

People with PD talk about walking

## **Everyday walking with Parkinson's disease: understanding personal challenges and strategies**

D. Jones<sup>1</sup>

L. Rochester<sup>1</sup>

A. Birleson<sup>1</sup>

V Hetherington<sup>1</sup>

A. Nieuwboer<sup>2</sup>

A-M. Willems<sup>2</sup>

E. van Wegen<sup>3</sup>

G. Kwakkel<sup>3</sup>

<sup>1</sup> Northumbria University, Newcastle, United Kingdom

<sup>2</sup> Katholieke Universiteit Leuven, Belgium

<sup>3</sup> Vrije Universiteit Medisch Centrum Amsterdam, The Netherlands.

Address for correspondence and reprints:

Dr Diana Jones PhD BA GradDipPhys MCSP  
Principal Lecturer  
School of Health, Community and Education Studies  
Northumbria University  
Coach Lane Campus  
Coach Lane, Newcastle upon Tyne, NE7 7XA, UK.  
Email: [anna.jones@northumbria.ac.uk](mailto:anna.jones@northumbria.ac.uk)  
Tel: 0044 191 215 6722  
Fax: 0044191 215 6683

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## **Abstract**

*Purpose:* This qualitative study was designed to explore the personal experience of everyday walking with Parkinson's disease (PD), the challenges and the strategies employed to compensate for difficulties, to help contextualise the scientific knowledge base.

*Methods:* Semi-structured interviews were undertaken with a sample of 20 people with idiopathic PD (12 male, 8 female; mean age 65 years (range 50-80); mean disease duration 10 years (range 2.5-26). Verbatim interview transcripts were analyzed thematically using NUD\*IST N6 qualitative data analysis software.

*Results:* Walking was invariably performed as an integral part of a purposeful activity within a specific context, termed walking 'plus', with challenges encountered by people with PD in three main areas: undertaking tasks; negotiating environments; and making transitions to walking. The two key strategies to compensate for difficulties experienced were monitoring through the use of concentration, and correcting through generating rhythm and size of steps. Carers supported monitoring and correcting.

*Conclusion:* People with PD need to constantly assess and drive their walking performance. Attentional resources, which can themselves be compromised in PD, were used to accomplish what is normally a largely automatic activity. Personal accounts support scientific hypotheses. Rehabilitation interventions and measurements in PD need to reflect both the physical and psychosocial context of everyday walking.

**Keywords:** Parkinson's disease, walking, tasks, environment, strategies, qualitative

## **Introduction**

For most people the ability to walk safely and independently without having to think about it underpins the ability to perform with ease the everyday activities that make up our personal, domestic and social lives. Walking is typically impaired in Parkinson's disease (PD) with an associated loss of independence [1]. These walking difficulties can be examined in the context of the International Classification of Functioning, Disability and Health (ICF) framework [2-4].

Impairments to body structure (anatomy) and function (physiology) as a result of neurodegeneration in the basal ganglia include effects on motor control, particularly the timing and size of well learned repetitive, internally generated (automatic) sequences of movements, like walking [4]. Characteristic gait impairments in PD include decreased speed, reduced step length, increased step frequency and decreased arm swing [1,5]. Other primary and secondary musculo-skeletal [6], cardiopulmonary [7], cognitive and psychological impairments [8-12] also affect walking ability in PD.

These impairments impact on walking activity in the context of the many different tasks and settings encountered in everyday life [3]. PD gait disorders vary with the nature and complexity of concurrent tasks [13-15], and with the complexity of environments [4]. These difficulties relate to loss of automaticity and the need for increased attentional control [16], which co-exist with impairments which are likely to reduce attentional capacity, such as executive dysfunction [12], fatigue [17] and depression [10,18]. Impaired balance in PD [19] is likely to further increase demands on attentional capacity [16].

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In addition people with PD become more reliant on external information in the environment as the disease progresses [20]. The use of external auditory, visual and somatosensory cues [5,21-25] and attentional cues [5], can improve gait in PD by directing attention to the walking task. However the performance of a secondary cognitive task, a feature of the planning required to move about in complex real world environments, can cancel out the improvement [5]. Whilst the majority of dual-task studies have been undertaken in the laboratory [5,13,14,26,27], increasingly clinic based tests are being designed to more closely resemble everyday situations [28,29], with home based functional tests being developed to enhance ecological validity [15,30,31].

From a biomechanical perspective walking can be defined as a “method of locomotion involving the use of the two legs, alternately, to provide both support and propulsion” [32]. However walking largely takes places within a social and attitudinal environment, captured in the environmental domain of the ICF [2]. Gait abnormalities are strongly predictive of PDQ-39 quality of life scores [33], with patients with fatigue reporting more distress on the mobility dimension of the PDQ-39 [34]. Unpredictable fluctuations in mobility are associated with frustration about not being able to fulfil valued roles and social withdrawal as a result of sensitivity about moving awkwardly [35]. The visibility of walking problems in PD is perceived as breaking societal rules in relation to public norms of behaviour and contributes to the conceptualization of PD as a problem of shame, promoting withdrawal from the public domain [36], which is likely to affect carers too.

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This qualitative study, which was designed to inform a community based trial of a cueing training programme (RESCUE) [37], aimed to enhance our understanding of the experience of walking from the perspective of patients with Parkinson's disease to help contextualize the predominantly laboratory based evidence base. The study sought firstly to explore the challenges that everyday life posed to walking from individuals' perspectives, and secondly to identify the strategies used to compensate for difficulties with walking.

## **Methods**

This qualitative study was part of mixed method pilot work to investigate gait and the use of rhythmical cues in people with PD using a home-based functional task [15,30] and interviews. Twenty people with idiopathic PD (12 male, 8 female) were recruited from regional PD clinics by researchers undertaking the quantitative arm of the study. Recruitment criteria were: a diagnosis of idiopathic PD; disease severity of stages 1 to 4 Hoehn & Yahr (H&Y) scale [38]; Mini Mental State Examination (MMSE) [39] score of 24 or higher indicating absence of dementia; no severe dyskinesias (score >2 Modified Dyskinesia Scale [40]); no long off-periods making stable testing difficult (score  $\geq 1$ , Unified Parkinson's Disease Rating Scale (UPDRS) [41] item 39); adequate vision and hearing; no severe co-morbidity - other neurological problems, acute medical problems and joint problems affecting mobility; age 80 years or less. Participants were assessed on the UPDRS motor examination section [41] to measure overall motor function; the Freezing of Gait Questionnaire (FOGQ) [42] to evaluate freezing as a specific gait impairment in PD. The Hayling and Brixton tests, shown to be valid and reliable indicators of dysexecutive function [43]; the Hospital Anxiety

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and Depression test (HADS) [44]; and the Multidimensional Fatigue Inventory (MFI) [45], a valid and reliable 20 item questionnaire which evaluates fatigue in five domains (only the physical and mental fatigue domains were used in the present study) were administered as executive dysfunction [12], fatigue [17] and depression [10,18] can influence attention, a focus of interest for the study. Ethical consent was granted by the Newcastle and North Tyneside Health Authority Joint Ethics Committee, UK. All participants gave informed written consent to both quantitative testing and qualitative interviews.

A semi-structured interview schedule was employed to elicit detailed descriptions of changes to walking experienced as a result of PD. Individuals were asked about the first effects that the condition had on their walking. Differences between walking inside and outside; alone or accompanied; at different times of day; in quiet or busy places; and when doing more than one thing at a time were explored, along with experiences of transfers, freezing and falls. Approaches to managing difficulties were also explored. A member of the research team (AB), skilled in qualitative research and not involved in the quantitative testing, undertook all of the interviews, which took place in participants' homes, lasted approximately 45 minutes to 1 hour and were audio-recorded. Carers could be present and contribute, but it was stressed that initially we were interested in the views of the person with PD. Field notes recorded those present at interview, any adverse interviewing conditions, researcher reflections and emergent themes. Verbatim transcripts of the interviews, noting pauses and emphases, were made and imported into NUD\*IST N6 [46] qualitative data analysis software for management. Transcripts were read on screen and data were coded to a developing node tree of categories, building on field note themes and agreed within

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the team. Key themes were derived by progressively linking the categories and subsequently testing them against other aspects of the study data set. Individual's interviews were coded in relation to their demographic profile and scores on key scales (Table 1) to allow cross-tabulation of quantitative data with qualitative text, a technique used in previously published studies [47,48]. Quantitative and qualitative results were fed back for confirmation and clarification at a meeting for participants with the UK research team. Participant codes (which link to details in Table 1) are used to identify quotations in the Results' section.

Insert Table 1 near here

## **Results**

The overall characteristics of the participant group will be presented, followed by the key themes to emerge from the data.

### **Characteristics of the interviewees (Table 1)**

The mean age of the 20 interviewees, 12 of whom were men, was 65, and they had been living with PD for approximately 10 years. The group's staging on the H&Y score indicated mild to moderate bilateral disease, with individuals physically independent but with possible postural instability developing. Freezing of gait would be likely, with some start and turning hesitation. All scored above the cut off for normal on the MMSE, indicating lack of dementia. Depression scores were at the top end of normal. The group was significantly more fatigued than a normal control group

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[49]. The moderate average mean score on the Hayling and low average score on the Brixton test highlighted the group's potential problems with executive function.

The majority of interviewees were married and living with a spouse; the four that were living alone were women. Spouses, 8 female and 2 male, were present for half of the interviews. Respectful of their partners' opportunity to speak, their presence was helpful when speech was difficult to understand or fatiguing. They sometimes challenged accounts, and provided contextual insights, concrete examples of scenarios and hypotheses.

### **Key themes**

The central theme to emerge from data analysis was that walking was invariably performed, and talked about, as an integral part of a purposeful activity within a specific context – “I think this is one of the worst aspects [of PD] ... not being able to walk and do the things that you want to do physically” (05). This theme, named **walking 'plus'**, was made up of three components related to additional challenges to walking encountered by people with PD:

- **walking 'whilst'**- walking and doing something else
- **walking 'in'** – walking in different environments
- **walking 'after'** – walking following another activity

The two key strategies for addressing the challenges were:

- **monitoring** walking using concentration
- **correcting** walking through generating rhythm and size of steps



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Carers supported both monitoring and correcting.

### *Walking 'plus' challenges*

#### Walking 'whilst' – walking and doing something else

The majority of interviewees reported having no difficulty walking and talking at the same time. Some changes were noted however: even at H&Y Stage 1.5, a leg starting to drag when having to think about talking too (08); and at Stage 3, talking getting faster when walking at the same time (12), and the ability to walk and talk outside but not inside (17). Spouses provided additional insights. “He has to put the cup down before he can answer ... He can't answer and walk and carry a cup ... he must be concentrating on walking without knowing it” (03). Some spouses of individuals in the later stages gently reminded their partners that they had stopped trying to do two things at the same time, or conjectured a link to falls (02). A respondent at H&Y Stage 3 gave an insight into how this might happen. “Sometimes if I concentrate too much on not spilling the tea I sort of forget about going up the stairs ... It's as if my nervous system is overloaded. Can't unscramble the two messages” (17). Freezing, increasingly encountered in the later stages (Table 1), was associated with trying “... to do 2 or 3 things together” (05).

#### Walking 'in' – walking in different environments

Walking both indoors and out of doors had their challenges. Of those who had a preference, it was mainly to walk out of doors. Space outdoors meant people could

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take long steps and stride out, which was less tiring than “the small walking” inside (07). Doorways and furniture, the need to constantly change direction and to change positions caused the main challenges indoors, especially noted by people with higher UPDRS and FOGQ scores. “Inside it’s too crooked. You can’t get a straight run on it” (20). Doorways were a major trigger for freezing. “... it just seems when I get close to the door that my brain switches everything off” (17).

Busy environments outdoors posed unpredictable challenges, and were disliked by all but one interviewee, a widow who liked to get out every day. Having to stop, start and change direction; being jostled; coping with distractions; feeling pressured and self-conscious; and having to concentrate on yourself and others, were all tiring and often frightening. Negative comments about coping with crowded places were most likely to be expressed by people reporting higher levels of physical fatigue, with lower scores on Hayling and Brixton tests, who experienced freezing. There was frustration that people did not understand the problems being experienced because “...they think you’re normal. They don’t know our brain’s half gone, do they?” (12).

Veering off whilst walking (16) and dyskinesia (17) could be misconstrued as drunkenness. Busy environments were worse if they coincided with ‘off’ time (01). Variability in walking ability from day to day and within a day, not always related to medication, made planning outings problematic. “... you cannot say to somebody, ‘I’ll go out with you’ ...because if the brain says you’re not doing it, you’re not doing it” (12).

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Trips and stumbles were common experiences. In the early stages there was a tendency to relate them to environmental hazards or a previous injury. Later, problems such as inability to control walking speed, freezing, loss of balance and being tired were highlighted. Fear of falling was universally reported, sometimes greater outside, exacerbated by loss of confidence, having to stop suddenly or to hurry; sometimes around the home in relation to turning in confined spaces, steps and stairs; and was of grave concern for carers. Over half the interviewees had fallen. The language of fear was strongest at H&Y Stage 3 when postural instability was likely, with several individuals using the word “terrified”.

### Walking ‘after’ – walking following another activity

From the earliest H&Y stage getting out of a low chair after a period of sitting could be effortful. Increasingly manoeuvring out of dining chairs at a table; rolling to the edge of the bed in order to get the legs over the edge; exiting the bath; turning after standing were reported as challenging, especially in the ‘off’ state. Initial walking after all these activities was likely to be characterised by shuffling steps, potentially stooped posture, often accompanied by unsteadiness. Stairs caused considerable anxiety, especially coming down. Depth perception was compromised (17), with difficulty determining “whether you are on a mythical step or the real one” (01). Catching a toe on a stair could trigger painful dystonia (12).

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*Walking 'plus' strategies*

### Monitoring and correcting

Interviewees needed to monitor walking quality and consciously correct deficits from the earliest H&Y stage. They recognised when the rhythm and size of steps was going wrong, “My top half of my body seems to be moving quicker than the bottom half. Sometimes I have to stop to sort of get my pace put right” (17); festinating steps on approaching a doorway could initiate a conscious strategy, “... I thought ‘smaller steps’. You have got to say to yourself, ‘Stop, stop dead, take a long stride out’” (11). Posture was invariably poor on initial standing after any time spent sitting. “I have to think about it. Straightening up” (16). Waiting a few moments before setting off to walk was important, “It’s as if I’m signalling to my feet. Asking for a response before I move. See if the nerves are connected first” (20). Even when walking well monitoring was required. “At the back of my mind it’s always there. When I’m walking and I’m going well, I’m 90% thinking about other things but there’s always that bit in my brain waiting for a signal” (20).

Concentration was required to maintain the basic rhythm of walking, “I am just concentrating on keeping going, keeping an even pace rather than slow down or try to quicken too much” (07); to correct the biomechanics of walking, “I had to think the whole time of putting my heels down first [but now] it is automatic” (06); to effect turns, “... if I’m just about to turn your brain says, ‘You’re moving, think about it’” (20); to maintain safety, “... but I’m always watching, thinking, terrified of falling over but there’s that feeling always that you must watch where you are going” (05).

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There was a clear link between walking quality, levels of conscious awareness required to monitor walking quality and levels of medication. “When [the drugs] start going out, I’ve got to concentrate. When they come back in again, I sort of relax a little bit” (17). Fatigue also impacted on walking. Descriptors used to convey the experience of walking when tired included: “struggle” (16); “sloppier” (04); “switched off” (07); “jerky” (18); “slurred” (02).

### Generating rhythm and size of steps

As H&Y stage increased marching or sideways swaying on the spot, swinging arms, counting or singing in your head were used to generate rhythm to initiate and maintain walking, prepare to turn, increase size of steps, get through doorways and overcome freezing. Over half the interviewees at all stages reported trying to take regular walks where they strode out.

Imagined or actual visual input was used to start and maintain stepping and overcoming freezing. “I had to rehearse mentally if I was going to take a step and then take the step” (20). An actual visual prompt such as a handkerchief to step over was helpful for some (03). Some individuals wanted to look down, using pavement cracks to help step length (17); others however felt that if they looked down they were “... concentrating on looking rather than walking” (07). Spouses often encouraged their partners to “get your head up” (20). A strip across a door threshold could prompt a large step to break the shuffling steps experienced prior to doorways. Without the strip “I just shuffle and bang and I forget the door” (12). Getting visual feedback could help counteract a stooped posture of which people seemed unaware (05).

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### Carer support

Carers were important partners in mobility, supporting both monitoring and correcting strategies. They provided much needed confidence, both in the house and outside, but often at an emotional and physical cost to themselves. In the home their presence lessened the fear of falling and freezing, especially at night. Outside their monitoring led to prompts to correct posture and stepping; they provided encouragement and promoted relaxation in difficult situations; they used the rhythm of their own walking to pace their partner appropriately; and provided physical support by linking arms, or a slipstream to walk in, in busy places. Their familiarity with problems led to optimal strategies even if they were difficult socially, like shouting to get someone through a door (12).

### **Discussion**

This qualitative study has provided a description of the challenges encountered with complex walking and key strategies used to address them from the perspective of people with PD. Walking was intricately woven into aspects of self-esteem such as independence; of social acceptability which require our bodies to behave appropriately; and of social relationships, with the people around us as partners in mobility, in a similar way to the communication and eating partners identified by Miller et al [47,48]. This mirrors the experience of people with stroke [50]. The study has also provided personal knowledge which can be mapped on to the scientific knowledge base.

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Complex patterns of impairments (Table 1) impacted on walking activity in the context of everyday [2]. Moderate/low average scores on the tests of cognitive function, high normal depression scores, and significant levels of fatigue were likely to be responsible for some of the interference in gait reported, caused by competition for limited attentional resources [8-12]. Executive dysfunction (Brixton test [43]) and physical fatigue [45] predicted up to 34% of the variance in walking speed during the dual-task conditions tested in the quantitative arm of this study [15]. The Brixton [43] is in part a test of the ability to set shift, involving dividing attention, and there is evidence of increased difficulties with set shifting in people with PD [51] likely to impact on multi-tasking.

Interviewees were able to discriminate gait changes in relation to level of complexity of additional tasks and environments. Minimal reported difficulty with walking and talking is commensurate with the findings that the Stops Walking Whilst Talking test is usually normal in people with PD with normal MMSE scores (Table 1) [52]. However individuals from as early as H&Y stage 1.5 reported subtle changes to talking whilst walking. Accounts also highlighted a link between dual task interference and potential falls, associated with an inability to “unscramble” messages in the brain. This difficulty prioritising is perhaps indicative of the tendency in PD to regard all aspects of a complex task as equally important [53]. Participants felt bombarded by multiple inputs, including sound and vision. Walking, long thought of as an automatic task, may itself be a dual or multi-task in which different sensory inputs and motor objectives are integrated and adjusted in real time [54]. Recent work has highlighted an association between visual and visuospatial problems and freezing [55]. There is a recognised need to address task and environmental complexity in

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relation to level of cognitive challenge in clinical tests [13-15,29], which will help provide guidance on risk factors and rehabilitation options. Individuals pointed to learning from reinforcing their own strategies in the earlier H&Y stages e.g. regaining heel strike (06). Always bearing safety in mind, in the therapeutic context simple component parts of a task can be practised and performed in an open and uncluttered environment, with treatment progressed by increasing task and environmental complexity [56]. External cueing devices can help to reduce attentional cost [30,31].

Reported difficulties with transitions to walking underlined the importance of seeing walking as part of a continuum of physical and cognitive activity. The basal ganglia play a role in stringing long sequences of movement together by preparatory activity contributing to the cortical motor set for a movement sequence, and generating internal cues via phasic neural activity to run the sequence on time and to size [57]. The strong themes of monitoring and correction fit with the need to counteract the deficits caused by loss of basal ganglia input to the preparation and running of complex sequences of well learned, automatic movement. Individuals were using their compromised attentional capacity to think about producing and adjusting activities in relation to different tasks, environments and transitions. This supports the basal ganglia's role in selectively directing attention to activities requiring subconscious motor task decision-making and processing [58].

Correction was accomplished largely by building up the rhythm and size of movements, by using both internal (attentional) and external cues, including arousal and motivation supplied by carers. Behavioural studies using functional imaging have shown that pathways which preferentially facilitate externally rather than internally



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cued movement, in the lateral parietal and premotor areas, are overactivated in people with PD in the face of impaired links from the basal ganglia to the SMA and dorsolateral prefrontal cortex [59]. Systematic reviews support the use of cueing as a compensatory rehabilitation strategy [25,60]. External auditory cues have been shown to be useful in reducing interference and maintaining gait performance during more complicated functional activities tested in the home [30,31]. It is helpful for carers to be encouraged in the role of external references for walking, and to understand why their partners with PD need their guidance for the loss of automaticity [56].

The variability of walking performance was distressing for individuals, making them uncertain about their ability to participate in activities. In PD dual tasking increases gait arrhythmicity and unsteadiness (demonstrated by stride time and swing time variability), possibly increasing the risk of falls [61,62]. The common experience of trips and stumbles accords with the findings of Stack and Ashburn [63] that near-misses were a familiar occurrence. Fluctuations in walking performance as a result of medication also precipitate falls as more fallers than non-fallers report functional improvement after levodopa, dyskinesia and on-off phenomenon [64]. Whilst PD medication improves bradykinetic aspects of gait relating to force production [65], there is marked deterioration in performance from peak to end of dose [66]. This small scale qualitative study was limited by its sample being based on the needs of the quantitative arm. It excluded people with complicating mobility (including marked motor fluctuations and dyskinesias) and cognitive problems, however this would arguably have added depth rather than new dimensions to the descriptions of challenges and strategies.

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The descriptions of walking recounted by people with PD have exposed their need to constantly assess and drive their walking performance, with attentional resources, which can themselves be compromised in PD, being used to accomplish what is normally a largely automatic activity. Their accounts support the hypotheses of the scientific literature base. However, there is a need for people with PD, their carers, researchers and therapists to work together to design and test rehabilitation measurements and interventions which reflect both the physical and psychosocial context of everyday walking.

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**Table 1** Key demographic and clinical characteristics of interviewees (individual and group), including presence of carer at interview

(See separate file)

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