Feel the Rhythm: a co-constructed conceptual model of freezing of gait based on the lived experience of people with Parkinson's

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Abstract

Freezing of gait (FOG) is one of the most disabling symptoms of Parkinson's. However, we understand little about lived experiences of FOG. The current study aimed to develop a new conceptual model designed to reflect the broad lived experience of FOG. In Phase 1 we carried out semi-structured interviews with 35 people with Parkinson's and FOG. Participants described memorable freezes along with factors that they considered to influence, or be influenced by, FOG. We used inductive thematic analysis to identify themes that served as foundation for an initial conceptual model. Phase 2 was a 5-year long iterative process of Patient and Public Involvement and Engagement. Through discussion with over 250 people living with Parkinson's, the conceptual model generated from Phase 1 was scrutinised and adapted to: i) provide additional context that supports the interpretation of findings from Phase 1 results; and ii) maximise the resonance of interpretations. Collectively, these processes highlighted the critical importance of one's perceived sense of rhythm. Several themes describe ways in which perceived rhythm can be compromised either through requirements for adapting movement (Changers), distracting attention away from the intended movement (Distractors) or causing problems with gait initiation (Blockers). Other themes describe factors that promote the maintenance (Maintainers) or regeneration (Initiators) of rhythm to avoid FOG or break a freeze and start walking. Results also highlight the importance of Accumulated Experiences of FOG (e.g. altered perceptions of one's sense of self and identity), and how these can amplify Rhythm Changers, Distractors and Blockers. Though Phase 2, a clear focus emerged on one's perceived uncertainty about how planned movements will feel and associated shifts in attention towards vigilant monitoring and control of movements. We provide a detailed interpretation of study findings (relating to cognitive, emotional, sensory and motor processes) using a Predictive Processing Framework, followed by descriptions of practical implications for managing FOG and associated Accumulated Experiences.

1. Introduction

Freezing of gait (FOG) is one of the most debilitating symptoms of Parkinson's. FOG is characterised clinically by paroxysmal episodes where there is an inability to step effectively, despite attempting to do so(1). In people with Parkinson's prevalence of FOG is estimated to be around 40%, but this can increase to over 70% as the disease progresses(2). FOG is one of the strongest contributors to walking difficulties in people with Parkinson's(3, 4), often resulting in falls, related injuries(5), fear of falling(6) and associated reductions in quality of life(7–9). FOG is often resistant to pharmacological intervention(10, 11), which highlights the importance of rehabilitation and approaches for self-management(12). However, current approaches including cueing and movement strategies only partially alleviate FOG. Effective management of FOG has therefore been identified as a critical unmet need in people with Parkinson's(11).

Different manifestations of FOG have traditionally been categorised into phenotypes that relate either to the motor pattern (e.g. akinetic, trembling and shuffling) or triggers (e.g. start hesitation, turning, destination, narrow-spaces and increased cognitive demands)(1, 11). However, the pathogenesis of FOG is unclear and there is no single unified pathophysiological model of underlying mechanisms.

Recent contemporary models attribute FOG to disrupted interactions between distributed brain networks, where crosstalk (i.e. interference(13)) between cognitive and limbic circuits induce transient inhibition of the Pedunculopontine Nucleus via projections to the Basal Ganglia(14). Emotions can further interact with these cognitive processes to potentially lower the threshold for FOG by exacerbating interference between brain regions, ultimately overwhelming the system(15). Indeed, anxiety and stress are now recognised as important triggers for FOG (16–21) and there is evidence for a specific FOG subgroup of so-called 'anxious freezers' who’s FOG appears to be particularly susceptible to stressful situations(22). Several mechanisms are implicated in underpinning this relationship and contributing to interference between brain regions. These include hyperresponsivity in regions regulating fear/arousal(15), as well as the processing of worrisome thoughts(23, 24) which may both increase cognitive demands when walking(25) and potentially amplify emotional responses to any perceived threat(26, 27).

While these pathophysiological models have advanced our understanding of FOG, they are predominantly derived from laboratory-based measures taken during tasks that are largely prescribed and constrained. They therefore fail to adequately capture the complexity of how sensory, motor, cognitive and emotional processes interact in and around FOG events in daily life(28, 29). Furthermore, the psychological processes relating to FOG are most often measured using numerical self-reported scales (16, 23, 24) which essentially reduce experiences into a pre-determined construct and linear numerical response. While these studies have the benefit of large sample sizes and have provided evidence for strong relationships between stress, worries and FOG severity(23), they are not sufficient to describe the broader experience of FOG in its various manifestations. Furthermore, the current literature focusses largely on (experimentally induced) fear, anxiety and associated distractions, meaning that we understand very little about the more general experience of FOG, especially in people where anxiety is less prominent. Improving our understanding of the lived experience and thoughts and/or feelings associated with FOG, is essential for the further development, testing and refinement of theoretical models of freezing.

The central aim of this study was to create a conceptual model that reflects the rich and diverse ways in which people experience FOG and to provide a detailed theoretical interpretation of these findings to reconcile descriptions of these lived experiences with existing literature. First, we conducted semi-structured interviews with a sample larger than is typical in qualitative Parkinson’s research. Second, we carried out a substantial and extended iterative process of stakeholder engagement, where initial qualitative findings and draft conceptual model depicting the lived experience of FOG were scrutinised and adapted. Here, people with Parkinson's and FOG and their carers and/or partners shared their insights about their lived experiences and the extent to which these were or were not represented by the model and associated descriptions. Finally, we develop novel theoretical interpretations based on emergent concepts that most resonated with stakeholders and provide a detailed discussion of these and their implications for research and practice.

2. Methods

The current study was carried out in two phases: i) semi-structured interviews, thematic analysis and the development of a draft conceptual model; ii) experience-based iterative evaluation and adaptation of the conceptual model and associated narrative, including the exploration of approaches for dissemination and related ethical considerations.

Institutional ethical approval was obtained from the College of Health, Medicine and Life Sciences Research Ethics Committee of Brunel University of London (ref: 7299-MHR-Oct/2017-8503-4). All participants provided written informed consent prior to participation.

2.1 Phase 1. Interviews, thematic analysis, and model development

Thirty-five people with a diagnosis of idiopathic Parkinson's and self-reported FOG were recruited though Parkinson's UK support groups to participate in a study designed to provoke and examine FOG in simulated virtual environments(30). All participants self-reported a score of ≥ 9 in the Freezing of Gait Questionnaire(31), self-identified as someone who "regularly experiences freezing of gait", scored ≥ 17 in the Montreal Cognitive Assessment(32) (indicating no severe cognitive impairments) and were able to stand unsupported for at least 1 minute.

Prior to the FOG-provoking protocol, participants undertook a semi-structured interview to explore experiences of FOG. This followed a simple topic guide developed with our Project Advisory Group (see Phase 2 methods). Participants were initially asked to describe recent or memorable freezes and were prompted to detail: i) the events that led to the freeze, ii) conditions that may have influenced the freeze, iii) any environmental factors they consider relevant, iv) how they felt, and v) any strategies used. These features were then expanded upon to consider their experiences of FOG across other contexts where the discussion points above were repeated and the interviewer prompted participants to explore commonalities and contrasts in the experience of FOG between contexts.

WY and AM conducted interviews in a private room at Brunel University of London. Participants were audio-recorded with permission, and all recordings were transcribed verbatim and anonymised, except for P20 who's speech was inaudible in the recording. Interviews lasted approximately 30 minutes.

Data analysis was performed by MN, a physiotherapist specialising in both neurorehabilitation and qualitative analysis. We determined that a different researcher should conduct the analysis, given that the interviewers specialised in cognitive psychology and FOG and might have had tendencies to regress towards established conventions and terminology in the current literature.

All anonymised transcripts were uploaded to Nvivo 12 pro [Lumivero, Co, USA]. Reflexive thematic analysis was undertaken following the steps as described by Braun and Clarke (33). This inductive approach prioritised the subjective meanings described by participants while acknowledging the constructive nature of themes through analytical reflexivity. Transcripts were read several times to assist with familiarisation. This was followed by line-by-line inductive coding in which semantic codes were designated. Following completion of all coding, nodes were created around prominent ideas. These both represented several codes and were deemed to have significance in the participants' narrative. Initial nodes were presented and discussed with research team members who had undertaken the interviews to check for coherence and act as a form of critical conversation to enhance the reflexive engagement of the analysis(34). Following this, the nodes were developed into sub-themes and then into candidate themes which captured key features shared across participants and were distinct in their focus(35). The original transcripts were re-read in light of the candidate themes to ensure they remained appropriately embedded in the data. To enhance rigour, a member of the research team randomly selected three transcripts and reviewed them considering the proposed candidate themes. Acting as a critical friend to the primary analyst and following further discussion, this resulted in renaming of some candidate themes. Indicative quotes were selected to illustrate the main themes developed.

Finally, established themes were visually presented to consider the relationships between them and a draft conceptual model was developed. This model was presented to the wider research team and discussed in relation to predictions of established theories, primarily in motor learning (36, 37)and cognitive psychology(38). The model was not changed at this stage but areas where the model supported or contradicted these theories were discussed to develop initial interpretations.

2.2 Phase 2. Evaluating resonance of interpretations and re-modelling

The main aim of this phase was to evaluate the resonance of (sub-)themes from the qualitative analysis and to refine the draft conceptual model and associated interpretations, through engagement with a large and diverse group of people with Parkinson's. This was carried out by WY through an iterative process that ran for 5 years (2020–2025), as summarised in Fig. 1. Here, the conceptual model and qualitative findings were presented to varied audiences across different geographical locations through a combination of online and in-person formats. Overall, themes were presented to > 1000 people with Parkinson's across an estimated 60 audiences across the UK. These were primarily at meetings of local Parkinson's support groups and exercise classes. The number of people attending each group/meeting ranged between approximately 6-120. These presentations led to > 250 individual conversations where an estimated 110 of these were with people who experience FOG. These conversations were either unscheduled immediately after in-person presentations or during scheduled follow-up conversations on the telephone or online video call. Approximately 50% of these scheduled conversations included a spouse or family member.

Discussions tended to focus on individual elements of the conceptual model, such as the meaning of, and relationship between, specific themes, rather than the whole model. Over time, this discussion expanded to include explicit consideration of ethical issues relevant to the design of interventions targeting freezing of gait and associated psychological factors. While the process described did not conform entirely to a Grounded Theory approach(39), it shared many characteristics. Throughout, WY would reflect on, and summarise comments received, before presenting these to subsequent audiences to support further theoretical sampling(40) and constant comparisons(41) between new and existing interpretations. Over time, changes in the model were agreed through consultation between the authors and long-standing Project Advisory Group (see Fig. 1) and adopted for further evaluation through this cyclical reflexive process. Combined, this flexible and pragmatic iterative approach optimally capitalised on opportunities to regularly engage with groups of stakeholders.

While no pre-defined duration or recruitment target had been set for phase 2, the large number (and the depth) of discussions over this five-year period were required to reach a point at which no new perspectives or theoretical insights regarding the meaning of themes were forthcoming regarding any aspect of the model. At this point, Phase 2 was stopped.

FIGURE 1 HERE

Figure 1. *Schematic showing the structure of Patient and Public Involvement and Engagement in Phase 2. This process was co-constructed with the PAG who then provided insights on each aspect of the model and new interpretations as they emerged throughout Phase 2.*

3. Results

Phase 1

3.1.1 Participant Characteristics

From the 35 participants (15 female, 20 male) the mean age was 67.4 (± 10.4) years with 9 (± 6.5) years since diagnosis. Mean UPDRS-III and MoCA scores were 21.1(± 4.9) and 27.2 (± 1.9), respectively. Detailed participant characteristics are shown in Table 1.

TABLE 1 HERE

3.1.2 Thematic analysis

Four themes were constructed from the analysis. Each of these are detailed below with indicative anonymised quotes (participant number indicated in brackets).

3.1.3 Theme 1: A freeze is not one thing.

This first theme illustrates the different ways in which participants talked about the nature of their freezing episodes. These were not a unified experience, with participants describing both different levels of freeze from moments of hesitancy, through to a deep freeze, and categories related to the reason for freezing.

"*Some freezes, it feels like your feet are stuck to the floor, almost stuck, whereas others, it's just like you can move a little bit, maybe your leg starts rattling and then you start leaning forward and you might be about to fall but you get your balance back again. But there are other ones where you just can't move."* P9

Levels of freeze

At one level was a light freeze which paralleled a sense of hesitancy in movement. Participants (P1, 31) described episodes when they were already walking, but their legs lagged behind, taking a short time to 'catch up' with the rest of the body. These situations were not considered a full-blown freeze, and as long as they remained calm the moment would usually pass.

The next level has been categorised a mid-freeze where participants described being able to move, but with noticeable changes in walking mechanics and/or feel. Different variations included a need to take very short steps 'worse than a shuffle…but not locked in'(P2), but also a sense of 'slowing right down' (P12) or 'not being able to get going '(P12). Participants noted that these were more common when they were tired, but if they concentrated and remained confident in their movement they could be overcome.

The final level, a deep freeze, had several different descriptions all which embody the efforts individuals had to make to overcome them. Descriptors of a 'strong freeze' (P27), 'full-blown freeze' (P1 and P15), being 'stuck to the carpet' (P6,8,12, 24) or 'glued to the floor' (P17) were common. These episodes were strongly linked to uncomfortable social situations which provoked anxiety (P6,11, 16,17,19, 22,23,27,30) and significant time was needed to support their resolution.

Reason for Stopping

In addition to the apparent different levels of freeze, participants noted three different reasons for stopping. These were either directly or indirectly related to a freeze. The first are labelled 'involuntary stops'. These included occurrences where the onset of the freeze forced the individual to cease moving, which parallels the description of the deep freeze. Second were 'legitimate stops'. These are not caused by a freeze but are rather occasions when participants ceased walking because of perceived necessity relating to the given context. For example, stopping when approaching a road crossing to carry out additional movement planning. The third was a 'strategic stop'. Here individuals chose to slow or stop walking to manage the pace of their movement and any perceived disruption to their movement flow, such as a light freeze or people crossing one's path. A further variation of a strategic stop was when participants consciously extended a momentary freeze to give them time to plan a strategy.

I think what I do is just freeze to give myself some time for those people to disappear around me […]. Sometimes I'm conscious [of the situation]. The freeze is unconscious but then I hang onto it to give myself time to strategise how I'm going to get round it…stop trying to take a step until I can work it out (P22).

These three types of stops are introduced here as they become relevant in the descriptions that follow.

3.1.4 Theme 2: Rhythm Facilitators

The concept of rhythm either through its maintenance or disruption became a strong feature in the way in which freezes were described. This theme focuses on Rhythm Facilitators with two sub-themes; 1) Rhythm maintenance: tactics participants described to either maintain their rhythm to continue moving, and 2) Rhythm initiators: the processes to re-ignite movement once a freeze had occurred.

Rhythm Maintenance

When potential problems occurred in walking, maintenance of rhythm in movement was key to avoid moving down the levels of freeze – from light to mid, or mid to deep. Participants discussed multiple ways to achieve this, of which cognitive strategies were the most frequent. Common to ten of the participants were approaches which increased their confidence. This included using walking aids (P2,16,29, 30) or another person (P14), tools that acted to support regular step taking but more importantly becoming a 'safety net' (P3,15,22, 31,35) or peace of mind (P14) to support movement. In the following excerpt participant 15 highlights the importance of this.

I read somewhere, I forget who said it, if you're in a war situation… it's all about confidence, and it is. There's definitely no question in my mind. Who do you have on your left and who do you have on your right? You need total confidence in those people. He'd [son] be one and Joe Fraser, bless him, would be the other.

The conversation continues to describe an example of this when navigating a walk down the stairs to the lounge.

That is like another hurdle for me…. If [son] and his wife and kids are coming up the drive to the house, something there goes click, the pressure of the freezing is gone and I walk through it onto that sofa.

What is notable about this example is that the support of his son does not need to be physically there to assist; visibility is enough for the confidence to emerge and the potential freeze to be postponed.

Other strategies to maintain rhythm included an intention to move forward (P12,14,15,17, 19, 22,26, 34), move properly with internal instructions to step with one's heel and toe (P21,23, 24, 26, 28), continue to step on the spot even if not moving forward (P34) or more specifically focusing on an end point, described as a visual horizon (P1,16) or a safe place (P2). Keeping calm in the moment was also noted as essential (P14), as well forward planning a route which avoided potential disruptions such as people and road crossings (P1,9,10,14,22), both of which could result in a legitimate or strategic stop.

Rhythm Initiators

Rhythm was also at the heart of descriptors of management when participants had to 'unlock' a deep freeze. In these examples participants highlighted the need to initiate rhythm which had stopped. Several of the strategies cited to enable this also related to rhythm of movement. Sixteen of the participants described using external rhythms to assist in shift of focus and re-engage movement. Singing songs (P4, 17, 24, 25, 31), methodical counting (P2, 3,4, 6,8, 11,13,15, 17, 19, 23, 30, 33), and imagining specific music such as marches (P6, 9, 11,12,13,16, 34) were common.

Focusing on intentional movements also supported a re-engagement with movement rhythm. These could be internally generated such as taking big or purposeful steps (P2, 8, 9, 10, 12, 13,17, 18, 21, 22, 28, 29, 30, 31) or shifting one's weight (P1, 7, 9, 12, 16, 19, 21, 23, 30, 34), which was described as a way of 'deceiving the body to act' (P7). Additionally, a few participants also gave examples of external cues for intentional movement such as laser beams (P28), or stepping over lines or sticks (P3, 10, 14, 17, 29)

Participants noted that these strategies had two functions, to get moving but also to distract from less helpful thoughts.

'*I'll count…I say it in my head…because it helps me to distract from what I am thinking…why I am not moving*" (P33)

This sense of needing to shift focus was important but required participants to have cognitive and emotional capacity to do so as highlighted by Participant 27.

"*It [strategy] works when you are in control and you've got time and not in distress, you know not just about to board a bus which is wanting to leave. When you're in a situation like that, it's a hell of a job to get out of it…in what I call a strong freeze…it is not easy to imagine anything but cos your mind is concentrating on getting your feet to come on, start, not much space leftover for figuring anything else*" (P27)

As with the rhythm maintainers, increasing confidence (P2,4,24,25,29) was deemed important as was giving time (P9, 17, 22,30). Both speak to P27's sense of needing to manage distress and having a sense of control for these to be successful.

3.1.5 Theme 3: Rhythm Disruptors

Several triggers were identified by the participants which resulted in a full freeze. While 'coming off' medication was identified by 12 of the participants, this was not the focus for most. More frequent and widespread were references to situations in which rhythm was changed, distracted or blocked from re-starting. This theme explores each of these.

Rhythm Changers

The majority of participants (P3,4,5,9,10,14,15,16,21,22,25,26,27, 29,31,32,35) identified mechanical disruption to movement where their planned trajectory and therefore rhythm of movement was forcibly changed. Examples were predominantly external and included requirements to turn, obstacles such as ticket barriers or doorways, or people stopping unexpectedly in front of them, each creating ‘legitimate’ stops.

“*At the Underground, approaching the ticket machine and as I approached the ticket machine I got slower and slower and then as I got to the machine, obviously you have to stop even for a second, to do the card and then another second to open and then you walk through. So as soon as I stopped, I couldn’t start again... the actual bottom line for me is the stopping. The stopping is the thing that makes you freeze. So I could just keep walking and walking. Do you remember that thing with Forrest Gump? He’s an inspiration to me, Forrest Gump, sometimes I just want to do that. But he ran but I don’t need to run, I just want to walk because I can’t ever remember walking in a flow and I freeze.”* (P9)

Important to note in this description is not only the impact of the disrupted flow, but also the awareness or anticipation of that altered sense of rhythm and associated consequences.

Rhythm Distractors

In addition to physical Disruptors were conditions in which participants were distracted from their flow. These came from both external and internal sources and appeared to result in a switch of attention and/or increased cognitive demand away from maintenance of movement. Internal Distractors identified included feelings of vulnerability often linked with unpredictable contexts and the perceived sense of negative judgement if their altered movement is impacting on others (P4,8, 13,19, 22,28), a loss of concentration (P16, 31) or nervousness around particular or unfamiliar people (P7, 22, 24, 28).

External factors included both real and anticipated interruptions to focus. Looking for cars or the awareness of animals or other people potentially crossing the path were noted (P1,4,8,22,24,25, 26, 27,28,30,32), alongside changes in flooring (P4,15,17, 30) and even the beeping noise at pedestrian crossings (P10) or someone talking (P32) had the potential to re-allocate attention away from movement. Most common though was up-coming narrow openings, between trees, cars or doorways (P4,8,9,14,18,19,22,24,26, 27,29,30,31, 34).

“*say like going to [shop]…So you’ve got to plan to get to that door and somebody walks across you halfway through, it completely throws your concentration so then that makes it really hard. And then because you’ve done that, you then think I’m not safe in my environment, so then you have another freeze, so it kinds of escalates*” (P22)

Rhythm Blockers

The final group of Disruptors are Rhythm Blockers or de-initiators, conditions participants identified as making the restarting of movement after a freeze particularly problematic. Again, there were two main sources for these, internal and external with the internal being dominant.

Multiple internal factors were discussed. Some related to physical sensations such as fatigue (P4,5,6,11,13, 22, 23, 31) and needing to exert excessive effort (P4, 9, 10, 33), or more cognitive reasons such as complex decision making on plan of action (P22, 25, 28), new situations where there were many unknowns (P9, 11, 12, 25, 27, 35) and split focus on something else (P1, 5, 11,12, 13, 16, 22, 30, 32, 33). It should however be noted that for one participant (P33) being distracted from the movement itself was considered an assist in regaining flow.

Most Blockers however related to worrisome thoughts about others and themselves. These included feelings of being rushed by people around them (P1,2,11,12,13,17,19,21,22,27,28,30), being watched (P1,3,7, 9,11,12,13,19,22,27,30, 31), fear of being in other people's way (P28), potential embarrassment (P3, 4, 31) and situations of potential confrontation (P17, 19, 23). Fear of falling was evident (P2,3,4,13, 14, 22, 34), alongside anticipation from past experience of not being able to move (easily) again (P2,9,11,27, 28, 30, see also Theme 4 below).

"*The worst freeze I had, I was in a shop… so I had to shuffle to the till because there was a big queue and er, once I paid, I could not step out of the till… People are waiting and people are looking at you, you know, like move on…and because you're anxious, you don't think of your cues, so your breathing, you forget everything and then I paid, and then I couldn't move and that was even worse because you hear comments, and that was the worse freeze I had and that lasted a good, I would say a good (pause) I don't know, 4, 5 minutes*" (P19)

As P19 notes a number of these factors often coalesce to create a significant impairment to re-initiating movement. This feature of escalation and compounding was also noted in the Rhythm Distractors above.

A common feature in many narratives was the pernicious role of anxiety and nervousness. These were considered to extend the freeze and make it worse because it restricts the ability to problem solve and use strategies to initiate/regain rhythm. As P22 states, "*it's more about training your brain not to get anxious. If there were strategies for doing that more than the actual waking…because the anxiety causes more of a problem, because you can find strategies for the walking. It's holding the anxiety that's difficult*".

Several participants expressed how this anxiety was often related to memory of previous events, as exemplified by P8:

"Well, the fact that I got stuck in the past means that I'm more concerned about what it's going to be like when I come to do it again. So it's like a feedback loop between having got stuck and then being worried about getting stuck, so I then freeze because I'm worried I'm going to freeze".

External Blockers were a collection of environments in which space to move was restricted. This included small and narrow spaces such as a larder/pantry or elevators (P1,3,16, 18, 22, 30), but also ones where there were a lot of people such as crowded train stations (P11,24,25). Each were predictable in making the re-initiation of movement troublesome.

3.1.6 Theme 4: Accumulated Experiences

In the previous themes it is evident that specific ways of thinking and framing a situation impacted on the lead up to a freeze and additionally played a part in their potential resolution or prolonging. There were also hints about the longer lasting impacts of a freeze on the participants and their sense of self. This theme explores these aspects more fully through three subthemes: 1) Vulnerability in a declining self, 2) Negative self-judgement and 3) Disrupted equilibrium and identity jeopardy.

Vulnerability and the Declining Self

Freezing and particularly episodes of freezing in public had a significant impact on the individuals' sense of the trajectory of their condition. Participants talked about the additional burden of the effort to manage episodes resulting in fatigue (P22), that they were scared of their more fragile state (P1,4,25), the potential of falls and resultant fractures which they visualised (P10,33, 34), and the increased risks of significant accidents such as being run over (P30). Freezing was described as a signal of a declining state (P16) and was considered dangerous (P9, 34), but also positioned them in a state of social disadvantage (P25,27) exemplified by participant 16:

"*I can see myself outside of the box from some other peoples' points of view. So sometimes I feel a little bit vulnerable to people who could take advantage of someone, you know, like a lion looking at a wounded animal*".

The vulnerability was accompanied and somewhat exacerbated by numerous references to negative self-judgement. An inability to overcome or avoid freezing resulted in frustration in a lack of control and self-blame (P28, 31) which challenged how they saw themselves.

"*I think I blame myself for not being able to go. I went through an upbringing that got me to pray and be the best in you... and if I do things, I do well ... I just think I can't overcome this problem*" (P28).

Disrupted equilibrium and Identity Jeopardy

Participants expressed feelings of inadequacy (P11,13) and gave derogatory descriptors of the self, such as being a 'fool' and 'idiot' (P27, 32) or looking 'like an orangutan' (P24). They described feeling embarrassed or humiliated, resulting in a sense of social inadequacy and discomfort (P3,25, 32).

A number of these resulted in descriptions of disrupted equilibrium where participants described not feeling in control (P13) and consequently limiting their activities and horizons due to the 'slippery slope of Parkinsons' (P27). Stories of cancelling family meets (P27), avoiding public transport (P25), not travelling alone (P4), no longer going on holiday (P15) or indeed not leaving the house without support (P14, 33) were common.

"[My wife] and I would not go on vacation now, just the two of us, because [my wife] doesn't have the confidence to go with me, knowing that I'm going to fall. Where does that leave her? Where does that leave me?" (P15)

As participant 15 indicates, these losses go beyond missed vacations, leading them to question who they are, jeopardising how they saw themself. Some participants were more explicit about their self-identity being challenged (P16), desperately holding onto to a desire to be seen as their normal self with friends (P15), but in some cases accepting that they are now different.

"*At first you're trying to avoid being seen as different, but in the end there's nothing I can do about this*" (P22)

3.1.7 Phase 1 results summary

While these four themes touch on different components of the experience of freezing, the overlap between and across them is evident. The interplay between environment, cognitive and emotional states had a clear impact on the type of freeze and the individual's capacity to navigate the situation. These then played into memory, interacting with confidence, vulnerability and how the individual saw themselves, all potentially influencing and potentially amplifying their response to the next challenge (e.g., freeze). These interactions were represented in an initial/draft conceptual model (see Supplementary Materials A). This was then further developed by the research team before being evaluated and adapted within Phase 2.

3.2 Results: Phase 2

PPIE-informed evaluation and adaptation of the conceptual model and associated interpretations

The final conceptual model is shown in Fig. 2. The following section describes changes to the model (and associated interpretations) made during Phase 2. While all themes and sub-themes presented in Phase 1 and the draft model were supported by Phase 2, adaptations were required regarding the relationships between themes/sub-themes as well as additional interpretations of the specific themes. These are described below.

The theme describing the levels of FOG and transitions between them (Fig. 2, part A) was strongly supported, although it became apparent that 'free movement' should be outside any specific FOG event. The boundary of the dashed oblong boundary for the FOG event was therefore relocated so that the higher ends of the spectrum as well as arrows B and C were exposed, thereby reflecting how Rhythm Maintainers and Disruptors can still be experienced in the absence of FOG.

One's sense of rhythm was deemed to be of critical importance as a central theme and this was pervasive across the heterogenous experiences of FOG and the factors that influence it. There was agreement that different manifestations of FOG require specific labels (e.g., shuffling, turning, akinetic). However, the experience of these phenotypes is highly variable and therefore not applicable to all. In contrast, one's sense of rhythm was widely considered to be fundamental and common to all manifestations of FOG.

Over time, a focus on the widely accepted concept of rhythm led to the presentation of ideas around the perception and prediction of musical beats(42). While lay terminology was used throughout, concepts based on ecological psychology (perceived time to contact events and the coupling of movements to ‘intercept’ upcoming beats; ‘tau-coupling’(43)) were broadly supported and led to a final focus on Bayesian Generative Models(44–46) in our main interpretations. Descriptions of the brain as a prediction engine clearly resonated with audiences. Metaphors were suggested by individual audience members. These were discussed, reviewed and presented to new audiences (Fig. 1). The most popular metaphor was that of a small group of musicians playing together, each representing a given brain function. This became known as ‘the quartet’ (see Supplementary Materials B). One of the reasons why this metaphor resonated so strongly was the sense of urgency and pressure the musicians must feel when trying to detect and resolve both miscommunication between players and associated timing errors. The highly subjective way in which players will perceive the dynamics and overall group performance fits well with the notion that our expectations can shape perceptions (e.g., the McGurk effect(47)). In the context of FOG, Accumulated Experiences were thought to shape one’s perceptions of movement and bodily sensations such that small movement errors might be perceived as the start of a freeze (Fig. 2, arrow E). This also related to feelings of arousal and nervousness where the expectation of fear, panic and Rhythm Blockers (arrow F & cyclical arrow G) contribute to the perception of those feelings. This was also relevant to the broader social context of FOG. For example, the expectation of negative judgement led to misinterpretations of others’ facial expressions (arrow E).

While rhythm Changers, Blockers and Distractors (part C) were considered distinct, they were also considered to fuel each other. Anticipation of Changers were seen as a potential form of distraction. One prominent example is of vigilant monitoring of body states and potential unplanned absence or presence of movements. Here, both the expectation and experience of Changers were often (not always) associated with a deep physiological reaction and the experience of physical and emotional stress. People also described compensations based on actively rationalising their experiences or avoiding thought-processes about freezing (part B). For those who did report pronounced physiological reactions, these appear to be a major source of cognitive Rhythm Distraction (part C) as people process those bodily sensations as well as worrisome thoughts about a potentially overwhelming array of possible consequences of FOG, including injury, failure to meet time demands (e.g. missing a ringing telephone), embarrassment and negative self-judgement. It was clear that these physiological/emotional changes were perceived as undermining one's sense of agency, especially as attempts to rationalise and control them were considered extremely difficult and largely ineffective. These collective experiences were thought to culminate in Rhythm Blockers, as the above forms of distraction all create difficulties in focusing on the intended movement outcome (part C). This experience was related to 'freezing of thoughts' with discussants often using the term "brain freeze" or similar. The collective weight of these combined processes led to the increased width of part C compared to B. The cyclical arrow G was also included through this process as it encapsulates ‘body vigilance’ and the cognitive and emotional response to physical sensations. For example, in response to a lighter FOG, some might adopt an excessively negative interpretation of bodily sensations that lead to the expectation of a deeper freeze and associated thought processes aligned to Rhythm Disruptors (part C).

Amplifiers were evident in the original conceptual model that linked Accumulated experiences (D) to Rhythm Disruptors (C). After further developing the meaning of Rhythm Disruptors (described above), it became clear that a distinction was needed between the types of Amplifiers that provoked them. First, worries about specific contexts and triggers of future FOG events are represented by arrow E. The second amplifier (arrow F) depicts how prior experiences of FOG shapes anticipated perceptions within future potential FOG events. Cyclical arrow G also represents negative (potentially disproportionate) perceptions of movement and emotional response to Rhythm Disruptors (as described above) often heightening anticipation of negative consequences of FOG. Importantly, these anticipated consequences of FOG often transcend immediate practical difficulties associated with the specific context (e.g. falling) and instead often relate to the implications for reinforcing perceptions of the declining self that come with repeated experiences of FOG. From the processes represented by arrows E and F, participants identified these as being most disturbing.

Rhythm Facilitators in arrow B were, to some extent, considered to reflect compensatory strategies, such as sensory cueing. But to a much larger extent this reflected processes summarised as ‘solving the puzzle of freezing’; i.e. aligning mind and body, including efforts to regulate emotions and physiological tension. This can involve active attempts to facilitate this alignment through movements such as jumping, stamping feet or shifting weight. Rationalisation of one’s wider predicament was also deemed to be very important. This was typically characterised by familiar thought processes employed to help avoid thoughts concerning the Declining Self to re-engage focus on the intended movement outcome and, potentially, a broader strategic plan to support this. These planning efforts were a direct reaction to the Declining Self (bi-directional arrow in Accumulated Experiences: Fig. 2, part D). Here, there was a conscious awareness of the degenerative nature of Parkinson’s and an acknowledgement of the many changes that gradually erode physical and psychological function. However, for some, there was an active decision to accept these changes and, despite the odds, employ purposeful positive decision-making in an attempt to overcome emerging tendencies that lead to apathy (arrow H). Some even referred to this as a ‘purposeful delusion’ or a way of finding excessive levels of confidence to solve the puzzle of FOG (part D). Importantly, this was considered to actively counter Rhythm Disruptors (arrow I) through a combined re-capture of attention towards the intended movement (arrow B) and the resultant clarification of the mental image (i.e. prediction) one has for the intended movement. However, the bi-directional arrow within Accumulated Experiences also represents the potential negative consequences of these planning efforts; where the conscious and physical efforts associated with planning were, despite the clear rewards, also fatiguing. The persistent necessity for Strategies of Resilience often served as a reminder of the Declining Self. For many this represented a call for even greater vigilance engage positive strategies, but there was acknowledgement that one’s resources required to achieve this vary between individuals, are influenced by a range of factors including social support and are finite.

FIGURE 2 HERE

Figure 2. *Conceptual model illustrating perceived experiences relating to freezing of gait*

A: FOG is experienced on a continuum

B: Rhythm maintainers and initiators facilitate the transition towards free movement, typically involving conscious involvement and focussing on the intended movement outcome.

C: Rhythm Changers, Distractors and Blockers serve to trigger or deepen FOG and represent a combination of factors relating to requirements for adaptability, distraction, anxiety and barriers to focussing on the intended movement.

D: Repeated experiences of freezing can lead to a sense of vulnerability and perceived loss of control, but people often engage in active strategies of resilience to resist and compensate for these changes

E: Prior experiences of FOG and associated Accumulated Experiences amplify anticipation for Rhythm Changers, Distractors and Blockers and associated consequences of resultant FOG and potential difficulties with gait initiation

F: Prior experiences fuel negative interpretations of sensory information during FOG events

G: Disproportionate perceptions of movement errors and the inability to resolve them contribute to uncertainty about one's ability to move, contributing to emotional and cognitive processes that further exacerbate Rhythm Changers, Distractors and Blockers.

H: Strategies of Resilience represent conscious attempts to plan and engage with tactics that enhance one's sense of control.

I: Focussing on the intended movement (and potentially experiencing associated improvements in movement) detract from Rhythm Disruptors

4. Discussion

The current study aimed to develop a conceptual model describing the lived experience of FOG in its various manifestations. Phase 1 interviews revealed that repeated FOG episodes undermined fundamental self-beliefs, triggering both adaptive and maladaptive responses. In Phase 2, interpretations of these findings were co-constructed through an iterative process (see Fig. 1) with people living with Parkinson's and FOG. To our knowledge, our integrated approach of using such a large-scale qualitative study and extensive Patient and Public Involvement and Engagement to add context and shape interpretations of findings is unique, provides important insights, and greatly improves the generalisability of the study findings.

4.2 FOG is experienced on a continuum

Our results show that FOG is experienced on a continuum where a given freeze can occur, and transition between, free movement and different levels of FOG (Fig. 2, part A) and *vice versa*. Transitions between lighter to deeper levels of freeze do not appear to be synonymous with changes in the *amount* of visually apparent movement *per se* but are instead primarily characterised by the degree to which one's sense of control over movement is periodically reduced. While descriptions highlight that transitions towards deeper levels of FOG often represent a conversion between shuffling/atypical gait and more pronounced motor blocks where there is an absence of progression, the current findings also imply that more *dynamic* FOG phenotypes (i.e. festination, trembling) have the potential to be perceived as *deeper* FOG.

4.3 Identification of strategic stops

The current findings highlight important distinctions in the way cessation of gait is perceived. Traditional annotation of FOG events has relied on subjective evaluation of a walker's intent, to distinguish between voluntary 'legitimate' (i.e. neurotypical) stops and involuntary stops (i.e. FOG)(48). The current results highlight the importance of also distinguishing so-called 'strategic' stops, where, upon the sensation of a light freeze or perceptions of bodily sensations associated with FOG, people elect to stop walking to prevent further transition to deeper levels of FOG. The new definition of FOG and recommendations for annotation (49) highlight the difference between 'core' FOG and atypical gait. Future work should evaluate if this distinction in the walker's experience of legitimate, strategic and involuntary stops can be reliably determined through subjective evaluation of videos as well as kinetic or kinematic data derived from sensors(50). More specifically, there is a risk that strategic stops might be misinterpreted as involuntary 'core' FOG due to the emergence of atypical gait that might precede cessation of walking.

4.4 Perceptions of rhythm

Across all levels of FOG there was a clear shared emphasis on the critical importance of one's sense of 'rhythm' and how this could be disrupted or lost, as-well as the conscious attempts made to maintain or re-generate it. Definitions of *rhythm* emphasise the predictability of recurring events. As described in Phase 2 results, considerable efforts were made to scrutinise existing concepts/theories to determine descriptions of FOG that resonated with the lived experience. Of these, lay summaries of a Predictive Processing framework emerged as a clear preference and were also broadly considered to translate across all freezing phenotypes/sub-types. In the following sections, we therefore use this framework to provide detailed interpretations of each theme shown in Fig. 2 and the additional co-constructed context provided by Phase 2. We first describe mechanisms potentially responsible for motor impairment, both within a given FOG event and changes that occur over time. We then offer interpretations about the role of cognition in delivering some degree of resolution. This leads to suggestions for how future interventions could be developed to manage FOG and associated changes in cognition and emotion.

4.5 Predictive Processing and the role of dopamine

Predictive Processing frameworks position the brain as a 'prediction machine' that continuously generates predictions about its sensory inputs(44–46). When there is a difference between expected sensory input and that which is received, a prediction error signal is generated. This is important because it drives both learning and perception. In situations where sensory evidence is deemed to be more precise (i.e. reliable) relative to the existing prediction, predictions and/or perceptual representations can be updated to accommodate the incoming sensory evidence. In contrast, where predictions are deemed to be precise and/or sensory input imprecise, prediction errors can be attenuated by treating them as noise. Collectively, this affords greater efficiency in perceptual, cognitive and motor processing (see Table 2 for descriptions of key concepts).

The precision of prediction errors (see descriptions in Table 2) is thought to be driven by various neurotransmitters, including dopamine(51, 52). When dopamine is low (i.e. in people with Parkinson's), it is claimed that prediction errors lack the necessary precision to initiate movement, given that the system is unable to predict 'how movement should feel'. Dopamine deficiency is also thought to impair the precision of temporal prediction errors(53). This causes the 'internal clock' to become unstable and drift, because the system cannot effectively update its timing model based on bottom-up sensory input (i.e. the sense of Rhythm is disrupted; Fig. 2, part C). In repetitive movements, like gait, motor commands depend on precise temporal predictions (i.e. expectation based on previous experience, also known as 'priors') to inform the timing, force and spatial characteristics of each movement(54, 55). Imprecise timing predictions and associated low confidence in motor plans are therefore expected to reduce gain in motor output(53). Failure to effectively correct these errors across repeated steps is likely to cumulatively increase spatiotemporal variability and reduce step length (widely observed in people with Parkinson's(56)). When considering the transition from free movement to FOG, this is widely known as the 'sequence effect'(57).

TABLES 2 & 3 HERE

We argue that reduced confidence in sensorimotor predictions and associated changes in precision weighting could account for different manifestations of FOG (see Table 3) as well as the various ways in which one's sense of Rhythm can be disrupted provoking the transition to deeper levels of FOG (Fig. 2, parts C and A, respectively). According to these interpretations, some manifestations of FOG (e.g. forward propulsion observed in festination) represent a failure to update high-level predictions (see Table 3). While the above rationale focuses on the neuromodulatory effect of dopamine, it is noteworthy that this might be partially attributed to dysfunction in serotonergic(58) and cholinergic(59) pathways that disrupt several processes including those relating to attention and executive function(60). Collectively, the above suggests that the sequence effect, festination, turning, destination (e.g. doorway) freezing and start hesitations are divergent expressions of the same fundamental mechanism. Based on results from Phases 1 and 2, we characterise these difficulties in resolving prediction errors as Rhythm Changers (Fig. 2, part C). This account is also represented by the analogy of 'The Quartet' and associated lay descriptions of Rhythm Changers (see Supplementary Materials B), describing how the accumulation of errors can, if not corrected, lead to a breakdown in a global sense of rhythm and associated movement.

4..6 Uncertainty and emotion

Results from Phase 1 highlighted that, while Rhythm Changers can often occur in the relative absence of stress and anxiety, they also have the potential to exacerbate each other. FOG can provoke fear and anxiety due to the perception of significant consequences (high pragmatic value), but in turn, fear and anxiety can increase the likelihood and depth of FOG (for review see (15)).

Disruption to one’s sense of Rhythm (Fig. 2, part C) and associated reductions in confidence in sensorimotor predictions can have downstream effects on emotional systems, particularly those involved in fear and anxiety(61, 62). In predictive processing, prediction errors are not merely a transient practical inconvenience. They are registered as a potential threat because it signals poor attunement to one's body and/or external environment, particularly in situations where prediction errors are highly relevant to task success/failure and physical safety(63, 64)(e.g. social concerns, time pressure, fear of falling). This helps to explain how emergent movement errors/variability, such as those often observed prior to FOG(57) could induce marked sympathetic responses(26, 27) even if they do not represent any overt threat to safety. Indeed, it is clear from Phase 2 that even the anticipation of prediction errors could be sufficient to drive a sympathetic response, a disruption to one’s sense of rhythm and associated movement difficulties. These relationships are potentially compounded by hypersensitivity in fear circuits, particularly within the amygdala(15). Heightened emotional reactivity is likely to make prediction errors feel disproportionately salient, serving to further undermine one’s trust in top-down sensorimotor predictions(64) and strengthening the brain’s expectation of danger during movement. This represents a potentially vicious cycle depicted by circular arrow G in Fig. 2. These interpretations based on the lived experience of FOG integrate naturally with established theoretical models describing how freezing arises when motor, cognitive, and limbic loops interfere with one another(13, 14) and how dysfunction in noradrenergic systems and those relating to fear and emotion can lower the threshold for FOG(15).

4.7 Rhythm Facilitators and Conscious Movement Processing

Results of the current study identify factors that often help to avoid or resolve FOG through Rhythm Maintainers or Initiators, respectively (Fig. 2, part B). These mostly relate to the walker consciously focussing on intended movement outcomes, often achieved with learned compensatory strategies and/or sensory cues that are well-documented in the literature(11, 65).

In Parkinson’s, conscious involvement in movement is considered in broad terms of compensating for defective basal ganglia circuitry(66, 67). However, we argue that conscious movement processing (CMP) represents two distinct functions that have divergent effects of motor performance. The first is consistent with traditional interpretations and relates to goal-directed focus where higher-order cognitive resources (e.g., attention, working memory, executive control) can supplement motor planning in circumstances where sensorimotor predictions are unreliable (e.g. where dopamine is deficient)(68), thereby minimising reliance on defective perceptual and motor processes that would otherwise be largely automatic(69, 70). In this sense, conscious motor processes can represent an adaptive mitigation of Rhythm Changers described above by (Fig. 2, part C) bolstering confidence in predicted action(71). As this is a cognitively demanding process, this interpretation fits with the widely reported increased cognitive demands of gait in people with Parkinson's and FOG, increased severity of FOG under conditions of increased cognitive load(72), and associations between deficits in cognitive and attentional processes and FOG severity(73). It should also be highlighted that dysfunction in cholinergic projections from frontal regions are also likely to compromise attention, cognition and flexible weighting of task-relevant sensory signals(74) thereby potentially jeopardizing these mitigation strategies. This interpretation is consistent with observations of FOG being strongly associated with attentional deficits and that FOG is still often evident even when dopaminergic medication improves basic motor function (in up to 40–50% of patients)(75, 76).

The second form of CMP relates to previous descriptions of fear and anxiety-related vigilance in *monitoring* movement errors and associated increases in precision afforded to bottom-up, stimulus-driven processes(63, 77–80). We argue that this body-vigilance not only detracts from potential conscious efforts to bolster sensorimotor predictions (Fig. 2, part B) but is also a key component in the vicious cycle involving maladaptive emotional, sensory, motor and cognitive processes described earlier in this discussion. This distinction is important because, to our knowledge, the current literature does not clearly account for body vigilance (and potential negative consequences) when describing the necessity for increased cognitive control of movement in people with Parkinson's. Future work should focus on distinguishing between the two forms of CMP in self-reported outcomes aimed at monitoring these processes.

4.8 Rhythm Distractors and Blockers

Aside from the potential role in provoking emotional responses, we must also consider vigilance to monitoring internal/movement errors and external environmental threats as the focus of cognitive Distractors that disrupt one's sense of rhythm (Fig. 2, part C). These potenntially absorb cognitive resources that might otherwise be allocated to Rhythm Maintainers and Initiators (Fig. 2, part B). Results from Phase 2 provided useful additional context for these observations. When attempting to initiate or maintain gait, focus of attention may or may not be relevant to the task of walking and the distinction between the two may not always be readily apparent. For example, a walker might consciously think to themselves "Pick your feet up" versus "Why can you not pick your feet up?" Here, a deviation in focus away from the intended movement outcome has the potential to become maladaptive. On one hand, the evaluation of movement difficulties could lead to adaptive problem solving and effective compensation strategies (Fig. 2, part B). Conversely, if the person does not consider themselves to have the necessary abilities to overcome the challenge, they are likely to enter a so-called 'threat state'(81) and engage in future orientated worrisome thoughts that can broadly be considered as a combination of unnecessary cognitive load and a potential propagation of sympathetic response (Fig. 2, part C; Rhythm Distractors). This highlights the importance of future work qualitatively evaluating the content of thought processes during walking tasks, as it could help to identify maladaptive processes that serve as a specific target for self-management.

The current results identified the sub-theme of Rhythm Blockers, representing difficulties engaging in conscious planning efforts, especially during attempted Rhythm Initiation. There are several reports in the literature of people with Parkinson's experiencing 'freezing of thoughts' or 'cognitive freezing'(82). This phenomenon is often interpreted with reference to underlying high-level deficits in cognitive and attentional processes such as set-shifting(15, 83). In the context of FOG, the current results and interpretations derived from Phase 2 suggest that freezing of thoughts can be characterised as the combination of threat vigilance, associated emotional responses and resultant cognitive processing of worries. These likely interact with underlying deficits in cognitive and attentional processes to disable adaptive reallocation of attention towards Rhythm Maintainers and Initiators (Fig. 2, part B).

4.9 Accumulated Experiences

So far, this discussion has only considered potential processes contributing to the manifestation of disrupted sense of Rhythm within a given situation/freeze (see Fig. 2). In this section we offer interpretations about factors reported to influence these mechanisms over time.

4.9.1 The Declining Self: sense of self and reduced agency

Repeated experiences of FOG had a broad range of long-term effects on participant's sense of vulnerability and changes in one's perceived identity. Similar experiences are documented in relation to the broad range of Parkinson's symptoms(84–87). These not only include a reduced sense of agency over one's body movements but also a sense of alienation and detachment from one's body(28) as well as a loss of the sense of self(84); all of which are consistent with the current results. Collectively, these findings help to identify sources of anxiety that can amplify (see Fig. 2, Arrows E & F) maladaptive physiological responses and cognitive behaviours described above.

In the current model, concerns relating to FOG extend beyond immediate potential practical consequences of freezing, such as falling. Rather, each freeze can be perceived as a symbol and reminder of the degenerative nature of the condition and the Declining Self (Fig. 2, part D). Ordinarily the brain would maintain a relatively stable sense of self by updating predictions in light of one's experiences. As described in earlier sections, neurochemical changes in the brain associated with Parkinson's are likely to disrupt the updating of such expectations(51), potentially leading to the emergence of disproportionate beliefs(88) or uncertainty about one's abilities. The experience of disrupted movement, such as FOG, could therefore lead to repeated violations of long-held beliefs, a feeling that familiar capacities are no longer reliably held and a sense of estrangement from one's own body/sense of self(89). These changes will not be unique to FOG and provide an explanation for how any symptom of Parkinson's could potentially contribute to disruption in the sense of self and agency(84).

A large body of research demonstrates that reduced sense of agency alters the perception of temporal relationships between intended actions and outcomes(90, 91). This increases the extent to which actions are perceived as unexpected, thereby directly amplifying prediction error signals(92–94). This relationship is represented by Amplifiers (Fig. 2 arrows E, F and G) that undermine the certainty of predictions and disruptions to the sense of Rhythm (Fig. 2, part C and arrows E,F&G) in a given situation, including heightened emotional reactions to prediction errors described earlier in this Discussion.

4.9.2 The Declining Self: trauma and cognition

It is important to consider how traumatic stressors, such as FOG, could reshape one's internal model of the self and the world. Literature on post-traumatic stress disorder provides a well-established example of how experiences drive changes in perception, expectation, and underlying neurobiology(95). Hyper-responsivity of the amygdala biases sensory processing towards threat, further amplifying fear-related predictions(96, 97). Concurrently, impaired function in pre-frontal areas compromises top-down modulation of these predictions(98, 99), possibly mediated, at least in part, by dysfunction in serotonergic and cholinergic pathways, thereby limiting cognitive reappraisal and the downregulation of fear responses. In other words, trauma can recalibrate the brain's generative models by assigning excessive precision to threat-related predictions, resulting in maladaptive schemas characterised by persistent negative expectations about future events and their consequences(100). Such trauma-based predictions often reactivate in later situations, even when threats are less salient; a concept known as 'kindling'(101, 102). This misalignment reinforces the assignment of excessive precision to predictions for negative outcomes and further trauma, allowing them to override perceptions and elicit negative emotions tied to present circumstances(103) (see Amplifiers in Fig. 2 arrows E & F). As such, Accumulated Experiences of FOG are not confined to negative cognitive appraisals of one's abilities and identity. The potential trauma associated with these experiences can shape the underlying neurobiology(95), including the sensitisation of fear circuits observed in people with Parkinson's and FOG(15).

The progressive nature of this phenomenon reflects the accumulative amplification of the relationship between perceptions of past experiences of FOG (Fig. 2, part D), negative expectations for future events (Fig. 2, arrow E) and associated maladaptive interpretations of current sensory information (Fig. 2, arrows F&G). For example, if someone is walking and they experience a 'light' freeze, parts F and G in Fig. 2 represent the progressive tendency to adopt negative interpretation of ongoing sensory information that drives expectations of: i) the freeze and its likely trajectory to deeper levels, and ii) the physical, social and emotional consequences (i.e. reinforcement of the perceived 'Declining Self').

Collectively, this might be considered as a 'diathesis'—a predisposition or specific vulnerability—for FOG, where negative Accumulated Experiences (Fig. 2, part D) influence one's expectations for social consequences (Fig. 2, arrow E) and sensorimotor predictions (arrow F). In turn, these interact with changes in underlying neurobiology (arrow G) and disrupt the sense of Rhythm thereby exacerbating FOG (Fig. 2, parts C & A). This phenomenon helps to explain why many people with FOG describe seemingly benign scenarios as triggers for fear(104, 105) and FOG (e.g. interacting with an attendant at a supermarket checkout; see video links in the section on Practical Implications below for filmed personal accounts).

4.9.3 Strategies of resilience

The current results highlight clear conscious attempts to regain a sense of control and counter factors associated with the declining self. Such strategies are clearly distinct from processes involved in the generation of motor plans associated with Rhythm Maintainers and Initiators (Fig. 2, part B) and are instead intended to establish greater certainty through conscious rationalisation and careful planning of daily routines (Fig. 2, H). This process is reflective, deliberate and can be effective in regulating primal systems, including the withdrawal of attention from unpleasant thoughts or memories; a major function is gaining perspective over basic cognitive reactions. The most common example used is the fear of flying, where people can overcome instincts not to board through a process of rationalisation(106). In this sense Strategies of Resilience reported here (Fig. 2, part D) largely represent the conscious mitigation of Accumulated Experiences (see bi-directional arrow within Fig. 2, part D) and associated Amplifiers (see Fig. 2, parts E and F) through a sequential process of acknowledging practical difficulties and then actively shifting attention away from them to focus on positive decisions to defy the odds, focus on hope and find light in the darkness. This could lead to the adoption of compensation strategies or mindset represented by Rhythm Facilitators (Fig. 2, part B), but also a process of using this to actively undermine Rhythm Disruptors (Fig. 2, part I).

Due to an awareness of the many changes that typically happen due to Parkinson's and the degenerative nature of the condition, adopting positive Strategies of Resilience were often said to require considerable effort and self-discipline. As such, descriptions of apathy(107, 108) represented a somewhat default trajectory that must be actively guarded against. This is often a prominent message delivered by patient advocates in online forums and support networks. Scientific evidence for the functional utility of these Strategies of Resilience is currently limited. However, the potential for these to generate meaningful and quantifiable improvements in motor and non-motor symptoms is exemplified by the case of Anne Hellevik(109).

4.10 Practical implications

In this section we first describe implications of the current study for the use of movement strategies and approaches to manage movement/FOG (i.e. Figure 2, part B). We then progress to discuss approaches to manage negative Accumulated Experiences relating to FOG.

4.10.1 Movement Strategies

A wide variety of compensatory movement strategies and sensory cues have been identified/developed for enhancing gait and managing FOG and there is ongoing debate around how the selection and long-term use of these tools can be optimised(110, 111). The selection of a given approach could be guided by individual differences in information processing styles(112, 113) or based on avoiding reliance on deficient functions (e.g. providing external sensory cues where cognitive decline could compromises the generation of internal cognitively challenging strategies). Regardless of the sensory modality or physical nature of the strategy, we recommend that the focus should be on scaffolding the sensorimotor prediction of upcoming movements, thereby enhancing one's sense of rhythm.

Considering this argument, it is relevant to compare the use of a temporally consistent metronome versus contemporary devices that provide real-time biofeedback for gait events(114–116). With a traditional metronome, the consistent external cue will provide more salient prediction errors as movements inevitably deviate from the rigid external pattern. The literature shows that this approach can lead to effective entrainment of movements to the cue, leading to reduced gait variability and even increase SL and gait speed(65, 117, 118). However, such adaptations rely on effective error-detection and associated corrections in motor output (i.e. updating of sensorimotor predictions). As described above, deficits in both are associated with Parkinson's and depleted dopamine (among other neurotransmitters)(53) thereby limiting the efficacy of external cues presented as a pre-determined pattern. In contrast, if biofeedback is provided in real time and representative of ongoing motor actions, this inherently carries out the role of detecting and resolving prediction errors on behalf of the walker while also establishing a salient sensorimotor prediction of anticipated augmented sensory feedback that is ultimately internally generated.

We must consider the time/learning required for a user to update their sensorimotor predictions. This will be dictated by the point at which the sensory feedback transitions from: i) generating salient prediction errors (therefore being considered as uncertain and assigned low precision), to ii) forming a salient component of—and increasing the precision assigned to—the sensorimotor prediction, thereby facilitating Rhythm. We speculate that this duration will be relatively short in the context of augmented sensory feedback. However, emerging technologies permit an ever-increasing range of options to manipulate device settings and the way a user is provided with feedback. Any changes that compromise the familiarity with feedback are likely to propagate predictions error and disrupt one's sense of Rhythm. This issue is particularly relevant to approaches that directly manipulate movement mechanics, such as exoskeletons(119, 120). These options are powerful because they can mechanically correct errors. However, this can also, perhaps ironically, generate salient prediction errors if the user does not have certainty in their predictions for the corrective forces that will be applied. Researchers and engineers must critically evaluate learning effects and their retention. The aim of course is that a device affords updating and certainty in sensorimotor predictions that are retained when the device is not in use. The risk is that the user develops a dependency on the external information (121) or forces applied, so that the removal of the device generates prediction errors and uncertainty in sensorimotor predictions.

4.10.2 Managing Accumulated experiences and Amplifiers

The prevention of the accrual of negative Accumulated Experiences appears to rely on the deployment of effective Strategies of Resilience, thereby highlighting the importance of these being integrated into future strategies and interventions. Opportunities to achieve this was deliberated at length within Phase 2. This process identified risks of transparently reporting results and interpretations described in this paper. On one hand, such emotive accounts might be informative and adaptive if they lead to effective cognitive appraisals and the adoption of associated Strategies of Resilience. However, such accounts could also trigger negative reactions and reinforce expectations for experiencing such thoughts and feelings in the future, potentially provoking maladaptive responses/amplifiers (Fig. 2, arrows E, F and G).

Our PPIE process in Phase 2 suggested that, in order to avoid emotive descriptions of Accumulated Experiences, training content for self-management might focus on Amplifiers and Rhythm Distractors experienced around given FOG events. We therefore co-developed video content on this topic with our Project Advisory Group (Fig. 1) and this was combined with content based on gait-initiation training (see https://osf.io/djxzw/files/osfstorage for links to all videos described here). These videos were compared in terms of their impact on FOG as well as subjective appraisals of thought processes when walking (122). Results showed that content on anxiety management alone was not sufficient to create any meaningful change in any outcomes, whereas the learned gait-initiation strategy was effective in creating meaningful reductions in perceived fear and worries and enhanced goal-directed focus of attention (122) (i.e., Rhythm Initiators).

Previous reports have criticised attempts to deliver training aimed at increasing APA amplitude and enhance gait initiation in people with Parkinson's and FOG(123). We argue that observed benefits are achieved through a combination of: i) promoting both goal-directed focus of attention/adaptive CMP (Fig. 2, part B) with ii) a more advantageous biomechanical position having unloaded the non-stepping limb(30, 122, 124). Furthermore, the repeated experience of improved gait initiation can be effective in undermining Rhythm Disruptors(122). We nevertheless anticipate that this combination of training alone will be insufficient to meaningfully impact longer-term changes and Accumulated Experiences. In Phase 2, the use of compensatory movement strategies and avoidance of addressing Accumulated Experiences was likened to "picking leafs of a weed" rather than "pulling up the root". Future work should look to embed training on movement strategies within a wider programme of Cognitive Behavioural Therapy, Acceptance Commitment Therapy or similar that offer psychological support necessary to address and manage Accumulated Experiences, perceptions of the Declining Self and associated Amplifiers (Fig. 2, part D and arrows E, F&G). In support of such approaches, we provide a further video of people describing Accumulated Experiences and the experience of living with anxiety and Parkinson’s (see link above). This video includes a warning that content could be distressing for some viewers.

4.11 Limitations

It is useful to evaluate the contribution and limitations of each study Phase described here. Conventional semi-structured interviews and reflexive thematic analysis successfully identified several themes that were ultimately upheld through the extensive processes carried out in Phase 2. While substantial additional and critical context was also provided through Phase 2, we must acknowledge that interpretations were based on exchanges that, for practical reasons, were not formally documented. Nevertheless, this process provided the basis for the detailed discussion above and enabled the translation of a Predictive Processing framework to the experience of FOG.

In the current analysis, we did not formally consider the influence of motor and non-motor symptoms beyond FOG. We speculate that the interpretations offered here will readily translate to the experience other symptoms of Parkinson’s(84, 85). As such, those experiences of disrupted rhythm and Accumulated Experiences, while discussed in Phases 1 and 2 with specific reference to FOG, are highly likely to also interact with other symptoms. The evaluation of such interactions was beyond the scope of the current work. However, future work should explore these inevitably complex relationships in more detail. One aim of this work could be to identify combinations of trait psychological factors and symptoms that might predispose individuals to the most disabling changes, thereby highlighting targets for tailored management.

There is a clear need to formally evaluate the interpretations and assertions made here through more conventional research methods. We must develop new and scrutinise existing patient reported outcomes that target the specific constructs described above and permit large-scale evaluation. For example, the distinction between body vigilance and associated arousal, goal-directed focus (adaptive CMP) and worrisome thoughts that emerged from Phase 2 led to a recent adaptation and formal validation of the Gait-Specific Attentional Profile (G-SAP(125)) in people with Parkinson’s(23); a questionnaire that broadly represents each of these constructs as individual sub-scales.

4.12 Conclusions

The current study aimed to evaluate the lived experience of FOG and co-construct a conceptual model and associated descriptions that resonated with people living with Parkinson’s and FOG. Our results highlight the importance of one’s sense of Rhythm and how repeated experiences of FOG and associated expectations and emotional reactions represent imbalance between top-down predictions and bottom-up sensory input. We argue that the above can be reconciled using interpretations based on a Predictive Processing framework and use this approach to scrutinise existing approaches for managing FOG.

Abbreviations

CMP
Conscious Movement Processing
FOG
Freezing of gait
PAG
Project Advisory Group
PPIE
Patient and Public Involvement and Engagement

Declarations

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Author Contributions

The study was conceived by members of the Project Advisory Group, WY, AM, EK, TE & MN. Data collection was done by WY and AM. MN carried out data analysis and drafted all results for Phase 1. WY, EK, TE, AM and MN contributed interpretations of Phase 1 results and initial evaluation of the conceptual model. WY carried out all activities in Phase 2 with the Project Advisory Group. WY produced an initial draft of the manuscript with support from MN, TE and EK. All authors contributed to editing the manuscript.

Data availability

A full range of quotes used as part of the analysis of Phase 1 data are available on request.

Conflict of Interest

None of the authors have any conflict of interest to declare

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Tables

Table 1 to 3 are available in the Supplementary Files section.

Figures

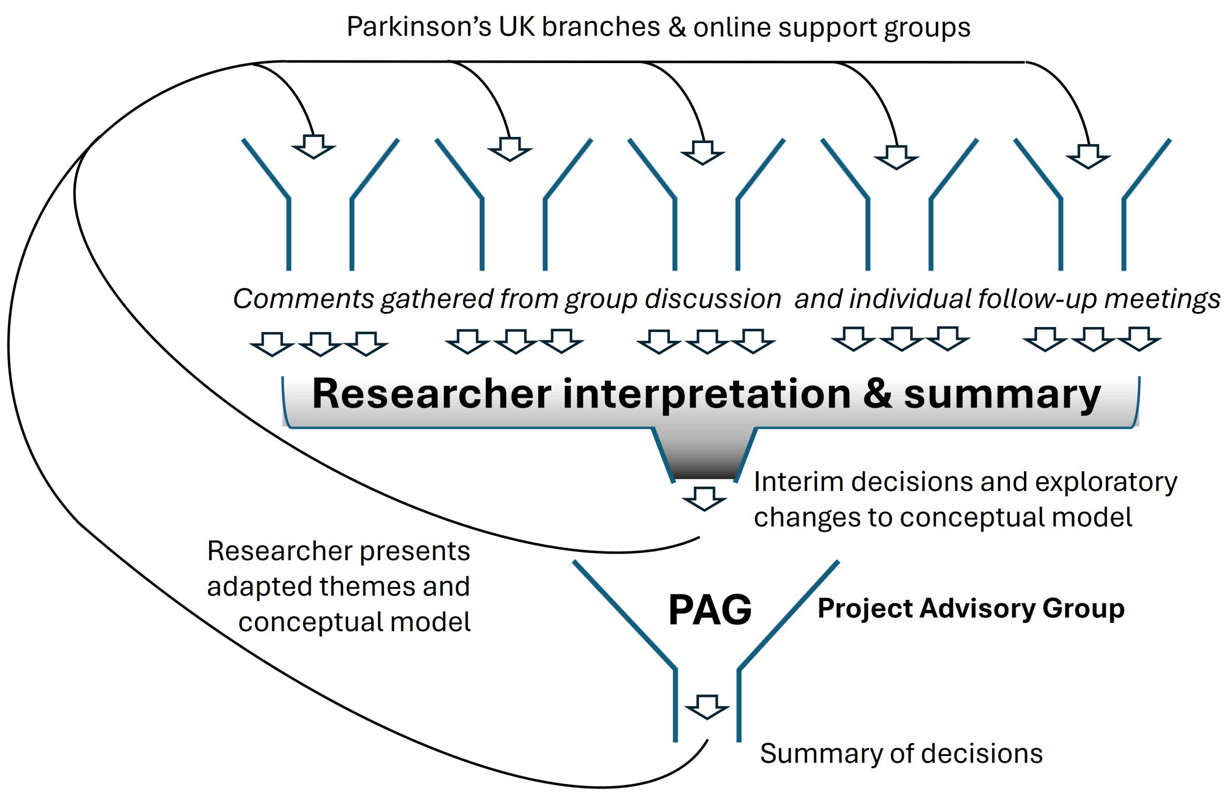

Figure 1

Schematic showing the structure of Patient and Public Involvement and Engagement in Phase 2. This process was co-constructed with the PAG who then provided insights on each aspect of the model and new interpretations as they emerged throughout Phase 2.

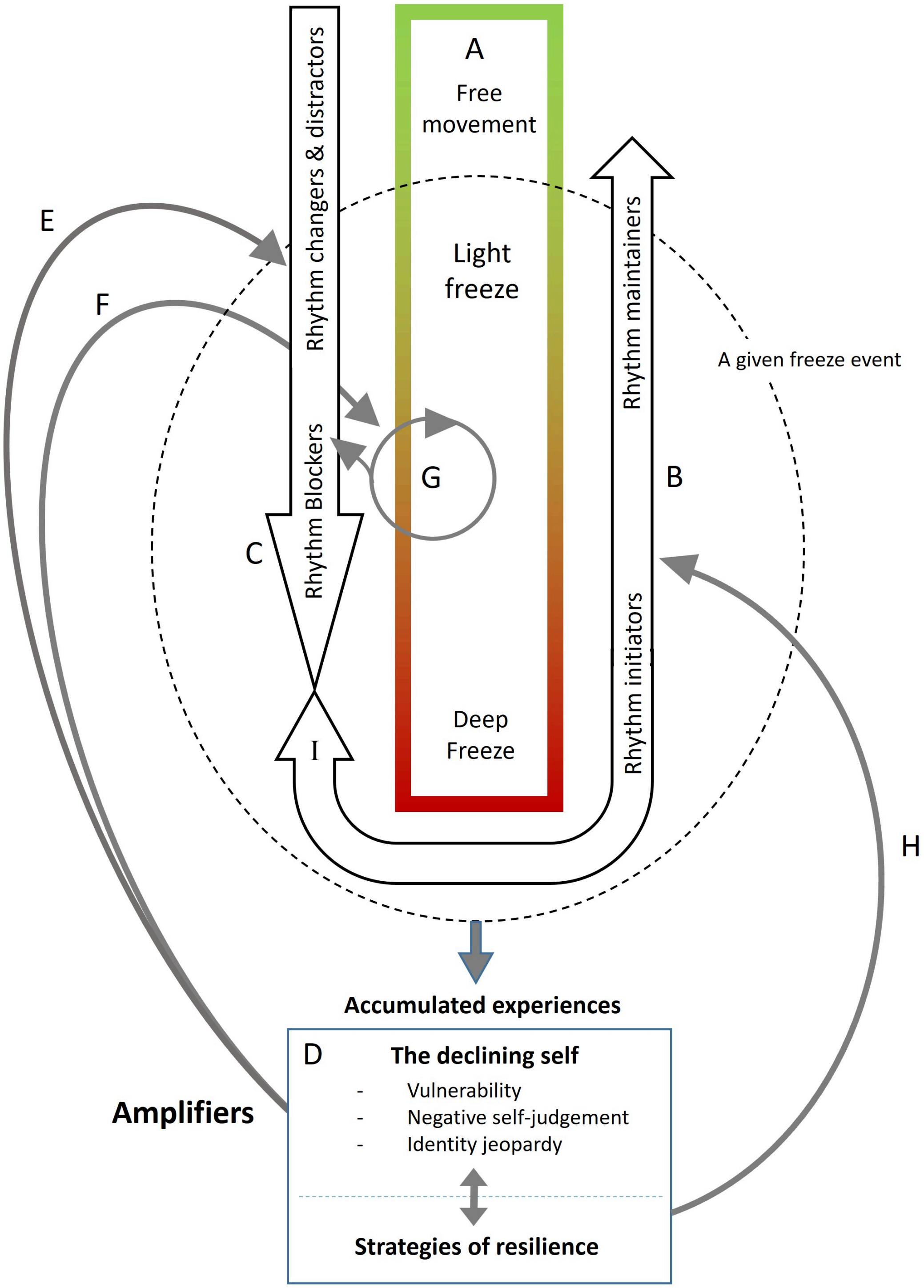

Figure 2

Conceptual model illustrating perceived experiences relating to freezing of gait

A: FOG is experienced on a continuum

B: Rhythm maintainers and initiators facilitate the transition towards free movement, typically involving conscious involvement and focussing on the intended movement outcome.

C: Rhythm Changers, Distractors and Blockers serve to trigger or deepen FOG and represent a combination of factors relating to requirements for adaptability, distraction, anxiety and barriers to focussing on the intended movement.

D: Repeated experiences of freezing can lead to a sense of vulnerability and perceived loss of control, but people often engage in active strategies of resilience to resist and compensate for these changes

E: Prior experiences of FOG and associated Accumulated Experiences amplify anticipation for Rhythm Changers, Distractors and Blockers and associated consequences of resultant FOG and potential difficulties with gait initiation

F: Prior experiences fuel negative interpretations of sensory information during FOG events

G: Disproportionate perceptions of movement errors and the inability to resolve them contribute to uncertainty about one's ability to move, contributing to emotional and cognitive processes that further exacerbate Rhythm Changers, Distractors and Blockers.

H: Strategies of Resilience represent conscious attempts to plan and engage with tactics that enhance one's sense of control.

I: Focussing on the intended movement (and potentially experiencing associated improvements in movement) detract from Rhythm Disruptors

Supplementary Files

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

- SupplementaryMaterials.docx
- Table1.docx
- Table2.docx
- Table3.docx