

Freezing of Gait in Parkinson's Disease: A Mixed-Methods Study of Patient Experience and Functional Burden

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JRM led this study and contributed to conceptualization, data curation, formal analysis, funding acquisition, investigation, methodology, project administration, resources, supervision, validation, visualization, writing of the original draft, and review and editing of the manuscript.

JMH and JLA contributed to conceptualization, funding acquisition, investigation, methodology, project administration, resources, supervision, visualization, and manuscript review and editing.

MT contributed to data curation, formal analysis, investigation, supervision, validation, visualization, and manuscript review and editing.

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KEM and FH contributed to conceptualization, funding acquisition, investigation, methodology, project administration, resources, supervision, visualization, and manuscript review and editing.

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DC contributed to methodology, validation, and manuscript review and editing.

Abstract (300)

Background

Freezing of gait (FOG) is a debilitating and poorly understood symptom of Parkinson's disease (PD) that is associated with falls, mobility impairments, and diminished quality of life. Despite growing recognition of its clinical importance, little qualitative evidence is available to show how people with PD actually experience FOG or how FOG impacts daily life. We aimed to characterize FOG from the perspective of people with PD, including the perceived characteristics, triggers, and personal impacts of FOG.

Methods

Forty-one participants with PD and FOG were enrolled from participating research sites in Australia, Canada, Israel, and the USA. Each individual completed a 1 hour online interview, using symptom mapping to identify all personally bothersome symptoms of PD, with a deep focus on any FOG-related experiences. Symptom maps were content coded to quantify prevalence and bothersomeness of symptoms and related impacts, and transcribed narratives were inductively analyzed to identify common themes related to FOG across participants.

Findings

Over two-thirds (68%) rated FOG among their most bothersome symptoms and 37% identified it as their single most bothersome symptom. Three related themes emerged: (1) FOG experiences are highly heterogeneous, context-dependent, and difficult to separate from other PD symptoms; (2) FOG is a disruption in “natural motion” that imposes

substantial physical and psychosocial burden due to the need for conscious effort and constant vigilance; (3) Participants intentionally adapt to manage FOG using behavioral, cognitive, and emotional coping strategies.

Interpretation:

FOG is more than an episodic gait disturbance. For PwP, it is a pervasive disruption of automatic movement that substantially affects daily function and psychosocial wellbeing. Our findings highlight the need for focused education, patient-centered assessments, and interventions that can address not only episode frequency, but also the contextual, cognitive, and functional burdens associated with FOG.

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Background

Freezing of gait (FOG) is a major contributor to mobility-related disability and loss of independence in Parkinson's disease (PD). FOG is characterized by brief paroxysmal episodes where there is inability to step and walk effectively, including sudden pauses, akinesia, or shortened, rapid steps, which disrupts balance and increases the risk of falls.¹ FOG will affect the majority of people with PD (PwPD) at some point in their disease, with the prevalence rising as PD progresses.² From a clinical and functional standpoint, FOG causes substantial mobility impairments that make it harder for individuals to safely walk and turn, and independently perform basic activities of daily living, such as dressing, showering, cooking, and other day-to-day activities. Fall risk increases substantially, along with greater likelihood of injuries that can lead to progressive physical impairments that further limit function. Psychologically, FOG has been connected to greater anxiety, depression, loss of self-confidence, and reduced quality of life.^{3,4}

For these reasons, FOG is a major focus in the clinical management of PD, as well as an important therapeutic target for PD research, representing an area with tremendous potential to improve lives and reduce disease burden. However, the ability to monitor progression of FOG clinically and development of new treatments continues to be hindered by a lack of sensitive, patient-centered outcome measures.^{5,6} Prior common-use self-reported measures, such as the FOG-Q and NFOG-Q have been shown to be insufficiently sensitive to capture change and lack specificity for assessing FOG.^{7,8} Consequently, the

International Consortium for Freezing of Gait (ICFOG) recently proposed development of a new patient reported outcome measure (PRO) to assess FOG in clinical practice and research trials, and studies to assess reliability and validity of this measure are currently underway.⁹

Understanding individuals' experiences with FOG is a critical first step towards improving clinical care for people with FOG and developing new clinical assessment tools that reflect real world events. Food and Drug Administration and CONsensus-based Standards for the selection of health Measurement INstruments (COSMIN) guidelines emphasize the importance of incorporating patient perspectives and prioritizing what is meaningful to people with the target condition.^{10,11} While it is anecdotally understood that FOG has a profound impact on those who experience it, rigorous qualitative evidence reflecting the patient perspective is markedly lacking, with few dedicated studies documenting PwPD experiences with FOG and personal accounts of effects on daily life.^{3,12} Most experiential data is derived from broader studies of PD symptoms and lacks the depth and specificity needed to truly understand FOG.^{13,14} Thus, the purpose of this study was to (1) characterize the lived experience of FOG in PwPD, including its features, triggers, and variability; (2) examine the physical and psychosocial impacts of FOG on daily life; and (3) explore how PwPD adapt to and manage these experiences. This knowledge can improve clinicians' awareness of the range of FOG experiences, facilitate earlier diagnosis and treatment, and enhance clinical care.

43

44

Methods

45 Ethical statement

46 IRB approval was obtained from the University of Rochester (IRB#00009458) and each
47 participating site. Participants gave informed consent prior to data collection, and the
48 study was conducted in accordance with the Declaration of Helsinki (0608-23-TLV).

49

50 Study context

51 This online interview study was conducted as part of an international, multi-site study
52 (hereafter **FOG-COA project**) evaluating a novel Clinician Reported Outcome (ClinRO)
53 measure of FOG (GP-FOG) plus a new 16-item Patient Reported Outcome measure of FOG
54 (FOG-QOL).¹⁵

55

56 Setting, Sample, Eligibility

57 Participants were recruited from participating sites in Australia, Canada, Israel, and USA by
58 each participating site using convenience sampling through participating clinics. A subset
59 of PwPD with FOG was purposefully selected from the parent study sample to participate
60 in one-on-one online interviews (41 of 107). Eligibility criteria were: (1) completion of all
61 parent study procedures; (2) diagnosis of PD with FOG by self-report; (3) English fluency,
62 and (4) ability to participate in an online interview via personal computer. Parent study

eligibility for PwPD and FOG were (1) diagnosis of idiopathic PD by a movement disorders specialist using MDS guidelines, (2) able to walk independently for 10 meters without aid, (3) absence of a deep brain stimulator, (4) stable with regards to PD treatment for 4 weeks prior to enrollment, and (5) responded “Yes” on item 1 of the New Freezing Of Gait Questionnaire (NFOG-Q; “Did you experience freezing episodes over the past month?”). Participants with any of the following were excluded: history of cardiac event, instability, or uncontrolled congestive heart disease within 3 months of enrollment, active cancer, acute psychosis, major psychiatric disorders, current substance abuse, other neurological condition, orthopedic impairment impacting gait, or inability to delay taking morning PD medication for parent study participation.

Data collection

Demographic and clinical characteristics were obtained from the main study database (**Table 1**). For the 1:1 interviews, symptom mapping was conducted online via video conferencing approximately two-weeks after the final FOG-COA study visit. Symptom mapping is a hybrid mixed-methods interview technique in which mind mapping software is used to capture detailed qualitative experiences (narrative) inside of a pre-defined quantitative framework (Likert scale), with key concepts (e.g., symptoms) rank ordered by relative bothersomeness to the participant.^{16,17} The systematic approach enables the quantification of symptoms and experiences captured in maps while retaining in-depth thematic and narrative evidence in transcripts. Symptom maps for this study utilized a five-

point Likert scale ranging from *not present* to *present and most bothersome* (range 0-4) as shown in **Figure 1**. A sample size of 40 was chosen based on saturation in prior work for all major concepts by the 17th interview and all minor concepts (affecting <10%) by the 37th.¹⁷

Interview procedures were pretested by patient advisory council members prior to implementation, with 2 full length training interviews conducted with volunteer PwPD with FOG prior to data collection to ensure protocol fidelity. Symptom mapping was conducted by a female movement disorders neurologist trained in the technique (NS, no prior relationship with participants) and lasted 1 hour on average (range 40-133 minutes, mean 63 ± 19). Comfort breaks were provided as needed. Interviews were conducted in English, with the participants at home using a personal computer, taking their usual PD medication. Prior to the interview, each participant completed a brief symptom survey via REDCap, which included free response questions about current FOG and PD symptoms, as well as a comprehensive checklist of all potential PD symptoms derived from the consensus conceptual model of PD symptoms and impacts.¹⁸ This survey was used as a starting point for interviews, to create a baseline map of PD symptoms the individual experienced.

Each interview was conducted within one week of completing the symptom survey. A semi-structured interview guide with probes was used, allowing for consistent questions about FOG while retaining flexibility to explore what mattered to each person (**Supplement A**). Mapping was conducted in real time using Xmind software,¹⁹ with the participant observing

105 the interviewer's screen and any details entered in the map about each key experience.
106 This enabled participants to confirm and validate information entered and make
107 corrections as needed to ensure personal experiences were accurately reflected in the
108 map. Participants were asked by the interviewer to describe their FOG in detail, including
109 characteristics of FOG, triggers, impacts, responses, and feelings. Each symptom checked
110 off in the survey was also briefly reviewed, and when completed, all PD symptoms were
111 rank ordered within the map by bothersomeness (most bothersome/Red to Not
112 bothersome/Green) to show the relative importance of FOG versus other PD symptoms.
113 Participants were also asked to identify other PD symptoms that related to FOG (i.e.
114 affecting or affected by), and to describe any important impacts; however, symptoms
115 unrelated to FOG were not probed in-depth to conserve time and preserve focus on FOG.
116 At the end of the interview participants were offered a copy of their personal map in
117 reciprocity.

118

119 **Data analysis**

120 Interviews were audio and video recorded and transcribed verbatim by a professional
121 transcription service with a second, validating transcriber. Analytic objectives were to (1)
122 identify and quantify symptoms and aspects of FOG that are important to PwP; (2) identify
123 and quantify impacts of FOG on activities of living and daily functioning; and (3) explore the
124 range of adaptive behaviors used to manage FOG. Two independent coders were used for
125 coding symptoms (MT, VR) and impacts (JS, MS) with discrepancies resolved with a senior

researcher (JM) to achieve 100% consensus. Content coding of maps in Excel was used to identify types, characteristics, and bothersomeness of symptoms and impacts, with a focus on impacts of FOG (present/not present).²⁰ Symptoms were coded based on ranked location in the map: 4 = Symptom is present & MOST bothersome; 3 = Symptom is present & SOMEWHAT bothersome; 2 = Symptom is Present & LESS bothersome; 1 = Symptom is Present but NOT bothersome; 0 = Symptom is NOT Present. Other PD symptoms were also coded for perceived relationship to FOG, if present. Narrative transcripts were analyzed using inductive thematic analysis to identify important or recurring ideas, common experiences, and perceptions, with themes emerging from the data through iterative coding and pattern identification. This included: (1) reading and annotating transcripts for recurrent ideas, (2) open coding to derive preliminary code list, and (3) pattern coding to develop themes (JM, MT).²¹ Emerging themes were iteratively reviewed with the interviewer and broader coding team to confirm interpretations and representations of findings. Strategies to minimize bias and promote transparency included: (1) systematic approach to qualitative data collection, (2) member checking and validation of data entered during interviews, (3) use of a codebook with clear definitions for symptoms/impacts, (4) two coder validation of content analysis (5) resolution of coding discrepancies by a senior researcher, (6) systematic audit trail with documentation of coding decisions and discrepancy resolutions, (7) use of participant identifiers for narrative quotations, and (8) discussion of interpretations with multi-site PI team.²²

Results

Demographics

Sample characteristics are shown in **Table 1**. Participants were geographically diverse, predominantly male, white, and well-educated, with average age of 71 years and PD duration of 9 years.

Relative bothersomeness of FOG versus other PD symptoms

In the context of all PD symptoms, FOG was among the most burdensome, with 68% rating it as one of the “most bothersome,” 56% ranking it among their top three, and 37% identifying it as their single worst symptom. For example:

P5: [FOG] has changed my life – I cannot do anything without being totally conscious of what I’m doing, every move. It seems like I have to focus on how I speak, ... how I breathe, and how I walk and move every moment. It’s very frustrating. Very disempowering.

P38: Sometimes I just freeze in place, especially if I'm making up my mind to do something ... I just stand there and until I make a decision, then it's the little stutter steps ... it's the biggest part of my Parkinson's, really...the thing that gets me the most is the freezing.

Symptoms reported as most bothersome by more than 10% of participants are shown in **Figure 2**, ranked by self-reported priority. Comprehensive frequency tables of all identified symptoms are presented in **Supplement B**.

Theme 1: FOG experiences are heterogeneous, context-dependent, and difficult to separate from other PD symptoms

Manifestations of FOG varied widely across individuals and contexts, based on differences in disease characteristics, environments, triggers, and personal responses. As illustrated in **Figure 3**, when asked to describe their FOG, PwPD generally focused on “What” freezing of gait looked and felt like, “When” it most often occurred, and “Where” it was more likely to happen. FOG descriptors ranged from clinical terminology to descriptive language (“leg thumping”) and metaphors (“stuck in concrete”). The context-dependent nature of FOG was reflected in a wide range of reported triggers, with some PwPD identifying specific triggers, whereas others reported FOG occurred unpredictably.

P1: I never know [when it will happen]. It's just unexpected.

P41: freezing of gait for me tends to be more in confined spaces, where I actually have difficulty turning around, backing up.

P37: The most typical situation is, I'll be in a place where it's either going downstairs, or going downhill, or in a little bit of a confined area, and I just freeze. It takes a moment for me to figure out how to take the next step

As presented in **Supplement C**, most commonly reported triggers included any sudden change in direction (88%), turning (78%), navigating narrow spaces (63%), specific locations (54%), initiating motion (49%), medication “off” periods (37%), uneven terrain, getting out of a chair, or multitasking (27%). Symptomatic triggers were also identified as causing FOG, including fatigue (24%), stiffness, shuffling, slowed movement, and anxiety

(12%, each, **Supplement D**). As one PwPD commented, “Everybody's Parkinson's journey is different (P29),” while another added “[other] people experience different things than I have (P36).” Because of the many variations, participants described how they often struggled to distinguish freezing from other co-occurring situations and triggering PD symptoms, such as stiffness, slowed movements, or mental freezing, or even age-related changes as seen in the comments below:

P14: a lot of these things are mixed up. I feel like some of these things involving gait are a combination of Parkinson's, the actual disease, and also—simply aging...the combination of aging, 30 years of Parkinson's, and the disease itself. It's tough for me to pick them out.

P11: [It's] interdependent. ... It's like everything with this neurological stuff, with Parkinson's for sure, 'cause everything's connected....

FOG experiences also often differed from what PwPD perceived as mainstream conceptions of “freezing” episodes. Less overt presentations made it harder for participants to recognize FOG, and many commented that they believed a better definition of the phenomenon was needed, along with specific patient education, to help people recognize different FOG presentations. For example:

P11: I remember seeing it when I was first diagnosed... I went on the internet and saw some nasty videos of old men shuffling ... they'll take a step, and then suddenly they'll totally freeze ... like they're going through a doorway or something. It's not like that with me.

P29: My understanding of FOG was you were walking and then you're frozen, then, because of gravity, you fell over and injured yourself. ... but I now understand that it can be a lot—the symptoms are a lot more subtle than that. It can be hesitation or just pauses.

210 **P9:** [we need] more education about freezing of gait and how that can affect other
211 symptoms of Parkinson's....

212

213 **Theme 2: FOG is a disruption of “natural motion” that imposes substantial physical and**
214 **psychosocial burden due to the need for conscious effort and constant vigilance**

215 Many commented that they would not have self-identified as having FOG because they did
216 not experience an isolated gait phenomenon but rather a global disorder of fluid
217 movement, as described below:

218 **P10** I wouldn't have described myself ...that I have difficulty freezing of gait. Now that I
219 realize that I do have it... I wouldn't have used the word freeze. I experience [it] as my body
220 forgets what to do.... inability to be natural in the motion, that's what it feels like to me...:
221 movement isn't natural, I have to think about it. ...It's not seamless or automatic...we have
222 so many micromotions throughout the day that we don't even think about until we can't do
223 them. Then we have to go, wait, how do I do that again?

224 **P9:** Sometimes it's not just my gait. Other things are freezing up as well. ... only [being]
225 interested in your gait—I think that's an oversimplification....

226 As shown in **Figure 4**, a wide range of adverse impacts were attributed to FOG. Freezing
227 was associated with widespread mobility limitations (98%), most commonly difficulty
228 turning after standing (78%), followed by impaired balance and increased fall risk (44%
229 reporting falls, 20% reporting injury). While gross motor difficulty was most often noted (i.e.
230 gait and balance), many also reported reduced ability to do tasks requiring hand and fine

231 motor dexterity due to motor disturbances from FOG (14%). Across participants, the most
232 consistently reported impacts were increased effort to do daily activities (93%), difficulty
233 turning while upright (78%), and heightened concerns about safety and falls (44%). PwPD
234 described in extensive detail how FOG increased the effort needed to move intuitively and
235 safely, carry out expected roles and responsibilities, and engage in and enjoy life, with
236 impacts becoming greater as FOG severity worsened. The following quotes illustrate the
237 substantial burden of FOG:

238 **P6:** Every step can be difficult because of the FOG.

239 **P12:** It just takes me longer to do everything. For example, I made a batch of brownies this
240 morning...to get the ingredients onto the counter, I'm only taking one item at a time, so I
241 keep my balance. I always have one hand free to grab the counter or a rail. Everything takes
242 longer.

243 For some, FOG extensively affected their daily function while others experienced
244 comparatively little functional impact:

245 **P14:** You have to remind yourself to pick your feet up. ...You constantly have to tell yourself,
246 "Take a step. Take a step. Pull your feet up."... It's like you're stuck in quicksand. You can see
247 what's going on in your mind's eye, but you can't do anything to make it better.

248 **P16:** ...the things I enjoy doing for fun. I still do them, but I can't, for example, I would hike
249 sometimes 20K a day. I'd be lucky to do 15 at the most now. It does affect my ability to do
250 things I enjoy, but it doesn't stop me doing them.

251 Psychological experiences of FOG commonly included heightened awareness of having
252 PD, greater vigilance, and distress. Many participants reported difficulty coping (78%),
253 sense of decreased independence (70%), concerns for personal safety (66%), altered self-
254 concept (56%), physical discomfort related to freezing (51%), reduced ability to participate
255 in and enjoy important activities (37%), trouble with self-care (32%), adverse effects on
256 social and interpersonal interactions (27%), and trouble performing usual roles and
257 responsibilities (15%).

258 **P5:** A freeze will cause me to be in a bad mood...last time when I fell outside, I just sat there
259 and swore for five minutes. ...Blood was coming out of my nose, my mouth, everywhere.... I
260 just was so pissed off ... for me to perform well and not fall, I have to be conscious of where
261 my feet are at all times, how my balance is. I need to be doing all these things.

262 **P28:** My activities been limited...my grandchildren... I used to take them for bushwalk. Now,
263 that, I cannot do anymore. Well, yeah, I don't venture too much outside the house...I have to
264 be careful.

265 **P13:** I don't wanna do anything too fast because I fear I might fall down.

266

267 **Theme 3. PwPD actively and intentionally adapt to compensate for and manage FOG**

268 Due to the highly disruptive experiences with FOG, most participants (83%) reported
269 actively using coping behaviors to manage FOG, such as incorporating adaptive strategies,
270 making positive life changes (e.g., exercise, stress reduction, patterning), and intentional
271 resilience that helped them to overcome the impacts of FOG. In their words:

272 **P9:** You try to develop strategies with this thing so that you can manage it—I went through a
273 period of time where it was like, oh, I'm gonna find a cure. I'm gonna get better. ... and then
274 you get to the point where you realize that you've gotta develop strategies to try to work with
275 some of this stuff, and that's where I'm at. I'm on a quest to come up with strategies and
276 figure out how I can still do some of the things I want to do.

277 Compensatory behaviors and cognitive adaptations in response to impaired automatic
278 movement associated with FOG are depicted in **Figure 5**. These included behavioral
279 changes like avoiding crowded spaces (17%) and intentionally decreasing gait speed to
280 manage FOG and prevent falls (22%). Others used cognitive distraction or “resetting” tricks
281 learned through physical therapy or online discussion forums.

282 **P4:** I do what I call a reset. ...Mentally I would say one, two, three, go!

283 **P11:** ... I have to slow my brain down and think my way through it.

284 **P12:** ... If I'm feeling like really frozen, singing a song takes your mind off the actual walking.

285 **P35:** One of the things that I generally do ... [is] rocking back and forth. Lifting my left foot
286 up, my right foot up, but not moving anywhere... it just keeps me in motion ...as long I'm
287 moving, it's fine but if I stop...my feet are glued to the ground.

288 PwPD also described mentally reorienting themselves and learning to accept functional
289 differences and limitations due to FOG. By internalizing effective adaptive behaviors and
290 normalizing disease experiences, PwPD were able to reduce awareness of adverse impacts
291 of FOG, which in turn diminished their sense of distress due to FOG.

P11: I know what it is, and I know how to deal.... part of the dealing is gonna be avoiding certain things. It's managing expectations. Looking at what's to come and making decisions that will make that event, or whatever it is, manageable and easier to deal with.

P13: I do miss who I was [but] I'm pretty much accepting where I'm at now and that's the best way to approach life.

Discussion

In this mixed-methods study, FOG emerged as not just an episodic motor phenomenon but also as a pervasive and highly burdensome disruption of everyday mobility. For many, it was their single most bothersome symptom of PD, and was experienced as a breakdown of the automaticity of natural movement they had come to rely on throughout life.²³ As a result, many described difficulty performing simultaneous motor or cognitive tasks when walking. This aligns with clinical observation studies where dual-tasking protocols have frequently elicited FOG through what is thought to be dysfunction of gait automaticity with need for increased attentional resources.²⁴⁻²⁶ However, PwPD in our study emphasized that what made FOG bothersome was the high degree of conscious effort and continual awareness needed to safely perform many daily activities. Cumulatively, this suggests that FOG could be better conceptualized as a disorder of impaired automaticity from the patient perspective.²⁷ This distinction is important as current clinical assessment of FOG mostly focuses on episode frequency and severity, whereas PwPD appeared to prioritize the downstream effects of continuous effort, vigilance, and attentional demands and corresponding increase in fatigue and time required to do daily tasks.

314

315 While some PwPD reported stopping certain activities altogether as a consequence of
316 FOG, others described strategies that enabled them to cope and manage mobility
317 challenges. This included behavioral and cognitive adjustments, such as “resetting” and
318 limit setting, some of which have been reported elsewhere.²⁸ However, we found that many
319 of these adaptations required additional attention and planning, further contributing to
320 overall disease burden. In older adults, where even small increases in task difficulty may
321 accelerate disability and dependency,²⁹ this underscores the far-reaching implications FOG
322 can have, and the need for targeted clinical management to preserve functional
323 independence, reduce falls and mobility limitations, and maximize quality of life.³⁰

324

325 Notably, we found that when PwPD developed coping strategies that were personally
326 effective, those behaviors sometimes became routine and automatic. This in turn reduced
327 effort to manage FOG, sense of disruption, and ultimately awareness of episodes, which
328 could explain previously noted inconsistencies in self-reported measures of FOG.³¹

329 Normalization of disease experiences and compensatory behaviors have been shown to
330 help people with chronic disease preserve function and protect quality of life,³² yet can be
331 challenging from a clinical monitoring perspective. Given the complexities inherent in
332 recognizing and recalling FOG, development of a clinical outcome measures that could
333 reliably elicit and quantify episodes would be invaluable in assessing effectiveness of
334 therapy and disease progression. Unfortunately, existing measures fail to capture

heterogeneous manifestations or account for the significant contextual variability observed here and in other studies.^{7,33} These findings highlight the importance of evaluating FOG using multiple modalities, including clinician-observed, digital, and patient-reported assessment approaches where possible.^{6,34} Achieving this goal will entail achieving consensus regarding terminology and what the phenomenon of FOG encompasses.

To our knowledge, this study provides the first in-depth, qualitative evaluation of FOG, using a systematic, patient-centered approach. Our findings offer a unique window into the personal experience of FOG within an international cohort and illustrate how clinical management should extend beyond reduction in episode frequency and duration. From our data, we infer that meaningful improvements in clinical management of FOG would likely require addressing the effort, environmental triggers, and adaptive strategies that can help people living with FOG. Educating patients and families regarding recently revised clinical definitions¹ and the spectrum of FOG manifestations can increase awareness and provide opportunities for earlier management and referral to physical therapy that will improve function, promote quality of life, and delay deterioration in mobility.

We acknowledge limitations to this study. All participants had FOG by self- and clinician-report. Convenience sampling from an existing study, the inclusion of solely English-speaking, and preponderance of highly educated participants increases the probability of missing cultural and socio-economic differences in FOG that may be present in other

populations. Experiences were elicited completely by patient self-report which is affected by ability to recognize FOG, recall episodes, and communicate details. Future studies with larger, diverse cohorts will be needed to understand how FOG varies across different populations and to assess broader generalizability. Nonetheless, we believe our findings shed light on the contextually dependent and heterogeneous personal experiences of FOG and the pervasive impact it has on affected PwP, and can contribute to better clinical education, evaluation, and management.

In conclusion, our study shows that FOG is a major, yet incompletely characterized, contributor to disability in PD. Recognizing FOG as a dynamic disorder of impaired automaticity and increased effort will inform the development of patient-centered assessment tools and clinical interventions aimed at preserving mobility, independence, and quality of life in aging populations.

Disclosures

Funding Source:

This study was funded by the Michael J Fox Foundation grant number (MJFF-024177). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement by, FDA/HHS or the U.S. Government.

Data sharing

Requests for deidentified data can be submitted to the lead author and are subject to institutional review and data use agreements.

Conflict of Interest:

Author	Relevant Disclosures
Jamie L. Adams	JLA has consulted for and received grant funding from Michael J Fox Foundation for Parkinson's research.
Dave Cella	Grant funding from NIH and Michael J Fox Foundation; Consultant to Oregon Health Sciences University
Moran Gilat	MG has consulted for and received grant funding from Michael J Fox Foundation for Parkinson's research.
Pieter Ginis	None
Jeffrey M. Hausdorff	JMH has consulted for and received grant funding from Michael J Fox Foundation for Parkinson's research.
Fay B. Horak	FBH has received grant funding from NIH and from the Michael J Fox Foundation for Parkinson's research.
Erika Howe	None to disclose

Simon J.G. Lewis	Supported by an NHMRC Leadership Fellowship (#1195830) and has received grant funding from Parkinson's UK and the Michael J Fox Foundation for Parkinson's research.
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Martina Mancini	MM has received grant funding from NIH, Michael J Fox Foundation for Parkinson's research, and OHSU Parkinson's center.
Kaylena A. Ehgoetz Martens	KAEM has received grant funding from Michael J Fox Foundation for Parkinson's research.
J. Lucas Mckay	JLM has received grant funding from Michael J Fox Foundation for Parkinson's research
Alice Nieuwboer	None
Jorik Nonnekes	JN has received grant funding from Michael J Fox Foundation for Parkinson's research.
Varun Reddy	None
Nami Shah	NS has received grant funding from the Michael J Fox Foundation for Parkinson's research.
Jocelyn Silva	None
Mathew Stephens	None
Mirinda Tyo, PhD	MT has consulted for and received grant funding from Michael J Fox Foundation for Parkinson's research.

Ethical Compliance Statement

Study funding was provided by Michael J Fox Foundation for Parkinson's Research (Grant#: MJFF-024177). IRB approval and electronic informed consent was obtained prior to data collection (University of Rochester IRB#00009458; University of Massachusetts, Dartmouth IRB# 25.042). The study was conducted in accordance with the Declaration of Helsinki (0608-23-TLV).

Affirmation of Ethical Publication Guidelines: We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this work is consistent with those guidelines.

Reporting guidelines

This study followed Consolidated criteria for reporting qualitative studies (COREQ) guidelines (show at end of manuscript).

Legends

TABLES

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Figure 2. Most bothersome symptoms of PD for people with FOG

Figure 3. PwPD descriptors of FOG episodes: “Everyone's experience is different”

Figure 4. Common impacts of FOG experienced by PwP

Figure 5. PwPD responses to FOG

SUPPLEMENTAL ONLINE MATERIALS

Supplement A. Interview Guide

Supplement B. Meaningful Symptoms for PwPD with FOG

Supplement C. FOG Contextual factors

Supplement D. FOG Relationship to other PD symptoms

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Table 1. Demographics and Clinical Characteristics

	Parent study (n = 107)	Interviews (n = 41)
Age, years, mean (SD)	71.2 (7.1)	70.8 (6.2)
Female, n (%)	20 (18.7%)	8 (19.5%)
Education > 12 years, n (%)	94 (87.7%)	38 (92.7%)
Country (%)		
Australia	15 (14%)	10 (24.4%)
Belgium	15 (14%)	-
Canada	15 (14%)	4 (9.8%)
Israel	14 (13.1%)	3 (7.3%)
Netherlands	16 (15%)	-
United States	32 (29.9%)	24 (58.5%)
PD duration, years, mean (SD)	9.02 (5.65)	9.27 (7.0)
Fall History, n (%)	61 (57.0%)	21 (51.2%)
Number of Falls	10.98 (23.04)	11.95 (24.3)*
MDS_UPDRS, n (SD)		
Part 1 (Nonmotor)	11.98 (6.34)	12.83 (6.19)
Part 2 (Motor Daily Living)	16.72 (7.55)	15.18 (7.14)
Part 3 off (Motor Exam)	43.71 (13.23)	43.51 (13.90)
Part 3 on (Motor Exam)	31.06 (11.73)	29.66 (11.82)
Part 4 (Motor Complications)	4.42 (3.73)	4.98 (3.69)
Not specified, n (%)	3 (2.8%)	1 (2.4%)
H&Y, on, n (%)		
Stage 1	7 (6.5%)	2 (4.9%)
Stage 2	79 (73.8%)	32 (78.0%)
Stage 3	15 (14.0%)	7 (17.1%)
Stage 4	4 (3.7%)	-
Not specified, n (%)	1 (0.9%)	-
MoCA, mean (SD)	24.58 (3.36)	25 (2.9)
NFOG-Q, mean (SD)	15.9 (5.6)	14.25 (6.1)

Notes. * = $p < .05$, MDS_UPDRS = Movement Disorder Society-Unified

Parkinson's Disease Rating Scale; H&Y = Hoehn & Yahr stage ≤ 2 is consistent with early PD; MoCA = Montreal Cognitive Assessment scores of 26-30 are considered normal; NFOG-Q = New Freezing of Gait Questionnaire with higher scores having more severity.

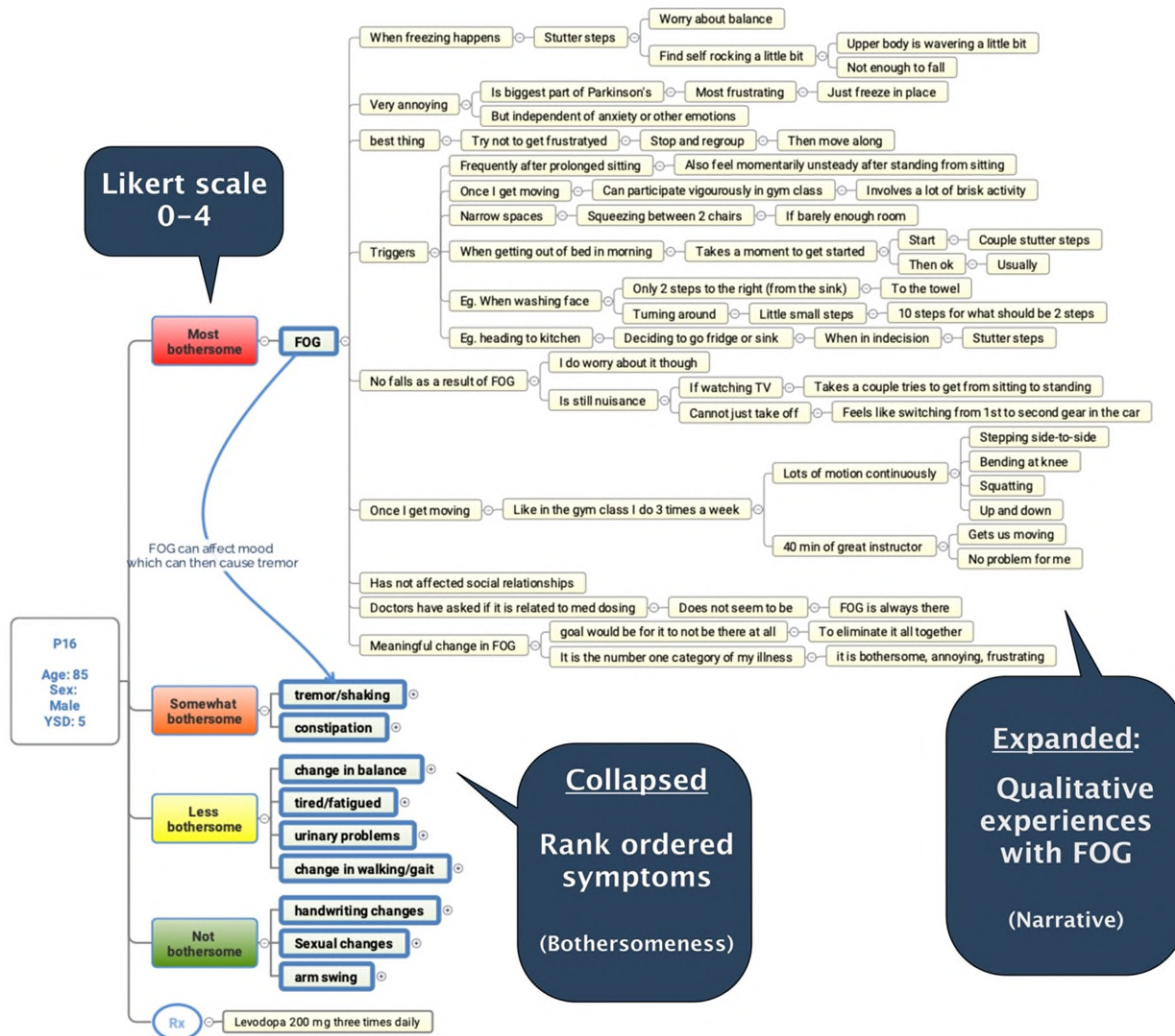


Figure 1. Section of map showing FOG experiences and Likert scale framework

Symptoms	Present	Not Bothersome	Less Bothersome	Somewhat Bothersome	Most Bothersome
Most bothersome to more than 10%	+	1	2	3	4
Gait changes (general)	100%	0%	10%	17%	73%
Freezing of gait	100%	0%	5%	27%	68%
Altered turning	78%	0%	5%	17%	56%
Impaired balance	98%	0%	17%	27%	54%
Fine motor/ dexterity	93%	7%	10%	37%	39%
Altered gait velocity	54%	2%	7%	5%	39%
Stiffness	93%	0%	12%	44%	37%
Slow movements	90%	5%	29%	24%	32%
Shuffling	46%	0%	7%	12%	27%
Voice changes (general)	81%	15%	22%	20%	24%
Constipation	78%	7%	29%	17%	24%
Quiet voice	71%	12%	20%	15%	24%
Handwriting changes	88%	15%	15%	37%	22%
Fatigue/lack of energy (general)	71%	5%	17%	27%	22%
Altered stride length	34%	0%	7%	5%	22%
Stiffness/Rigidity	85%	0%	24%	42%	20%
Decreased range of motion	73%	2%	27%	24%	20%
Altered voice quality	46%	2%	12%	12%	20%
Mood & Affect (general)	78%	10%	24%	27%	17%
Tremor (general)	71%	12%	17%	24%	17%
Frustration	59%	7%	17%	17%	17%
Physical fatigue	39%	5%	5%	12%	17%
Dyskinesias	54%	7%	20%	10%	17%
Loss of coordination	32%	0%	7%	7%	17%
Difficulty word finding	80%	7%	15%	44%	15%
Changes in Thinking (general)	73%	5%	10%	44%	15%
Attention & Processing (general)	76%	7%	12%	42%	15%
Urinary dysfunction (general)	85%	10%	24%	37%	15%
Slower thinking	63%	5%	7%	37%	15%
Urinary frequency	73%	7%	17%	34%	15%
Pain (general)	29%	0%	7%	7%	15%
impaired ability to multitask	68%	5%	10%	42%	12%
Sleep disturbances (general)	71%	2%	22%	34%	12%
Impaired mental alertness	54%	2%	7%	32%	12%
Cramping/spasm	63%	2%	22%	27%	12%
Nocturia	63%	5%	20%	27%	12%
Reduced sleep quality	56%	2%	17%	24%	12%
Negative feelings/emotions	39%	0%	12%	15%	12%
Speech changes	41%	2%	12%	15%	12%
Monotone (Prosodic impairment)	32%	2%	7%	10%	12%
Postural changes	68%	7%	15%	37%	10%
Insomnia	68%	2%	22%	34%	10%
Difficulty staying asleep	61%	2%	17%	32%	10%
Depressed mood	49%	0%	15%	24%	10%
Decreased facial expression	54%	5%	20%	20%	10%
Sexual dysfunction	68%	22%	17%	20%	10%
Apathy	49%	5%	15%	20%	10%
Loss of interest	49%	5%	15%	20%	10%
Hand tremor	51%	10%	12%	20%	10%
Urinary incontinence	34%	0%	5%	20%	10%
Anxious mood	56%	10%	20%	17%	10%
Difficulty falling asleep	34%	0%	7%	17%	10%
Anorgasmia	39%	10%	7%	12%	10%
Impaired body temperature control	39%	5%	20%	5%	10%

Notes . Darker colors indicate higher frequencies. Blue cells represent the percent of participants reporting the symptom as present to any degree, red cells show distribution of reported bothersomeness. Symptoms marked as "general" combine prevalence of symptom subtype: For example, Urinary dysfunction encompasses, urinary frequency, urinary urgency and nocturia, based on Conceptual model of PD symptoms. A participant reporting one or more subtype would be counted once in the general symptom category.

Figure 2. Most bothersome symptoms of PD for people with FOG

Theme: Everyone's experience is different" - PwP descriptors of FOG

what happens				when it happens					where it happens		
Change in Step Pattern	Arrest in motion	Complex movement regulation	Trouble initiating	Situational triggers	Symptom triggers	Psychologic triggers	No trigger		Troublesome spaces	Challenging surfaces	Common locations
festinating	freezing	trouble walking	trouble getting started/initiating	late at night	shifting one leg to another	tired	anxious	unexpected	small spaces	transitions	kitchen
tiny steps	glued to floor	trouble changing directions	trouble getting up	early in the morning	sudden moves	pain	under pressure	not predictable	crowded places	level changes	bathroom/restroom
shuffling	stuck to ground	trouble turning	Other	decision making	going to the bathroom	stiff	worried about falling		narrow places	uneven ground	around the bed
faster and faster	stuck in concrete	trouble moving sideways		new situations	prolonged sitting/standing	balance is off	Other		new places	lines on the floor (gaps)	doorways
	leg locks up	loss of coordination	hesitating	change in direction	carrying something	hard to see/poor depth perception	later on in PD		change in temperature	cold floor	stairs
	stiff and frozen	tell my foot what to do	leg thumps	backing up	standing still	posture/stooped forward	off meds				escalator

Notes. Concepts are verbatim experiences emerging across participant interviews and are not indicative of prevalence.

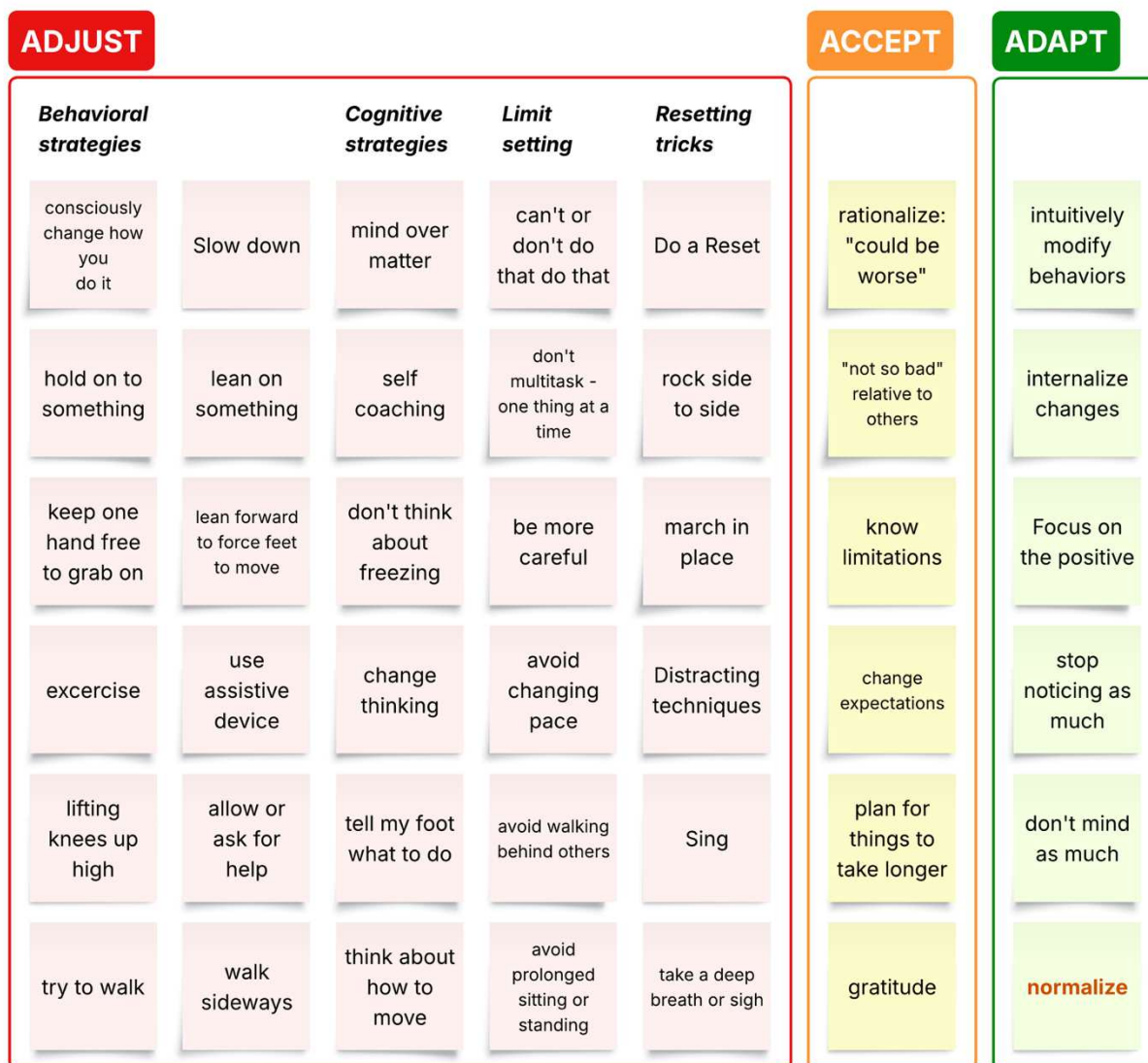
Figure 3. PwPD descriptors of FOG episodes: "Everyone's experience is different"

PHYSICAL FUNCTIONING			PSYCHOSOCIAL FUNCTIONING		
	n	%		n	%
MOBILITY			INDEPENDENCE		
Turning while standing upright	32	78%	House work, home maintenance, & gardening	10	24%
Getting out of bed, chair, or car	15	37%	Travel & Driving	8	20%
Walking in a confined space	13	32%	Doing shopping	7	17%
Getting to standing position	11	27%	Increased dependence on others	7	17%
Lifting and carrying	11	27%	Cooking/Meal prep	6	15%
Exercise and sports	9	22%	SELF-CONCEPT		
Turning while sitting	6	15%	Sense of ability to manage (Self-efficacy)	10	24%
Standing	5	12%	Feeling embarrassed or self-conscious	10	24%
Climbing stairs	5	12%	Sense of self confidence	9	22%
Walking backwards	4	10%	Sense of helplessness	1	2%
Limited walking distance	3	7%	Feeling stigmatized	1	2%
Sitting Down	3	7%	COPING		
Turning in bed	2	5%	Finding ways to compensate	28	68%
Prolonged standing	2	5%	Fear of falling	18	44%
Walking in the dark	1	2%	Feeling frustration or anger	11	27%
Walking on hills	1	2%	Avoidance	9	22%
SELF-CARE			Making positive changes to control disease	7	17%
Personal hygiene and self-care	5	12%	Preoccupation with disease	6	15%
Dressing	2	5%	Feeling stress or distress	5	12%
Eating tasks	1	2%	Feeling annoyed or bothered	5	12%
PHYSICAL COMFORT			Living with uncertainty	3	7%
Increased physical discomfort	8	20%	Fear of future	3	7%
Difficulty relaxing	5	12%	INTERPERSONAL INTERACTIONS		
Feeling unwell	2	5%	Social life	7	17%
EFFORT OF LIVING			Relationships with Friends	3	7%
Effort of living	33	80%	Loneliness/isolation	3	7%
Functional slowness (Longer to do things)	16	39%	ROLES & RESPONSIBILITIES		
Having to plan around symptoms	5	12%	Job/occupational impact	2	5%
SAFETY			Taking care of family and childcare	2	5%
Tripping or falling	18	44%	Taking care of pets	1	2%
Accidental self-injury	8	20%	Financial impact	1	2%
			IMPORTANT ACTIVITIES		
			Hobbies & leisure activities	8	20%
			Playing musical instrument	2	5%

Notes . Darker colors represent higher percentage of participants reporting the specific impact.

Figure 4. Common impacts of FOG experienced by PwP

Theme: PwP respond to FOG by adjusting behaviors, accepting changes, and adapting to a new normal



Notes. Concepts are verbatim experiences emerging across participant interviews and are not indicative of prevalence.

Figure 5. PwPD responses to FOG

COREQ Checklist

: 32-item checklist

Page, line		
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	p11, lines 88-99
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	author list and affiliations; p11, line 88-99
3. Occupation	What was their occupation at the time of the study?	p11 interviewer paragraph ("female movement disorders neurologist")
4. Gender	Was the researcher male or female?	p11 interviewer paragraph ("female movement disorders neurologist")
5. Experience and training	What experience or training did the researcher have?	p11 interviewer paragraph ("trained in the technique")
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	p11 interviewer paragraph ("no prior relationship")
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	p11, lines 88-99
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	p11, lines 88-99
Domain 2: study design		
Theoretical framework		N/A
9. Methodological orientation and theory	What methodological orientation was stated to underpin the study? e.g. grounded theory,	p12-13 Data Analysis ("inductive thematic analysis")
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	p9-10, lines 56-72

11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	p9-10, lines 56–72
12. Sample size	How many participants were in the study?	p9-10, lines 56–72
13. Non-participation	How many people refused to participate or dropped out? Reasons?	All recruited participants completed the study.

Setting

14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	p11, line 94 (“at home”)
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Not reported
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	p14, lines 150-154; Table 1

Data collection

17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	p11, lines 101-103; Supplement A
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	No – cross sectional
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	p12, lines 120 (“Audio and video recorded”)
20. Field notes	Were field notes made during and/or after the interview or focus group?	Notes were taken on screen in real time as part of mapping.
21. Duration	What was the duration of the interviews or focus group?	p11, lines 92-93 (“lasted 1 hour on average (range 40-133 minutes, mean 63 ± 19)”)
22. Data saturation	Was data saturation discussed?	Exceeded – pg11 (“sample size of 40 was chosen based on saturation in prior work”)
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	p12, lines 116 – Symptom maps were returned (“participants were offered a copy of their personal map”)

Domain 3: analysis and findings

Data analysis

24. Number of data coders	How many data coders coded the data?	p12, lines 124 (“Two independent coders”)
25. Description of the coding tree	Did authors provide a description of the coding tree?	N/A - Content analysis
26. Derivation of themes	Were themes identified in advance or derived from the data?	p13, lines 133–135 (“themes emerging from the data through

		iterative coding and pattern identification")
27. Software	What software, if applicable, was used to manage the data?	p11, line 104, ("Xmind"); lines 126 ("Excel")
28. Participant checking	Did participants provide feedback on the findings?	p13, lines 140 ("member checking and validation of data entered during interviews")
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number	Throughout results for each theme, with identifiers
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes – Three major themes
32. Clarity of minor themes	Were minor themes clearly presented in the findings?	NA

Research in Context

Evidence before this study

Freezing of gait (FOG) is a prevalent and highly burdensome symptom of Parkinson's disease (PD) characterized by the sudden inability to step and walk effectively. Over time it leads to physical deterioration, poor psychosocial outcomes, and decreased quality of life. Available clinical measures fail to accurately and sensitively capture FOG experiences, and new tools to assess FOG from clinician and patient perspectives are being developed by the International Consortium for Freezing of Gait. However, qualitative evidence to understand the FOG phenomenon is almost entirely lacking. We searched several databases (PubMed, CINAHL, Web of Science) and found no prior studies that comprehensively explored FOG from the patient perspective. This information is needed to raise clinical awareness, develop better approaches to monitoring, and ultimately improve outcomes for patients with this debilitating disorder.

Added value of this study

This study provides a unique window into the personal experience of FOG within an international cohort, showing that FOG manifestations are highly heterogeneous and context dependent. We found that FOG is perceived by patients as a loss of "natural motion" which causes a burdensome increase in the effort and attention needed to perform many daily activities. Consequently, affected people develop a range of expected and unexpected adaptive strategies to mitigate the impact of FOG.

Implications of all the available evidence

FOG is a disorder of impaired automaticity that has far-reaching implications for patients and is not just an isolated gait phenomenon. This points to a need for clinicians and researchers to evaluate and address the functional effort, environmental triggers, and adaptive strategies used by patients in the management of FOG, while striving to reduce episode frequency and duration.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [SupplementalMaterialsFOGqual.pdf](#)