic systems. The basal ganglia of an individual that does not experience freezing is able to process these parallel inputs without consequence. However, among individuals suffering from FoG, this crosstalk then triggers inhibition within the voluntary movement system, resulting in freezing of gait (Lewis & Barker, 2009). The *cognitive model* of FoG focuses on cognitive inflexibility combined with executive function and attentional set-shifting deficits in FoG (Ehgoetz Martens et al., 2018; Heremans et al., 2013; Nieuwboer & Giladi, 2013). This theory suggests that due to a loss of cognitive control and automaticity, complex dual tasks require increased use of cognitive resources. As a result, there is an increased reliance on voluntary, controlled processes. This increased cognitive load then overwhelms available cognitive resources and these resources break down, resulting in FoG (Vandenbossche et al., 2013). The fourth model category, *decoupling/coupling*, focuses on inappropriate or uncoordinated interactions across neural networks that normally work well together to help an individual anticipate and initiate movements appropriately (Fasano et al., 2015). For example, the cerebral cortex and the striatum work synchronously to either encourage or inhibit movement so that when we think “I would like to walk now,” (cerebral cortex activity) our bodies are able to act upon this desire and initiate movement (limbic striatum activity). This also means that if these two systems are working optimally, we are also able to think “I would like to stop walking now” and our bodies are able to then stop moving. When these systems, the cognitive control and limbic systems broadly, do not work together optimally or appropriately, this can result in a mismatch between the cognitive desire to move and the body’s response to

this neural command. To illustrate this phenomenon, Jacobs and colleagues (2009) showed that although control subjects were able to accomplish both a single anticipatory adjustment to move (e.g., shifting weight to one foot to begin walking or adjusting feet to prepare to walk) followed by a single step, individuals experiencing FoG evidenced multiple anticipatory adjustments (e.g., multiple shifts in weight between feet or adjustments in feet placement in preparation to walk) followed by delayed, inappropriate steps or no steps at all. Hence, an inappropriate interaction between cognitive and limbic systems may impair voluntary movement, or an inability to walk when and how desired despite the cognitive intention to do so.

The current study focused on the coupling model proposed by Ehgoetz Martens and colleagues (2018), a model which integrates the aforementioned cognitive, crosstalk, and decoupling models. Essentially, the coupling model combines the following factors from the aforementioned models to explain FoG: (1) attention shifting and dual-tasking contribute to cognitive overload and limited cognitive resources (cognitive); (2) neural signals that should be parallel to one another can become inappropriately integrated (crosstalk); and (3) networks that normally work well together can interact inappropriately or in an uncoordinated manner (decoupling/coupling). Inappropriate coordination between cognitive and limbic networks contributes to cognitive overload within a context of PD-related depleted cognitive resources to handle this overload, resulting in FoG. In a study of the neural mechanisms contributing to the heterogeneity of FoG, Ehgoetz Martens and colleagues (2018) utilized a virtual reality paradigm to investigate the role of cognitive, motor, and affective functioning in producing individual differences in FoG outcomes. Participants engaged in control (e.g., wide doorway) versus known FoG-triggering (e.g., narrow doorway, cognitive dual-tasking, or attention shifting) virtual reality scenarios while in a functional MRI machine which allowed them to “take steps” using foot

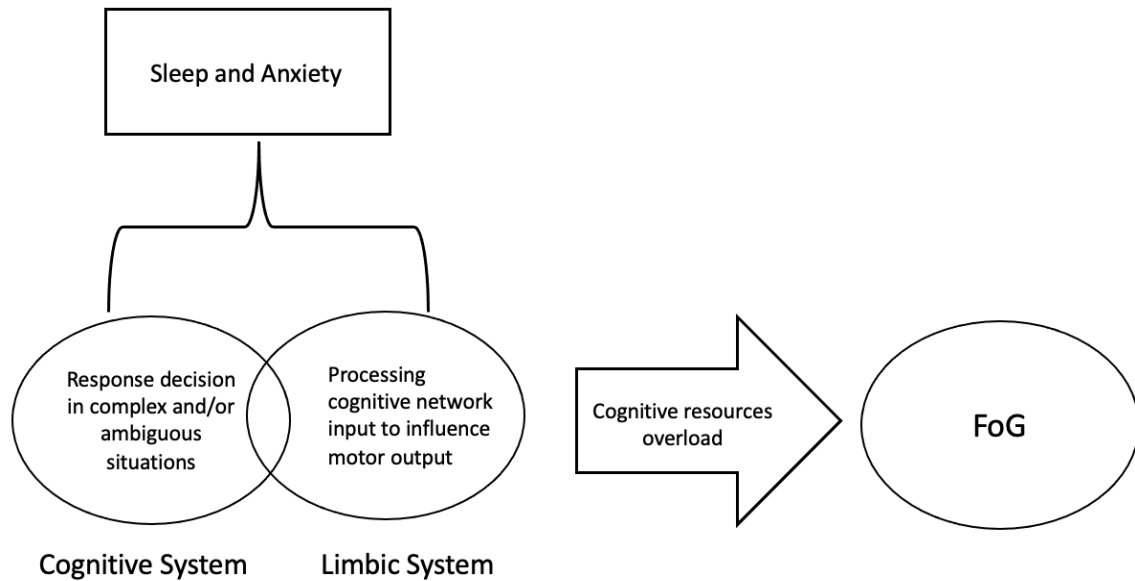
pedals. Notably, individuals who experienced freezing exhibited higher levels of cognitive inflexibility (e.g., difficulty with attention shifting) and higher levels of anxiety as measured by the Hospital Anxiety and Depression Scale. Overall, these results, combined with confirmatory functional MRI neuronal network analyses, suggest that coupling between cognitive and limbic systems contributes to FoG.

A more thorough examination of this model suggests that FoG results from both inappropriate coupling between cognitive and limbic networks as well as underpowered cognitive resources. In particular, according to the coupling model, in FoG there is a “loss of specificity between the cortex and striatum...increas[ing] the vulnerability of the system to ‘overload’” (Ehgoetz Martens et al., 2018, 1147). In general terms, neuronal signals that are supposed to run parallel to one another through the basal ganglia structures, including the striatum, instead become entangled. With such entanglement, information processing is less efficient which places the burden on other cognitive domains to compensate. Hence, this entanglement draws upon depleted cognitive resources (characterized by PD-related decreased dopamine levels and limited output nuclei) and as the limbic system tries to compensate, it gets overloaded and momentarily halts all voluntary walking movement. This overload is complicated by cognitive and emotional limbic input which has the potential to further stress the already stressed motor system. For example, competing inputs, such as the desire to walk, but a fear of falling, may tax an already taxed cognitive compensatory system. Essentially, an individual with PD may already have limited baseline cognitive resources without the additional stress of implementing additional cognitive efforts (e.g., coping mechanisms) to minimize anxiety about falling. As a result, these usually parallel inputs become coupled and entangled, due in part to depleted cognitive compensatory resources. Then, the overwhelming cognitive load is

exacerbated by stress and individuals have an inability to properly engage the voluntary movement system. Thus, despite an individual having the desire to walk, this overload creates the exact opposite reaction - inhibited forward movement or freezing of gait. This model supports and furthers the work done on the crosstalk model in that it suggests that the over recruitment of neural communications that are normally parallel may allow for limbic, or emotional, input (e.g., anxiety) to interfere with motor output (e.g., walking). In fact, the authors, Ehgoetz Martens and colleagues (2018), suggest that this model may offer an explanation for increasing research and clinical interest in anxiety and FoG.

### **Psychosocial Pathways to Freezing of Gait**

Indeed, there has been increasing focus on anxiety as a psychosocial factor that can contribute to the cognitive load known to precede FoG due to its interference with simultaneous cognitive and limbic information processing (Ehgoetz Martens et al., 2018; Lewis & Barker, 2009). An emerging body of research also suggests that objectively and subjectively measured sleep is associated with both anxiety and FoG outcomes in individuals diagnosed with PD (de Almeida et al., 2021; Zhang et al., 2016). Taking into account anxiety as a form of affective disturbance manifest within the limbic system and the potential for poor sleep to impact both cognitive flexibility and mood states/affective reactivity (Goldstein & Walker, 2014), anxiety and sleep are two psychosocial mechanisms with the potential to contribute to and exacerbate coupling between cognitive and limbic systems, resulting in FoG when applied within the coupling model (see Figure 1).



*Figure 1.* Theoretical model of the coupling between cognitive and limbic systems, influenced by sleep and anxiety factors, in contributing to FoG episode outcomes. Adapted from Ehgoetz Martens et al., 2018 and Vandebossche et al., 2013.

**Anxiety.** As aforementioned, anxiety impacts 40 to 55% of individuals diagnosed with PD (Broen et al., 2016). The factors that contribute to anxiety for individuals living with PD include: day-to-day fluctuations in functioning; declines in the ability to carry out ADLs independently; fear of falling; history of depressive and/or anxious disorders; and generally living with PD itself (Broen et al., 2016; Ghielen et al., 2020). An ever-growing body of research supports an association not only between anxiety and PD broadly, but between anxiety and FoG specifically. For example, in a study examining potential contributing factors to FoG in a sample of individuals diagnosed with PD with varying disease severity, worse self-reported quality of life, higher disease severity, depression, and anxiety were all positively associated with self-reported FoG (Pimenta & Valenca, 2019). Indeed, stressful situations (e.g., time constrained activities, crowded environments, and dual tasking) and decreased self-efficacy related to balance and falls may explain the association between anxiety and FoG outcomes. Additionally, anticipatory anxiety related to low self-efficacy to carry out activities (e.g., walking, balance)

may contribute to FoG outcomes (Bloem et al., 2004; Bryant et al., 2014; Pimenta & Valenca, 2019).

In a virtual reality study of the association between anxiety and FoG, Ehgoetz Martens and colleagues (2016) utilized a paradigm which required participants to “walk” across a plank that was either located on the ground (low anxiety condition) or above a deep pit (high anxiety condition). In this study, anxiety levels were assessed at baseline using the State and Trait Anxiety Inventory and following each virtual reality task trial using a 9-point self-assessment scale of anxiety developed for the study. Individuals who experienced FoG had freezing episodes with significantly higher frequency and duration in the high anxiety condition compared to the low anxiety condition. Additionally, a systematic literature review on anxiety and FoG specifically determined that out of 26 studies on this association, 16 showed a significant association between anxiety (measured by the Hospital Anxiety and Depression Scale, State and Trait Anxiety Inventory, and Parkinson’s Anxiety Scale among others) and either FoG itself or increased FoG severity (measured by the Freezing of Gait Questionnaire, virtual reality paradigms, and gait tasks; Witt et al., 2019).

It is worth noting that the authors of the aforementioned review suggest that future research should focus on clarifying the role of anxiety as a causal factor of FoG, rather than solely a disease-related symptom or a consequence of experiencing FoG itself (Witt et al., 2019). This suggestion positions anxiety as a potentially independent contributing factor to FoG. Placed within the proposed coupling model, according to a systematic review of anxiety and PD focused on existing neuroimaging studies of this association, anxiety has been shown to impact both structures associated with fear (e.g., amygdala, hypothalamic nucleus, etc.) and the broader limbic circuit (Carey et al., 2021). The impact of anxiety on these structures may explain not



only the high prevalence of anxiety among individuals diagnosed with PD, but also associated cognitive and motor impairments (e.g., FoG).

**Sleep.** Poor sleep has a known association with a variety of health consequences in the general population including increased inflammation (Motivala & Irwin, 2007), viral susceptibility (Prather et al., 2013), worsened cognitive functioning (Dzierzewski et al., 2018; Wardle-Pinkston et al., 2019), and enhanced emotional reactivity (Alvaro et al., 2013; Goldstein & Walker, 2014; Tempesta et al., 2020). Although past sleep research has historically focused solely on disturbed or dysfunctional sleep, research has increasingly focused on sleep across the sleep health spectrum. Indeed, attaining good sleep is more than simply acquiring the recommended 7 to 9 hours of sleep per night. Healthy sleep is composed of several factors including sleep duration, timing (e.g., bed and wake times), restfulness/alertness, efficiency, consistency, satisfaction with sleep, and overall sleep quality (Buysse, 2014).

Up to 75% of individuals diagnosed with PD experience sleep difficulties (Goetz et al., 2005). The most common sleep disturbances among individuals with PD include: multiple nighttime awakenings, REM sleep disorders, excessive daytime sleepiness, nighttime restless leg movements, nocturnal hallucinations, sleep-wake cycle disturbances, and sleep-related breathing disorders (Comella, 2007; Stavitsky et al., 2010). In a study of sleep quality of PD with a sample of PD patients with moderate disease severity, subjective survey measures, sleep diary, and an objective measure of sleep, actigraph, were used to assess not only overall sleep quality, but also correlations across measurement modalities. Sleep quality showed significant impairment across clinical scales of sleep disturbance and quality (e.g., Pittsburgh Sleep Quality Index, Epworth Sleepiness Scale, Parkinson's Disease Sleep Scale), sleep diary, and actigraphy. Interestingly, different information about sleep was garnered from each different modality and subjective and

objective sleep measurements showed moderate correlations at best. For example, although the sleep diary and actigraphy provided similar information, there was a marked difference between objectively recorded and subjectively reported sleep onset latency (time to fall asleep after getting into bed). Additionally, participants were shown to overestimate their total sleep duration in their sleep diaries compared to total time asleep captured by actigraphy (de Almeida et al., 2019). A potential application of attending to such a discrepancy between measurement modalities may be garnering important information about perceived restfulness and sleep quality versus recorded sleep duration and efficiency. Although this study confirms sleep disturbance in the PD population, it also highlights the importance of utilizing multiple sleep measurement modalities to capture the complexity of sleep experiences. This is in line with other research on objective and subjective sleep measurement in the general older adult population (Hughes et al., 2018).

Although there is a small body of literature on sleep and PD broadly, there is less research available on sleep and FoG. Notably, there is a higher occurrence of sleep disturbance among individuals who are diagnosed with PD and experience FoG compared to those diagnosed with PD who do not experience FoG. Indeed, individuals diagnosed with PD who live with FoG experience both a higher rate of sleep disorders (Banks et al., 2019) and worse sleep quality (Sawada et al., 2019) compared to those without FoG. Further, in a study of individuals diagnosed with PD experiencing FoG, it was evidenced that sleep plays an important role in exacerbating the cognitive, mobility, and anxiety mechanisms that contribute to FoG. de Almeida and colleagues (2021) discovered that worse sleep quality (measured by the Pittsburgh Sleep Quality Index) was associated with poorer cognitive performance (measured by the Montreal Cognitive Assessment), higher anxiety (measured by the Hospital Anxiety and

Depression Scale), and worse scores on the Timed Up and Go mobility test. Worse sleep quality was further associated with increased self-reported FoG in this sample. Although the impact of poor sleep on FoG specifically has been understudied, existing research in other domains does support the association between disturbed sleep and impaired cognitive control network functioning - a key component of the aforementioned coupling model of FoG. For example, among middle-to-older adults, poor sleep, specifically short sleep duration and poor sleep quality, has been associated with overall cortical thinning in the frontal networks and frontal-parietal networks essential to cognitive control functioning (Scullin, 2017). Essentially, poor sleep has been shown to independently contribute to a depletion in functioning of the networks responsible for an individual getting from Point A, “I would like to walk”, to Point B, limbic processing of this desire resulting in appropriate motor output and voluntary movement.

Anxiety and sleep are both psychosocial mechanisms with the documented potential to contribute to FoG when applied to Ehgoetz Martens and colleagues (2018) coupling model. Given the vulnerability of individuals living with PD to both anxious symptoms and sleep difficulties, combined with what is presently known about each mechanism’s influence on systems responsible for voluntary motor movement, further objective and subjective examination of these factors is an important next step for both research on and intervention for FoG. Although existing research has begun to document the associations between sleep quality, anxiety, and FoG using actigraphy for sleep data collection with the PD population (de Almeida and colleagues 2019, 2021), given the unique experiences of FoG in individuals with PD, there is a need for a mixed methods approach to capture individual nuances utilizing multiple measurement indices for each factor. Multiple modes of measurement are necessary in order to quantitatively capture both objective and subjective experiences of sleep and anxiety in relation

to FoG, as well as qualitatively exploring the lived experience of FoG. Remembering that the experience and presentation of FoG can be unique to each individual diagnosed with PD, incorporation of narrative alongside quantitative data is essential to creating a representative picture of the association between these target factors and FoG outcomes.

### **Qualitative Research on Freezing of Gait and Psychosocial Contributors**

Qualitative research is used to investigate and communicate the lived experiences of a phenomenon, such as FoG, beyond solely quantitative representations of phenomena (e.g., summative scale scores). Indeed, through qualitative research we can draw conclusions about phenomena in individuals' own words. A small body of research has investigated the links between sleep and anxiety and PD symptoms for individuals living with PD as well as FoG symptoms broadly. Importantly, existing qualitative research in this area at this time has only investigated these factors separately.

First, the role of sleep in PD symptoms was investigated utilizing a grounded theory approach (van Gilst et al., 2016). Grounded theory research is an inductive qualitative approach which is often conducted with the goal of creating or supporting an existing theory (Charmaz & Thornberg, 2021; Creswell & Poth, 2018). Results of van Gilst and colleagues' (2016) investigation into the potential benefits of good quality sleep on PD symptoms were mixed. The researchers conducted semi-structured interviews with open-ended questions over the phone with patients about their experiences of symptoms upon awakening, napping behaviors, day-to-day variability in functioning, and sleep quality. Out of a sample of 14 patients living with varying stages of PD, six reported that following a night of good rest they noticed improvement in motor symptoms, five reported not noticing any benefit, and three reported that they were unclear about whether any benefit they experienced was directly related to sleep (van Gilst et al., 2016).

Another qualitative study employed a phenomenological approach to investigating and understanding the lived experiences of anxiety for those diagnosed with PD (Lovegrove and Bannigan, 2021). Notably, a phenomenological approach is one which focuses on the essence of a phenomenon or *what it is like* to experience a phenomenon. Although other qualitative approaches may be conducted with an established *a priori* thematic structure, phenomenology allows themes to emerge from the data (Braun & Clarke, 2006; Neuendorf, 2019). Therefore, Lovegrove and Bannigan (2021) investigated not only the presence of anxiety in PD, but how anxiety is *experienced* among six individuals from the UK living with differing stages of PD in their own words. The researchers utilized a semi-structured interviewing approach with participants in their own homes. Interview questions were open-ended and designed to prompt the participants about the phenomenon of interest, anxiety (e.g., “What is your experience of anxiety?”). The three main themes that emerged from this study included: finding ways to cope to try not to let anxiety rule their lives; the potential for anxiety to exacerbate symptoms such as “it’s emotionally draining [and] it’s also physically draining”; and “anxiety is a funny thing.” Participants further reported that anxiety impacted their ability to engage socially as well as their functioning across cognitive, emotional, physical, and self-identity domains (Lovegrove & Bannigan, 2021).

A single phenomenological study has been conducted to date on the lived experiences of FoG. Researchers Redmond and Suddick (2012) conducted a phenomenological investigation utilizing semi-structured interviews over the phone with six individuals diagnosed with PD from the UK. The main phenomenological question that participants were asked was, “Can you tell me about your experience of freezing/times when you were unable to move?” Key themes arose related to freezing as an entity/a living thing, emotional consequences of FoG, emotional and

physical links to FoG, and the impact of FoG on relationships and life changes (e.g., increased dependency on important others; Redmond & Suddick, 2012 ).

These qualitative investigations represent important first steps to understanding the experience of anxiety, sleep, and FoG. However, the limited number of such investigations alongside the narrow scope of existing qualitative investigations on PD and FoG point toward a need for more comprehensive qualitative studies in this area.

### **Current Study**

FoG is a complex and burdensome motor symptom with the potential to reduce an individual's quality of life which impacts over half of individuals diagnosed with PD, and up to 81% of individuals in later disease stages (Giladi & Hausdorff, 2006; Hely et al., 2008).

Although pharmacologic and non-pharmacologic interventions exist for FoG, treatment response is modest at best and varies from individual to individual (Delgado Alvarado et al., 2020).

Despite the substantial research into the biological mechanisms of FoG, psychosocial mechanisms remain understudied and underutilized.

This gap in the research is important to address as FoG is not a one-size-fits-all phenomenon. Consequently, there is a need to explore psychosocial factors that may influence FoG outcomes in order to broaden the available treatment repertoire and increase chances of successful treatment outcomes in this population. Sleep and anxiety show potential as psychosocial factors that predict FoG outcomes; poorer sleep and greater anxiety are associated with higher frequency and severity of self-reported and objectively measured FoG episodes (de Almeida et al., 2021; Ehgoetz Martens et al., 2016; Sawada et al., 2019; Witt et al., 2019). As such, further investigation into sleep and anxiety as potential psychosocial mechanisms contributing to FoG is warranted to (1) better understand their associations with FoG and (2)

provide a foundation for further avenues of research into and implementation of psychosocially-targeted intervention and treatment programs for FoG. In particular, there remains a need to better understand and illustrate the heterogeneous, complex nature of FoG (Ehgoetz Martens et al., 2018; Fasano et al., 2015) and this cannot be done by studying each psychosocial mechanism separately under strictly quantitative or qualitative methodological conditions. With a mixed methods approach, there is an opportunity to identify and highlight potential points of commonality among lived experiences of FoG (e.g., contributions of sleep and anxiety to freezing outcomes) as well as individuals' unique experiences of FoG.

The current study sought to better understand the experiences of anxiety and sleep in relation to FoG, and FoG itself, among individuals diagnosed with PD through observations and in their own words. Although there is a small body of quantitative and qualitative studies investigating sleep and FoG and anxiety and FoG separately, there is no research which attends to the associations between observed and lived experiences of sleep, anxiety, and FoG. The present study builds upon existing quantitative and qualitative research on sleep, anxiety, and FoG, utilizing in vivo and retrospective measures of sleep (actigraphy, Pittsburgh Sleep Quality Index, Sleep Diary, semi-structured interview), anxiety (State Trait Anxiety Inventory, salivary alpha amylase biomarker collection, semi-structured interview) and FoG (New Freezing of Gait Questionnaire, semi-structured interview) validated for use within the PD population in prior investigations (see de Almeida et al., 2019, 2021; Redmond & Suddick, 2012; Sancho Cantus et al., 2019; Witt et al., 2019). In addition to exploring the associations between anxiety and sleep and FoG, and potentially identifying avenues for intervention in the treatment of FoG, the current study's use of a phenomenological approach highlights the essence of *what it is like* to experience FoG.

## **Study Research Questions and Aims**

### ***Research Questions***

#### **Qualitative.**

1. What are the lived experiences of FoG among individuals diagnosed with Parkinson's Disease?
2. How are psychosocial factors associated with FoG?
  - 2.1 What is the lived experience and role of anxiety in FoG outcomes?
  - 2.2 What is the lived experience and role of sleep in FoG outcomes?

#### **Quantitative.**

3. What are the characteristics of sleep in this population?
4. What are the characteristics of anxiety in this population?
5. What are the associations between sleep and anxiety and FoG in this population?

#### **Mixed Methods.**

6. What results emerge from comparing phenomenological qualitative data about the role of sleep and anxiety in FoG with quantitative data collected via self-report, actigraph, and biomarker measurements?

### ***Study Aims***

The overarching purpose of the current mixed-methods, phenomenological study was to build and expand upon existing descriptions of the lived experiences of freezing of gait among individuals diagnosed with Parkinson's Disease. Specifically, the current study aimed to understand the lived experiences of PD and FoG and potential psychosocial contributors to FoG through use of mixed methods (semi-structured interviews, actigraphy, sleep diary, salivary alpha amylase biomarker collection, and self-report measures). Overall, the current study aimed



to use a mixed methods approach to obtain a more comprehensive understanding of FoG and to add richness to the existing literature.

## **Chapter 2: Methods**

### **Participants**

Participants included 14 individuals diagnosed with Parkinson's Disease from the United States recruited by medical providers from the Virginia Commonwealth University (VCU) Parkinson's Disease and Movement Disorders Center as well as participant self-recruitment via clinicaltrials.gov. Notably, this sample size is within range of sample sizes utilized in other qualitative studies of PD and FoG (Lovegrove & Bannigan, 2021; Redmond & Suddick, 2012; van Gilst et al., 2016). In order to participate, individuals must have been at least 18 years old, diagnosed with PD by a movement disorder specialist consistent with the United Kingdom Parkinson Disease Society Brain Bank Diagnostic Criteria, and able to walk independently or with simple walking aids (e.g., cane, walker). Participants must also have been observed by the larger research team to experience FoG in at least two of five of the following situations: gait initiation; walking through tight quarters; when changing directions; approaching a visual target; dual tasking; and engaging in time sensitive scenarios (e.g., entering an elevator before the doors close, answering a ringing phone). Study exclusion criteria included: being diagnosed with Parkinson plus syndrome; presence of dementia (e.g., a Montreal Cognitive Assessment Score <21); an additional disorder unrelated to PD which impairs gait; history of implantable cardiac or other devices that are not related to deep brain stimulation; peripheral neuropathy; pregnancy; or any other condition determined by the principal investigator to potentially compromise participant safety, data integrity, or data interpretation. Participants were compensated via \$25 USD gift cards following each study visit, up to a maximum of \$75 USD across three study

visits. Participants were also given the opportunity to receive a summary of results following the study's completion. Notably, as one participant did not evidence freezing behavior during their first visit, their quantitative data were not included in the final dataset. However, their interview responses were still retained for final qualitative analyses. As such, the sample size for quantitative data was  $N=13$ , while the sample size for qualitative data was  $N=14$ .

### **Study Design**

The current study employed a mixed-methods design to investigate objective, subjective, and interview measures of sleep, anxiety, and FoG to capture the complexities and lived experiences of these factors in individuals diagnosed with PD. Although there are many definitions of what constitutes mixed-methodology in the literature, the current study was guided by the definition where the researcher (1) collects, analyzes, and interprets both quantitative and qualitative data and (2) integrates both quantitative and qualitative approaches (Creswell, 2015). There are many advantages to utilizing a mixed-methods approach, specifically to address questions related to health and healthcare that are often multifaceted in nature. In particular, the advantages of using a mixed-methods study design include: triangulation, completeness, offsetting weaknesses, different research questions, and illustration (Doyle et al., 2016). Indeed, through the use of multiple measurement modalities of target variables, findings can be corroborated between quantitative and qualitative measurement and vice versa. Further, a more holistic and comprehensive explanation of the phenomena being investigated can be uncovered using a mixed methodology. Additionally, the use of multiple modes of measurement is a way to minimize weaknesses that may arise from method to method (Creswell, 2015). An additional strength of mixed-methods research is that more complicated, multifaceted research questions can be asked (e.g., quantitative, qualitative, and mixed-methods research questions) and

answered within a single study. Lastly, quantitative data can be used to highlight and contextualize qualitative findings and vice versa, in order to increase rigor and richness (Creswell, 2015; Doyle et al., 2016).

Mixed-methods research is an umbrella term used to refer to different types of mixed-methods study designs. The current study utilized a convergent design in which quantitative and qualitative were collected concurrently (not in a sequential or embedded fashion as may be indicated in other mixed methods designs; Creswell & Plano Clark, 2011). A convergent design is particularly useful in healthcare research due to potential patient time constraints and turnover (e.g., patients being discharged from hospital). The current study adhered to the data analytic structure embodied in most convergent designs whereby both quantitative and qualitative data and results are equally important and merged for comprehensive interpretation of the results (Doyle et al., 2016).

### ***Qualitative Phenomenological Approach***

For the qualitative portion of the project, specifically the semi-structured interview, the current study utilized a hermeneutic phenomenology qualitative method of inquiry to conceptualize and explore the lived experiences of freezing of gait among individuals diagnosed with PD. A phenomenological approach assumes that although humans undoubtedly engage with the realities of their world daily, there are pieces of the lived experience that become subconscious, or at least not readily on the mind of the experiencer. According to Husserl, the philosopher who originally introduced the idea of phenomenology, a lived experience must be actively probed and reflected upon in order to unearth its essence - *what it is like* to have that experience (Liujpen & Koren, 1969). A well-known phenomenological thought experiment speaks of a girl named Mary who has only ever seen the world in black and white. Though she

has had the biological process of seeing colors and every possible description of red described to her, she will be unable to experience *what it is like* to see red, the *essence* of experiencing red, unless she is able to *see* it (Nida-Rumelin, 1996). Similarly, we can collect quantitative data on the frequency of anxiety, how many times an individual wakes up at night, and how long an individual freezes, but we cannot begin to understand *what it is like* to experience FoG until we *ask and listen*.

Heidegger built upon Husserl's phenomenology by positing that culture, which influences and is influenced by the individual, is an integral pathway through which the individual makes meaning and understands the world. Thus, an individual's understanding of the world is both subjective and constructed (Dowling, 2005; Heidegger, 1962). The choice to utilize a hermeneutic phenomenological framework was intentionally made with attention to the *essential* nature of the present study's main qualitative and mixed methods research questions. These questions lend themselves to the Heideggerian postulation that one's experience is inseparable from their context, that the two are "co-constructed" (Lavery, 2003). Each individual's experience and understanding of PD will be unique to their own context, culture, meaning-making, and worldview.

## **Procedure**

The present study was approved by the Institutional Review Board at VCU. The current study was funded by the National Institute of Neurological Disorders and Stroke, a diversity supplement (NS120560) awarded to Sarah Ghose, M.A., as part of the parent NIH grant project SCH: Context-Aware Freezing of Gait Mitigation in the Real-World Setting (R01NS120560; PIs- Ingrid Pretzer-Aboff, Ph.D. and Leslie Cloud, M.D.). The current study is a part of a larger study in collaboration with The College of William and Mary focused on the role of vibration

therapy for FoG. Specifically, the parent study is focused on improving upon vibration technology that is currently available by utilizing a closed loop system that can be individually tailored to reduce FoG in commonly known triggering conditions. This involves two major device components: an Ultigesture (UG) motion sensor and the PDVibe3 which provides vibrational stimuli to the foot once a FoG event is detected. These devices are both small and wearable. The UG sensor is attached to an ankle band to which the PDVibe3 is also attached. The UG sensor collects raw data both to detect FoG and to develop models of FoG. Once the UG sensor detects a freezing episode, the PDVibe3 provides vibration stimuli to the surface of the foot and heel. These devices can be controlled by Android and iPhone devices.

For the current study procedures, first, a member of the research team reached out to potential participants and each participant participated in a screening call. During this call, participants were asked questions related to qualifying characteristics (see inclusion and exclusion criteria in the “Participants” section). All qualifying participants were scheduled for an initial visit to engage in the consenting process, given time to ask for more information pertaining to any questions they have, made aware of the voluntary nature of the study, and received a copy of the consent form for their records. The current study was divided into three separate participant visits. During this initial visit, following the consenting process, participants completed the MoCA screening questionnaire. If a participant scored  $<21$  on the MoCA, their participation was discontinued at this point. If a participant scored  $>21$ , they then provided a baseline saliva sample and engaged in walking wearing both UG and PDVibe3 devices through known 5 FoG-triggering scenarios (turning, narrow walkway, time-sensitive task, dual-tasking, and walking toward a visual target) for two minutes per scenario. The purpose of these first walks through the triggering scenarios at Visit 1 was to collect data illustrating the nuances of

each individual's gait abnormalities and freezing episodes. Participants' walking tasks were video-recorded at feet-level and these videos were later scored by the research team to identify freezing of gait episodes to train the algorithm. Prior to the end of the first visit, participants were given a packet of questionnaires, including those utilized for the current study, to complete before they came back for Visit 2. Participants were also given an actigraph and instructed on how to wear it as well as how to complete the daily sleep diary in the time between the first and second visits. They were given a \$25 Walmart gift card for their time.

During the second visit, participants returned their actigraph devices and baseline measure packets and again provided a saliva sample and completed state STAI and PANAS anxiety measures (see "Instruments" section below) before engaging in walking tasks. They had UG and PDVibe3 devices placed on both ankles and were given comfortable socks and shoes to wear, designed to keep the vibration sensors in the appropriate places on their feet during their time in the research space. Notably, participants were given ample opportunities to rest and to drink water as needed over the duration of the visit. Participants then again engaged in the aforementioned 5 FoG-triggering scenarios. They engaged in each scenario 3 times, for two minutes each, for a total of approximately 30 minutes total. Each participant was assigned a random level of vibration as part of the parent study's aim to determine optimal levels of vibration for decreasing frequency and duration of FoG episodes. At the end of walking tasks, participants again complete state STAI and PANAS measures as well as they provided a third and final saliva sample. They were again provided with a \$25 Walmart gift card for their time.

The third and final visit was conducted via phone. Participants engaged in an hour-long semi-structured interview about their experiences of sleep, anxiety, and FoG, as well as any feedback they had about their participation in the study overall. They were then provided with a

\$25 virtual gift card for their time. See “Instruments” and “Analyses” sections below for more information on how interviews were conducted, transcribed, and analyzed.

## **Instruments**

### ***Demographics***

Participants answered questions about their age, age at diagnosis, sex, race, ethnicity, level of education, falls in the past year and past 6 months, year of diagnosis, medical history, and current medications.

### ***Cognitive Functioning***

The Montreal Cognitive Assessment (MoCA; Nasreddine et al., 2005) is an assessment designed to test for mild cognitive impairment. The MoCA is administered by an individual trained in the assessment and is composed of items assessing cognitive functioning across eight domains including: short-term memory recall (delayed recall of five nouns); visuospatial ability (e.g., clock-drawing); executive functioning (trail making); phonemic fluency; verbal abstraction; sustained attention (target detection utilizing tapping behavior); language (e.g., naming); and orientation to time and place. Scores range from 0 to 30, with scores of  $\geq 26$  indicating normal cognitive functioning. The MoCA has been evidenced to be a valid and reliable measure of cognitive functioning across both general (Nasreddine et al., 2005) and PD-diagnosed (Dalrymple-Alford et al., 2020) adult samples. Individuals with a MoCA score of  $< 21$ , indicating likely cognitive impairment or dementia (Davis et al., 2021) were excluded from participating in the present study.

### ***Illness Self-Concept***

The Illness Self-Concept Scale (ISCS; Morea, 2006) is a 23-item scale assessing illness self-concept, specifically the directionality and pervasiveness of an individual’s illness as central

or peripheral to the self. Responses are made on a 6-point Likert scale (1 = Strongly Disagree; 6 = Strongly Agree) to such items as, “My illness has affected nearly all aspects of my life.”

Higher scores indicate higher levels of illness centrality. The ISCS has evidenced high internal consistency among individuals diagnosed with chronic illness, specifically fibromyalgia (Morea, 2006; Morea et al., 2008).

### ***Self-Efficacy***

**General self-efficacy.** The General Self-Efficacy Scale (GSE; Schwarzer & Jerusalem, 1995) is a 10-item scale assessing participants’ beliefs in their general ability to influence desired outcomes. Responses are made on a 4-point Likert scale (1 = Not at all true; 4 = Exactly true) to such items as, “I can always manage to solve difficult problems if I try hard enough” and “I am confident that I could deal efficiently with unexpected events.” Higher scores indicate higher levels of perceived general competence and ability to implement/achieve behaviors across goal-oriented scenarios broadly.

**Fall self-efficacy.** The Falls Efficacy Scale International (FES-I; Yardley et al., 2005) is a 16-item measure assessing an individual’s level of concern about falling when considering 16 different social and physical activities, both within and outside of the home. Individuals provide responses about their level of concern associated with items such as, “Walking on a slippery surface” on a 4-point Likert scale (1 = Not at all concerned; 4 = Very concerned). Higher scores indicate increased levels of concern associated with falling/the possibility of falling. The FES-I is evidenced to be a reliable and valid measure of falling concern and perceived efficacy specific to falling (Yardley et al., 2005).



### ***Anxiety and Affectivity***

**State and Trait Anxiety.** The State Trait Anxiety Inventory (STAI; Spielberger et al., 1983) and the Positive and Negative Affectivity Schedule (PANAS; Watson et al., 1988) are both composed of trait (baseline) and state (*in vivo*) components of anxiety or affect. The STAI is a 40-item measure split into two forms, one form for trait feelings and one form for state feelings. Responses are made on a 4-point Likert scale (1 = Not at all; 4 = Very much so). Individuals respond to items such as, “I feel calm” and “I take disappointments so keenly that I can’t put them out of my mind”. Scores range from 20 to 80 on both trait and state subscales. Scores are interpreted as follows: “no or low anxiety” (20-37), “moderate anxiety” (38-44), and “high anxiety” (45-80). The STAI is considered to be a reliable and valid measure of state and trait anxiety (Gustafson et al., 2020; Spielberger et al., 1983).

**Affectivity.** The PANAS is a 20-item measure which asks individuals to rate to which extent they feel different feelings right now (state) or in the past week (trait; Watson et al., 1988). Responses are made on a 5-point Likert scale (1 = Very slightly or not at all; 5 = Extremely) to such items as “Distressed”, “Enthusiastic”, and “Irritable”. Positive affect items and negative affect items are summed to arrive at positive and negative affective scores respectively. Scores range from 10 to 50, with higher scores indicating higher levels of positive and/or negative affect. The PANAS has been shown to be a reliable and valid measure of affectivity (Crawford & Henry, 2004; Watson et al., 1988).

**Salivary Alpha-Amylase.** Participant saliva was collected at three separate times throughout their participation in the current study with the aim to assess salivary alpha amylase (SAA), a biomarker shown to be a reliable indicator of anxiety and stress in the general population as well as among individuals with PD specifically (Ali, 2020; Sancho Cantus et al.,

2019). Indeed, salivary secretion of SAA is regulated by the sympathetic nervous system and, as such, is often used in research to approximate sympathetic nervous system activity (Granger & Taylor, 2020). Saliva was collected using a passive drool method, a method of saliva collection that requires participants to lean forward and allow saliva to naturally pool into the collection vessel rather than actively spitting. This method of saliva collection allows for whole saliva to be collected, avoiding localized salivary secretions and providing for a more consistent biospecimen (Yau et al., 2022). Notably, salivary alpha amylase levels are documented to peak between 10 and 20 minutes following an anxiety or stress inducing task (Granger et al., 2007; Granger & Taylor, 2020; Maruyama et al., 2012). As such, salivary alpha amylase was intentionally collected within this time window following participants' completion of the FoG-inducing task protocol during their second visit.

Saliva samples were collected utilizing Salimetrics Saliva Collection Aid, a mechanism which fits securely into a collection vial designed to reduce sample foaming and facilitates direct sample collection and storage. Samples were refrigerated within 30 minutes of initial collection and frozen at or below -20 degrees Celsius within 4 hours of collection. Samples can be stored for up to 6 months and were stored until all participant samples were collected, at which point an alpha amylase assay was run. Prior to participating in saliva collection, participants received verbal instructions on how to correctly provide a saliva sample. Participants were also advised to avoid eating a major meal for at least one hour and were asked to rinse their mouths thoroughly with water 10 minutes prior to collection.

Saliva samples were analyzed in collaboration with a team of researchers at the VCU SON Lab, headed by Dr. Theresa Swift-Scanlan in the School of Nursing. All samples were assayed according to the Salimetrics Salivary Alpha Amylase Kinetic Enzyme Assay Kit

protocol (Salimetrics, 2019).

### *Sleep*

**Pittsburgh Sleep Quality Scale.** The Pittsburgh Sleep Quality Index (PSQI; Buysse et al., 1989) is a 19-item self-report questionnaire designed to measure respondents' sleep quality over the past month. Respondent scores across seven components, namely, subjective sleep quality, sleep latency, sleep duration, sleep efficiency, sleep disturbance, use of medication, and daytime dysfunction are aggregated to arrive at a single global score. Responses are made on a 4-point Likert scale to such items as, "During the past month, how many hours of actual sleep did you get at night?" Lower scores are indicative of better sleep. A global score of  $>5$  is considered a cutoff point which differentiates between good and poor sleepers. The PSQI has been shown to be a reliable and valid measure of sleep quality across general (Beaudreau et al., 2012; Buysse et al., 1989) and PD-diagnosed (Högl et al., 2010) adult samples.

**Sleep Health.** The RegUlarity, Satisfaction, Alertness, Timing, Efficiency, Duration Scale (RU-SATED; Buysse, 2014) is a 6-item measure of general sleep health across six key dimensions: sleep regularity (daily sleep/wake time consistency); satisfaction with sleep; wake time alertness (oftenness of staying awake without dozing); sleep timing (oftenness of sleeping/trying to sleep between 2:00am and 4:00am); sleep efficiency (oftenness of spending less than 30 minutes awake nightly); and sleep duration (oftenness of sleeping between 7 and 9 hours per night). Responses are made on a 3-point Likert scale (0 = Rarely/Never; 2 = Usually/Always) to such items as, "Are you satisfied with your sleep?" Higher scores indicate better sleep health. The RU-SATED is considered to be a reliable measure of sleep health in a general adult sample (Buysse, 2014).

**Sleep Disturbance.** The Insomnia Severity Index (ISI; Bastien et al. 2001) is a 5-item measure of insomnia and associated distress over the past 2 weeks. Responses are made on a 4-point Likert scale (0 = not at all; 4 = very much) to such items as, “How worried/distressed are you about your current sleep problem?” Higher scores indicate worsened insomnia. Scores range from 0 to 28 and are interpreted as follows: “no clinically significant insomnia” (0-7); “subthreshold insomnia” (8-14); “clinical insomnia- moderate severity” (15-21); “clinical insomnia- severe” (22-28). The ISI has been evidenced to be a valid and reliable measure of insomnia (Bastien et al., 2001).

**Sleep Diary.** The Consensus Sleep Diary (Carney et al., 2012) is a daily self-report measure for which participants complete questions about the following aspects of their daily sleep: bedtime; time to sleep; nighttime awakenings; wake time; napping behavior; sleep duration. Participants also rate their nightly perceived sleep quality on a 4-point Likert scale (0 = very poor; 4 = very good). Current study participants completed sleep diaries for up to 14 days. The Consensus Sleep Diary has been shown to be a reliable and valid measure of self-reported sleep in a general adult sample (Carney et al., 2012).

**Actigraphy.** Participants wore the ActiGraph GT9X Link for up to 14 consecutive, 24-hour days beginning at baseline, pre-intervention, between their first and second visits. Actigraphs are devices that are worn on the dominant wrist and contain a built-in accelerometer that records movements in order to estimate sleep parameters, including total sleep time, sleep-onset latency, wake after sleep onset, and sleep efficiency. Notably, actigraphy has been established as a valid, low burden sleep measurement method comparable to polysomnography (Ancoli-Israel et al., 2003; Martin & Hakim, 2011). Further, actigraphy has been well-established as an appropriate measure of sleep indices for individuals diagnosed with PD (de

Almeida et al., 2019; Stavitsky et al., 2010). Sleep data was analyzed using the ActiLife 6.0 data analysis software platform and bedtime and waketime were verified via sleep diary-reported data. Prior to receiving the actigraph, participants received verbal instructions regarding the purpose of the actigraph (i.e., that the actigraph records movement to estimate sleep parameters) as well as appropriate use (i.e., should be worn on the non-dominant wrist at all times for up to fourteen consecutive days unless bathing, swimming, etc.). Participants were provided with moleskin as necessary to minimize risk of skin abrasion and were encouraged to reach out to study personnel with any questions or concerns related to wearing the actigraph device while at home.

### *Quality of Life*

The Parkinson's Disease Questionnaire-8 (PDQ-8; Katsarou et al., 2004) is an 8-item self-report measure which asks individuals to respond to questions about Parkinson's Disease-related quality of life over the past four weeks. Indeed, responses are made on a 5-point Likert scale (0 = Never, 4 = Always or Cannot do at all) to such items as, "Over the past 4 weeks have you, because of your Parkinson's Disease, felt unable to communicate with people properly?" and "...felt embarrassed in public due to having Parkinson's Disease?" Responses are summated and divided by the total score in order to provide a final percentage score. High scores indicate higher levels of an individual's perception of the impact which PD has on their quality of life. The PDQ-8 is considered a valid and reliable measure of health-related quality of life among individuals diagnosed with Parkinson's Disease (Katsarou et al., 2004).

### *Freezing of Gait*

**New Freezing of Gait Questionnaire.** The New Freezing of Gait Questionnaire (NFOG-Q; Nieuwboer et al., 2009) is a 9-item self-report measure which asks individuals to respond to questions about frequency, duration, associated distress, and functional impact of FoG episodes

over the past month. Responses are made on a 5-point Likert scale (0 = Never; 4 = Very often, more than once a day) to such questions as, “How frequently do you experience freezing episodes?” Responses are also made on a 4-point Likert scale (0 = Not at all; 3 = Significantly) to such questions as, “How disturbing are the freezing episodes for your daily walking?” Scores range from 0-28, with higher scores indicating worse FoG severity. The NFOG-Q has historically been considered a reliable and valid measure of FoG (Giladi et al., 2000; Nieuwboer et al., 2009), however recent concerns have been raised as to the utility of using this questionnaire as a sole outcome measure of FoG (Hulzinga et al., 2020).

### ***Interview***

**Semi-Structured Qualitative Interview.** Participants engaged in a 1-hour semi-structured interview via telephone (see Appendix for interview schedule). The choice to engage in phone interviews with participants was made intentionally with consideration given to important factors including: technology accessibility and literacy; variability in residential distance from the clinic; confidentiality; and comfortability. Further, there is evidence to suggest that, despite biases against telephone interviewing, there is no significant difference in information garnered from phone interviews compared to other interviewing modalities (e.g., teleconferencing, in person; Novick, 2008; Sturges & Hanrahan, 2004). Additionally, phone interviewing has been shown to result in richer data, especially when navigating traumatic or more sensitive topic areas (Trier-Bieniek, 2012).

Phenomenological interviews place a high level of importance on the use of open-ended questions to allow for an array of experiences and experiential descriptions to emerge (Merriam & Tisdell, 2016). As such, the current study’s interview schedule utilized open-ended questions geared toward eliciting discussion related to the lived experience of PD, anxiety, sleep, and FoG

broadly. Additionally, interviews were recorded on an audio recording device with each participant's permission. Following the end of each interview, audio recordings were uploaded to a secure drive accessible only to members of the research team and promptly deleted from the recording device. All interviews were conducted in a quiet, private space that was free of distractions as much as possible for both interviewer and interviewees. Interviews were then transcribed verbatim utilizing both Otter AI software (Otter.ai, 2021) and graduate student members of the research team to prepare them for use in qualitative analysis (see qualitative section under "Analyses" below).

## **Analyses**

### ***Quantitative***

SPSS v 28 software was utilized to analyze descriptive statistics. Indeed, as the size of the current sample was  $N=14$ , there was not sufficient power to compute analyses beyond those that are descriptive (e.g., regression analyses). Means, standard deviations, range, frequencies, and minimum and maximum values were calculated for demographic, sleep, anxiety, and FoG characteristics. In addition to providing context and richness to qualitative data that was also collected and analyzed, mean values were compared to established cutoff values for some variables (e.g., the PSQI, ISI, and STAI) to provide clinical information about the current sample's sleep and anxiety. Target variables were assessed graphically for potential data trends.

Actigraph data were downloaded to ActiLife sleep software version 6.0. In line with recommendations made by Maglione and colleagues (2013) for collecting and scoring actigraphy data collected from individuals living with Parkinson's, a threshold of 30 was utilized. This threshold is what is used by the actigraphic device to determine the difference between "sleep" and "wake" states. The Cole-Kripke algorithm was used for scoring the activity data for sleep

(Cole et al., 1992). If activity counts exceeded the threshold, the epoch was scored as “wake”, while if activity counts were equal to or below the threshold, the epoch was scored as “sleep”. Epoch length was set to 60 seconds. Data from sleep diaries, which participants completed while they were wearing the actigraphic devices, were used to facilitate accurate scoring by setting the time in and out of bed.

### ***Qualitative***

Thematic analysis, a qualitative method utilized for identifying, analyzing, and reporting patterns of themes within data, was used to code and analyze qualitative data in the present study (Braun & Clarke, 2006). Importantly, although content analysis is often utilized in qualitative research, it is guided by a positivist approach. As phenomenological work is inherently constructivist, a philosophy that stresses that meaning is constructed through lived experiences (Neuendorf, 2019), thematic analysis is more appropriate and in line with exploring the *essence* of a phenomenon.

Engaging in reflexive thematic analysis requires that a researcher acknowledge and express underlying biases and assumptions, as well as their own positionality, that may influence both data collection and interpretation (Braun & Clarke, 2019; Lazard & McAvoy, 2020). Indeed, this approach necessitates attention to and bracketing of researcher positionality and biases throughout the coding and reporting processes (Braun & Clarke, 2006, 2019). Traditionally, bracketing is a method used in phenomenological research which requires the researcher to write down and put aside their own biases and prior knowledge before engaging in the data collection process (Carpenter, 2007). However, the current study operated from the hermeneutic perspective on bracketing, which is that pre-understanding or positionality cannot simply be eradicated (Chan et al., 2015; Koch, 1995). The current study utilized bracketing and

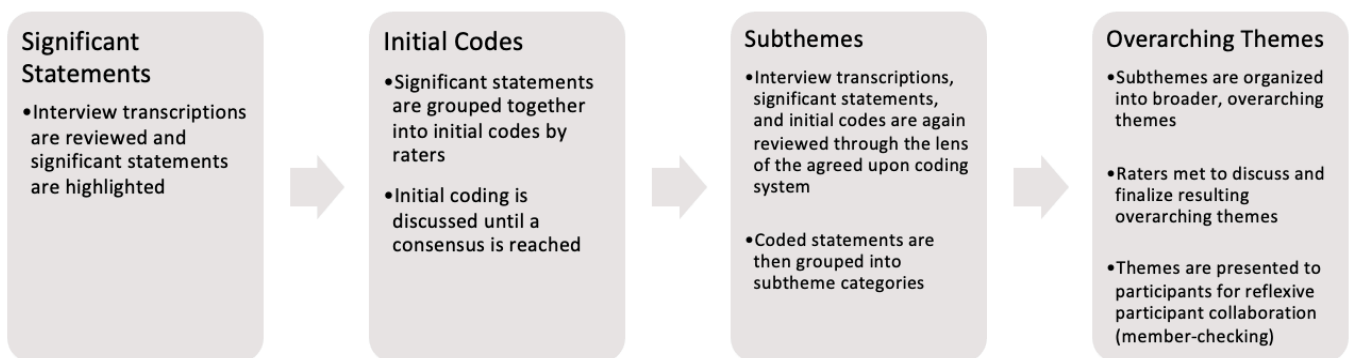


memoing to detail and control for biases and assumptions as much as possible throughout the process. However, the purpose was not to merely set these biases, assumptions, reflections, and positions aside, but to highlight them in later phases of the project because *who is telling the story* is just as important as the story itself. A reflexive journal was kept toward this aim.

Transcribed interviews were analyzed using inductive, reflexive, and emergent thematic analysis, line by line, until coherent, clear, themes were achieved (Clarke & Braun, 2014; Laverly, 2003); allowing for analyses to be driven by the data, rather than an *a priori* framework. Specifically, the current study utilized a 6-step process for emergent, thematic analysis proposed by Clarke and Braun (2014). First, the researcher familiarizes themselves with the data. Then, initial codes are generated based upon significant statements provided by participants in their interviews. Initial themes are then reviewed to determine if they accurately represent the story that the data is telling/the lived experiences that the participants are communicating. Emergent themes are then further defined and named. Finally, both the narrative and the data are woven together.

In line with the steps of emergent, thematic analysis detailed above, four coders (three graduate student researchers and a faculty member of the research team) engaged in the overall coding process. First, two graduate student members of the research team engaged in transcribing recorded interviews using Otter AI software (Otter.ai, 2021). Otter AI is an online service that provides automated transcription of either *in vivo* or pre-recorded audio, including meetings, speeches, etc. (Sterne & Sawhney, 2022). Importantly, Otter AI can be considered a novel, efficient, and cost-effective method for research transcription (Corrente & Bourgeault, 2022). Following transcription, individuals are able to review and edit transcriptions alongside audio recording associated with each transcribed speech segment, allowing the transcript to be

updated in real time. As transcripts were finalized, the author engaged in random transcription checks to ensure that the quality of transcription was sufficient to move forward in coding and analysis steps. Next, the author pulled significant statements from each transcription and compiled these statements into spreadsheets for each coder to review. Importantly, all significant statements were cleared of any potentially identifying information to protect participant privacy and confidentiality. Then, an initial coding process whereby the author categorized significant statements. Following initial coding, the four coders met to discuss which initial codes emerged and which should be retained for the next stage of the coding process. Following reaching a consensus, the coders then conducted a process by which initial codes were categorized into subthemes. Next, coders discussed which subthemes emerged and which should be retained for the final stage of the coding process—grouping subthemes into overarching themes. Following a final discussion of overarching themes, all qualitative coding processes were reviewed by a subject matter expert, an additional faculty member of the research team. See Figure 2 for an illustration of the qualitative coding process utilized in the current study.



*Figure 2.* Illustration of the process of thematic analysis. Adapted from Clarke & Braun, 2014 and Motulsky, 2021.

### ***Mixed Methods***

As aforementioned, the current study utilized a convergent design, meaning that both quantitative and qualitative results were combined for a holistic, integrated interpretation of the results (Creswell & Plano Clark, 2011; Doyle et al., 2016). In line with a convergent mixed-methods study design, the current study employed an explanatory bidirectional framework for data analysis and presentation. Utilizing this iterative mixed methods framework, quantitative and qualitative data were first assessed separately, then interpreted and presented together. Indeed, results were integrated both narratively and visually, whereby quantitative and qualitative data were blended together in writing as well as quantitative data represented visually alongside qualitative results (Moseholm & Fetters, 2017).

### **Positionality Statement**

I, the author, am a white, nonbinary person assigned female at birth (AFAB) who is adopted, bisexual, married, chronically ill, a young adult, a United States citizen, and a first-generation college and graduate student enrolled in a Counseling Psychology doctoral program. As I have lived with chronic illnesses for many years, I do have *a priori* assumptions about what it means to be diagnosed and live with a chronic condition(s). As I am also in training to become a Counseling Psychologist, I have had exposure to lived experiences of chronic conditions beyond my own that inform my assumptions. For example, one of my assumptions is that being diagnosed with a chronic illness is life changing and requires a redefinition of the self. I also recognize that some of my assumptions may be generation-specific, informed by both my age and cohort. Additionally, I have been raised and socialized as a woman, alongside my nonbinary identity, and this has the potential to impact my interpretations of responses from participants who identify as men. Before engaging in data collection and analysis, I intentionally planned to

keep these assumptions in mind as I engaged in interviews with participants and to be careful not to allow them to impact the way I delivered and followed up on interview questions. However, it is worth noting that I do not have personal experience with, nor have I known anyone close to me who has lived with, PD beyond didactic readings, seminars, and engaging with participants. As such, I do not have my own lived experiences or vicariously lived experiences of PD or FoG. I believe that my lack of personal or vicarious exposure to this phenomenon allowed me to maintain curiosity and make less assumptions during the interview process than I might if I were interviewing about chronic illnesses or diseases with which I have had personal experiences.

### **Research Team Positionality**

Qualitative coding and analyses were conducted by a team composed of two faculty members and three graduate students. Specifically, at the time during which qualitative analyses were conducted, the team included one Counseling Psychology faculty member, one Nursing faculty member, one Nursing graduate student in their first year, and two Counseling Psychology graduate students in their third and fifth years (see Author's positionality statement in depth written above). Four research team members identified as women and 1 research team member identified their gender as non-binary. All research team members were white with graduate education levels with a combination of research interests in sleep, anxiety, and PD and personal experiences with PD broadly. Research team ages ranged from young adulthood to midlife.

## **Chapter 3: Results**

### **Participants**

The final sample of participants included 13 adults diagnosed with Parkinson's Disease (23.1% female-identifying, 76.9% male-identifying) who were predominantly white (92.3%) with an average age of 69 years ( $SD = 6.73$  years). Additionally, a majority of the sample

(84.6%) attained at least a 4-year college education. On average, participants in this sample were 57 years old ( $SD = 8.22$  years) when they were diagnosed with PD. At the time of their participation, it had been an average of 13 years ( $SD = 5.75$ ) since they received their initial PD diagnoses. MoCA scores were 25 ( $SD = 2.42$ ) on average in the current sample indicating close to normal or normal cognitive functioning. Additionally, although having a diagnosed sleep disorder was not part of exclusion or inclusion criteria for the current study, one participant did report a diagnosis of restless leg syndrome. Importantly the sample size was 14 for qualitative data, while 13 participants completed the quantitative measures. This discrepancy is due to one individual being screened out of participation in the larger study protocol due to minimal freezing of gait. Although this individual was not able to participate in the larger protocol, they still engaged in sharing their general lived experiences of Parkinson's Disease with the author via the semi-structured interview. See Table 1 for more information about participant demographic characteristics.

**Table 1.** Total sample demographic characteristics ( $N = 13$ ).

| Sample Characteristics |  | Frequency | %     |
|------------------------|--|-----------|-------|
| Age                    | $M = 69$ yrs, $SD = 6.73$ yrs, range 58-79 |           |       |
| Sex                    |  |           |       |
|                        | Female                                     | 3         | 23.1% |
|                        | Male                                       | 10        | 76.9% |
| Race/Ethnicity         |  |           |       |
|                        | Asian                                      | 1         | 7.7%  |
|                        | white                                      | 12        | 92.3% |
| Education              |  |           |       |
|                        | High School                                | 1         | 7.7%  |
|                        | Some College/Trade School                  | 1         | 7.7%  |
|                        | College Degree                             | 4         | 30.8% |
|                        | Graduate Degree                            | 7         | 53.8% |

**Table 2.** Interview participant characteristics ( $N = 14$ ).

| Participant Pseudonym | Age Range | Sex    | Race/Ethnicity |
|-----------------------|-----------|--------|----------------|
| Participant 1         | 75-80     | Male   | white          |
| Participant 2         | 75-80     | Male   | white          |
| Participant 3         | 55-60     | Female | white          |
| Participant 4         | 65-70     | Male   | white          |
| Participant 5         | 70-75     | Female | white          |
| Participant 6         | 70-75     | Male   | white          |
| Participant 7         | 65-70     | Male   | white          |
| Participant 8         | 55-60     | Male   | white          |
| Participant 9*        | 60-65     | Male   | white          |
| Participant 10        | 70-75     | Male   | white          |
| Participant 11**      | 65-70     | Male   | Asian          |
| Participant 12        | 60-65     | Female | white          |
| Participant 13        | 60-65     | Male   | white          |
| Participant 14        | 75-80     | Male   | white          |

*Note.* The above table is modeled after the table utilized by French et al. (2023). \* Participant 9 was screened out of participating in the larger protocol due to minimal freezing of gait symptomatology. However, they were still interviewed about their experiences living with FoG and PD broadly. \*\*Participant 11's interview was unfortunately not recorded. However, their data, based on notes transcribed during their interview, is reflected in final emergent themes.

### **Anxiety and Affectivity**

The current study utilized a phenomenological, emergent, and reflexive approach to analyzing and understanding the lived experiences of individuals living with PD and FoG. See Table 2 above for information corresponding with Participant Numbers that will be utilized to identify quotes from semi-structured interviews throughout the Results section. As the current study utilized a mixed methods approach to data collection and analysis, results include data

garnered across self-report, biomarker, and actigraphy measures alongside information gathered via semi-structured interviews. As such, quantitative results are presented alongside qualitative results. Additionally, data will be described as being collected at baseline, pre-task, and/or post-task for the quantitative results. Notably, pre-task refers to measures of anxiety and affectivity collected at the study site before participants engaged in the Visit 2 Protocol, while post-task refers to measures of anxiety and affectivity collected on site following participants' engagement in the larger Visit 2 Protocol. Measures collected at baseline were completed by participants at home following their first visit during which they provided an initial saliva sample and initial walking data, approximately 2 weeks prior to their engagement in the larger protocol at their second visit. Pre-task measures were collected before participants engaged in the Visit 2 protocol requiring them to engage in a series of known FoG-triggering tasks. Post-task measures were collected within 15 minutes of participants' completing these tasks, at the end of their visit. See Table 3 below for measurement timing information. See Procedures section above for more information on the larger protocol.



**Table 3.** Anxiety, affectivity, sleep, and FoG measurement timing for study protocol.

| Measure                      | Baseline<br>(completed at<br>home or on site ~ 2<br>weeks before pre-<br>task) | Pre-Task<br>(completed on site<br>~15 minutes pre-<br>task) | Post-Task<br>(completed on site<br>~15 minutes post-<br>task, SAA ~10<br>minutes post-task) |
|------------------------------|--|---|---|
| Salivary Alpha Amylase (SAA) | X  | X   | X   |
| PANAS State                  |  | X   | X   |
| STAI State                   |  | X   | X   |
| PANAS Trait                  | X  |   |   |
| STAI Trait                   | X  |   |   |
| NFOG-Q                       | X  |   |   |
| Self-Report Sleep Measures   | X  |   |   |
| Actigraphy                   | X  |   |   |

Utilizing the State Trait Anxiety Inventory (Spielberger et al., 1983), participants reported moderate anxiety at baseline, moderate anxiety pre-task, and low anxiety post-task. Additionally, participants' scores on the Positive and Negative Affectivity Schedule (PANAS; Watson et al., 1988) were in the moderate range of negative and positive affectivities at baseline, pre-, and post-task when compared with the scale range from 10 to 50, with higher scores indicating higher positive or negative affectivity. Additionally, participants in the current sample exhibited slight increases in salivary alpha amylase from baseline through post-task (note: saliva was gathered at baseline, pre-, and post-task time points). Further, both positive and negative affectivity decreased slightly on average for participants from baseline through post-task, but still remained in the moderate range across all timepoints. Although quantitative measures of anxiety and affectivity suggest low to moderate levels of anxiety and moderate positive and negative affectivities, high levels of distress associated with PD and FoG were pervasive throughout semi-

structured interviews. See Table 4 and Figures 3 through 5 below for more information about average anxiety and affectivity characteristics for this sample.

**Table 4.** Average values for anxiety and affectivity measures at baseline, pre-task, and post-task ( $N = 13$ ). Pre-task = prior to Visit 2 protocol; post-task = following Visit 2 protocol.

| Anxiety Index                 | Baseline ( <i>M, SD</i> ) | Pre-Task ( <i>M, SD</i> ) | Post-Task ( <i>M, SD</i> ) | Normed Cutoff Values   |
|-------------------------------|---------------------------|---------------------------|----------------------------|--|
|                               |                           |                           |                            | No or low: 20-37   |
|                               |                           |                           |                            | Moderate : 38-44   |
| State Trait Anxiety Inventory | 39.36, 9.98               | 40.80, 11.07              | 34.25, 11.17               | High: 45-80 (General adult population; Spielberger et al., 1983) |
| Positive Affect Schedule      | 26.9, 5.84                | 25.89, 3.14               | 23.82, 5.84                |  |
| Negative Affect Schedule      | 22.7, 4.30                | 21.89, 1.54               | 21.75, 2.90                |  |
| Salivary Alpha Amylase        | 149.57, 114.36            | 157.29, 102.93            | 158.30, 97.35              |  |

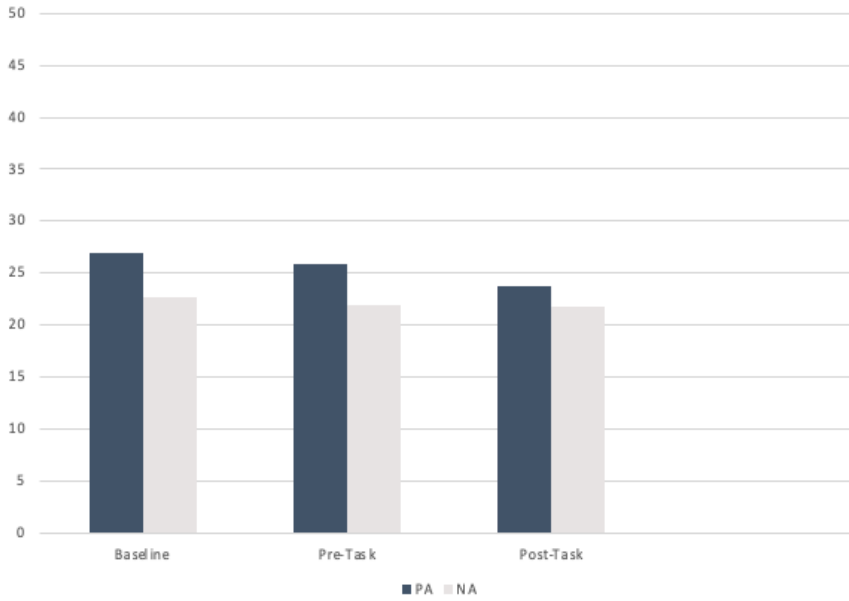


Figure 3. Average positive and negative affectivity schedule (PANAS) values at baseline, pre-, and post-task. PA = positive affectivity schedule, NA = negative affectivity schedule.

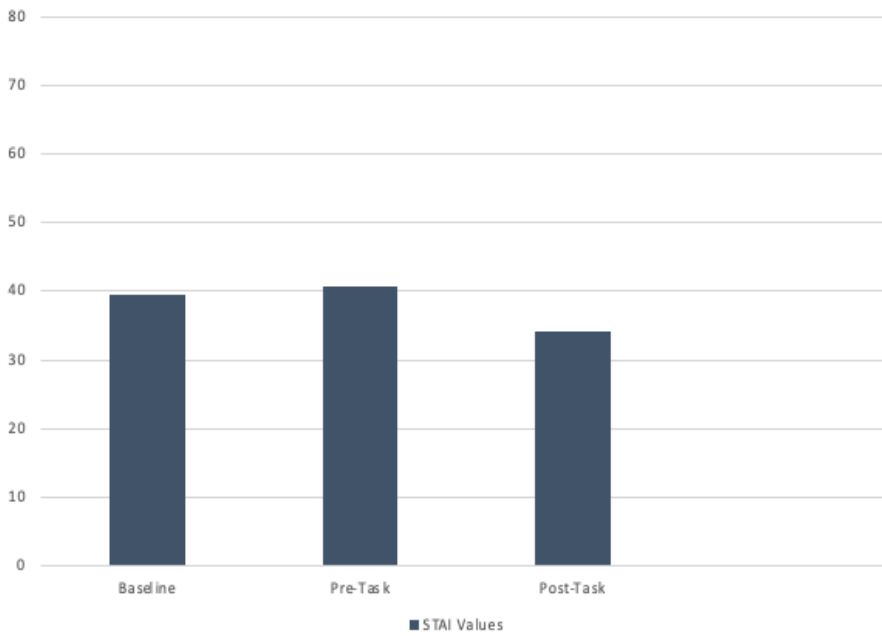


Figure 4. Average STAI values at baseline, pre-, and post-task.

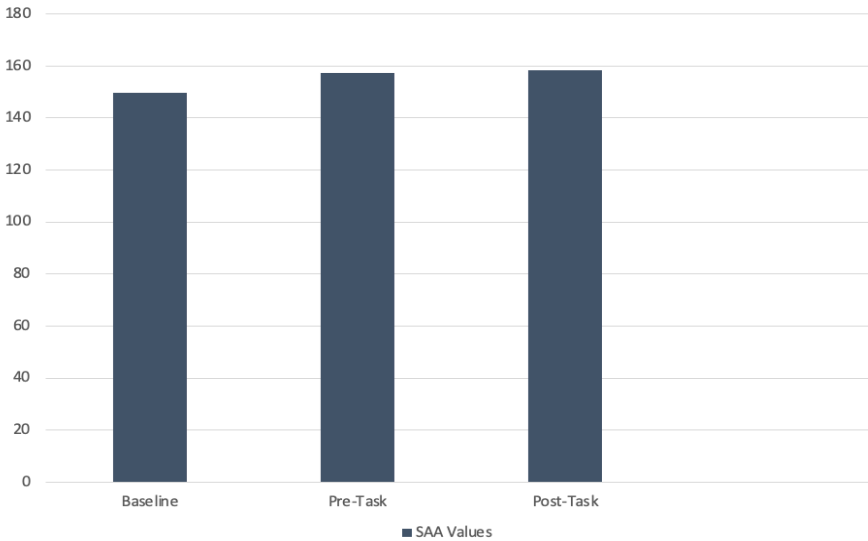


Figure 5. Average salivary alpha amylase values at baseline, pre-, and post-task.

### ***Anxiety is a “never-ending cycle”***

The main theme which emerged from analysis of anxiety-related interview responses is that anxiety is a “never ending cycle” for individuals living with PD and FoG. Specifically, participants reported noticing an association whereby increased anxiety contributes to increased episodes of FoG and vice versa. Participants reported a range of experiences including feeling anxious and worried before, during, and following episodes of FoG. For some individuals, their anxiety contributed to them avoiding feared activities altogether (e.g., avoiding airports and travel due to past experiences of freezing in that context). Experiences of anxiety and related FoG episodes varied across individuals from an obstacle to cope with until it subsided, using techniques such as deep breathing, to a debilitating entity composed of both physical and mental health consequences.

The following excerpts pulled from participant interviews illustrate some participants’ experiences of the association between experiences of anxiety and FoG.

One participant communicated an awareness of anxiety as a factor which makes her FoG worse.

*“I tend to have a lot of anxiety, which makes the freezing of gait worse, because I get anxious.”* (Participant 5)

Another participant noted that anxiety was the sole factor she could identify which contributed to her FoG onset.

*“The only thing I can pinpoint is it [freezing of gait] usually happens when I’m worried about something.”* (Participant 9)

Lastly, one participant identified the association between anxiety and FoG as a “never ending cycle” characterized by a bidirectional association between their experiences of anxiety and FoG.

*“It’s terrible. It’s so limiting. The more anxious I get, the worse it [freezing of gait] gets, the more anxious I get....So, yeah, it’s this never-ending cycle.”* (Participant 12)

### ***Living with PD and FoG is Distressing***

Regarding additional affective experiences of living with PD and FoG, a common theme underlying the lived experiences of individuals diagnosed with PD which emerged from interviews is distress. For the current sample, disease-related distress was reported to come in many different forms including anxiety, sadness, isolation, and frustration.

One participant reported frustration associated with being unable to engage in spontaneous movement due to FoG and feeling as if they were glued to the floor.

*“It can be very frustrating. You want to move and you know where you need to get to. But, it’s like you’re glued to the floor almost. That’s the best way to describe it.”*  
(Participant 4)

Another participant shared that during FoG episodes, their feet felt like lead.

*“Sometimes my feet feel like lead, like lead, like I can’t pick them up.”* (Participant 5)

Two participants spoke about feeling limited and confined in the context of PD and FoG.

*“I can’t go out and do things. I can’t go out and just say, ‘I’m gonna take a walk by myself.’ I mean, I can do it, but I have to take a rollator [rolling walker] with me. So that’s annoying. I feel like it’s my appendage. It’s very limiting.”* (Participant 12)

*“Very confining and isolating at times. Like being controlled.”* (Participant 14)

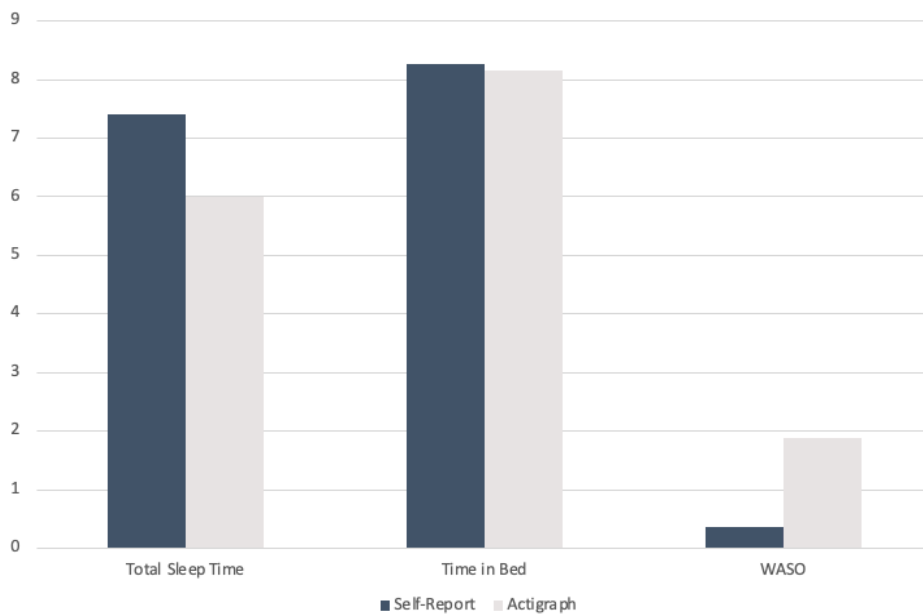
## Sleep

Participants reported sleep difficulties on the ISI consistent with subthreshold insomnia on average ( $M = 9$ ,  $SD = 4.77$ ; Bastien et al., 2001). Participants reported average sleep health overall on the RU-SATED measure of sleep health ( $M = 7.40$ ,  $SD = 1.96$ ; Buysse, 2014).

Importantly, one participant reported a sleep disorder diagnosis of restless leg syndrome. No further sleep disorder diagnoses were reported by study participants. However, utilizing the established PSQI cutoff score of  $>5$ , on average the current sample largely reported poor sleep quality ( $M = 10.42$ ,  $SD = 2.50$ ; Beaudreau et al., 2012; Buysse et al. 1989). Notably, Waketime After Sleep Onset (WASO), Sleep Efficiency (SE), Time in Bed (TIB), and Total Sleep Time (TST) as measured by self-reported daily sleep diaries were, on average, reported to be consistent with good sleep compared to average actigraphically measured values. For example, using sleep diaries, participants reported sleeping for an average of 7.4 hours per night, while actigraphically collected data suggests that participants were sleeping an average of 5.99 hours per night. See Table 5 and Figure 6 below for more information about average sleep characteristics for this sample.

**Table 5.** Average sleep diary and actigraph values for selected sleep indices in hours and minutes ( $N = 13$ ).

| Sleep Index                       | Sleep Diary        | Actigraph          |
|-----------------------------------|--------------------|--------------------|
| Total Sleep Time (TST)            | 7 hours 24 minutes | 5 hours 59 minutes |
| Time in Bed (TIB)                 | 8 hours 16 minutes | 8 hours 9 minutes  |
| Waketime After Sleep Onset (WASO) | 22 minutes         | 1 hour 53 minutes  |
| Sleep Efficiency (SE)             | 90%                | 73%                |

*Figure 6.* Self-reported and actigraphically measured sleep indices. The Y axis represents hours. WASO = Waketime After Sleep Onset.

### ***Sleep Variability and Functioning***

Following analysis of sleep-related interview data, one key theme emerged - sleep is variable. Two key areas were identified by individuals living with PD and FoG as being impacted by sleep variability - functioning and the role of sleep in FoG symptomatology. One

thing became very clear upon analyzing sleep-related interview data - each individual's sleep was unique. Participants reported variability across many aspects of sleep including: sleep quality; movement while sleeping; nighttime awakenings; sleep onset; sleep duration; napping behaviors; daytime wakefulness; and whether or not they took medication for sleep. In fact, the one common thread across sleep behaviors for this sample was that this variability was present within and across individuals. Participants reported noticing an association between their sleep and overall functioning the next day. Specifically, multiple participants reported noticing increased symptomatology as a result of feeling tired and/or having poor sleep the night before. Alternatively, some participants reported noticing decreased symptomatology, or better functioning, following nights of better sleep.

*“When I’m tired, everything goes slower.”* (Participant 3)

*“Then all the symptoms are worse...anybody can’t perform as well if you’re tired or stressed.”* (Participant 13)

*“The more sleep I get, the more functional I am.”* (Participant 6)

*“My symptoms and also, being tired, a little falling. Those things all happen more when I get tired.”* (Participant 3)

*“If I don’t sleep, I dread the next day.”* (Participant 12)

*“The thing is, when I get more tired, this condition gets worse.”* (Participant 13)

### ***Sleep Variability and Freezing***

As participants reported noticing an association between sleep and functioning/PD symptomatology overall, it is not surprising that participants further reported noticing worsened FoG in the context of poor sleep. Indeed, similar to results garnered by van Gilst and colleagues (2016) in their qualitative investigation of sleep and PD broadly and de Almeida and colleagues'



(2021) investigation quantitative investigation of poor sleep and FoG specifically, individuals in the current sample reported both noticing and not noticing any association between poor sleep and/or tiredness and freezing outcomes.

Some participants reported noticing that the more tired they were or the poorer quality of their sleep the night before, the worse their FoG and walking abilities were.

*“[It’s a] noticeable difference once I get tired. I notice the freezing gets worse.”*

(Participant 7)

*“It’s strange. But, I get no sleep and I’m in trouble. Yes, then I’m in big trouble. I get four to five hours of sleep, pretty much not enough sleep. So that’ll definitely affect my walking.”* (Participant 12)

Some participants did not notice an association between their sleep and FoG outcomes at all, as illustrated by the following quote:

*“Eh, it’s just the Parkinson’s.”* (Participant 4)

## **Coping**

Overall, while individuals in the current sample reported high levels of self efficacy in general (GSE;  $M = 28.55$ ,  $SD = 5.97$ ), they also reported low levels of fall-related self-efficacy (FES-I;  $M = 36.85$ ,  $SD = 5.19$ ), and high levels of illness centrality (ISCS;  $M = 81$ ,  $SD = 18.54$ ). Thus, while the sample reported higher levels of confidence toward navigating the world at large, they also reported less confidence related to preventing PD-associated falls specifically. Further, the sample reported higher levels of illness centrality, suggesting that, on average, individuals in the sample were more likely to internalize their PD as a core piece of their identities rather than one external, peripheral factor among the many that make up their larger identities (Morea, 2006; Morea et al., 2008).

Key coping-related themes that emerged from semi-structured interview data include: “just deal with it”; rest as a resource; resourcefulness; and fostering agency and predictability. Major coping strategies reported among the sample included prayer, exercise, enjoyable activities, and utilizing social support (i.e., family, friends, and others diagnosed with PD).

### ***“Just deal with it”***

A common theme which emerged among participants when asked about how they manage living with PD and FoG is “just deal[ing] with it.”

*“I just deal with it. I mean, just keep going.”* (Participant 8)

One participant likened their experience to continuing to “get up and go”, to move forward until they could not anymore.

*“I just get up and go. I don’t know how else to explain it other than I just do what I need to do and as far as I can just keep going and pushing as hard as I can till I can’t go anymore.”* (Participant 13)

Another participant spoke to the idea of willpower and “mind over matter” in helping them to manage living with PD and FoG.

*“I don’t know that there’s anything I do. You just go mind over matter where you say, ‘I can do this.’”* (Participant 14)

### ***Saving Spoons—Rest as a Resource***

Many participants spoke about the idea of having to carefully select which activities they could engage in, as well as building in time to rest in order to recuperate. Indeed, one participant likened their experience to feeling like a budget that they have to adhere to.

*“I’d say the evening’s pretty tough for me. I think I try and be pretty active during the day. I think it just adds up. And I almost have to budget how much I do. I feel like I’m on*

*a budget, so I don't overdo it.*" (Participant 12)

Another participant spoke about the importance of resting and slowing down in order to conserve energy and manage symptoms.

*"I have to build in time for myself to rest during the day."* (Participant 3)

*"The whole routine right now is really trying to slow down."* (Participant 3)

The same participant spoke about the balance between planning and resting, sharing that while they can engage in two out of three parts of their day, they cannot engage in all three.

*"I think of it as dividing my day in three parts. I have two of those, but I can't do a third."*

*I have to take a rest somewhere in there. If I don't, I feel really bad."* (Participant 3)

### ***Resourcefulness***

Participants reported myriad ways of obtaining and utilizing both information and physical aids/techniques necessary to live their lives with PD. Indeed, living with PD requires resourcefulness, from researching what medical resources are available to finding and utilizing myriad strategies and tools to navigate unpredictable symptoms throughout the day (e.g., placing pool noodles over floor transitions to interrupt FoG or wearing knee pads to keep oneself safe in the event of a fall during the day).

The following selected quotes from participants illustrate multiple forms of resourcefulness including utilizing physical aids, learning, and maximizing one's arsenal of available tools.

*"I always wear knee pads all the time."* (Participant 1)

*"You try to learn as much as you can about the disease and what you can do to slow it down or handle it and do those things."* (Participant 2)

*"It's like fighting a war, a battle. If you were to do that, you'd have rifles, and you'd have*

*tanks, you know, artillery, missiles, and all these different things. And this is the kind of way you approach Parkinson's - you use all the resources that are available to you."*

(Participant 2)

### ***Fostering Agency and Predictability***

Participants in the current sample spoke about the many ways in which they increased agency and predictability in the context of living with PD, including: medication timing; planning safe pathways inside the home; weekly physical therapy; intentionally engaging in enjoyed activities (e.g., gardening); engaging in medical self-advocacy; and creating routines overall.

One participant spoke of the predictability that familiar paths within the home can offer.

*"[At home] I know where everything is, and I know what trips me up. And I know what I'm hanging on to as I go through, hanging on to the furniture and walking around that way. I know my trip and what places trip me up so I can avoid those."* (Participant 3)

Another participant spoke of agency in the form of advocacy.

*"You have to be your own advocate. Sometimes, you know, physicians are sometimes blind to certain things or don't want to talk about certain things and you need to be pushy. You need to be investigative. You need to be your own best advocate."*

(Participant 6)

### **Support**

The importance of social support was highlighted across participants' interviews. Indeed, two main support-related themes which emerged in the current study were that living with PD and FoG not only takes a village, but it takes a village that *fits*.

### *It Takes a Village*

Living with PD requires a village. This village may include friends, neighbors, spouses, helpful strangers, doctors, faith leaders, and disease-specific support groups. Roles of “village members” were reported in this sample to include caregivers, medical providers, accountability partners, sounding boards, cheerleaders, and many other roles in between. Participants spoke of the role of friends in providing help, encouragement, and non-judgment.

*“I got a lot of friends. Lots of friends, that’s what’s made it really easy.”* (Participant 1)

*“[My friends] encourage me to do better. It just doesn’t make a difference to them. I mean, they don’t judge me or anything.”* (Participant 1)

Willing strangers were also reported as an important source of help to those living with PD.

*“I get people to help me when it’s beneficial....I take advantage of people who are willing to help or want to help you.”* (Participant 2)

Additionally, participants spoke of the role of romantic partners, specifically spouses, in providing encouragement, nonjudgement, emotional and practical support, and friendship.

*“[My wife] is encouraging. She’s not embarrassed by my tremors or anything like that, she’s supportive - encouraging me to go on and telling me I can do all the things I want to do.”* (Participant 7)

*“My husband helps me a lot. I don’t know how I would do this [without him]. He helps me. He’s my manager. He’s my coach. He’s my helper. He’s my assistant. He’s my friend. He’s who I depend on every day.”* (Participant 12)

*It Takes a Village That Fits*

Analysis of interview data made it clear that just because a village makes itself available to an individual, it does not necessarily mean that the help offered from this village is always desired and/or appropriate. Multiple participants shared that while strangers may be well-intentioned, they may draw attention and provide help where it is not wanted. Indeed, these well-intentioned yet unneeded attempts at help may bring unwanted visibility to an individual living with PD and this unwanted visibility may actually result in increased nervousness and symptomatology (e.g., freezing).

*“Sometimes I just want to be invisible. I don’t want anyone to see me....I feel like they’re invading my space and people are trying to be nice, but some people overreact.”*

(Participant 5)

*“Everyone wants to help you, which is terrific. But, sometimes they will actually stand in your way, or you see them as an obstacle.”* (Participant 6)

*“I freeze and, you know, nobody likes to make a spectacle and stand out in a crowd and have people to worry about you and come rushing to your aid...Nobody enjoys that sort of attention. It’s all well intended, but it happens on a regular and frequent basis.”*

(Participant 8)

*“I get very nervous when people are looking at me in public...That’s the worst and people are looking at you and they try to help. I can tell you so many people try to help me. I say ‘Please don’t help me. Thank you so much, but I don’t need your help.’ They’re very kind. Most will try to help, but it just is not helpful for me at all. It makes you more...Always makes me more nervous actually.”* (Participant 12)

### **Living with Parkinson's Disease and Freezing of Gait**

On average, the current sample reported that living with PD mildly to moderately impacts their overall quality of life (PDQ-8;  $M = 31.25$ ,  $SD = 16.44$ ). The sample also reported high levels of FoG severity on average (NFOG-Q;  $M = 23.31$ ,  $SD = 5.78$ ). When considering the role of anxiety and sleep in FoG outcomes, it is important to gain a better understanding of the context within which such biopsychosocial mechanisms are operating. This context is the lived, or phenomenological, experiences of PD and FoG themselves. Following analysis of lived experience-related interview data, five themes emerged, including: loss; unpredictability; involuntary visibility; distress (see Anxiety and Affectivity section); and resilience- “just get up and keep going”.

#### ***Living with PD and FoG Means Loss***

Living with a chronic condition often requires a redefinition of self which incorporates and accommodates the condition itself and all of the life changes which it entails (e.g., activity limitations and adaptations, treatment regimens, medication timing, etc.). Many participants, when asked what their condition(s) represented to them, spoke of loss- loss of careers, loss of enjoyed activities, loss of engagement in daily tasks they used to take for granted, and loss of the futures they once envisioned for themselves, to name a few.

Two participants shared about their decisions to retire earlier than planned and changing retirement plans in light of their PD diagnoses.

*“When I was younger, I planned out what I wanted to do when I retired, and I can’t do those things anymore.”* (Participant 7)

*“Well, Parkinson’s was part of it [decision to retire]. I probably would have worked longer if it hadn’t been for that.”* (Participant 2)

Other participants spoke of the impact of living with PD on their ability to engage in daily tasks and to do the things they used to do before they received their diagnoses.

*“I can’t push a broom or anything like that or I get off balance. I wish I could sweep my floors and do other things. But, I know that I shouldn’t.”* (Participant 3)

*“I used to say that I want to be the same old person I always was, and that doesn’t always work out.”* (Participant 3)

*“When I was younger, I ran a marathon. I ran a few half marathons. One of the ways that the Parkinson’s diagnosis [affected my life] is it was said I couldn’t run anymore.”*  
(Participant 5)

One participant shared that living with PD is characterized by loss.

*“There are a lot of things that I’m not able to do, that I used to be able to do...It’s a lot of loss. It’s a lot of loss.”* (Participant 5)

The following participant quote illustrates the shift in self-identity that can often accompany living with a chronic condition:

*“There was a before Parkinson’s and now there’s an after Parkinson’s stage in my life.”*  
(Participant 12)

### ***Living with PD and FoG Means Unpredictability***

During their interviews, many participants spoke of the unpredictability and uncertainty that comes with living with PD and FoG.

*“The switch goes on and the switch goes off. As quickly as it comes, it goes. When the switch is on, it’s great. I do what I want for the most part. I can get out and do things. When it’s off, I freeze up...So, always good days and bad days.”* (Participant 4)

*“It’s really terrible. I have bruises all over my knees and my hips, my elbows. But, I don’t*



*know when it's gonna happen again.” (Participant 3)*

A few participants shared about an inability to make plans due to not being able to predict whether they would feel well enough to participate in what they have committed to on a day to day, and even hour to hour, basis.

*“I can't make any plans. Really, I don't know how I'm going to be. I don't know if I'm going to be able to walk.” (Participant 5)*

*“I can't really make any plans because I don't know how I'm going to function. Even just every hour is different. So, I might make a plan and initially I'm feeling okay and then 10 minutes into it, I start having the freezing gait.” (Participant 5)*

### ***Living with PD and FoG Means Involuntary Visibility***

PD, like other chronic conditions, is composed of both visible and invisible symptoms/facets. Unfortunately, certain symptoms, such as FoG, are unable to be concealed despite an individual's strong desire to have such symptoms go unseen, resulting in a decreased ability to control how they are perceived by others. Multiple participants spoke about an inability to blend in and be invisible when out in public due to very visible PD symptoms, namely FoG and associated falling. This involuntary visibility was associated with embarrassment, frustration, isolation, and an inability to avoid being the center of attention.

*“It's become a major part of my identity and everyone can see. It's become very visible, whereas in the past it was not visible so people did not know that I had Parkinson's. But now it's become a lot more visible because of the freezing of gait.” (Participant 5)*

*“It's really embarrassing. People look at you.” (Participant 7)*

*“I'm always noticeable. I always have to be the center of attention. I don't want to be anybody's center of attention. I want to be left alone....so I just shut myself in my house.*

*It's easier than going out and being made a fool of myself....It is isolating in that sense."*

(Participant 12)

***Resilience: "Just get up and keep going"***

Many individuals interviewed as part of the current project exhibited and communicated high levels of resilience. Higher levels of resilience can actually serve as a protective factor against disease-related depression and anxiety outcomes among individuals living with PD (Robottom et al., 2012). One pathway through which resilience can protect against non-motor symptoms of PD is through the maintenance and adaptation of a self-concept not solely defined by one's disease (Kralik et al., 2007). Many participants spoke of decentralization of their illness, whereby PD and FoG are just one facet of their identities rather than a sole defining factor.

One participant spoke about other facets that they believed defined them beyond their PD diagnosis.

*"I don't see myself as being defined by Parkinson's. I am a man, a teacher, or I was a teacher who happens to have Parkinson's."* (Participant 4)

Another participant shared that they defined PD as something outside of their identity- something to overcome.

*"I don't really see it as part of my identity. I just see it as something I need to work with and try to deal with and try to overcome as much as I possibly can."* (Participant 13)

Other participants spoke about the hope of getting by in life beyond PD and the idea of getting up and continuing to move forward in life despite PD and FoG.

*"I'm very hopeful. I don't know if I'm being delusional here. But I want to. I do feel like I can get by in my life."* (Participant 12)

*"How do I get through it [freezing of gait]? I just do it. I just do it. I just do it. I just keep*

*doing it. Just keep doing it till I...maybe I fall. I get up and just keep going.”*

(Participant 1)

A key takeaway message that underlies every interview and emergent theme, each lived experience shared and not shared, is encapsulated by the following quote:

*“Once you’ve seen a person with Parkinson’s, you’ve only seen one person [with Parkinson’s].”* (Participant 6)

#### **Chapter 4: Discussion**

PD is a chronic neurodegenerative disease whose prevalence increases with each passing year. FoG, a distressing gait abnormality strongly associated with health-related quality of life, is estimated to affect over 50% of individuals diagnosed with PD (Giladi & Hausdorff, 2006; Hely et al., 2008). The heterogeneity and complexity of PD broadly, and FoG specifically, are indeed summarized by the aforementioned sentiment – “Once you’ve seen a person with Parkinson’s, you’ve only seen one person with Parkinson’s.” At present, treatment interventions available for FoG are modest at best and ineffective at worst. To date, a majority of PD and FoG-related treatment research approaches and interventions have been focused solely on neurobiological pathways hypothesized to contribute to FoG. Indeed, existing interventions for FoG are largely pharmacologic and surgical (e.g., levodopa and deep brain stimulation). Pharmacologic and surgical interventions are costly, have side effects and potential complications, and results are poor to modest at best (Davis et al., 2006; Lewis & Barker, 2009; Nieuwboer et al., 2007; Schaafsma et al., 2003). Given the strong psychosocial elements of PD and FoG, and the mind-body link in movement disorders (Bega & Malkani, 2016; Jin et al., 2020), there is a need for more holistic, psychosocial approaches to understanding and treating FoG. Thus, there is a need to explore potential psychosocial underpinnings of neurobiological pathways for (1) a more

holistic approach to understanding psychosocial commonalities underlying FoG as well as (2) an approach that can inform interventions psychosocially tailored individual by individual.

The current study, in line with a novel body of literature investigating potential psychosocial correlates of FoG, sought to examine the role of sleep and anxiety in FoG outcomes among individuals diagnosed with PD. The current study also sought to elucidate the lived experiences of sleep, anxiety, FoG, and PD itself using a mixed methodology composed of self-report, biomarker, actigraphy, and semi-structured interview data with the aim to garner a comprehensive understanding of these phenomena individually and holistically in the larger context of living with a PD diagnosis. In other words, although sleep and anxiety are two understudied yet potentially potent contributors to FoG in PD, our goal was to investigate these factors within the whole context of living with PD. As such, this is the first study to investigate the lived experiences of sleep, anxiety, and freezing of gait among individuals living with PD in one study. It is also the first to investigate the proposed model (Figure 1; Ehgoetz Martens et al., 2018; Vandebossche et al., 2013) as a means by which to understand the role of sleep and anxiety in exacerbating the coupling between limbic and cognitive symptoms, resulting in heightened cognitive resource overload, in producing FoG outcomes. Key overarching areas which were examined and/or emerged through semi-structured interviews included: anxiety and affectivity, sleep, coping, support, and the phenomenological experience of FoG and PD.

The current study sought to investigate the aforementioned model (see Figure 1) as a potential framework through which to understand the pathways, cognitive and limbic, through which sleep and anxiety may influence FoG outcomes. Indeed, a body of literature suggests that the impact of both sleep disruption and anxiety on both cognitive and limbic neurological systems have the potential to influence FoG outcomes among individuals diagnosed with PD.

First, poor sleep has been evidenced to disrupt cognitive processes responsible for voluntary movement, control, and coordination (Goldstein & Walker, 2014; Scullin, 2017). In the current study, many participants shared that they experienced an association between poor sleep and worsened overall functioning (including cognitive functioning) and increased episodes of FoG the next day. Additionally, anxiety has been evidenced to impact, and even dysregulate, information processing by important limbic brain structures, including the limbic striatum (Ehgoetz Martens et al., 2018; Lewis & Barker, 2009), responsible for translating a cognitive desire to engage in voluntary movement into the physical action of forward movement. In the current study, many participants reported experiencing a bidirectional association between anxiety and heightened distress, which, in turn, was linked to FoG episodes. According to the proposed model, both sleep disruption and heightened anxiety may contribute to cognitive overload indirectly via cognitive or limbic impacts and, thus, halt voluntary walking movement, or cause freezing of gait. Accordingly, given mixed methodological support for cognitive overload in this group (e.g., budgeting energy/saving spoons, impression management, adapting to unpredictability and uncertainty), the proposed model has explanatory potential.

### *Anxiety and Affectivity*

In the current study, self-reported anxiety decreased on average from baseline through post-task, suggesting at first glance that perhaps FoG and anxiety may not be related. Further, self-reported levels of both positive and negative affectivity decreased on average from baseline through post-task as well. However, this decrease in anxiety and affectivity from pre- to post-task may be representative of (1) a small homogenous sample and/or (2) decreased anxiety related to having just completed an anxiety-provoking protocol prior to post-task measurement. It is also possible that participants may have learned what to expect from FoG-triggering tasks

during their first visit during which they engaged with FoG-triggering tasks to allow the vibration device to create an individualized algorithm per participant, resulting in overall decreased anticipatory and post-task anxiety levels at Visit 2 from baseline. However, interestingly, this decrease in self-reported anxiety and positive/negative affectivity appeared solely on self-reported measures of anxiety and affectivity.

Notably, salivary alpha amylase levels appeared to increase from baseline to pre-task and from pre-task to post-task, suggesting the possibility that although participants may have experienced decreased anxiety on a conscious level, their autonomic nervous systems were still activated by their engagement in the larger protocol at the biological level. One potential explanation for these findings is that interoceptive capabilities have been shown to be diminished in individuals living with PD, particularly those with tremor dominant and postural instability/gait difficulty subtypes (Santangelo et al., 2018), such as the individuals living with FoG in the present sample. Interoception, broadly, refers to the ability to accurately perceive physical sensations which represent the body's physiological state as well as to detect changes in this physiological state (Craig, 2002). The limbic system, broadly responsible for emotional processing and regulation alongside voluntary movement, plays an important role in interoceptive awareness. As it is well documented that limbic system functioning is impaired in the context of both PD and FoG (Banwinkler et al., 2022; Gilat et al., 2018; Jacobs et al., 2009), it is not surprising that individuals living with PD may experience decreased interoceptive awareness and accuracy.

The differing findings across objective and subjective measures of anxiety are enriched and contextualized by qualitative findings garnered as part of the mixed methods study protocol. Further support for the association between anxiety and FoG in the present study were

participants' multiple interview reports of experiencing an association between anxiety and their episodes of FoG, one even referring to this association as a "never ending cycle". Participants described a bidirectional association between their experiences of anxiety and FoG, with increased anxiety exacerbating FoG episodes and vice versa. This association was also reported to be a challenging, limiting experience for individuals living with PD in the present sample. Additionally, participants shared that alongside being anxiety-producing, living with PD and FoG can be distressing, with distress manifesting as frustration, sadness, isolation, and feelings of being controlled and limited. Indeed, participants described the frustration of being unable to engage in spontaneous forward movement during FoG episodes, likening the experience to being "glued to the floor" or having feet made of lead. These experiences of confinement and limitation extended to daily activities, with some participants feeling further constrained or controlled by the need for assistive devices such as a rolling walker. These reported experiences highlight the strong emotional toll of living with PD and FoG for participants in the current sample. The current study's qualitative findings that FoG is distressing as well as that anxiety is associated with FoG are similar to the results of Redmond and Suddick's (2012) phenomenological inquiry on anxiety and FoG. Increased levels of salivary alpha amylase from baseline to post task considered alongside participant's reports of anxiety and distress associated with PD overall and FoG specifically support anxiety as a key psychosocial factor not only in FoG outcomes, but in the proposed model itself.

Future research may also consider utilizing a framework that allows for consistent garnering of anxiety-related data not solely pre- and post-protocol, but throughout an entire protocol, to better capture fluctuations in anxiety related to FoG utilizing methodology such as ecological momentary assessment. Notably, a method such as ecological momentary assessment

would allow for *in vivo* recordings of anxiety levels throughout the protocol, allowing for more accuracy in identifying in-the-moment anxiety levels associated with in-the-moment occurrences of FoG. Further, it is possible that a combination of measurement fatigue and decreased interoceptive awareness could have contributed to blunted or minimized symptom reporting on subjective measures used for anxiety and affectivity reporting in the present study. For example, in the case of the STAI, the STAI was administered three separate times across the larger protocol per participant following completion of a larger battery of baseline measures. Future research may consider utilizing shorter measures such as the Generalized Anxiety Disorder 7-item scale (GAD-7; Spitzer et al., 2006) to better mitigate potential fatigue effects on anxiety symptom reporting. Future research may also consider including a self-report measure targeted toward interoceptive awareness alongside gathering self-report and biomarker data on anxiety for a more comprehensive picture of the role of interoception in the association between anxiety and FoG.

### ***Sleep***

On average, participants reported average sleep health (RU-SATED), subthreshold insomnia (ISI), poor overall sleep quality (PSQI), and good sleep on average across indices (e.g., sleep duration, nighttime awakenings, etc.) using the Consensus Sleep Diary. Notably, the current sample reported longer sleep duration, less wake time after sleep onset, and better sleep efficiency using their sleep diaries compared with actigraphically collected values for these same sleep values. This finding is consistent with prior research showing discrepancies between self-report and objective sleep data among individuals generally, and those diagnosed with PD specifically. For example, individuals living with PD have been evidenced to overestimate their sleep duration via self-report sleep diaries compared with sleep values captured via actigraphy



(de Almeida et al., 2019). Interestingly, as adults age, poor sleep associated with increased aging and aging-related health concerns is anticipated by older adults, potentially inflating self-reported sleep values (e.g., reporting being satisfied with sleep overall or reporting low levels of distress associated with poor sleep) as this poor sleep becomes more “acceptable” to them (Gooneratne & Vitiello, 2014). Further, consistent with research conducted by Gooneratne and colleagues (2011), individuals in the present sample also overestimated their sleep efficiency, with self-reported efficiency reported as 90% on average while actigraphically collected sleep efficiency was 73% on average. In light of this changing perception of sleep quality across the lifespan, it is not surprising for studies of objective and subjective sleep in older adults to evidence differences between objective and subjective sleep indices across general and PD-diagnosed samples (de Almeida et al., 2019; Gooneratne et al., 2011).

It is a possibility that actigraphic measures of sleep, specifically sleep efficiency, total sleep time, and waketime after sleep onset, may have been influenced by tremor activity as actigraphic devices register movement as being “awake”. However, research conducted by Maglione and colleagues (2013) on the utility of actigraphy sleep measurement in individuals living with PD determined that there were no statistically significant differences in key sleep indices for participants wearing actigraphs on tremor-prominent versus non-tremor-prominent wrists. Indeed, they concluded that actigraphy continues to be a useful tool for assessing objective sleep metrics, namely total sleep time, sleep efficiency, and waketime after sleep onset for individuals with mild to moderate PD diagnoses. Research conducted by de Almeida and colleagues (2019, 2021) and by Stavitsky and colleagues (2010) further supports the utility of actigraphy sleep measurement within the PD-diagnosed population. The complexity of sleep measurement and assessment among individuals with PD further stresses the importance of

attending to subjective and subjective sleep metrics in those living with PD. Indeed, differences in subjective and objective sleep measures highlight the importance of collecting sleep information across self-report measures, sleep diaries, and actigraphy to allow for a more comprehensive understanding of an individual's sleep. For example, poor sleep quality on self-report measures may not necessarily equate to poor objectively measured sleep and the difference between measurements can help inform which treatment modalities may be most effective in improving sleep on an individual by individual basis.

Average sleep in the present sample was largely comparable to documented average sleep among the general older adult population. In a study conducted by Klerman and Dijk (2008), on average older adults in their sample subjectively reported sleeping approximately 7.4 hours per night. Individuals in the present sample subjectively reported sleeping approximately 7.5 hours per night although the actigraphic duration was closer to 6 hours per night. Current sleep duration recommendations are 7 to 8 hours per night for older adults (Hirshkowitz et al., 2015) suggesting that this sample may or may not be meeting this recommendation depending on the measurement. Sleep efficiency, or the ratio of how much time an individual spends in bed to how much time they actually spend asleep, is documented to decrease naturally with age. Average sleep efficiency in older adults is evidenced to fall between 76% and 81% (Desjardins et al., 2019). In the current sample, averaged self-reported sleep efficiency was 90%, while average actigraphically measured sleep efficiency was only 73%. Importantly, sleep efficiency measured actigraphically below 70% has been associated with increased risk of frailty, cognitive decline, and overall poor health outcomes in older adults (Blackwell et al., 2006; Blackwell et al., 2014; Desjardins et al., 2019; Dew et al., 2003). Overall, the sample had sufficient sleep duration and efficiency based on subjective measures and insufficient according to actigraphic assessments.

Qualitative findings related to sleep and FoG further illustrate both the complexities and importance of sleep for overall wellbeing and functioning and PD symptoms, specifically FoG, within the present sample. Interview reports of the potential association between sleep and functioning broadly, and FoG specifically, were mixed. Some participants reported noticing an association between their sleep the night before and next day functioning and freezing while others reported not noticing any association between these factors. Indeed, some participants reported noticing that when they are tired, everything seems to slow down and their symptoms worsen. Poor sleep was associated with not only affecting next day performance broadly, but exacerbating PD symptoms, and FoG specifically. For example, one participant reported that his ability to walk was significantly impacted the next day if he experienced short sleep duration the night before. Alternatively, participants reported that the more sleep they were able to achieve the night before, the better they functioned broadly and symptomatically. Notably, while participants reported perceiving and experiencing an association between sleep and FoG symptomatology, at least one participant attributed FoG solely to their PD diagnosis rather than their sleep behaviors. These findings are similar to those which emerged from van Gilst and colleagues' (2016) grounded theory investigation of sleep and PD symptoms – some participants reported an association between poor sleep and next day functioning and symptom exacerbation broadly while others reported no association at all.

### ***Coping***

Coping refers to the modifiable behavioral and cognitive processes utilized by individuals to ameliorate distress (Wang & Saudino, 2011). Navigating the progressive nature of PD necessitates the adoption of coping strategies to navigate day-to-day disease-related stressors and the unpredictable nature of PD itself. Coping strategies employed by individuals living with PD

in response to physical and emotional distress (e.g., experiences of FoG-related anxiety) are evidenced to have marked impacts on disease-related outcomes (Liebermann et al., 2020; Schreurs, et al., 2007). Notable forms of coping which emerged from interviews in the current sample included saving spoons, learned resourcefulness, and fostering agency and predictability.

The current sample spoke of the importance of prioritizing rest during the day and budgeting energy. These sentiments are reminiscent of the idea of saving and spending *spoons* as posited by spoon theory. Spoon theory, originally proposed by Christine Miserandino (2003), is a theory which likens the energy an individual has to dedicate to a task as a “spoon.” Essentially, those living without chronic illness maintain a larger arsenal of spoons to spend, meaning they are more likely able to engage in a larger variety of activities without running out of spoons. However, for those with chronic conditions, such as PD, spoons are limited - meaning that activities, even daily activities such as showering and cooking meals, must be chosen intentionally, and overspending can come at the cost of more or exacerbated symptoms. Participants in the current sample likened their experience of living with PD to maintaining a budget, where they must strategize and choose activities wisely in order to avoid overexertion and worsening symptomatology as a result. Relatedly, participants shared that resting was a crucial component for recuperating, saving spoons, and managing symptoms, with some participants emphasizing the need to build in intentional time for rest during the day. In this way, rest has become a resource for individuals in the current sample navigating the balance between spending and saving spoons.

Saving spoons goes hand in hand with being resourceful. Living with chronic, progressive conditions requires individuals to engage in the process of learned resourcefulness. Learned resourcefulness, in the context of chronic illness, requires an individual to assess

internal and external events which may present obstacles to functioning and quality of life (e.g., emotions, cognitions, symptoms) and utilize available resources alongside developing adaptive strategies to overcome disease-related obstacles (Braden, 1990; Huang et al., 2008; Rosenbaum & Jaffe, 1983). Participants in the current sample demonstrated resourcefulness in managing PD and FoG by sharing about various strategies that they have employed. One participant emphasized the importance of using knee pads as a practical tool to navigate challenges, specifically falling, associated with his PD diagnosis. Other participants highlighted the importance of educating themselves about their diagnoses and implementing learned strategies to manage and cope with PD. Another participant likened PD to fighting a battle, sharing that individuals living with PD must employ all available resources, such as an individual might utilize many tools and weapons in battle, to manage and fight back against PD. Notably, higher levels of self-efficacy have been evidenced to contribute to increased ability to engage in resourcefulness. The more self-efficacy an individual embodies, the more confident they are in their ability to effectively utilize available resources and cope with challenges as they arise (Akgun, 2004; Bandura, 1977). Thus, it is no surprise that the present sample, with its high average report of general self-efficacy, spoke of the multiple ways in which they are resourceful in the face of PD symptomatology.

Regarding creating agency and predictability in the context of living with PD, according to Blalock's (1984) Self-Help Model as it is applied to chronic illness (Braden, 1990), as chronic illness progresses, feelings of uncertainty and dependency increase. Increased uncertainty and feelings of dependency then translate to decreased quality of life. Engagement in resourcefulness and planning which fosters increased independence and agency can decrease uncertainty, thus mitigating the impact of uncertainty and dependency on quality of life. Participants in the current

sample shared the many ways that they foster agency and predictability in their lives. For example, participants highlighted the importance of engaging in creating routine and safety through attending to medication timing and planning safe pathways at home. Indeed, a familiar home environment was reported by many participants to be preferable to navigating the world outside of the home as a familiar environment provided a sense of predictability and control, allowing participants to navigate their homes safely with a keen awareness of potential FoG triggers and fall risks. They also spoke of regaining some control over their day-to-day routines through such activities as gardening. Further, participants spoke of the importance of advocating for themselves in the medical setting, taking a proactive approach to their healthcare, creating agency by bringing their voice to the table alongside healthcare professionals. In these ways participants in the current sample are reducing uncertainty and unpredictability where and how they are able in the context of living with a complex diagnosis with often unpredictable symptoms.

### ***Support***

Living with PD requires a supportive social network. Key sources of support in the present sample included friends, strangers, family members, significant others, and PD group members and these social supports were reported to fulfill a myriad of roles. Social support is especially important for individuals living with PD as emotional communication, expression, and interpretation difficulties as a result of the disease can greatly impact one's ability to engage socially with others, often resulting in feelings of isolation and loneliness (Prenger et al., 2020). In the current study, some individuals, such as spouses, were reported to fulfill the roles of caregivers, encouragers, and helpers. Friends took on roles as supporters, encouragers, and a

source of non-judgment. Even willing strangers were acknowledged by participants as, at times, being valuable resources for assistance when necessary.

Beyond contributing to worsened PD-related outcomes broadly, poor social support and isolation are associated with worsened emotional (e.g., anxiety and depression) and cognitive outcomes (Schreurs et al., 2000). Among individuals living with neurodegenerative diseases broadly, social support has also been shown to increase adjustment to illness (Ovaska-Stafford et al., 2021) and increase an overall sense of belongingness (Kourakos et al., 2016). Importantly, results which emerged from interviews conducted with the present sample highlight that there is a large difference between general social support and social support that is both voluntarily selected by an individual and is tailored to the individual's needs. In other words, there is a stark difference between having a village and having a village *that fits*. Indeed, while at times strangers were a welcome, unexpected source of necessary assistance, at other times unsolicited assistance from strangers was described as being unwanted, unneeded, and even symptom-inducing in itself. Some participants expressed discomfort with unsolicited help from albeit well-intentioned strangers, as this help can draw unwanted attention, increase anxiety, inspire embarrassment, and even exacerbate FoG. Interview feedback on social support from the current sample highlights that while an individual living with PD can function with support, they can better thrive with support that *fits*.

### ***Living with PD and FOG***

The current sample reported that the phenomenological experience of living with PD was one composed of involuntary visibility, loss, unpredictability, and resilience. Chronic illnesses are composed of both visible and invisible facets. Individuals with chronic illnesses may often work to conceal symptoms in order to have control over how they are perceived by others and

reduce attention that may be drawn by visible cues of pain and distress (Joachim & Acorn, 2001; McDaniels et al., 2023). Indeed, prior research has shown that a majority of individuals living with PD actively engage in attempts to conceal their diagnosis to avoid health-related stigma (Vann-Ward et al., 2017). Further, there is a potential for self-stigma, fueled by a changing kinetic body image associated with PD and FoG, to contribute to distress associated with being “seen”. Indeed, kinetic body image is defined as how an individual “perceives themselves or are perceived while performing activities such as walking or talking rather than from actual or perceived changes in appearance” (Behel & Rybarczyk, 2012, 644). In the case of living with PD and FoG concurrently, individuals may experience distress associated with what they fear others will think of them due to their visible symptomatology (e.g., FoG). Notably, heightened experiences of self-stigma and associated internal distress for those diagnosed with PD has been evidenced to be most salient in unfamiliar places, most often in social contexts composed of individuals living without PD (Hanff et al., 2022). Distress and awareness of self-stigma associated with living with PD and FoG can be further exacerbated by holding multiple minoritized identities and/or multiple comorbid health conditions (Islam, et al., 2022; McDaniels et al., 2023; Subramanian et al., 2022). Indeed, participants in the present study spoke about their frustration and embarrassment associated with being unable to control the visibility of their freezing episodes, often resulting in unwanted attention from others while in public. Individuals shared that FoG has become a prominent aspect of their perceived identity as they are more visible in public spaces due to this symptom. This involuntary visibility was reported to be emotionally distressing to the point that at least one participant reported withdrawing from leaving the home to avoid “making a fool of [them]self”. Notably, these findings are similar to



those garnered by Walton and colleagues (2015), which determined that frustration and embarrassment are strong emotional correlates of living with FoG.

Alongside frustration and embarrassment associated with being unable to control freezing symptomatology, and thus related inability to control others' perceptions of them, many participants spoke of loss associated with their PD diagnoses. Indeed, participants in the current sample spoke of loss beginning with the loss of their *self*, specifically the *self* they were pre-diagnosis, as well as the loss of future plans they had made with this pre-diagnosis *self* in mind. Novel diagnoses, particularly those of a chronic and/or neurodegenerative nature, require a redefinition of this pre-diagnosis self which incorporates the disease as part of one's identity. In the present sample, loss encompassed the loss of careers, enjoyed activities (e.g., running marathons), and envisioned futures. Some participants retired earlier than they once planned or altered their retirement plans due to a novel PD diagnosis. Others spoke of the inability to engage in daily tasks or activities that they once engaged in without difficulty. Participants described feeling like they were not the same people they were pre-diagnosis – that there was a clear divide between their lives pre- and post-diagnosis. This redefinition of self, alongside the life disruption that illness can present, has often been likened in the literature to loss – a process which often requires grieving the old self and integrating illness identity into one's definition of self (Charmaz, 1983, 2002; Morea, 2006).

According to Morea and colleagues (2006, 2008), individuals who do not define themselves solely by their illnesses are more likely to have better health outcomes. Indeed, the more peripheral, rather than central, that one's diagnosis is to their identity, the more likely they are to experience increased adjustment and decreased overall distress. Individuals in the current sample reported higher levels of illness centrality. In the current sample PD is a large disruption

marked by profound loss which can result in defining oneself by their PD diagnosis and making it more difficult to achieve illness peripherality.

It is not surprising that individuals in the current sample may report high levels of illness centrality due to the amount of planning, resourcefulness, and creating predictability and agency involved day to day from planning for medication timing to doctor's visits and everything in between. Illness centrality has been associated with feelings of frustration, isolation, and loss in individuals with chronic illnesses, alongside worsened health outcomes (Golub, 2014; Morea, 2006; Morea et al., 2008; Rassart et al., 2022; van Bulck, et al., 2018), many of which were reported by individuals in the current sample. Living with PD and FoG was reported as bringing about a sense of unpredictability and uncertainty for many participants. One participant described living with PD and FoG as having an "on and off switch", whereby functioning within a day can fluctuate rapidly and unpredictably. Even on an hourly basis, symptom unpredictability and severity made it difficult for participants to be able to make plans and anticipate how they would be functioning later in the day, let alone later in the week or month. Future research may consider investigating the nuances of illness centrality and peripherality in individuals with PD specifically as well as developing strategies for individuals with PD to adaptively redefine the self, attending to disease-specific nuances in this process.

Despite all of the loss that participants reported, they also reported incredible resilience—continuing to "get up and keep going" in the face of uncertainty, unpredictability, and involuntary visibility. A few participants in the present sample reported viewing PD as just one aspect of their identity, rather than a solely defining factor. Some participants expressed a determination to overcome PD, viewing it as a challenge or obstacle to overcome and manage. Resilience in individuals living with PD has been evidenced to be associated with less

depression, fatigue, and increased overall optimism and health-related quality of life across levels of PD severity (Robottom et al., 2012). Interestingly, individuals with increased support and feelings of agency are also more likely to foster resilience in the context of living with PD (Choi, 2018). The current sample's reports of resiliency coincide with reports of having a village, or social support, and creating agency and fostering predictability where possible.

In summary, the results of the current study do suggest that the proposed model (Figure 1) has explanatory potential as a model which takes into account the interplay of both neurobiological and psychosocial mechanisms contributing to FoG outcomes. Importantly, there are ample opportunities for future research to better investigate and attend to the complexities of how exactly sleep and anxiety are influencing FoG outcomes across PD and FoG presentations and intra- and inter-individual variabilities as well. The results of the current study also highlight the distress, resourcefulness, resilience, strength, and *voices* of a sample of individuals living with PD and navigating day-to-day life with an array of symptoms, inclusive of poor sleep, anxiety, and freezing of gait. The interplay between neurobiopsychosocial mechanisms contributing to FoG does not occur within a vacuum, but rather within a *lived* context. Attention to both empirical evidence and qualia, the symptoms and the humans experiencing them, will only serve to enrich and bolster future investigations of and treatments for FoG.

### **Clinical Implications**

The current study provides a multimethod insight into the role of sleep and anxiety in FoG outcomes among individuals living with PD. Participants in the present sample described FoG as being associated with experiences of anxiety and poor sleep. The growing prevalence of PD within an increasingly aging society signals the importance of identifying modifiable psychosocial processes, such as sleep and anxiety, which may contribute to underlying

mechanisms responsible for PD symptomatology, including FoG. As poor sleep and anxiety are increasingly studied and identified in a growing body of literature, the current study included, as correlates of PD symptomatology broadly, and FoG specifically, screening for sleep and anxiety is indicated beginning at initial post-diagnosis visits with medical and behavioral health providers alike. Research conducted by Ehgoetz Martens and colleagues (2016) suggests that early identification of anxiety in individuals living with PD can even be a useful indicator of who may develop FoG, more specifically FoG that is troublesome or distressing, later on. Further, individuals with PD and FoG, rather than PD without FoG, tend to report worse sleep quality, higher levels of daytime sleepiness, and increased waketime after sleep onset (Milane et al., 2024).

Established, evidence-based treatment protocols for anxiety and sleep, such as Cognitive Behavioral Therapy (CBT; Beck, 1963) and Cognitive Behavioral Therapy for Insomnia (CBT-i; Bootzin & Nicassio, 1978), have shown efficacy not only in the general adult population, but also in reducing anxiety (Zhang et al., 2020) and improving sleep health (Humbert et al., 2017) in those diagnosed with PD. These treatments are modifiable and deliverable by a range of practitioners. For example, a recent investigation determined that greater daytime light exposure and lower nighttime light exposure are significantly associated with improved objectively-measured sleep in individuals diagnosed with PD (Obayashi et al., 2024). Providing psychoeducation on the importance of daytime light exposure and minimized nighttime light exposure is an example of a targeted, modifiable intervention that can be delivered by practitioners across disciplines to improve sleep and, hopefully, related FoG outcomes. The earlier that sleep disruptions and anxiety are identified on a patient-by-patient basis, the sooner

that targeted, evidence-based interventions can be applied, with the aim to reduce, manage, and/or delay FoG severity and frequency.

### **Limitations and Future Directions**

The current study has notable strengths and weaknesses. A significant strength of the current study is that it is the first mixed-method phenomenological investigation of FoG, sleep, and anxiety in individuals diagnosed with PD. A further strength of this study is its multi-method approach to data collection across target indices (e.g., utilizing actigraphy, self-report, and interview methods to collect sleep data). This multi-method approach to data collection allowed for a more comprehensive examination of target variables within a holistic mixed-method framework integrating both qualitative and quantitative data. Additionally, through the use of a multimethod assessment pre- and post-enacted FoG experience I could assess changes in anxiety across participants' engagement in the study's protocol. However, this study is not without limitations. First, this study is limited in its ability to generalize to the larger PD population due to utilization of a majority white, male, college-educated sample. Indeed, the current study was conducted with participants recruited from a medical research hospital located within a suburban neighborhood. Future investigations of sleep, anxiety, and FoG in individuals living with PD should be conducted with attention to racial, ethnic, gender, and socioeconomic diversity within a community setting. As self-stigma associated with PD is known to be exacerbated according to health comorbidities and identity locations (Islam, et al., 2022; McDaniels et al., 2023; Subramanian et al., 2022), future research should not only attend to generalizable sampling, but also intentional focus on the phenomenon of "involuntary visibility" across identity locations. Further, the current study did not account for medications which the participants were taking to manage PD symptoms which may have impacted their sleep. Future investigations should attend

to and account for the potential for PD medications to influence study outcomes of interest. Additionally, although the current investigation originally aimed to utilize count data as a FoG outcome, unfortunately this count data was difficult to ascertain accurately due to multiple factors (e.g., human error, video recording obstacles, etc.). Despite being unable to utilize count data as a FoG outcome, the current study was still able to utilize participant responses on the NFOG questionnaire as a meaningful indicator of FoG severity and impact on quality of life in the present sample. Future research should work to mitigate potential obstacles to collecting accurate count data to bolster investigations utilized FoG as an outcome variable.

In addition to recommendations for future research which appear throughout this discussion section broadly, here are a few notable methodological considerations that future research in this area may consider implementing. First, the current study utilized solely aggregate average values of target sleep indices. Future research may consider assessing not only aggregate indices of sleep in individuals with PD, but also intraindividual variability in these indices day-to-day. Indeed, PD is a complex neurodegenerative disorder where symptoms fluctuate throughout each day and day to day. While an individual may appear to sleep well on average across 7 days (e.g., 8 hours of sleep per night on average) this aggregate value does not provide potentially meaningful fluctuations in sleep day to day (e.g., 10 hours one night, 5 hours another night) that may influence FoG symptomatology the next day. Additionally, as REM sleep behavior disorder is a documented sleep disruption of interest within the PD population that may have the ability to influence actigraphic data collection (Louter et al., 2014), increased attention to sleep disorder diagnoses among participants and the collection of collateral data from participants' bed partners is warranted. Further, it is further worth mentioning that while participants in the current sample were able to provide saliva samples to assess for salivary alpha

amylase, many participants reported difficulty engaging in this process due to multiple factors (e.g., dry mouth from medication, tremors). Future research may consider different methods of saliva or salivary alpha amylase collection which may be better suited toward this population.

Additionally, an important next step for future research utilizing the qualitative data collected for the current study is to incorporate feedback from the study participants themselves utilizing reflexive participant collaboration. Due to research delays, reflexive participant collaboration was not completed as part of the present study. Reflexive participant collaboration (e.g., member-checking; Motulsky, 2021) would involve presenting participants with overarching themes derived from the interviews in order to receive feedback on and engage in discussion about whether they believe their experiences have been correctly captured. While member-checking has long been established as a gold standard of quality, trustworthiness, and rigor in qualitative research (Birt et al., 2016; Doyle, 2007), reflexive participant collaboration is defined as “participants and researcher(s) collaborat[ing] on meaning-making and analysis” (Motulsky, 2021, 402). Historically, researchers have held the privilege of determining and reporting “what an interviewee really meant” within their own theoretical frameworks (Kvale, 2006, 485). A critical and decolonial approach to the reflexive participant collaboration process encourages instead giving serious consideration to and incorporation of the legitimacy and visibility of participants’ lived experiences and their interpretations of these experiences (Brear, 2019; Motulsky, 2021).

Lastly, an imperative next step of future research would be to perform a grounded theory investigation of the proposed model of FoG (Figure 1). While the current investigation is an important first step to determining the explanatory potential of the proposed model, additional research is needed to further explore and determine the utility of this model. Indeed, future

research should examine subjective and objective measures of key model variables, namely cognitive and limbic functioning, anxiety and sleep, and FoG outcomes using the model as an *a priori* framework on which to lay emergent results. Additional confirmatory analyses can then be utilized to assess the factor structure of the proposed model as well as the pathways through which sleep and anxiety impact FoG specifically toward the aim of determining the model's utility theoretically and practically for informing FoG-targeted treatment intervention research and execution.

### **Conclusion**

FoG is a pervasive and debilitating symptom of PD that warrants further investigation and attention, not solely from a biomedical lens, but through a lens that also incorporates psychosocial factors such as sleep and anxiety. The findings of the current study offer a first and important step to conceptualizing FoG through a combined cognitive and coupling model with sleep and anxiety posited as contributing psychosocial mechanisms. Indeed, the current study offers novel support for the complex associations between sleep, anxiety, and the manifestation of FoG in individuals living with PD. Future research geared toward (1) further investigating the proposed model and (2) addressing underlying neurobiological mechanisms through psychosocial interventions targeted at improving sleep and anxiety may enhance both the applicability and efficacy of existing and novel treatments for FoG moving forward.



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## Appendix: Semi-Structured Interview

PID: \_\_\_\_\_

Date: \_\_\_\_\_

1. Tell me about yourself.
  1. How do you define yourself in relation to your PD?
2. What is it like to live with Parkinson's Disease?
  1. How would you describe PD to someone else?
3. What does it mean to you to have PD?
  1. What does your diagnosis represent to you?
4. What impact does PD have on your day to day life?
5. How do you manage living with the PD on a day-to-day basis?
6. What is it like to live with freezing of gait (FoG)?
  1. What is your experience of FoG? When is it likely to happen?
  2. Are there any circumstances which you notice make your FoG worse? Better?
  3. What emotions do you experience when you are dealing with FoG?
    1. Does it make you feel tense, on edge, worried?
    2. Do you ever notice anxiety related to PD or FoG?
  4. How do you deal with it emotionally? Physically? Spiritually?
    1. How do you cope with PD? Who is your social support?
7. What aspects of FoG may be obvious to people around you? What aspects may not be obvious to anyone but you?
8. What techniques have you been taught for FoG (e.g., from physical therapists)?
9. How confident are you that you can walk from one place to another, in the home, outside the home?
10. I will now ask about your sleep and functioning broadly. How would you describe your sleep?
  1. Did you sleep well last night?
  2. Do you notice any problems with your sleep generally? (e.g., sleep walking, acting out dreams)
11. What is your experience with variability in your daily functioning (within days, across days)?

1. Do you see this as being related to your sleep?
  1. Do you notice sleep impacting your physical activity the next day? In what way?
  2. How about experiences of FoG the next day?
12. Regarding your experience of the vibration device in this study, there may have been times when you received a vibration during times when your gait was abnormal, not necessarily only when you were experiencing freezing. Would you rather experience vibration during those experiences or solely experience vibration when you are experiencing freezing of gait?
13. Did you notice any difference or benefit from the vibration you experienced during this study?
14. Is there anything else you would like me to know today that we have not gotten a chance to talk about?
15. How would you describe your experience of participating in this interview? In this study overall?