

Falling in Parkinson's disease: the impact on informal caregivers

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Abstract

Purpose: The aim of this study was to explore the views and experiences of the informal caregivers of repeat fallers with Parkinson's disease.

Method: Individuals were invited to participate in this study if they were the informal caregiver of a person with Parkinson's disease (PD) who had experienced more than one fall in the previous 12 months. Participants were interviewed about their experience of managing falls using a semi-structured interview schedule. Interview data were transcribed and analysed using thematic analysis.

Results: Fourteen caregivers (11 female) participated in the study. All were marital partners of a repeat faller with Parkinson's disease. The average age of the participants was 69.9 years (44–79). Their partners had had PD for an average of 16.7 years. Six major themes emerged from the analysis of the interview data, four directly related to falls management (the falls; consequences of the falls for the person with PD; caregivers' experiences of falls; consequences of falls for the caregiver). The majority of caregivers were frightened about their spouse falling. They used a number of methods of getting their spouse up from the floor but often injured themselves as a consequence. Caregivers highlighted the high level of care they provided and the social and psychological impact of the condition on them. They received limited help in looking after their spouse and little information about falls or about the disease in general.

Conclusion: Caregivers in this study felt unprepared for their role and expressed a need for more support and advice, especially about managing falls.

Introduction

Falling among older people has been highlighted as a serious issue, not only for the people concerned but also for health services.¹ It has been suggested that falls can

cause serious disability² as well as having a significant impact on quality of life. This is true not only for groups of older people,³ but also for people who have had strokes,⁴ people with Parkinson's disease,⁵ and caregivers.^{3,4} The aim of this study was to explore the views, experiences and information needs of the informal caregivers of people with Parkinson's disease who had experienced repeated falls.

Parkinson's disease (PD) is a progressive condition with a varying prevalence of 3–30 per 10000 of the population.⁶ People with PD are at particular risk not only of falling⁷ but also of having repeated falls.^{8,9} Ashburn *et al.* found that two thirds of a group of people with PD living in the community had fallen within the previous 12 months, compared to a third of a group of similarly aged people without PD.⁵ They also found that people who had fallen two or more times in the previous 12 months would be likely to fall again in the next 3 months.¹⁰ The risk of falling is likely to increase as the disease reaches its later stages¹¹ but disease severity does not explain all fall events. Bloem *et al.*¹² and Ashburn *et al.*⁵ have reported that some people in the early stages of PD fall while those in a severe state are less likely to fall because of immobility. Modifiable risk factors for falls among the general elderly have been well defined: they include loss of muscle strength and impaired balance¹³ as well as use of multiple (psychotropic) drugs, frailty, mood disorders and fluctuations in blood pressure.^{14,15} Although the medical management of PD is effective, patients still gradually develop increasing physical problems and unfortunately postural instability and falls are difficult to treat pharmacologically. The development of management programmes through exercises and problem solving is important and needs to be evaluated.

Falls, therefore, have potentially serious consequences for the faller and have been cited as a contributory

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factor to decreasing quality of life for people with PD.¹⁶ However, there is evidence that falling not only has an impact on the faller but also on his/her caregiver. Forster and Young found that caregivers of people who had had strokes and who had fallen, were significantly more stressed than the caregivers of people who had had strokes but who had not fallen.⁴ It has also been reported that the emotional consequences of falling may be greater for caregivers than for the person who has fallen.³ Research indicates that caring for someone who has PD has a significant negative impact on caregivers' physical, social and psychological well-being.^{17–22}

There appears to be a general lack of knowledge about the disease among people with Parkinson's disease and their caregivers²² and a lack of support to assist informal carers to manage. Satisfaction with the care provided by hospitals and general practitioners has been reported, and contact with a Parkinson's disease nurse advisor has been identified as helpful.¹⁷ However, there appears to be limited contact with services provided by the professions allied to medicine—such as occupational therapy, physiotherapy and speech therapy. This is despite the fact that people with PD often have a significant level of disability,¹⁷ and that a multidisciplinary team of health professionals is recommended in the management of PD.²³

Purpose

Findings from previous studies into falls and the impact of falls on caregivers, suggest caregivers of people with PD may be significantly affected but this topic has not been investigated. The aim of this study was to explore the views and experiences of the informal caregivers of people with PD who had experienced repeated falls, with the objectives of identifying what information or support caregivers receive and what might best help them to manage this problem.

Method

This study was conducted in 2001. A qualitative approach was used comprising in-depth, semi-structured interviews. People were invited to participate if they were the informal caregivers of people with Parkinson's disease who had experienced repeated falls during the previous 12 months. A fall was defined as an event that resulted in someone coming to rest unintentionally on the ground, or other lower level, not as a result of a major intrinsic event or overwhelming hazard.²⁴ A repeat faller was defined as someone who had fallen more than once in the previous 12 months. The study

participants were recruited from two sources. Some ($n = 8$) were recruited from two PD support groups in Hampshire (UK) and others ($n = 6$) were recruited from a list of people with PD who had participated in a previous study. Ethical approval for the study was granted by Southampton and South West Hampshire Local Research Ethics Committee.

Interviews were conducted with 14 caregivers. The following topics were pursued in the interviews: caregivers' accounts of their relatives' falls; caregivers' concerns and anxieties about their relatives' falls; how falls had been managed; what advice or support had been received about managing falls and from whom; what help, information or support caregivers would find useful. Demographic details about interviewees were also collected comprising: their age, their relationship to the person with PD and the length of time they had been a caregiver. Interviews took place in caregivers' homes, they were audio-taped and lasted an average of 45 mins (range 30–90 mins). At the end of the interviews the participant was given the opportunity to comment on, or to discuss, any further concerns. As it was expected the interviews would raise caregivers' concerns about falls, we planned to leave participants some written information about falls and the contact number of the PD Society. However, a search for information leaflets or booklets relevant to caregivers indicated a lack of information on this topic. As a result we gave study participants two general booklets on PD produced by the PD Society ('Living with Parkinson's Disease' 1982; Moving on ... An A–Z guide for people who have had Parkinson's for some time, 2000') and a general booklet on avoiding falls (Avoiding slips, trips and broken hips, DTI, 1999).

Each audio-taped interview was fully transcribed immediately following its completion. All identifying information was removed from the transcript so that the participant could not be identified. A grounded theory approach was used in data collection and analysis in which the findings emerging from the first few interviews were used to inform the topics explored in subsequent interviews with the sample.²⁵ Transcripts of the first five interviews were coded independently by members of the research team who then met and agreed the emergent themes. In grounded theory the concurrent collection and analysis of interview data is used to refine initial themes and identify new themes.²⁶ In this study six initial themes were identified following the first five interviews and these were found to capture the issues emerging from the subsequent nine interviews. The process of coding and analysis of these later interviews was conducted primarily by the researcher. Regular

meetings between the researcher and the research team were used to confirm the refinement of the initial themes and to ensure that no new themes had been overlooked.

Results

Fourteen people agreed to take part in the study, all of whom were marital partners of a person with Parkinson's disease. Eleven were female and three were male. The age of the participants ranged from 44 to 79 years, with an average age of 69.9 years. Their partners had had PD for an average of 16.7 years. The length of time since diagnosis ranged from 6 to 29 years. All participants were the main caregiver for the person with PD. Twelve respondents said that their spouse needed some help, six indicating that a lot of help was required.

Six major themes emerged from the analysis of the interview data. Within each of these six themes a number of sub-themes were identified. The six themes were: causes and consequences of falls; managing falls; information about falls; impact on caregivers; the general impact of PD and managing the impact of PD. The first four themes relating to falls will be reported in this paper. In presenting the findings of this study, quotes from study participants are used to illustrate the specific issues raised. The number at the end of each quote denotes the participant's identification number in the study.

CAUSES AND CONSEQUENCES OF FALLS

Caregivers confirmed that their spouses with PD fell. Many respondents had difficulty reporting how often their partner fell. However, what was apparent was that falling or 'near falls' were a frequent event:

I should say a dozen times, 20 times. It isn't that frequently, luckily, at the moment. But he has very many near falls, that if I wasn't there or somebody wasn't there, he would have fallen, so, if you, if you, were to call those falls then, yes he would have had quite a lot'. (008)

Falls occurred in a number of different locations such as in the house, in the garden, or in public places such as the street. Falls not only occurred during the day but also at night. During the night falls tended to be either as a result of falling out of bed, or falling when using the bathroom.

Caregivers highlighted a wide range of factors that they thought were the cause of their spouses falling. The majority of these were related to Parkinson's

disease, such as the forward posture and movement, 'freezing' and difficulty in turning. The side effects of medication taken to combat the effects of the disease were also identified as another factor causing falls, especially when this caused involuntary movement. Hallucinations and low blood pressure were two other side effects identified as causing falls. Other factors identified as causes of falls were a desire for independence which resulted in the person with PD 'taking risks' and the use of walking aids which the person with PD was not able to control adequately. The following quotes illustrate participants' views about some of the main causes of falls:

'he'll call me when he freezes - you see he freezes going between two doors sometimes - something to do with the Parkinson's. He gets there and he can't speak and he can't move and he's gripping this, this frame. He has the frame so tight and he can stand for five minutes like that and then he'll say, "get me a chair I'm going to fall"'. (004)

'He's never fallen when he's been rigid, it's always been as a result of the medication, the side effects of the medication'. (007)

Participants in the study described a number of physical, psychological and social consequences for their spouses when they fell. Participants noted that their spouse frequently injured themselves physically when they fell with injuries ranging from cuts and bruises to more serious fractures. Loss of confidence and fear were two psychological consequences of falling that participants observed in their partners. It was also evident that falling, or the risk of falling, had an impact on social activities outside of the home.

MANAGING FALLS

Many of the participants indicated that the possibility of their spouse falling was a constant worry and a source of considerable anxiety and fear. Many of these concerns related to the possibility of the person with Parkinson's disease hurting themselves. These concerns went beyond the immediate consequences of the fall and raised issues about the impact the fall might have on quality of life, or even survival. As one participant noted:

'There's always that constant worry that if he breaks a bone then he can't take his anti-Parkinson's medicine for 6 weeks while the bone mends

because he's so terribly dyskinetic ... and that then opens the door to what happens when he can't clear his lungs and he gets very phlegmy and he coughs a lot., Um, and the risk of a chest infection, um, which could kill him. So there's all that that like links up, you know'. (007)

The caregivers described several ways in which they tried to manage falls. Three issues were identified regarding the management of falls: preventing falls; minimizing the potential consequences of falls and helping the person with PD to get up from the floor after they had fallen.

Several strategies were used by caregivers to try to prevent their spouses from falling. These included constant vigilance, leaving the spouse alone for as little time as possible, giving advice about posture and walking and careful positioning. Other strategies involved making changes to the environment or using equipment. For example some participants tried to reduce the environmental factors that might precipitate a fall. Others used appropriate equipment, furniture or had adaptations in their houses such as grab rails. The following quotes illustrate the prevention strategies used:

'He would fall everyday if I wasn't vigilant but I have to make sure I'm with him when he tries to go to the lift, or tries to go to the toilet, or anything on his own. I have to make sure I'm with him to help him, to steady him, as he falls down when he tries to do it on his own. When I go downstairs for anything I tell him don't move until I get back, and then I hear a crash and I think oh dear he's moved'. (009)

'He had a fall in the bathroom when he was turning from the toilet around, and the edge of the bath is right there. So the occupational therapist got some pole, a pole fitted, right on the corner of the bath so, as he turns, he can hold onto that'. (007)

Despite having strategies to try to prevent falls occurring, it was apparent that falls could not always be avoided. Participants described ways in which they tried to minimize the potential effect of falls. These comprised having things in place to make the management of the fall easier or smoother, such as adapting housing so that falls in awkward locations could be avoided and the severity of injuries could be minimized, or having a named person to contact in the event of a fall.

Most participants noted that the person with PD required help to get up from the floor following a fall. Participants reported using equipment, asking for help

from other people, trying to lift their spouse or assisting them to get up themselves. Many caregivers reported difficulties in lifting their spouse because they lacked the physical strength, although this did not appear to stop some participants from trying to do so. A common strategy was to assist their partners to get up from the floor themselves. This involved getting them into a position where they could use a piece of furniture, or a walking aid, to pull themselves up. In situations where these techniques failed participants said they had no choice but to call on other people, such as family, neighbours or occasionally paramedics, to help them. Some participants were reluctant to ask for help unless it was an emergency, as they did not want to 'bother' other people especially when falls were a common occurrence. The following quotes illustrate these issues:

'He just fell over and fell in the doorway with his hands down here and his body over here [demonstrates]. I had to pull the settee out to get him up but I can't lift him. I have to just support him until he can roll onto his knees and lift himself up'. (004)

'If he's on his back I've had it I know I'm not going to get him up, I'm going to have to get help. I don't want to go and ask anybody you know, I want to be able to do it myself [but] I'm not a spring chicken anymore. I'm full of arthritis and various ailments and just can't do it'. (013)

Some people had equipment to help them lift, however for several participants equipment was not an option. Reasons for this included a perceived danger of using hoists for people with PD, general reservations about using equipment and shortage of available space in the home. As one interviewee commented:

'I can't have a hoist because the bedroom's not big enough. You know in hospital there's two nurses and they use a hoist. Here there's me and these two hands, but I was told "no", there's not room in the bedroom for that'. (013)

INFORMATION ABOUT FALLS

The majority of the caregivers had not received information from health professionals about managing falls and the consequences of falling. A great need for information on how to help a partner to get up after a fall was reported. Participants were unsure where, and from whom, they would get such information and there was some confusion about whose role it was to give such

information. There was a sense in participants' accounts that the expectation from health and social care professionals was that caregivers should find ways of managing the problems themselves. The following quotes illustrate this:

'No I haven't [had any information]. Where would I get that information? Would somebody come to the house or what?'. (011)

'No [the occupational therapist] has really come to deal with things like um a seat in the bath to help me to bath him and um you know equipment really more than anything else and to put handrails in the bathroom and various other things but nothing as regards to actually falling ... I would like to have had more information about lifting him up'. (009)

Where advice and information had been received from health professionals, it related to preventing falls by removing environmental hazards or advice about helping their partner with PD to move around. This type of information and advice tended to be given by occupational therapists and/or physiotherapists but contact with these health professionals was minimal. Participants reported receiving one-off sessions with the onus on caregivers to contact the health professionals if they needed more assistance. The information and advice received from therapists was not necessarily tailored to people's needs or given at the most useful time. One interviewee reported receiving services from a PD specialist nurse who visited with an occupational therapist and who had provided helpful and relevant information about managing falls. This support was highly valued but ceased after a period of 2 years due to a lack of funding.

Participants who were members of the PD Society and/or local support groups had access to written information and support from other members in relation to falls. Falls was not a topic given great prominence in written information and where this was available it was, by its nature, at a general level and therefore perceived as not particularly helpful in enabling caregivers to manage their particular circumstances. Support from co-members was highly valued but caregivers did not identify this as helpful in identifying strategies specifically to assist in the management of falls.

One spouse reflected on the irony of professional caregivers attending courses on manual handling while she had to work out the best way to move her husband:

'I have to smile because a carer will say "oh I won't be here such a day because I'm on a course" and I

think damn it, I should be on one of these courses, you know, to learn'. (013).

IMPACT ON CAREGIVERS

Participants in the study described experiencing physical, psychological and social effects as a result of their spouses with PD falling. Several of the caregivers highlighted that they had injured themselves when their spouse had fallen. They indicated that these injuries had occurred either as a result of attempting to catch their spouse when they saw them falling, or from trying to help them get up from the floor. The age of caregivers coupled with the strain of caring meant that many of the caregivers had health problems of their own, often musculoskeletal in nature, which meant that lifting, moving or catching their spouse was hazardous. The situation was all the more difficult for some caregivers, particularly some of the older women in the sample, because of their lack of physical strength and the size of their spouse. The following quote is illustrative of responses in relation to this:

'I've found that catching him puts a strain on my arms and shoulders. My right hip's a bit arthritic and that went completely about six years ago. Then I had a slipped disc about three years ago and now I have this flippin' shoulder. I put it down to catching him'. (003)

It was evident that many caregivers not only experienced anxiety, worry and fear as a result of their spouses falling but also experienced other psychological consequences such as shock, anger, and frustration:

'I got him back on the bed and settled him all down and then when I went into my own bed, I shook, I shook, my heart was like this (hitting her chest) and I was shaking, you know. While I was seeing to him I was alright but once I got back into bed I was shaking'. (001)

As described earlier, not leaving a spouse on their own was a strategy used by some people to try to prevent falls occurring. This limited the opportunities caregivers had for going out, as illustrated in the following quote:

'I never like it. I never like to leave him on his own because if he falls no one's here to help him. ... I have done it but very rarely and very much with a feeling of, you know, sort of resisting the idea of leaving

him on his own . . . so normally I just, I go out at the speed of light and come back at the speed of light so there's a certain tension in, you know, I go out and I do everything I have to do as quick as possible'. (007)

Discussion

This study was conducted on a small sample of caregivers of people with Parkinson's disease. Although the interviews are not necessarily representative of all informal caregivers of people with Parkinson's disease, the findings concur with those of other studies in relation to the impact of falls on caregivers in other conditions^{3, 4} and the lack of support provided to caregivers of people with PD.¹⁷ Areas in which improvements in services could usefully be made, and research and evaluation conducted, are highlighted.

The findings indicate that informal caregivers had the major role in looking after their spouses with PD. The various roles and responsibilities undertaken by the caregivers, particularly in managing falls, placed significant demands on their physical, psychological and social well-being. They had received little help, information, or advice in relation to the management of falls and said they would have welcomed some guidance. The strategies they used in managing falls were mainly derived from their own experience but the strategies often placed the caregivers at further risk of physical injury, psychological distress and social isolation.

The Manual Handling Operations Regulations (1992) have had a significant impact on health professionals' and formal caregivers' practice regarding moving and handling patients in public health and social care settings.²⁷ It is interesting to note that while formal caregivers are protected from harm resulting from moving and handling patients, the same regulations do not apply to informal caregivers caring for relatives in their own homes. There was some evidence that health professionals, such as occupational therapists, had tried to encourage some of the caregivers to use equipment to assist in handling people who fall at home. However, these caregivers appeared reluctant to use such equipment because of lack of available space at home and uncertainty about the use of such equipment. Such findings suggest the need for caregivers to be provided with proper training in the use of equipment that can be used to assist people with PD to get up following falls at home, and the development of user friendly equipment.

The lack of support received by caregivers from health professionals and the uncertainty about from whom advice, information, or support regarding the

management of falls, is evident. Occupational therapists, physiotherapists and PD nurses appear to be the most appropriate professionals to provide advice and information on preventing falls, minimizing injury and advising on safe ways of helping the person with PD to get up following a fall. Health professionals need to be proactive in providing services to informal caregivers and the onus should not be on caregivers to seek out support and information themselves; many caregivers do not have the time, energy or knowledge to know where, from whom, or how, to seek advice on their concerns.

The lack of written information for caregivers about falls and their management in people with PD is evident. Written information is generalized and has its limitations.²⁸ However, the provision of good, clear, written information would provide caregivers with a starting point for managing falls and for identifying falls as a legitimate concern and one for which they are entitled to seek help. There is a growing trend for health professionals and others to provide educational courses for informal caregivers to assist them in their caring role. For example St John Ambulance Dorset run an Informal Carers Support Programme which includes advice on safe moving and handling, first aid and stress management. There is a need for more courses of this nature to be developed and evaluated in order to identify the most appropriate ways of meeting the unmet need of caregivers of people with PD in relation to the management of falls.

Conclusion

The various roles and responsibilities undertaken by the caregivers of people with PD in this study, particularly in managing falls, placed significant demands on their physical, psychological and social well-being. Individuals in this study had received little information or advice and said that more would be helpful. There appears to be a need for health professionals to be more proactive in the support that is offered to caregivers of people with PD and for programmes to be developed, and evaluated, that would meet the unmet need with regard to managing falls.

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