Parkinsonism and Related Disorders 21 (2015) 55–60

Contents lists available at ScienceDirect

Parkinsonism and Related Disorders

journal homepage: www.elsevier.com/locate/parkreldis

Fall frequency, predicting falls and participating in falls research: Similarities among people with Parkinson's disease with and without cognitive impairment

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ARTICLE INFO

Article history:
Received 7 July 2014
Received in revised form
31 October 2014
Accepted 3 November 2014

Keywords:
Falls
Research participation
Parkinson's
Cognitive impairment

ABSTRACT

Objective: We compared fall frequency and prediction among People with Parkinson's Disease (PwP) with and without cognitive impairment (CI); researchers sometimes overlook the former, concerned about consent, recall and adherence and differences in fall frequency and predictability.
Methods: We recruited 101 PwP from one clinic, used the Montreal Cognitive Assessment to measure CI, noted repeated falls recalled retrospectively over 12 months and evaluated 'repeated falls' and 'difficulty turning' as predictors of falls over three months.
Results: Participant median age was 76 years, and time since diagnosis 6 years. Of 40 participants without CI, 40% recalled falls and 55% fell during follow-up (1.9 (±3.8) falls/person), the sensitivity of fall history being 57% and of turning 36%. Of 36 participants with mild CI, 42% recalled falls and 42% fell during follow-up (1.2 (±1.8) falls/person), the sensitivity of fall history being 67% and of turning 69%. Of 25 participants with moderate CI, 60% recalled falls and 58% fell during follow-up (1.2 (±1.8) falls/person), the sensitivity of fall history being 71% and of turning 69%.
Conclusions: Researchers need not exclude people with CI assuming falls are more frequent and less predictable than among those without. Fall rates (falls/person during follow-up) were similar among people with and without CI. Falls and difficulty turning were more sensitive predictors of falling in those with CI than those without: a simple mobility test may suggest an individual's risk of falling if a history is unavailable. Most PwP with moderate CI fall repeatedly: carer involvement facilitates their inclusion in research.

1. Background

Parkinson's Disease (PD) is the second most common neurodegenerative disorder in the UK, with an estimated prevalence in the population of between 1 and 2% above the age of 60 [1]. Falls (with a range of serious and costly, physical and psychological consequences) are common among people with PD (PwP), with a frequency of approximately 50% over 12 months, and a history of 'repeated' falls over 12 months strongly predicting further falls [2,3]. The non-motor features of PD (including neuropsychiatric manifestations such as cognitive impairment (CI) and dementia) are increasingly well recognized [4] and potentially more disabling than the motor features. Mild CI appears common in early PD [5], with the risk of dementia significantly higher among people with PD than without [6], probably resulting from Lewy body pathology involving the limbic structures and neocortex [7].

Dementia is a risk factor for falls among older people [8,9] and some have reported that its presence in PD significantly increases the risk of falling and fracture [3,10]. Central cholinergic deficit (associated with reduced attention and concentration) is evident among PwP, particularly those with Parkinson's dementia, and in dementia with Lewy bodies [11,12]. There is evidence of a reduced falls rate among those prescribed anti-cholinesterase medication,

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http://dx.doi.org/10.1016/j.parkreldis.2014.11.001
1353-8020/

albeit from one small ($n = 23$) study [13]. We know less about falls among PwP with mild (but measurable) CI, though we could anticipate a positive correlation between falls rate and cognitive dysfunction, if dysfunction is deemed to include not just measurable impairments but to encompass a range of subjective difficulties. Indeed, a 12 month longitudinal study ($n = 52$) suggested that mild CI significantly increases the risk of falls among PwP [14] and others have reported greater postural instability and falls among PwP who score poorly on tests of attention and frontal lobe function [11,15,16].

Despite the likelihood that PwP and CI fall at least as frequently as their cognitively intact peers, researchers sometimes exclude them from falls research, limiting the applicability of findings, concerned about them skewing falls rates, not being able to give informed consent (a wider concern than in falls research, [17]) or a reliable fall history or to adhere to protocols. In one such study ($n = 57$ cognitively intact PwP [2]), 64% reported falling in the previous year and 39% fell during three months of follow-up; a history of repeated falls predicted future falls with sensitivity 86% and specificity 86%. In studies that included PwP with CI, between 36% and 59% fell within three months: treating 473 PwP with and without CI as a single group in a pooled analysis of six studies, 46% fell [19]. Again, the best predictor of falling was a history of falls, though sensitivity (68%) and specificity (81%) were (lower than in the study that excluded people with CI [2]).

We designed the current study to address some of the concerns (about fall frequency, reliability and adherence) that have led to the exclusion of PwP and CI from previous falls research. We set out to compare the frequency of falling among PwP with and without CI drawn from the same clinic and to compare the accuracy of two fall predictors among people with and without CI. We chose to examine an established predictor (repeated prior falls) and a mobility test – because the latter was not reliant on people being able to give a history of events over the previous year. To be clinically applicable, we chose to use a simple single test of people's ability to turn round as a predictor. If we could demonstrate that PwP with CI fall with similar and predictable frequency to their cognitively intact peers and that, given appropriate support, they can participate satisfactorily in research, we believed future researchers would have more confidence about being more inclusive.

1.1. Aims

We aimed to recruit people with and without CI from a single movement disorders clinic to:

a) Compare retrospective and prospective fall frequency
b) Evaluate the potential of fall history and a simple mobility test in predicting future falls
c) Identify ways of enabling PwP and CI to participate in research

2. Methods

2.1. Study design

In this observational study, initial review of the medical notes identified PwP with normal cognition and mild and moderate CI. We further assessed a sample of participants from each group at home and monitored falls over three months, a follow-up period we and others have used in previous studies [2,18].

2.2. Participants and setting

With approval from the Southampton and SW HANTS Research Ethics Committee A (09/HO201/19), we wrote to everyone attending one movement disorders clinic in southern England (or, if they lacked capacity, the person designated to give an opinion on their behalf), seeking written consent to review their medical notes and consider them for face-to-face assessment. Potential participants had a working diagnosis of probable idiopathic PD (according to UK Brain Bank diagnosis criteria [19]) for at least six months.

2.3. Data collection

We reviewed the notes of everyone who permitted us to do so, noting:

- Age; gender
- PD duration (years since diagnosis); severity (Hoehn and Yahr stage [20]; UPDRS [21])
- Domestic living arrangements
- Cognitive function (recent Mini-Mental State Examination (MMSE [22]), the tool of choice in clinic)
- Number of falls in the previous 12 months
- Indicators of cognitive dysfunction (including visual hallucinations; REM Sleep Behaviour Disorder; Excessive Daytime Sleepiness (EDS); self- or carer-reported memory problems; mood disorders such as anxiety or depression; psychiatric diagnoses)
- Indicators of fall risk (including Hoehn & Yahr III-plus; falls since diagnosis; diagnoses likely to affect balance (such as stroke); self- or carer-reported balance problems; referral for balance assessment; postural hypotension)

We used this information to select a cross-section of 100 participants for face-to-face assessment and prospective monitoring, targeting those living with a partner so that we could invite their involvement. We cross-tabulated recent fall history with MMSE and populated the cells, highlighting those not living alone. We initially mailed repeat-fallers with abnormal MMSE, then worked across the sub-groups (first approaching those with partners) until we recruited the required participants.

We visited the sample at home and:

- Secured written informed consent from participant and/or carer
- Verified and updated information previously abstracted from their clinical records
- Assessed cognition using the Montreal Cognitive Assessment (MoCA [23]), shown to allow better examination of the frontal cognitive domains than MMSE [24]
- Took a detailed history of falls over the previous 12 months [25]
- Video-recorded the Standing-Start 180° Turn Test (SS-180 [26]); we instructed participants to stand facing away from the camera and, when ready, walk towards it. After initially turning in an unspecified direction, the participants repeated the task turning the opposite way. We tested all participants during their 'on-phase', at their chosen appointment time.
- Left 'Falls Diaries' to complete for three months, asking participants (with carers' support, assistance or leadership, as appropriate) to note falls and describe the circumstances. To assist the participants, we included a lay definition of falling on the diary: 'You accidentally lose your balance, cannot save yourself and land on the ground or on a piece of furniture'. We telephoned throughout follow-up, at an individually agreed frequency, to support participants and we collected the diaries in person after 3 months, clarifying ambiguous entries.

2.4. Analysis

We excluded participants whose medical notes were too sparse or historic to permit data abstraction, then used summary statistics to describe the remainder. From the medical notes we classified participants as normal cognition (MMSE > 26/30), mild (MMSE 21–26/30) or moderate cognitive impairment (MMSE < 21/30).

After review at home, we used the MoCA to classify the selected participants as:

- No CI (MoCA > 25/30)
- Mild CI (MoCA 20–25/30)
- Moderate CI (MoCA < 20/30)

From their notes and retrospective recall at home, we classified participants as fallers (any falls in 12 months) and/or repeat-fallers (two or more falls). We attempted to optimize the accuracy of reported falls by interviewing the participant alongside a carer (e.g. spouse) when possible, which is why we targeted those living with a partner.

One researcher recorded the turn tests on video and another (who did not know the participants MOCA scores or fall frequencies) rated them, to preserve masking. The masked assessor rated the SS-180 for turning steps (n) and turn quality, a composite score, from 0 (worst) to 5 (best), based on independence (yes/no), feet clearing the floor (yes/no), apparent stability (yes/no), continuity (yes/no), and posture maintenance during turning (yes/no). We calculated mean turning steps and quality (left + right turn/2).

Prospectively, we classified participants as fallers if they recorded any falls during follow-up. We calculated the sensitivity (the true positive rate) and specificity (the true negative rate), and positive and negative predictive values in predicting future falls over three months of both a history of repeated falls and difficulty turning (SS-180 Step Count > 5, or Quality < 4/5).

Sensitivity (number of true positives divided by the total true positives and false negatives) relates to a test's ability to identify a condition correctly, e.g. by measuring

the proportion of fallers correctly predicted to fall. A 100% sensitive predictor would predict all fallers as being likely to fall. Specificity (number of true negatives divided by the total true negatives and false positives) relates to a test's ability to exclude a condition correctly, e.g. by measuring the proportion of non-fallers correctly predicted not to fall. A 100% specific predictor would not predict any non-fallers as being likely to fall.

3. Results

Of 489 PwP contacted, 317 (65%) gave consent for us to examine their notes: median age was 77 years (range 48–100); 188 (59%) were men; median time since diagnosis was 5 years (range 1–31); 129/304 (42%) were Hoehn and Yahr III–IV; and 175/250 (70%) resided with a partner. We excluded nine sparse sets of notes from further analysis, leaving 308. Although most notes (171, 56%) did not include a MMSE, and most (227, 74%) did not mention recent falls, most (264, 86%) contained other indications of cognitive dysfunction and/or fall risk; 143 (46%) participants had indications of both.

We noted indicators of cognitive dysfunction in 194 notes (63%) most frequently hallucinations (87, 28%), EDS (57, 19%) and/or an abnormal MMSE (48, 16%) that indicated mild CI in 38 cases and moderate in 10. We noted indicators of postural instability in 216 notes (70%), most frequently falls since diagnosis (118, 38%), postural hypotension (59, 19%) and recent falls (81, 26%), both single (55) and repeat falls (26).

The 101 PwP interviewed (one participant with moderate CI died during follow-up) ranged in age from 48 to 93 years; 53 were men; 67 resided with a partner, 12 with other people and 22 alone; participants were taking a median six prescription medications daily, seven among those with moderate CI. Median Hoehn and Yahr stage was III; diagnosis ranged from 1 to 23 years earlier; median UPDRS score was 15. MoCA indicated no CI in 40 cases, mild CI in 36 and moderate CI in 25 (Table 1). When questioned, 21 participants recalled one fall within 12 months and 46 recalled repeated falls. We also recruited 68 carers, mostly spouses.

Among 58 participants with CI, a partner/carer contributed to diary completion in 37 cases (64%). Nine (16%) lived alone or with someone not contributing to the study but the researcher was satisfied with their diary completion (having made telephone reminders during follow-up and gone through the diary with the participant at the time of collection). Care home staff documented falls in five cases (9%). The researcher felt that seven participants (12%) would have been unable to complete their diaries reliably without her assistance throughout follow-up and on collection. In one case, at least two falls had occurred but probably more. Therefore, we excluded this repeat-faller with moderate CI from parts of the analysis where an exact number of falls was required: falls per person in the moderate CI group remained unchanged, however.

CI and falling appeared more frequent and severe at interview than in participants' notes. Among 83 participants with no MMSE or a normal score in their notes, MoCA suggested 35 (42%) had mild CI, and 9 (11%) moderate CI. Of 56 participants with no recent falls in their notes, 8 (14%) recalled falling once and 18 (32%) falling repeatedly.

Recalled falling rose progressively from those with no CI (60%) to those with mild (64%), then moderate CI (80%). The median number of falls recalled per person was 1 among those with no or mild CI, and 2 in moderate CI. Outliers with high numbers of recalled falls distorted the mean numbers of falls per person (e.g. a maximum of 208 among someone with no CI). Prospectively, over three months, falling was least common in those with mild CI (42%) and higher in those with no CI (55%) and moderate CI (58%). The median number of falls recorded per person was 1 in all three groups. The pattern was similar for repeated falls over three months: lowest in mild CI (31%) and higher in no CI (33%) and moderate CI (38%).

Two participants could not attempt the SS-180 and errors (e.g. turning twice in the same direction) meant we excluded four participants' data. Median turn quality ($n = 95$) deteriorated and the median step count increased from no CI, to mild, then moderate CI. The diaries revealed that a smaller percentage of participants with CI (48%) than without CI (55%) fell during the three-month follow-up. This was the case at every Hoehn & Yahr stage (as shown in Table 2), though at stage III the difference between the percentages of those with no CI and moderate CI who fell was minimal (55% *versus* 56%).

As shown in Table 3, the best predictor of falling among those without CI, correctly classifying 70%, was a history of repeated falls (sensitivity 55%; specificity 78%). In other words, slightly more than half the PwP without CI who fell during follow-up were predicted to fall because they had fallen repeatedly before. Having fallen

Table 1
Sample characteristics, by cognitive impairment (CI) group ($n = 101$).

		Group		
		No CI	Mild CI	Moderate CI
		n = 40	*n = 36*	*n = 25*
Gender	Men (%)	25 (63)	14 (39)	14 (56)
Age (years)	Median (IQR)	75 (67–79)	74 (69–80)	79 (77–86)
Years since diagnosis	Median (IQR)	06 (3–8)	06 (3–10)	06 (3–11)
Hoehn and Yahr				
I–II	*n* (%)	16 (40)	11 (31)	04 (16)
III	*n* (%)	20 (50)	15 (42)	09 (36)
IV–V	*n* (%)	04 (10)	10 (28)	12 (48)
UPDRS (III)	Median (IQR)	13 (8–20)	15 (11–23)	20 (15–30)
Medication				
n Parkinson's drugs	Median (IQR), min–max	2 (1–2), 0–3	2 (1–2), 0–4	1 (1–1), 1–3
L-Dopa	*n* (%)	36 (90)	32 (89)	24 (96)
Dopamine agonists	*n* (%)	25 (63)	16 (44)	3 (12)
Other	*n* (%)	4 (10)	3 (8)	3 (12)
n other drugs	Median (IQR), min–max	4 (2–7), 0–12	4 (3–6), 1–13	6 (5–7), 0–11
Residential status				
With partner	*n* (%)	28 (70)	26 (72)	13 (52)
With friend/relative	*n* (%)	02 (5)	01 (3)	03 (12)
Alone	*n* (%)	08 (20)	03 (8)	04 (16)
RH/NH/carer	*n* (%)	02 (5)	06 (17)	05 (20)
Case notes				
Abnormal MMSE noted	Yes (%)	01 (3)	01 (3)	16 (64)
Repeated falls noted	Yes (%)	06 (15)	05 (14)	05 (20)
Recalled falls			*n = 35*	*n = 23*
(over 12 months)	*n*	353	179	155
Any falls	*n* (%)	24 (60)	23 (64)	20 (80)
Single fall	*n* (%)	08 (20)	08 (22)	05 (20)
Repeated falls	*n* (%)	16 (40)	15 (42)	15 (60)
Falls per person	Median (IQR), min–max	1 (0–3), 0–208	1 (0–2), 0–100	2 (1–12), 0–45
	Mean (SD)	8.9 (33.6)*	5.1 (17.1)	6.7 (10.7)
SS-180		*n = 39*	*n = 32*	*n = 24*
Steps (*n*)	Median (IQR)	4.5 (3.5–7.5)	5.5 (3.5–7.5)	9.0 (5–14.5)
Quality (score, 0–5)	Median (IQR)	4.5 (3.5–5)	4.0 (3–5)	3.5 (2–4)
Falls in follow-up			*n = 35*	*n = 23*
(over 3 months)	*n*	74	41	28
Any falls	*n* (%)	23 (58)	14 (40)	13 (57)
Single fall	*n* (%)	13 (33)	03 (09)	05 (22)
Repeated falls	*n* (%)	10 (25)	11 (31)	08 (35)
Falls per person	Median (IQR), min–max	1 (0–2), 0–20	1 (0–2), 0–6	1 (0–2), 0–8
	Mean	1.9 (3.8)	1.2 (1.8)	1.2 (1.8)

n = number; % = percentage; IQR = inter-quartile range; min–max = minimum to maximum (or range); * = one participant estimated falling 4 times/week; excluding that data gives a mean 3.7 (9.4) falls/person in the no CI group.

Table 2
Comparison of fall rates in PwP with and without CI, by Hoehn and Yahr stage ($n = 101$).

Fall rate	Stage	*n*	Cognitive impairment			
			None	Any	*Mild*	*Moderate*
Retrospective (12 months)	I	15	2/10 (20%)	0/5	*0/4*	*0/1*
	II	16	2/6 (33%)	0/10	*0/7*	*0/3*
	III	44	16/20 (80%)	24/24 (100%)	*15/15 (100%)*	*9/9 (100%)*
	IV–V	26	4/4 (100%)	19/22 (86%)	*8/10 (80%)*	*11/12 (92%)*
	All	**101**	**24/40 (60%)**	**43/61 (70%)**	***23/36 (64%)***	***20/25 (80%)***
Prospective (3 months)	I	15	5/10 (50%)	1/5 (20%)	*1/4 (25%)*	*0/1*
	II	16	2/6 (33%)	2/10 (20%)	*1/7 (14%)*	*1/3 (33%)*
	III	44	11/20 (55%)	11/24 (46%)	*6/15 (40%)*	*5/9 (56%)*
	IV–V	25	4/4 (100%)	15/21 (71%)	*7/10 (70%)*	*8/11 (73%)*
	All	**100**	**22/40 (55%)**	**29/60 (48%)**	***15/36 (42%)***	***14/24 (58%)***

The columns in italics illustrate the numbers of people with mild and moderate CI who fell: these are combined as 'Any CI' in the preceding column.

repeatedly in the past was a more sensitive predictor of falling in mild CI (67%): two-thirds of those who fell were predicted to fall because they had done so before. Repeated falling was most sensitive among those with moderate CI (71%). Among those with mild CI, poor turn quality (again correctly classifying 72% of participants) was a more sensitive (69%) and specific (74%) predictor of falling. In other words, over two-thirds of those who fell during follow-up were predicted to fall because they had difficulty turning round. Among those with moderate CI, taking more than five steps to turn round (correctly classifying 70%) was a more sensitive (85%) and specific (50%) predictor of falling. In other words, 85% of those who fell were predicted to fall by the high number of steps they needed to take when trying to turn.

The researcher who collected the Falls Diaries estimated that 11% of those from the mild CI group and 21% of those from the moderate CI group would have been unreliable without carer involvement, telephone reminders and/or a clarification visit at the end of follow-up. Among the group with moderate CI, support in monitoring/recording falls came from a carer in 14 cases (61%) and care home staff in 4 (17%).

4. Discussion

Two-thirds of the PwP attending one movement disorders clinic allowed us to review their notes; they varied widely in age and in PD duration and severity. In half the notes reviewed, we found indications of both CI and fall risk, illustrating the complexity of the condition and the caseload – and a need for inclusive research.

Table 3
Predicting falls, by CI group ($n = 100$).

Predictors		Group		
		No CI	Mild CI	Moderate CI
		n = 40	*n = 36*	*n = 24*
History of repeated falls	Sensitivity	55%	67%	71%
	Specificity	78%	76%	60%
	+ predictive value	75%	67%	71%
	– predictive value	58%	76%	60%
	Correctly classified	65%	72%	67%
		n = 39	*n = 32*	*n = 23*
Turning steps > 5	Sensitivity	43%	69%	85%
	Specificity	56%	63%	50%
	+ predictive value	53%	56%	69%
	– predictive value	45%	75%	71%
	Correctly classified	49%	66%	70%
Turn quality < 4/5	Sensitivity	38%	69%	69%
	Specificity	78%	74%	50%
	+ predictive value	67%	64%	64%
	– predictive value	52%	78%	56%
	Correctly classified	56%	72%	61%

A clinic population may not represent PwP at large (care homes residents, for example, perhaps being under-represented) and we cannot say how representative was our sample of the people who declined to participate. Nevertheless, researchers need not exclude everyone with CI from falls research assuming fall rates (falls per person) are higher and/or fall prediction less accurate than among those without CI. Our findings make it difficult to justify excluding people with mild CI from falls research.

In the current study, seven participants with CI (11%) lived alone, so we acknowledge the possibility that some fall data will have been less accurate than if someone had supported them throughout follow-up. However, the researcher felt confident that six of the seven provided reliable diaries, and she took steps to improve the accuracy of diary entries (e.g. adding detail from reports left after a fall by the attending paramedics), whether or not the participant had CI. Living with someone else does not ensure reliable diary completion: in five of the seven cases in which the researcher was concerned about reliability, the participant lived with someone else; three supportive carers and two non-participating spouses.

Our selection process was an attempt to recruit a representative cross-section of the clinic sample for face-to-face assessment and follow-up. Because clinicians do not routinely record falls, we did not expect the proportion of fallers we identified face-to-face to match what we had seen in the notes. Likewise, not every participant had an objective measure of cognition (e.g. MMSE) in their notes: therefore, we expected to identify CI in people without previous clinical documentation of CI. However, we hoped to recruit a sub-sample similar to the clinic sample in terms of their residential status: 72% of the former lived with a relative or friend *versus* 74% of the clinic sample with documented residential status. We recruited 18 people whose notes gave no indication of whether or not they lived alone; this partially explains why we had a higher proportion of people living alone in the face-to-face study than we could have anticipated until we recruited them.

4.1. Retrospective and prospective fall frequency

In clinical notes and following purposive inquiry, among PwP of similar disease progression, the proportion falling was no higher among people with mild CI than among those without CI. In every group (normal cognition, mild and moderate CI), approximately one fifth recalled a single fall in 12 months. The only notable difference was that three-fifths of those with moderate CI recalled repeated falls (a risk factor for further falls), compared with just two fifths of those with no or mild CI. We support the call for specific investigation into preventing falls and fractures in people with CI and dementia [27].

Both the case notes and retrospective recall appeared to underestimate fall frequency in those with and without CI: 50% of

those we followed fell within three months but only 18% had falls in their notes and 45% recalled falling in the previous 12 months. We encourage clinicians routinely to document patients' and carers' comments about postural stability (falls and 'near-misses', for example) and to test and document cognitive function (encouraging discussion about 'thinking' or 'remembering', for example) to reveal issues that patients otherwise might not mention. For example, three participants who recalled falling at least monthly had no recent falls in their notes, and four had only a single fall recorded; five people without a MMSE in their notes had a MoCA suggesting moderate CI. Though using the MMSE and the MoCA to evaluate CI may have contributed to the differences in the rates and severity of CI noted in different parts of the current study, we agree with others [28,29] who suspect MMSE underestimates the degree of cognitive dysfunction in PD.

4.2. Predicting falls

Both fall history and difficulty turning were more sensitive predictors of falling in those with CI than those without. A meta-analysis of six studies (with 46% falling over three months, similar to the current study's 50%) estimated the sensitivity of repeat falls to be 68% and specificity 81% [18]. We found similar sensitivity in mild CI (67%) and moderate CI (71%). Though, in the current study, specificity was somewhat lower (76% and 60%, respectively), the degree of specificity should not deter clinicians from trying to reduce the risk of falling through further assessment and intervention. Among the participants without CI, we found the sensitivity of repeated falls (55%) much lower than the 86% that has been reported [2] while the proportion falling was much higher (55% *versus* 39%).

Two studies published since that meta-analysis [30,31] have predicted falls with combined batteries of measures in samples similar in size to ours but younger and at an earlier stage of PD, fewer of whom fell during longer follow-up. Five- or six-item batteries may achieve prediction that is slightly more accurate than a single, simple test: one battery correctly classified 77% of fallers after following 113 PwP over 12 months [30]; another demonstrated 78% sensitivity in predicting fallers after following 101 PwP over 6 months [31]. But extensive batteries are not applicable to routine application among people who have limited capacity, particularly in a busy clinical setting.

A history of two or more falls within 12 months is a recognized risk factor for falling again in PD but it is not always possible to secure a reliable history. Our findings suggest that a simple mobility test (the SS-180) may elucidate an individual's risk of falling, eliminating reliance on recall. Among the 23 people with moderate CI followed, taking more than five turning steps was the most sensitive fall predictor we evaluated, achieving 85%.

4.3. Enabling the participation of people with moderate CI in research

PwP with moderate CI warrant inclusion (if not prioritization) in falls research; they face complex problems, and most fall repeatedly. In the current study, repeat-fallers with moderate CI recalled more falls on average than those with no or mild CI but this was not the case prospectively. Participants with moderate CI could complete the turn test (with fewer missing data than in a trial involving 47 cognitively intact PwP [32]): they found it more challenging than the other groups and took more steps (median 9, IQR 5–14.5) than previously reported among 28 cognitively intact PwP (median 4.5, IQR 3.5–6.4) [25]. Analysis of the Falls Diaries will reveal whether the groups fell in different circumstances (and we will publish the findings separately): together, impaired cognitive and motor function may increase fall risk during complex activities.

Working with carers and reducing participant burden by conducting research in people's homes facilitates inclusive research for PwP and CI who want to participate. We strongly recommend tailoring diary reminders to the individual's needs and choices, rather than imposing (potentially intrusive) prompts on everyone and collecting diaries in person, to clarify entries. In the current study, the researcher telephoned every participant after one month's follow-up, and those conversations determined whether and how often the researcher telephoned again. Because most participants were sharing the completion of their diaries with a carer or managing successfully alone, only a few received additional phone calls before the researcher met with everyone to collect (and clarify) their diaries.

5. Conclusions

Researchers need not exclude people with CI on the assumptions that fall rates (falls per person) are higher and/or fall prediction less accurate than among those without CI. Falling was no more frequent among people with CI than among their cognitively intact peers. Clinical notes and retrospective recall underestimated fall frequency in those with and without CI. Clinicians need to have a higher index of suspicion towards falls among PwP (particularly those with moderate CI), a positive history prompting assessment of modifiable risk factors and intervention. Both fall history and difficulty turning were more sensitive predictors of falling in those with CI than those without: if a reliable fall history cannot be taken, a simple mobility test may highlight an individual at risk of falling. Research focussed on PwP with moderate CI should be a priority; most face a complex combination of postural and cognitive impairments, and fall repeatedly. Working with carers facilitates inclusivity in research, which will, in turn, generate more widely applicable findings.

Acknowledgments

The Bupa Foundation funded this work (BUPAF/33a/05: The prediction, assessment and prevention of falls among people with Parkinson's disease and cognitive co-morbidity). The authors gratefully acknowledge the support of the clinical team that assisted in identifying potential participants and the contribution of the participants and their careers.

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