

The impact of non-motor manifestations of Parkinson's disease on partners: understanding and application of chronic sorrow theory

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ABSTRACT

INTRODUCTION: Parkinson's disease (PD) can cause many emotions, including grief and a sense of isolation for both the person with PD (referred to as Parkinsonian) and their partner. Such ongoing grief and emotional turmoil can be termed chronic sorrow. The aim of this research is to present accounts of partners' perspectives, analysed in the context of chronic sorrow theory, to offer health professionals an insight into the impact of non-motor PD symptoms on partners.

METHODS: A group of partners of Parkinsonians provided the data through individual stories. These stories were subjected to thematic analysis, using a seven-step process leading to the establishment of themes.

FINDINGS: Caregiver burden and chronic sorrow is not related to providing physical care, but the emotional care of attempting to minimise the effect of PD, coping with disturbance to sleep, and helping the Parkinsonian to maintain as much independence as possible. Contributors to this article found chronic sorrow theory provided a framework for understanding their emotions. Sharing their experiences with others provided an opportunity to be heard, and enabled them to make sense of individual situations.

CONCLUSION: Chronic sorrow theory provides a useful framework for both partners of Parkinsonians in understanding their emotional responses, and for health professionals in considering the challenges partners face in coping with living with a person with PD.

KEYWORDS: Grief; Parkinson's disease; support group; support partners; symptoms

Introduction

There are approximately 10 000 people in New Zealand (NZ) who have Parkinson's disease (PD).¹ While the most common visible manifestations are tremor, rigidity, bradykinesia, and postural instability,²⁻⁴ increasingly, attention in the literature focuses on non-motor manifestations, including sleep disorders,⁵⁻⁸ depression, apathy,^{3,4,7} or skin irritation.^{7,9} In NZ, a variety of support groups have been established through the 20 NZ Parkinson's Society branches.¹ During one support meeting, attended by contributors to this article, it emerged that the most significant impact on partners of Parkinsonians was the non-motor symptoms. These symptoms led to a

sense of grief and isolation for these partners. It was also during one of the meetings that the notion of chronic sorrow was discussed as a theory that could provide a potential explanation for the 'rollercoaster' of emotions each of the partners reported experiencing at different times.

The concept of chronic sorrow, which describes the emotional turmoil experienced by parents of developmentally delayed children, was first introduced in 1962.¹⁰ Chronic sorrow is a reaction to numerous losses that are part of parenting or partnering a person with chronic illness or disability.¹¹ In contrast to grief associated with death, and which eases over time,¹² chronic sorrow ebbs and flows in association with the

J PRIM HEALTH CARE
2015;7(3):221-227.

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changes to quality of life that occur in chronic illnesses,¹¹ especially in acknowledgement of the losses in each stage of the disease.¹³ Furthermore, chronic sorrow differs from depression.¹¹ In cases of depression, individuals demonstrate reduced self-esteem or self-regard. In contrast, those with chronic sorrow are not affected by loss of self, but loss of opportunities triggered by changes in condition.¹¹ Encouraging people to 'tell their stories' can be a therapeutic strategy in dealing with chronic sorrow, as listeners identify the strengths within each story.¹³

The purpose of this article is to provide an illustration for health professionals of how chronic sorrow can be triggered each time the partner intervenes to minimise the impact of PD for the Parkinsonian. Excerpts of stories are used to illustrate how living with a Parkinsonian can trigger frustration and sadness, that is, chronic sorrow.

Methods

Design

The framework used for gathering the data was that of narrative methods, a method that has recently emerged as a qualitative research methodology in social sciences.¹⁴ There is no single definition and no single way to carry out narrative research,¹⁵ rather, the shared narratives are used to lead to a means of making sense of the experiences.¹⁶ An essential point related to narrative inquiry is that, whereas phenomenology is a philosophical approach to understanding life through interpretation of the stories, narrative inquiry uses the telling of stories to describe life.¹⁷ It is how the stories are told and understood that is the pivotal difference between phenomenology and narrative methods.¹⁸ Shared stories can generate a sense of belonging and act as a catalyst for collective action.¹⁹ In the case of this study, the partners realised that sharing their experiences helped each other make sense of the lifeworld of chronic sorrow associated with living with a Parkinsonian.

Participants and setting

The concept of chronic sorrow was presented at a support meeting where only the partners of Par-

kinsonians attended; a meeting where members could express their experiences in a safe environment. At the meeting, the author spoke of the theory of chronic sorrow and how the theory resonated with her situation. The others attending the group agreed, especially as it related to coping with the day-to-day challenges of being a partner. The possibility of sharing the partners' experiences of the impact of PD, as well as the application of chronic sorrow through development of an article to inform health professionals, was subsequently discussed.

Health and Disability Ethics Committee ethical approval was sought for this study, but was not required as the contributors had control over participation and contribution to the study. Group members were invited, via the [Parkinson's Society] field officer, to write their perceptions of the effect of living with someone with PD on themselves, and the link between these perceptions and chronic sorrow. In order to minimise the risk of accidental identification of contributors or the Parkinsonian, an invitation for additional contributions to the article was made to another support group in another NZ city. Seven partners of Parkinsonians wrote contributions for the article.

Analysis

The accounts were subjected to thematic analysis, a process in which raw data were compared and main points aligned into common categories.²⁰ As these were individual accounts, there was the risk that the accounts illustrated comparative, but separate isolated stories.²¹ Therefore, a seven-step process was used, in which each account was read to determine initial perceptions, before more in-depth comparison and contrasting between the accounts was used to aggregate and order the data, and to establish links and themes.²⁰ The drafts of each article were read by all members of the support group, whether or not they had written individual accounts. While reading the first draft, members added further comments that validated the emergent themes, and the link between the themes, their own experiences and the application of chronic sorrow theory. Excerpts have been used to illustrate the links between themes and collective stories.

Findings

Shared uncertainty and partner's vulnerability

As identified in the literature, while tremor and bradykinesia are often the first physical manifestations of PD,^{2,4} these are not always the symptoms that cause chronic sorrow among partners. Although chronic sorrow may be always present, partners identified that sorrowful episodes were triggered by troublesome situations, such as the strategies they implement to avoid having the Parkinsonian becoming upset and exacerbating the non-motor effects of PD; changes in sleep patterns, including REM nightmares; the lack of spontaneity, and humour; and the Parkinsonian's concern or 'fretting' when the partner goes out.

The experiences of this group were that being exposed to the theory of chronic sorrow enabled them to use the concept to make sense of their own experiences.

Hearing about chronic sorrow makes sense [of my experience]. I now can understand why I feel OK sometimes, and not at other times, say when he is particularly frustratingly slow. (#1)

While health professionals may not see the diagnosis of PD as significant,²² all contributors noted that they needed to be strong at the time, and focus on their partner's needs. However, a perceived lack of empathy from a health professional could trigger a sorrowful episode.

She [the health professional] treated me dismissively and only spoke really to [the Parkinsonian], like I didn't matter. Yet I was the one that was asking the questions that [he] was unable to ask. (#2).

Feelings of having been strong at the time of diagnosis and coping with the unknown, resulted in later overwhelming grief.

I hit the wall and went and cried at the Doctors—extremely out of character—I'm a coper [good at coping with problems]. She immediately got out the prescription pad. (#2)

Six months later I had what I call my 'meltdown'. After thinking I was always of very strong mind, I

WHAT GAP THIS FILLS

What we already know: Parkinson's disease (PD) is manifested in several ways, and there is now an increasing amount of literature that focuses on the non-motor effects of PD and literature related to the grief (termed chronic sorrow) experienced by those with PD and their partners. Chronic sorrow theory was originally designed to explain the 'peaks and troughs' of a sorrow associated with coping with the illness of a child, and has more recently been applied to those with multiple sclerosis, Parkinson's disease and Alzheimer's disease.

What this study adds: Coping with the life-changing effects of PD, including sleep disturbances, and having to keep a 'watchful eye' on the Parkinsonian, as well as loss of their planned future, is physically and psychologically demanding for partners. Health professionals may find it useful, when considering the needs of the partners of Parkinsonians, to draw on theories such as chronic sorrow theory and to encourage the partner to share their experiences.

made a small mistake at work one day, and I burst out crying. Well, I cried for three days. My problem was that lots of little stuff was bugging me, and I couldn't seem to sort any of it out. (#3)

Partners also experienced sorrow as a result of the Parkinsonian's reluctance to tell others that they have PD. As the Parkinsonian did not want to acknowledge the disease, the partners experienced feelings of isolation due to friends and health professionals being unaware that they were also suffering, but it was from the hidden impact of PD.

I found it incredibly lonely as people's awareness was minimal to the effect [that] this was happening in our lives. (#4)

Protection from exacerbating the effects of Parkinson's disease

Several participants spoke of striving to keep the Parkinsonian emotionally 'safe' by ensuring things ran smoothly, and not adding any stress that would then exacerbate the effects of PD. Contributors identified instances when they needed to intervene in interactions with business people; for example, when slurred speech was misinterpreted as someone being under the influence of alcohol, and slow thinking as incompetence. Not having the opportunity to explain without offending or undermining the Parkinsonian who was there beside them, or within hearing distance,

triggered episodes of sorrow in the partner. It has been reported in the literature that those with PD are frustrated by the unpredictable nature of knowing how the disease will affect them on a daily basis.²³ Contributors to the current article also experienced the impact of unpredictability—not knowing whether the Parkinsonian could mentally or physically participate, meaning that the partner needed to be present ‘just in case’.

He is lacking in confidence with new technology, including using the Eftpos [automatic teller banking] card. This means he cannot go off by himself to fill up with petrol at one of those pre-paid pumps that do not have an attendant, as he may or may not get muddled with the order of identifying the pump, or pin number. I have to be standing beside or behind him to make sure that he is OK. (#5)

In addition, contributors talked about the impact of PD on employment status. It was noted that PD can affect anyone, and that there are a variety of employment roles that both the person with PD and the partner may have. One contributor spoke of the effect on the Parkinsonian being ‘managed out’ of an executive position he held, using the firm’s performance management programme. His role had been important to his self-esteem, and to be ‘forced’ into retirement resulted in his loss of identity, and bitterness that his partner would maintain her own role in paid employment. Another contributor wrote of the effect of her partner’s demotion, and a third of how her partner who was self-employed kept pushing himself in his work.

He told his boss and within days [he] was demoted and moved sideways. This was totally demoralising for him in terms of his self-esteem. (#2)

Although he still works, I see how much it takes out of him. I see ways of how we can manage better so that he can remain at work longer... So the whole denial that he can manage [is a problem], and it is hard to squash that as you do want them to be independent as long as possible. (#4)

Changes in employment status mean that there is often a change in income levels at a time when people are saving for retirement. In a study conducted in Ireland among a population of those

who had developed PD under the age of 65 years old, almost half had retired from employment at aged 58 years. Reasons for retirement were both the physical and cognitive effects of PD, resulting in an extreme financial and social burden.²⁴ The contributors to the current article identified the impact of the loss of income on the Parkinsonian, and often that they had a change in their own employment status. The effect of PD had denied some retirement plans. However, the grief associated with this and loss of quality of life is a sorrow that is expressed privately.

We still have a mortgage and no real savings. We were absolutely stricken with what our financial situation might be and had no one to really discuss this with. I have found that more and more I have taken over the finances... the daily stuff... but also the longer-term planning. He can’t cope with the stress of the future longer-term plans and sometimes I am blindsided [struck] with fear about our and my future. (#2)

Sleep disturbances

A common phenomenon of PD is sleep disturbances;^{6,8,25} however, it is acknowledged that there is little written about the effects of sleep disturbances on the partner.²⁶ Two aspects of sleep disturbances were reported to affect partners. The first aspect was sleep disturbance due to restless legs. Restless legs are acknowledged as causing sleep disturbance in the Parkinsonian,⁶ but the contributors wanted to draw health professionals’ attention to the fact that their sleep is disturbed as well.

Not getting a night’s sleep affects me. We have a king bed now with separate bases which helps heaps... with the disturbance. You really notice this when you stay somewhere else in a smaller bed! (#4)

It is also noted in the literature that REM sleep disorder is an early indicator of PD²⁵ and contributes to caregiver burden.²⁷ Contributors talked about the terrifying nightmares for the Parkinsonian, which can trigger chronic sorrow among the partner.

He woke up... certain someone had jumped over the fence into our back garden. No amount of convinc-

ing would settle him. He had to go outside and see that there were no footprints in the garden before he could be persuaded to go back to bed. (#1)

Other times he will lash out at the intruder who has broken in... but of course it is me in the bed who cops the punch. He is always upset when he realises what he has done, so I calm him down by saying 'it is OK; you did not hurt me'. But I am crying deep down inside with the heartache. (#5)

While, anecdotally, it is recommended the couples move into separate beds, it should be noted that if the person with PD has a nightmare at 2 a.m. and is running down the hallway, for example, separate beds are not going to prevent the supportive spouse from being disturbed. Some contributors reported the need to be work-ready the next day, resulting in their either having to go to another room, leaving the person with PD to cope with their own disturbed night, or having the interrupted sleep affect their own work performance. Whatever the reason, disturbed sleep has the potential to exacerbate chronic sorrow.

Strategies the partners use to help maintain independence

All contributors spoke of the challenge of maintaining the Parkinsonian's independence, yet doing more and more to ensure that the person did not get too tired. For example, one talked of the lovely vegetable garden that her husband was maintaining. However, as a result, she now has taken on all other chores around the house as he does not have the energy to do more than the garden. Another talked about other frustrations relating to minor daily tasks.

I need to be there in case he needs a hand to carry stuff, or to take the lid off jars. When he carves meat, he always blames the knife for not being sharp enough. It is very frustrating. (#6)

Others talked about the worry when their partner went out fishing. They did not want to stop them from going, but wanted to balance the independence with acknowledgement of what their husband was now capable of doing, particularly if they had to take over managing the boat. The

supportive spouse may not be always able to ask for help from others, as they are trying to protect the feelings of the Parkinsonian. Each contributor reported the cost of PD on themselves. As one reported that she struggled with being told how well her partner was looking:

They said 'gosh, he looks well', when he only looks well because I am running myself ragged looking after him. (#7)

When people ask me 'How's x [name]?'...I don't know how to answer... He's still got Parkinson's thanks? ...but honestly, I don't really know. I feel like the only people who really understand what I'm dealing with are my [support] group. (#2).

Prisoners in our homes

There is a reported reduction in socialising among those with PD; for example, dining out may be difficult because of inability to manage the food, waiters struggling to take their orders, or the surroundings being difficult for conversation due to noise.²⁵ Lack of facial expression, and lack of spontaneous laughter can contribute to isolation in social situations. Others commented that, in conversations among larger groups of people, the person with PD would go to contribute to the conversation, but that the conversation would already have moved on to another topic.

It breaks my heart to see this! (#1)

Coupled with the work in getting the Parkinsonian to participate in public activities, there can be a sense of anxiety and distrust when surrounded by what is now unpredictable and unfamiliar that adds to the potential for the partner to become a 'prisoner' in the home. Not only does the partner need to wait as the Parkinsonian takes longer to get ready, the partners also noted that unless they persist, there is a disinclination to go out.

He lacks confidence in groups and in public, and would be happy to be in his shed full-time. (#3)

The constant cajoling to participate can be tiring.

I feel I am constantly trying to make life easier for him without being too obvious. You end up doing everything as far as organising family, work, and

events. I feel isolated and guilty for the feelings I have at times and the lack of patience I have with him. (#4)

Coupled with the anxiety associated with socialising, the Parkinsonian may fret when the partner goes out, adding to a sense of being imprisoned in their own homes.

I was at the hairdresser and he knew I was going to be gone for two hours. He rang wanting to know where I was. He was nearly in tears because he had heard sirens and assumed because I was not yet home that I had been involved in an accident. (#5)

And now everywhere I go, my husband either wants to come with me, or I get interrogated as to where I'm going, who with, and for how long. (#4)

Discussion

Although there is material about living with PD, or caregiver burden effect in the latter stages of the disease,^{2,21,28-29} there appears to be a dearth of information related to the effect on partners in the early stages of PD, or examples of chronic sorrow experienced by the partner. What contributors to this article wished to voice is the need for health professionals to appreciate the effects of PD on them as partners, and that the concept of chronic sorrow may provide some explanation for their fluctuations in emotions, as opposed to other possibilities, such as depression. The partners need recognition that the caregiver burden is not only related to providing physical care, but the emotional care of 'cushioning', and standing alongside the Parkinsonian to help them to maintain as much independence as possible. Health professionals also need to appreciate that PD may result in the partner feeling like a prisoner in their own home, or making the decision to go out alone; both potential triggers for chronic sorrow.

Similar to findings reported elsewhere that women face greater levels of care burden-related stress and poorer physical health,³⁰ the contributors to this article all reported a constant sense of sorrow in living with someone who has PD. These findings confirm those of earlier research that the diagnosis of PD results in relentless

demands to manage the mental and physical aspects of the disease, leading to chronic sorrow.¹¹ However, the focus of care and support is not on the supportive partner. Therefore, they provide the support in the background, and put on a 'public face', especially if a health professional asks the couple how they are, with an emphasis on the Parkinsonian.

One therapeutic aspect of managing chronic sorrow proposed is for counsellors to foster storytelling in which the partner is able to express their perceptions of hardship, and the counsellor to draw on the strengths expressed in each of the stories, acknowledging that the source of sorrow is exacerbated with the progression of the disease, and cannot be resolved.¹³ What the contributors to this article found was that, in sharing their experiences, they incidentally provided 'counselling' for each other through this sharing of experiences. Hearing about chronic sorrow theory provided a framework for understanding their emotions, and they appreciated this as being something other than depression. It is suggested that health professionals may be able to draw on the accounts identified in this paper, and inform the supportive spouse about chronic sorrow, providing them with a venue where they can express their own experiences, without fear of being disloyal to their loved one.

Final comments

Although the concept of chronic sorrow is dated, it is a theory that is still applicable some 50 years after it was first proposed. The explanation of the theory and sharing of stories enabled the contributors to this article to make sense of their own experiences supporting someone with PD, and to appreciate that, although each felt lonely and isolated, they were not alone. Health professionals, especially those in primary health or general health, may glean additional insights from this paper on the extent to which a chronic disease such as PD has an impact on the couple, both the person with PD and their partner. The person with the illness may be recognised as benefiting greatly from the care of a supportive partner, but the sorrow for the partner in that role may not always be recognised.

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ACKNOWLEDGEMENTS

The author would like to thank members of the Parkinson's Society support groups for their contributions to the content of this article and along with the Field Officer/Community Educator for their support in the development of this article.

COMPETING INTERESTS

The author is also a member of a Parkinson's disease support group and contributed to the material used in this article.