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# Parkinson's diagnosis from the caregiver's perspective

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Signature: *Helen Maree Bradley*      Date: *27 October 2014*

Parkinson's Diagnosis from the Caregiver's Perspective

Helen Maree Bradley

A Report Submitted in Partial Fulfilment of the Requirements for the Award of Bachelor of

Science (Psychology) Honours, Faculty of Health, Engineering and Science,

Edith Cowan University.

Submitted 27 October 2014

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## Parkinson's Diagnosis from the Caregiver's Perspective

## Abstract

Parkinson's disease (Parkinson's) is a progressive neurodegenerative disorder. The irreversible and accumulating disability experienced means that people with Parkinson's progressively lose their autonomy, eventually requiring complete care. Consequently, Parkinson's significantly impacts sufferers and the people who care for them. Informal care, predominantly provided by female spouses becomes exceptionally demanding over time, and caregivers experience significant morbidity. Stress manifests across all stages of the caregiving trajectory, with diagnosis reported as a particularly stressful period for caregivers; however, few attempts have been made to understand what makes it stressful. The current study explored female spousal caregivers' subjective experience of the Parkinson's diagnosis, and asked how the diagnosis could be enhanced to manage caregiver stress. The researcher interviewed nine female spouses of people with Parkinson's using a semi-structured interview guide, and subjected the transcripts to interpretative phenomenological analysis. Participants' perceived the diagnosis of Parkinson's as an extended, temporal and psychologically complex process, of which the clinical diagnosis was only one aspect. Participants reflected that during the process their needs were unmet. The study underscored the importance of understanding the psychosocial impacts of change in the lives of female spousal caregivers during the transition to the caregiving role.

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### Parkinson's Diagnosis from the Caregiver's Perspective

Parkinson's disease (Parkinson's) is an incurable, neurodegenerative disease, with sufferers presenting with the cardinal motor features of tremor, akinesia, rigidity and postural instability (Jankovic, 2008); these features appear when more than 50% of the dopamine producing neurons of the substantia nigra have degenerated (Fearnley & Lees, 1991).

However, at the forefront of Parkinson's neurological research is a more expansive view of the disease that suggests a widespread brain disorder that includes non-dopamine pathology associated with non-motor symptoms (Lang, 2011; Olanow & Obeso, 2012). For this reason Parkinson's can be conceptualised as a complex, multisystem brain disorder with debilitating effects caused by the combination of physical and mental symptoms (Jankovic, 2008; Mason & Barker, 2012). The irreversible and accumulating disability experienced means that over time people with Parkinson's require ongoing, full time assistance from others (Martinez-Martin, Rodriguez-Blazquez, & Forjaz, 2012). As a consequence, Parkinson's significantly alters the lives of both sufferers and caregivers (McLaughlin et al., 2011; Phillips, 2006).

Research aimed at improving the outcomes for Parkinson's caregivers has become of increasing importance, and is driven by demographic and economic factors (Martinez-Martin et al., 2012). Demographic factors are related to both the age-relatedness of the disease and the ageing population. The onset of the disease generally occurs between the ages of 50 and 65 years, with very few younger onset cases. Prevalence estimates suggest that 0.7 % of people over the age of 50 years, increasing to 4% in those over 85 years, develop Parkinson's (Mehta et al., 2007). Current estimates suggest that 80,000 people in Australia have Parkinson's; the majority of whom receive care in their own homes by elderly informal caregivers (Access Economics, 2011). Population projections predict an overall increase in the number of people with Parkinson's due to the ageing population and the duration of the disease with increased lifespan (Access Economics, 2011). Forecast suggest that during the

period 2000 to 2050 a tripling of people aged over 60 years, and a fivefold increase in those over 80 years, will place greater demands on informal caregiving (United Nations, 2001).

Second, the disease places an economic burden on the person with Parkinson's and their direct family, which most often includes the caregiver (Martinez-Martin et al., 2012). The major direct costs associated with Parkinson's are aged care services, medications and in-patient and out-patient services; while indirect costs, estimated at 30-40% of direct costs, include loss of income for the patient and the caregiver, as well as hours required for caregiving (Access Economics, 2011). The main impetus for research arises from the combination of these two factors applying pressure to public policy initiatives, which are aimed at decreasing formal health costs and increasing informal caregiving through quality support (Department of Health, 2008).

Pearlin, Mullan, Semple, and Skaff's (1990) stress process model provides a widely used theoretical framework for understanding the caregiving role in progressive neurodegenerative disease. According to Pearlin and Aneshensel (1994) the caregiving role transitions through interconnected and overlapping phases, with the potential for stress at one stage to underpin stress at the next. Caregiver stress results from a number of interrelated conditions according to the stress process model (Pearlin et al., 1990). In Parkinson's, stress primarily relates to the management and physical care of the individual with Parkinson's; however, the gender of the caregiver and the relationship of the caregiver to the patient also have important implications for caregiver stress outcomes.

From the perspective of the caregiver, the very nature of Parkinson's creates a "multiplicity of difficulties" (Martinez-Martin et al., 2012, p. 221). For example, the heterogenic nature of the disease manifests as variability between patients' symptoms, in rates of progression, and involvement of the motor and non-motor systems (e.g. Davis, Ehrhart, Trzcinski, Kille, & Mount, 2003; Jankovic & Kapadia, 2001). This makes it difficult

for caregivers to compare patients and apply generic information. Furthermore, motor and non-motor fluctuations occur daily or hourly switching between mobility and immobility as medication produces the characteristic on-off phenomenon (Cheon, Park, Kim, & Kim, 2009). Under these circumstances, caregiver concerns arise for the patient's safety and medical compliance (Cifu et al., 2006).

One certainty for Parkinson's caregivers is that the trajectory of motor decline is similar for most people with Parkinson's (see stage and duration of illness scale; Hoehn & Yahr, 1967). Once the therapeutic benefits of medication are outweighed by the side-effects, usually around the 10 year period, patients become increasingly disabled until eventually very little movement is possible (Marjama-Lyons & William, 2001). Although Parkinson's patients want to remain at home for as long as possible, whether they can do so is completely dependent upon the caregivers' ability to physically and mentally cope with the demands of the role (Aoun, Kristjanson, & Oldham, 2006).

Much of the existing research on Parkinson's caregiving has focused on the implications of the nature, duration and intensity of these demands, reporting that caregiver strain increases with Parkinson's impairment (e.g. Carter et al., 1998; Leiknes, Tysnes, Aarsland, & Larsen, 2010; Stella, Banzato, Barasnevicius-Quagliato, Viana, & Christofeletti, 2009). When compared to non-caregivers and caregivers of other chronic illnesses Parkinson's caregivers fared worse socially, physically and psychologically (e.g. Hooker, Monahan, Bowman, Frazier, & Shifren, 1998; O'Reilly, Finnan, Allwright, Smith, & Ben-Shlomo, 1996). More than that, the psychological health of Parkinson's caregivers equalled that of sufferers of chronic disease (Aarsland, Larsen, Karlsen, Lim, & Tandberg, 1999). Martinez-Martin et al. (2012) conclude that when taken together there is overwhelming evidence that caregivers of individuals with Parkinson's develop a range of physical and psychological ailments, and that as the disease progresses the impacts worsen.

Role-socialisation-cohort effects and the age related nature of Parkinson's lead to a predominance of a particular demographic as caregiver, that is, mid to late life female spousal caregivers. This is more pronounced in Western Australia, where 60% of people diagnosed with Parkinson's are male, a variation on the global incidence rate of approximately 50% (de Lau & Breteler, 2006; Western Australian Health, 2007). Simply being a female caregiver predisposes individuals to greater vulnerability to psychosocial effects such as loneliness, difficulty sleeping, anger, frustration and emotional stress, and higher and faster rates of role strain as compared to males (Lyons, Zarit, Sayer, & Whitlatch, 2002; Lyons, Steward, Archbold, & Carter, 2009). That said, female caregivers are more likely to seek emotional support from others than males, and in couples dealing with chronic illness, females benefited more than males when they engaged with their partner in shared appraisal, communication and support (Berg & Upchurch, 2007; Tamres, Janicki, & Helgeson, 2002).

Yee and Schultz (2000) have advanced a number of reasons that role-socialisation-cohort effects contributed to the experience of greater psychological distress in female spousal caregivers over male spousal caregivers of elderly chronic disease sufferers for a number of reasons. Yee and Schultz suggested that female spouses acquired the primary caregiving role at a greater rate than males, doing both more general and personal tasks, while male caregivers are more likely to assume the secondary caregiving role. Additionally, female spouses accepted less informal or formal support than males reducing opportunities for stress reduction (Hooker, Manoogian-O'Dell, Monahan, Frazier, & Shifren, 2000). Social conditioning plays an important part in a woman's decision to take up the role, giving it an involuntary aspect; equally, women only reluctantly relinquish the role once they become stressed (Yee & Schultz, 2000). Yee and Schultz additionally concluded that the role-socialisation-cohort effect had a greater influence on older women than on younger women.

Spousal caregivers experienced decreased health outcomes as compared to other relatives (e.g. adult children; see Pinqart & Sörensen, 2003). Researchers have put forward a number of reasons in the context of dementia, and this warrants consideration in Parkinson's due to both conditions being progressive and age related. Spousal caregivers devote considerable time to caregiving due to the very nature of their cohabitation (Tennstedt, McKinlay, & Sullivan, 1988). Being present day and night differentiates them from caregivers who do not co-habitate. As a consequence they are more likely to have, for instance, disrupted sleep patterns, and are more likely than non-spousal caregivers to report less social and alternative roles that may act to protect against stress (Barber & Pasley, 1995; Mott, Kenrick, Dixon, & Bird, 2005). Spousal caregivers experience greater age related health issues and disabilities (Schneider, Murray, Banerjee, & Mann, 1999). Additionally, spouses' responsibilities for individuals with Parkinson's may accrue insidiously, such that their role is not easily distinguished from their mutual exchange of assistance (Houngaard, Pedersen, & Wagner, 2011). Therefore, spouses of individuals with progressive neurodegenerative diseases may not recognise that they have transitioned to caregiving, and may be consequently unprepared to meet the challenges of the role (Ducharme, Kergoat, Antoine, Pasquier, & Coulombe, 2013).

Female spousal caregivers find the role of Parkinson's caregiving exceptionally demanding, with caregiver stress reported across all stages of the disease, and significant health decline over time for a range of reasons (Carter et al., 1998; Martinez-Martin et al. 2012). Researchers have mostly focused on the advancing stages and management of Parkinson's, and the effects this had on caregivers. However, as Mott et al. (2005) note, the support needs of Parkinson's caregivers are not well understood. Recently researchers have turned their attention to understanding the range of factors that affect Parkinson's caregivers' stress, with the aim to benefit the development of specialised services and interventions to

reduce stress levels (Drutyte, Forjaz, Rodriguez-Blazquez, Martinez-Martin, & Breen, 2014).

McLaughlin et al. (2011) identified the clinical diagnosis of Parkinson's as a stressful period for female spousal caregivers. The clinical diagnosis is based on the presence of motor symptoms that meet the diagnostic criteria, followed by a confirmatory period based on a positive response to medication (Fearnley & Lees, 1991). The irreversible nature of the disease is confirmed by the clinical diagnosis, and marks the beginning of a cognitive shift in the spouse towards accepting the caregiver role (Keady & Nolan, 2003; Pearlin & Aneshensel, 1996). During this transition caregivers are likely to be vulnerable to the challenges of change (Pearlin & Aneshensel, 1996). While D'Amelio et al. (2009) advocated for better outcomes for caregivers and patients through early mitigation of caregiver stress, little can be achieved without further knowledge.

To further examine the questions that McLaughlin et al. (2011) raise, this study will consider the diagnostic experience. Therefore, the aim of the current study is to qualitatively explore the experiences of Parkinson's spouses in relation to the diagnosis of Parkinson's. The research question underlying the current study is: "How do female spousal caregivers experience the diagnosis of Parkinson's and how can the diagnosis be enhanced for caregivers?"

## **Method**

### **Design**

The research employed interpretative phenomenological analysis (Smith, 1996) to make sense of the mutual understandings and shared experience of female spousal caregivers during the Parkinson's diagnosis. This approach is suitable as it involves data analysis of the accounts to make interpretations of "the participants view of the world, and as far as possible, an insider's perspective" (Smith, 1996, p. 264). This involves an assumption whereby a 'chain of connection' (p. 54) exists between what the women say and their thinking and

emotional states (Smith, 2008). Furthermore, the phenomenological component involves a focus on the essence of the shared phenomena (Paton, 2002). The use of this approach is highly appropriate for studying the diagnosis, as it cannot be fairly captured at one point in time. The aims, methodology, methods, sampling and analysis complied with the Australian Palliative Residential Aged Care guidelines for qualitative research (National Health and Medical Research Council, 2006).

### **Participants**

The sample consisted of nine participants who met eligibility criteria. The criteria for the study were that participants had to be female, they had to be partners of people with Parkinson's at the time of diagnosis and the diagnosis had to be made in Perth, Western Australia (see Table 1).

Table 1

*Details of Participants*

Participant	Age at diagnosis (Years)	Time since diagnosis (Years)	Parkinson's WA Membership (Current)
P1	46	2	Yes
P2	70	4	Yes
P3	53	8	Yes
P4	67	4	Yes
P5	60	12	Yes
P6	62	8	Yes
P7	65	2	Yes
P8	80	5	Yes
P9	69	4	Yes

**Procedure**

After favourable ethical approval was granted by the Edith Cowan University human research ethics committee and the Parkinson's WA research advisory committee (see Appendix A), the study was advertised in community based newspapers (see Appendix B) and through the Parkinson's WA network (see Appendix C). In response participants volunteered, and were screened using criterion sampling. After participants had read the research information (see Appendix D), written informed consent was obtained (see Appendix E). The researcher conducted individual interviews at mutually acceptable times and places.

A semi-structured interview format guided the interviews with the researcher probing and clarifying to facilitate complete descriptions (see Table 2). Interviews were audio-recorded with an average length of 45 minutes. The researcher transcribed encrypted audio-recordings verbatim.



Table 2

*Semi-structured Interview Guide*

- 
1. Provide a brief account of what it was like to go through the diagnostic experience as a partner of someone with Parkinson's.
  2. From your perspective evaluate what was helpful/unhelpful at the diagnostic stage.
  3. If you were to recommend the best service possible, what would that be like?
- 

**Data Analysis**

Transcripts were analysed thematically utilising interpretative phenomenological analysis by the researcher (Smith, 1996). Firstly, each transcript was read to obtain an understanding of the diagnostic experience, and reread several times to generate annotations of new ideas and insights. Secondly, the transcripts were analysed for meaningful units, which captured the essence of the emerging analysis into themes. Themes were discussed and verified with the academic supervisor as an independent auditor. Finally, a master list of themes was organised around clusters of related ideas. This was further analysed to extract a number of subordinate themes. The process was repeated with subsequent transcripts. Themes were compared across cases, resulting in master themes across the group. Each transcript's master list was combined and any new themes were checked against transcripts. Analysis was therefore iterative, ever vigilant for new insights and ideas, adding or removing less significant themes (Biggerstaff & Thompson, 2008). Finally, themes that were not significant for the majority of the women were omitted, ensuring that the final themes were relevant to all participants in the study.

**Rigour and Ethical Considerations**

Theoretical rigour was accomplished by ensuring that the study's research strategy and methods were consistent with the research objectives (Liamputtong, 2009). Illustrating key points with verbatim quotes encouraged methodological and interpretative rigour, which established how interpretations were reached, thus increasing trustworthiness. A reflexivity

journal recorded the researcher's personal reflections of thoughts, interpretations and perceptions (see exemplar extract; Appendix F). The researcher frequently revisited field notes and audio recordings during the analytical process to ensure meaning was considered within the context from which it emerged (Groenewald, 2004). Member checking through transparent discussion of themes with participants and the academic supervisor enhanced substantive validation. During the process divergent accounts were reported and discussed, providing further enhancement of the rigour and trustworthiness of the research (Angen, 2000).

Ethical consideration when engaging with the sample population centred on issues of distress in recounting the diagnostic process (McLaughlin et al., 2011), and occupational health and safety for the researcher visiting private homes. For this reason, a resource sheet was provided to participants at the conclusion of the interview (see Appendix G).

Furthermore, risk management strategies were employed to minimise potential harm to the participant and researcher and to provide a process for incident reporting (see Appendix H).

### **Findings and Interpretations**

When asked to talk about the diagnostic experience, participants felt compelled to explain to the researcher, "you need to go back further" [P3.2.3]. In effect they described diagnosis as the period from when things began to go awry for their spouse (pre-diagnosis), the clinical diagnosis of Parkinson's, the subsequent commencement of a medication regime, and finally with a measure of acceptance (post diagnosis). Consequently, the diagnosis was described by the participants as a temporal process, rather than a discrete event at the time of the clinical diagnosis.

*I suppose the whole process took two years from when I sort of suspected ... that there was something wrong ... in the beginning the neurologist wasn't sure ... after a while he prescribed medication to see how my husband responded ... then the neurologist*

*said he did have Parkinson's ... I was certainly doing some research on it, realising that things were going to ... change [P9.1.7].*

Using the definition of diagnosis as provided by the participants, five core themes emerged from the data analysis (see Table 3).

Table 3

*Themes and Sub-themes Derived from the Perceptions of Female Spousal Caregiver's of the Diagnostic Process*

Themes	Sub-themes
Uncertainty	
The disclosure	Relief Shock Unfamiliarity
The specialist	Receiving information Expectations Lack of communication
The black cloud	Loss Denial Betrayal
What about me	Finding meaning Support Time to talk Individualisation

**Theme 1: Uncertainty**

Participants' experience of the diagnostic process was strongly influenced by being caught in a state of flux for an extended period. The uncertainty seemed perpetual as the majority of participants experienced a lengthy period, of at least one year, for many considerably longer, where they were dealing with their spouse's problematic early signs. Without definite answers, participants were left feeling unsettled. Many experienced considerable anxiety as they observed that something was seriously wrong and yet they could not get answers. Relationships suffered along the way.

*I felt something was wrong with my husband but I couldn't pinpoint it ... At times it was very stressful because I didn't sort of understand that it could be related to an*

*illness ... I suppose maybe for about five years before the diagnosis I felt there were some behavioural issues there and I guess I was fairly unhappy with our relationship in those years [P5.15.16].*

*I was worried about our relationship in those preceding years; especially our intimate relationship ... I thought things were bad. (I questioned) whether he still loved me. He couldn't seem to come up with a reasonable explanation. He had physical issues ... He went to many doctors about it, but no answers ... There were changes and I couldn't figure out what was going on [P1.15.1].*

One participant thought the diagnostic process was a very frustrating time, as the couple repeatedly accessed health professionals seeking answers. The early signs of Parkinson's were not recognised by the general practitioner (GP) and referral to a neurologist was not made for many years.

*The period of diagnosis was quite an extended period of time where my husband was repeatedly consulting with the GP ... and being referred to specialists of various kinds. He was eventually, after four or five years, sent to a neurologist [P1 1 10].*

In consultation with a neurologist a diagnosis was often difficult to make, and participants endured extended periods of time at this stage waiting for a diagnosis.

*We consulted the neurologist but nobody was sure. No one can tell in the early stages of Parkinson's. We just had to wait and see how things developed ... We had to wait for 12 months to say which way things were going and what was happening [P2.2.9].*

Delays in receiving a diagnosis coupled with lack of information at this stage resulted in emotional distress fuelled by speculation and fear of the unknown.

*My husband went to a neurologist ... and (then) he was reviewed by a panel of 14 neurologists ... Even that period was quite extended ... a month to six weeks ... and it was very stressful for my husband and for me at the time because we didn't really*

*have any idea of what it was ... No one was saying anything ... We thought it could have been motor-neuron disease or even something worse along those lines [P1.2.10].*

One participant expressed anger as she described a seven year period when the neurologist would neither deny nor confirm a diagnosis of Parkinson's.

*For seven or eight years it never came from the neurologist's mouth ... He eventually said, "You have Parkinson's" ... In all that time you just wanted someone to say, right, you've got Parkinson's so let's go from here and then you know what you're up against [P3.11.16].*

## **Theme 2: The Disclosure**

The clinical diagnosis of Parkinson's was received with mixed feelings. This theme has three predominant sub-themes: relief, shock and unfamiliarity.

**Relief.** Many participants met the diagnosis with a sense of relief, even though they knew little about the condition. To finally "put a label on it" [P5.9.12] relieved some anxiety, and they felt they could address it with medication.

*So in a sense it was a bit of a relief to say, okay, he's got a condition, we're taking medication for it [P6.14.22].*

**Shock.** At the same time, there was a clear sense for many of feeling incoherent and "shell shocked" [P1.3.10]. One participant described a defining moment as she and her husband sat in the car after the diagnosis.

*We were small sitting in the car, very alone, with broken hearts. The freeway was close by. I could see cars rushing by but everything had stopped for me. It wasn't like we cried. It was like we were paralysed [P1.3.20].*

The unexpected diagnosis accentuated the shock for this participant:

*It was a difficult one to come to grips with. I've found it very difficult because I just was shocked. In my wildest dreams I never suspected Parkinson's and if he'd had a heart attack I think I would have taken it easier [P8.6.19].*

**Unfamiliarity.** Many participants reflected how they felt unfamiliar with the condition and its prognosis. Ignorance played a major role in their initial reactions to hearing the diagnosis.

*I probably think I was a bit naïve about it all. I don't think I really grasped what it meant [P6.9.2].*

One participant described how initially the implications of the diagnosis were not apparent to her. With the benefit of hindsight she felt her initial reaction was understated.

*I don't think I was shocked in any way ... because the symptoms were not severe at that stage. You really don't know what's going to be hitting you down the track, so you're sort of pretty blasé about this. Alright, we've got Parkinson's. We've got medication and you're not going to die of Parkinson's and so why are we worried? [P9.1.16].*

The disease was foreign to many of the women and they tried to draw on any knowledge that they could to make sense of it.

*We needed a bit more information in the early stages. You know. I didn't know anyone with Parkinson's or anything about it ... only Michael J Fox and Muhammad Ali [P3.22.6].*

### **Theme 3: The Specialist**

The most frequently referenced aspects of the diagnostic process were related to the quality of the specialist interactions. Overwhelmingly, participants' expectations of specialists to provide informational and emotional support remained largely unmet. This

theme had several prominent sub-themes: receiving information, expectations, and lack of communication.

**Receiving information.** All participants mentioned that receiving information from the specialists was very important; however, in almost all cases this expectation remained unmet.

*I was looking for more answers than what he was sort of giving. Maybe he felt you didn't want to know. I don't know [P9.2.4].*

Some participants felt that it was difficult to communicate with the specialist, because firstly they needed more time to absorb the diagnosis, and secondly they needed more information.

*We were just trying to make sense of what he was telling us. He asked were there any questions ... but really we hadn't had time to understand what was going on because we had plenty of questions when we left but no one to answer them [P1.7.15].*

*At the beginning we didn't really know what questions to ask ... we needed him to sort of come out with things rather than ourselves ask questions [P3.15.22].*

In contrast, when the relationship was perceived as supportive the participant felt satisfied with the information they received.

*Of course, he's the expert and (my husband) the client, but I think there is a good relationship there ... (My husband) likes to get all the facts and the neurologist is always very supportive with the facts and encouraging [P7.6.17].*

**Expectations.** All participants expected that the specialist would provide emotional support and engage empathically during the diagnostic process. However, this expectation was unmet in all but one case. Participants felt particularly wronged by the lack of empathy. In one case the participant's spouse had been a chief executive officer and disclosed his inability to continue work.

*This was a pretty big thing at that stage that we were dealing with. It was just an insulting thing and I thought, “You arrogant man. You didn’t show any empathy for the situation. There was no warmth”. When he told (my husband) he could be a storeman, that’s when I was about to exit the room [P6.7.8].*

Several participants perceived the specialist as disinterested in their case, implying that the nature of the disease had an influence on the concern and empathy that was meted out.

*Once he decided on his diagnosis and prescribed the medication, I don’t think he was really very interested [P5.16.20].*

**Lack of communication.** Most participants felt that the lack of effective communication with the specialist left them perplexed and alienated.

*He was up on his pedestal. Just keep quiet and listen and do as you’re told and go away [P3.16.12].*

In contrast, the one participant who initially, and the others who eventually, consulted with a supportive specialist highlighted the specialist’s ability to communicate effectively in an informative, warm and friendly manner.

*I just think he’s very, very efficient and you can talk to him. You can say something to him and he listens [P8.4.11].*

The contrast in neurologist’s styles is exemplified in this excerpt.

*He was a very arrogant doctor ... I just thought how rude. But we go now to a very warm, friendly, kind neurologist and that is just the difference [P6.8.12].*

One participant reflected on the consequences that resulted from the unsatisfactory relationship with the neurologist in the early stages of her spouse’s condition. First, she had to find out about the disease herself. Second, her husband remained disinterested and apathetic about having the disease. She suggested that a more engaging neurologist may have



provided more encouragement and support for her, and both she and her husband may have experienced better outcomes.

*I think perhaps if (my husband) had been approached a bit differently (by the neurologist), it might have been different for both of us. Not just for myself to do the research but for (my husband) to start taking an interest in (Parkinson's) ... from that day onwards I had to manage all his medications ... encourage him to exercise ... eat properly ... he didn't want to do anything [P9.29.6].*

#### **Theme 4: The Black Cloud**

Participants experienced tumultuous emotions as the reality of the situation dawned upon them, and they yielded to a future with Parkinson's. This theme had four principal themes: loss, denial, betrayal and finding meaning.

**Loss.** Overwhelmingly, the participants conveyed a deep sense of sadness like a "black cloud over your life" [P7.15.6]. The grief experienced was in response to the perceived loss of their husbands.

*I was devastated for the loss of my husband ... I can only imagine how he felt [P1.7.9].*

One of the women tearfully described how accepting Parkinson's into her life made her feel that there was no way out. She felt that she had lost part of her life and part of herself to Parkinson's.

*(You think) God this is tough and eventually you do come to some sort of peace with yourself about where you are at and acceptance of the fact that you are trapped. I didn't think there was anything I could do about it ... but this is my life ... And I must say, a little bit of your personality dies. You've got to give it up [P2.29.7].*

**Denial.** There was an overwhelming impression that although the participants had a strong sense of what the future might hold for people with Parkinson's and their spousal caregivers, many chose to cope through biasing their personal futures more optimistically.

*(My husband) was the best of all of them at that time and you think he is never going to get like that and I think you don't really want to believe it [P4.15.6].*

**Betrayal.** All participants described the conflict of conceding to the future demands of the illness without the opportunity of negotiation. For many participants this was a time of anger as they reconciled a sense of betrayal, where their future hopes and dreams had been taken away.

*I thought now in my twilight years I should be having a bit of fun. I am stuck with this situation that is going to lock me in for the rest of my life. By the time I might be free I will be too old. I will be in the same boat myself probably and that was a lot of anger that I had to work through [P2.7.15].*

*It just didn't seem fair that I'd waited for my children to grow up before I did what I wanted and as soon as that happened someone else needed me [P1.6.18].*

Many described a sense of injustice at the hand they had been dealt. They felt that they deserved a better future.

*I feel very cheated of my retirement and what we could be doing. I think you feel cheated of your life [P6.20.13].*

Sometimes a sense of betrayal was directed towards the relationship. Participants felt that there was a present or anticipated role reversal that they felt unprepared for.

*It was really weird because everything changed at that point in time. I thought I had to become the strong one and I was the one that was always the one breaking down. Now I had to be the one that couldn't break down, the one that couldn't be sick, the one that had to be positive. It was difficult [P1.5.23].*

**Finding meaning.** Finding meaning in their grief was important to many women. One woman described the depth of the soul searching she underwent in order to come to terms with a sense of giving over her desires for the sake of her husband, knowing that he would equally do the same for her.

*After I found out I knew it was final. I knew that this was something I was really going to have to dedicate my life to and that was a very tricky time of moral thinking because on one hand this was the last thing in the world I wanted ... but on the other hand it really made me think about marriage, what it meant to love somebody and overwhelmingly I suppose my sense was of I will do it, I will dedicate myself to my husband because I love him and I know that he would do this for me [P1.6.14].*

#### **Theme 4: What About Me**

Overwhelmingly, when asked about their views of an optimal service, participants described the need for caregivers' support, as opposed to being ancillary to the person with Parkinson's.

*It's not all about (my husband). There's me, too ... Not taking anything away from him but ... there's two in it together [P6.20.5].*

This theme had three main sub-themes: support, time to talk, and individualisation of services.

**Support.** To cope with the future demands of the role, spousal caregivers identified that they required greater support to develop knowledge about the nature of the disease and its prognosis, together with practical knowledge on managing the disease.

*I think the biggest thing is awareness. Having things confronting you - that's quite stressful when that hits you and you didn't know that it was coming. It is like a sneak punch [P2.31.12].*

*It's a waiting game for a while to make sure that the diagnosis is right but then once the diagnosis is made, I feel that there should be as many supports in it as possible. It might be early days, but there's a lot to learn about it and where you're going to go with this business [P9.28.20].*

While there are several support networks available such as Parkinson's WA, and Moss Street Geriatric Clinic, Fremantle Hospital, participants were largely unaware of them during the diagnostic process. In most cases, the specialist neurologists or GP's did not promote such facilities. Contact was made in a haphazard manner, often by word of mouth or by the participant's own initiative.

*We could have been directed to Parkinson's WA sooner ... we would have had better information. (The neurologist) could have perhaps directed us to the Parkinson's Association. We'd have had much better information than what he gave us [P6.18.9].*

*When I suggested Parkinson's Association (the neurologist) said that there was no need for us to be going there, that that would only make it a lot worse for us and that he didn't advise it at all [P9.2.9].*

In many cases considerable time had lapsed since diagnosis before contact was made with support networks leaving participants largely unsupported.

*Probably it would have been nicer if someone had stepped in earlier with perhaps the neurologist saying that you need to find out a little bit more about this. You need to be aware of the outcome, or start looking and learning about it, and see what you can put in place because your future's going to change, which you don't realise at this stage. You don't know that you're not going to be able to manage [P9.20.17].*

Participants felt that contact with support networks provided them with a sense of security and should be accessed early.

*There's lectures and things you can go to (at Parkinson's WA). You need to find out, and I felt then that that was a bit of a safety net, that we have got something out there that we can use and get to know [P9.20.18].*

Participants felt that being in a supportive environment meant that they could let go of some anxieties.

*After attending Moss Street ... it sort of fell into place from there. It felt as if we were taken into a cocoon [P9.10.13].*

It was perceived that services such as GPs provided “moral support” [P9.10.12] but limited informational support.

*The GP's in general have been very unhelpful with their knowledge. It's just really limited in this field, limited or non-existent, really [P1.8.20].*

**Time to talk.** Having more time to talk to someone could enhance the diagnostic process. This suggestion appeared to serve several purposes. The first was to receive information, to clarify and ask questions about the disease.

*I wonder perhaps if the GP could have equally delivered the diagnosis. Discussed it ... taken time, if necessary, extended the time that you're seeing the doctor [P5.20.22].*

The second was to talk through the emotional impact of the diagnosis.

*After you come out of that neurologist's office you just don't go out into the big wide world and have to cope, something in between, something where you could just sit and talk to somebody [P1.10.15].*

Some participants thought access to a counsellor would have been good.

*You can go to one of these (counsellors) and they listen to you and they don't ask you any questions or pass any comments but you're talking about your own inside [P4.23.6].*

The third was for the women to have the opportunity to be understood.

*The best thing of all is (to talk to) people who've been through not necessarily Parkinson's, but who've been through a difficult time ... It's so important because it's difficult to explain to others what you're going through [P5.30.8].*

**Individualisation.** Participants recommended flexible services to meet the individual needs of spousal caregivers. First, participants felt that information should be made available at a time right for them.

*Maybe people need to just have a bit of information to sit on in an initial diagnosis and not get too overwhelmed ... maybe they have to sort of ease into it and not get overwhelmed [P7.22.8].*

Second, participants felt that it was their choice as to how much information they would receive.

*I want to know. I want to know everything I can possibly find out, so, I know down the track he might get dementia, down the track he might start dribbling ... I don't panic or situations don't really phase me if I know what I'm going into [P3.24.12].*

Third, some suggested that ongoing counselling support would have been beneficial at the time.

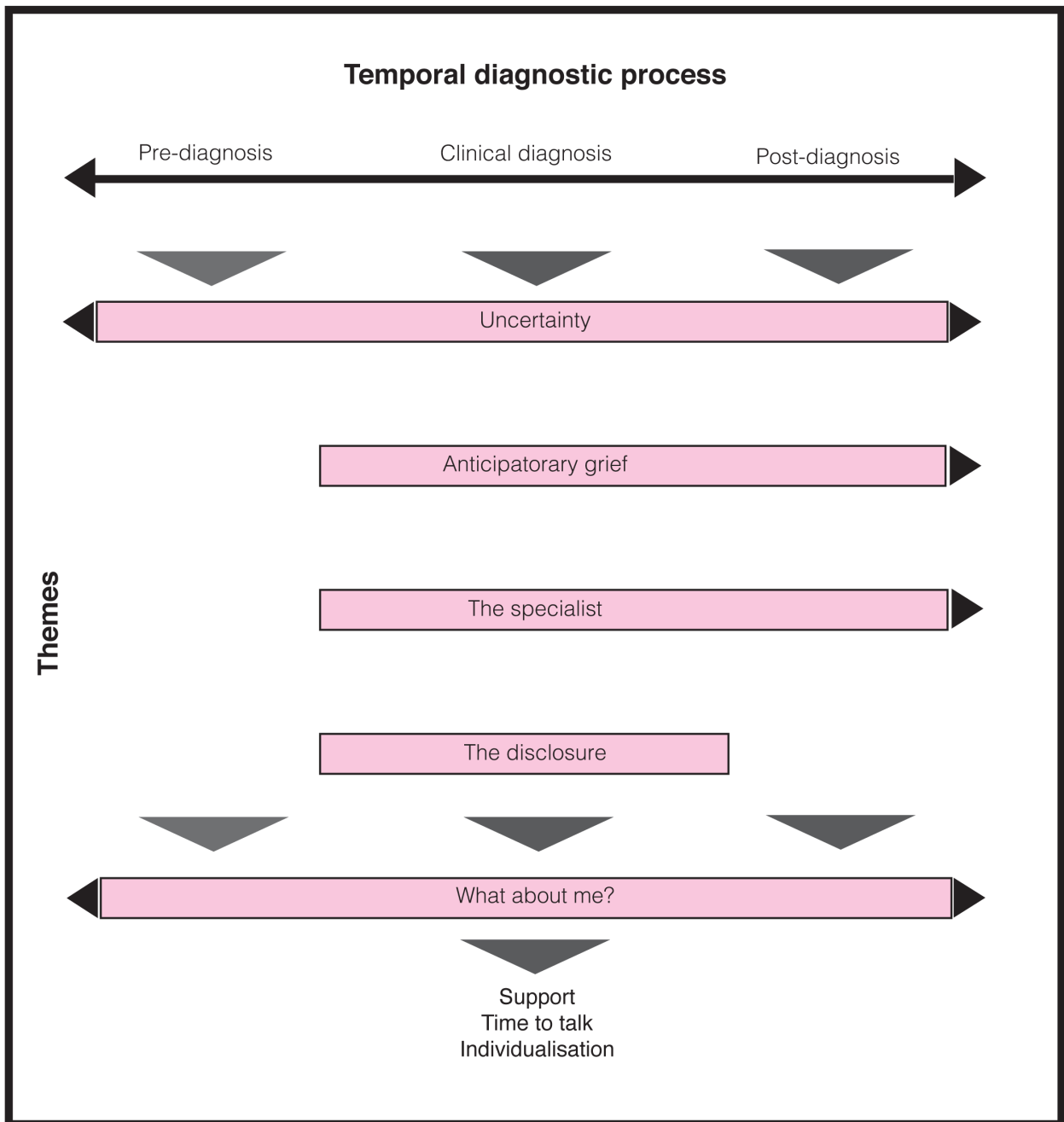
*I don't know whether it would be too much to absorb all at one time. I think may be. I think really ... someone should sit down about three, four, six months later after you've got over this, and tell you this is what you got to do, this is the what you are dealing with, on that level then ... by then you are ready to absorb the next stage [P2.27.18].*

And finally, participants recommended individual services, rather than groups.

*I didn't want to gallop into there and everybody tell me what my future was going to be [P6.23.16].*

### Discussion

This study employed qualitative methods to explore the lived experience of female spousal caregivers' during the diagnosis of Parkinson's, and asked how they believed the process could be improved to better manage caregiver stress. Based on the information provided it appears that participants perceived the diagnosis as a lengthy, temporal and psychologically complex process, in which the clinical diagnosis is one aspect. Similar to McLaughlin et al.'s (2011) finding, the current study reveals that participants were left to their own devices in dealing with these complexities. Participants offered retrospective suggestions to improve the process, which included providing clear pathways to medical and support services, and provision of opportunities to talk about concerns through individualised and flexible services. The analysis of the data reveals that participants defined the diagnosis as an extended period of time made up of a series of interconnected stages: pre-diagnosis, clinical diagnosis, and post-diagnosis. The dominant themes in this study form the components of the process: *uncertainty, the disclosure, the specialist, anticipatory grief* and *what about me* (Figure 1).



*Figure 1.* The temporal diagnostic process of Parkinson’s as described by participants: The arrowed line across the top represents the temporal diagnostic process, while the horizontal bars represent the themes. At the bottom are participant’s recommendations for enhancement of the diagnostic process.



Participants characterised the diagnostic process as a period of pervasive uncertainty, a finding not captured in previous studies. A significant body of research supports the assertion that uncertainty is a powerful stressor (e.g. Monat, Averill, & Lazarus, 1972; Zakowski, 1995), and a key component of worry and anxiety (e.g. Carleton, Norton, & Asmundson, 2007). According to Carter et al. (1998), worry impacted on Parkinson's caregivers in the early stages of the disease; however, they did not determine its source. In the current study it appears that uncertainty contributed to worry during and after a clinical diagnosis, but notably also in the pre-diagnosis period.

Whilst medical specialists would generally think of the diagnostic process as starting from when they first see the patient, the process started for the participants when they perceived that something was wrong and they started looking for answers. Participants found the diagnostic process as lengthy, and medical researchers suggest that Parkinson's has a lengthy prodromal phase, with the presence of a cluster of probable prodromal markers (Gaenslen et al., 2014; Postuma et al., 2012). These symptoms include sleep disorders, depression, and autonomic dysfunction (Berg, 2012). According to Walter et al. (2013), people with Parkinson's retrospectively reported that before the clinical diagnosis the most problematic symptoms were depression and anxiety, which generally developed three to six years prior to the classic motor symptoms. Pfeiffer (2010) described the presence of common autonomic dysfunctions, such as gastrointestinal, urological and sexual dysfunction also arising in the prodromal phase. Although problematic these symptoms are insufficient to allow clinical diagnosis based on the current diagnostic criteria (Gaenslen et al., 2014). As a consequence, patients and partners are locked in a diagnostic limbo that's drives uncertainty.

Participants reported that facing this uncertainty resulted in them making negative attributions about their husband's uncharacteristic behaviour, which affected on the quality of the marital relationship. Decreased marital harmony has been associated with increased

caregiver burden in Parkinson's; in particular, it has been associated with increased depression for both caregiver and recipient (e.g. Carter et al., 1998; Lyons, Sayer, Archbold, Hornbook & Stewart, 2007; Tanji et al., 2008). Lyons et al. (2009) recommended early detection of marital problems as an important area of intervention for the stability of long-term caregiving. The current research suggests that providing an opportunity for female spousal caregivers to talk about their marriage in the early stages of Parkinson's is important.

A further challenge for caregivers during the diagnostic process concerns the quality of specialist interactions, which was foreshadowed in the literature as a potential influence on the diagnostic process. Patients with Parkinson's have previously reported a mismatch between the expectations of specialists and patients (e.g. Phillips, 2006; Pinder, 1992). It is therefore not surprising that in this study participants vividly recalled dealing with specialists, not only because the specialists disclosed the diagnosis, but also as there was a disparity between delivery and expectations.

Participants experienced the diagnostic process as a period of unmet needs. They identified conflicts between their expectations, and the amount of informational and emotional support they received at the time, compounded by the communication style and attitude of the specialist. Furthermore, specialists were often seen as taking a paternalistic approach, particularly in terms of metering out information and facilitating access to additional sources of support. Similarly, Munoz Sastre, Sorum, and Mullet (2011), found that while specialists perceive quality of diagnostic information and supportiveness as being additive, recipients combine quality of information and supportiveness in such a way that low supportiveness could not be compensated for by high information quality. Importantly, in the current study, it appears that participants who perceived the specialist to be supportive, were satisfied with the information they received.

Participants revealed possible reasons for the perceived imbalance in their relationship with the specialist. First, participants were engaged in a novel experience where they were both unfamiliar with Parkinson's and in dealing with specialists. Second, participants had endured a lengthy period of uncertainty, so they were already anxious. Finally, upon hearing the diagnosis participants were often unable to absorb information due to the emotional impact of the news.

Participants in the current study highlighted experiencing a number of emotional challenges including anticipatory grief (anticipatory grief; see Rando, 1984). Participants experienced loss that encompassed the past, present and future and it appeared to be a multidimensional experience. Participants mourned the change in the relationship and lifestyle foreshadowed by the disease, and experienced grief over what was presently slipping away. They became aware that changes that they had noticed in the pre-diagnosis period formed part of a larger picture, and they grieved the loss of a number of different aspects of their healthy husband, such as dimensions of his personality, and emotional closeness in the relationship. Participants looked to the future and saw progressive debilitation, increasing dependence, continual uncertainty and decreasing control. Holley and Mast (2009) found that anticipatory grief was strongly related to caregiver burden, and suggested its inclusion in the stress process model (Pearlin et al., 1990), as an important predictor of caregiver stress.

Participants spoke of the major issues that affected them during the diagnostic process and the minimal care and support they received. From the pre-diagnostic period onwards, these participants identified a lack of opportunity to discuss their needs at any time during the process. Most participants were unaware of support services available to them, and the medical practitioners did not suggest avenues for support. Given the significance of their partner's diagnosis, participants felt unable to voice their concerns for their own health and

well-being during the diagnostic process. However, with the benefit of hindsight, participants advocated for much better support for those spouses just beginning the journey.

When asked participants said they would prefer to receive informational and emotional support through talk and discussion in a friendly, non-confronting environment without time constraints. Many described the complex personal emotions they grappled with during the diagnosis process and felt that support needed to be individually delivered through flexible services, such as counselling.

Parkinson's support group interventions for spouses of the newly diagnosed are cautioned, as participants in this study described feeling distress and reluctance, and in some cases defiance, in taking part in that kind of intervention. Readiness to receive information and support is a salient point highlighted previously by Lindgred (1996) in her chronic sorrow research of Parkinson's caregivers. Fulton, Madden, and Minichiello (1996) warn that support groups do not always provide adequate support to those individuals whose needs differ from those of other members of the group or the organisation. Individuals often simply seek emotional support during a period of grieving, rather than problem solving strategies (Fulton, Madden & Minichiello, 1996).

Participants identified the need for information to assist in their emotional and pragmatic preparation for the journey ahead. Importantly, participants conveyed a desire for autonomy as to when and how they received information. The identification of a range of approaches, for example, full disclosure to incremental disclosure of information, highlights the need for individualisation of services. This finding supports that of Kristjanson, Aoun, Samar, and Yates (2006) for tailored, flexible services for caregivers of people with neurodegenerative disorders.

While the current research provides a glimpse at the diagnostic process from the perception of female spousal caregiver, it is important to acknowledge the limitations of this

study. The researcher intended to procure participants from outside the membership of Parkinson's WA, however, all participants who responded to the community recruitment drive were members. There is a chance that caregivers who are unaware of or unable to access support services were not included in this study. The individual interview methodology enabled individuals to describe their unique experience of the diagnostic process in their own words, and allowed the researcher to probe in areas of interest to develop descriptions further. However, the strengths of this approach also have inherent limitations. This study represents a single group of people. Therefore, these findings cannot be generalised to other populations of Parkinson's female spousal caregivers, nor is statistical analysis possible. Furthermore, a methodological limitation was that all accounts were retrospective in nature and therefore accounts may not be accurate. The benefit of hindsight may have increased or decreased the intensity of the memories of the diagnostic experience.

Despite its limitations, this study facilitates an expanded conceptualisation of the clinical diagnosis, allowing the inclusion of a pre-diagnostic period. In view of recent neurological research on the presence of probable prodromal markers in Parkinson's disease (Postuma et al., 2012), and given the current exclusion of non-motor symptoms for a clinical diagnosis (Lang, 2011), the current study provides an insight into the consequences for participants when engaged in an extended period of diagnostic limbo. The current study advances knowledge in its revelation that several challenges underscore the diagnostic process for female spousal caregivers. An expanded conceptualisation of diagnosis additionally allowed participants to describe their perceived challenges more fully. These challenges appear sensitive to interventions.

In this regard, future research should engage formal intervention trials to provide diagnosis specific interventions. It is important to encourage a pro-active intervention approach from the beginning of the caregiving trajectory, as older women do not actively

seek support. Caregiver adaption to psychosocial challenges amidst a period of significant change can be facilitated through interventions. In so doing, the risk of caregiver strain at other stages of the journey is minimised. Interventions should be targeted to the needs and expectations of female spousal caregivers. The unsuitability of support groups for female spousal caregivers of the newly diagnosed offers important insights into intervention preference. Two suggested interventions for research and development include a Parkinson's information kit for caregivers providing steps to initiate support, and a needs and preparedness checklist for utilisation by medical practitioners to ascertain individual female spousal caregivers requirements.

The findings suggest a number of clinical implications. First, greater public and health care professional awareness of the early signs of Parkinson's should be engendered. Second, the communication of the perceived discrepancies in expectations between specialists and caregivers, to enhance cognitive and affective support of female spousal caregivers of newly diagnosed people with Parkinson's. Finally, individual counselling services for female spousal caregivers, to provide talk therapy, grief counselling, marriage counselling and psychoeducation. Importantly, with the presence of depression in the prodromal stage and after, psychological therapies to assist female spousal caregivers manage their own psychological well-being within the relationship is crucial.

In summary, the purpose of this study was to explore the diagnostic period of Parkinson's from the perspective of the female spousal caregiver, in order to illuminate opportunities to improve the process and minimise stress. The information shared by the participants in the current study provides further evidence that the diagnostic process is perceived as stressful by female spousal caregivers. It further extends upon existing research by adding a greater understanding of the psychosocial challenges experienced by participants. Furthermore, it gives a more expansive view of the clinical diagnosis providing additional

insights into the lengthy nature and associated individual impacts of the diagnostic process.

The study highlights the need for individualised, supportive services from the outset of caregiving.

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Appendix A

Application for Non-financial Research Support

Application for Non-Financial Research Support:

Parkinson's WA

Application was sought for non-financial support from Parkinson's WA Research Committee by completing an application. Details are available from <http://www.parkinsonswa.org.au/research/research-grants>

Appendix B

Community Newspaper Copy

## Community Newspaper Copy

## Partners of People with Parkinson's Speak Up

Partners of people with Parkinson's are being sought to take part in a study exploring their experiences of diagnosis of Parkinson's disease in their spouse.

"Partners of people with Parkinson's are in a unique position to provide first-hand information about what it is like to go through the diagnosis of Parkinson's disease with their spouse - what was helpful at the time and what was unhelpful", said researcher Helen Bradley from Edith Cowan University.

"The period around diagnosis is often the first time that partners have engaged with health care professionals about Parkinson's disease. However, there is a lack of research focusing on this period of time, particularly around the needs of partners," said Ms Bradley. "Finding out what is important to partners at this stage will inform more effective services in the future".

The study will investigate and describe in detail interpretations of partner's experiences and perceptions of the diagnostic period.

Ms Bradley is completing her thesis as part of a Bachelor of Science (Psychology) Honours under the supervision of Prof Alfred Allan, and is seeking up to 15 volunteers who live in Perth and who are partners of people with Parkinson's for her study.

The volunteers will take part in a one-on-one confidential interview about their experiences during the diagnostic period. The interviews will take 1 hour, and will be arranged at a mutually acceptable time and place, including home visits. Ms Bradley may follow up with volunteers to check her interpretations.

This research has ethics approval through the Edith Cowan University Human Research Ethics Committee and the School of Psychology and Social Sciences Human Ethics Sub-Committee. People interested in participating are invited to contact Ms Bradley on 0438 899 748.

## Media Reference

Professor Alfred Allan (ECU School of Psychology and Social Science) Phone: 6304 5536 or Email: [a.allan@ecu.edu.au](mailto:a.allan@ecu.edu.au)

Appendix C  
Parkinson's WA Network Recruitment

Parkinson's WA Network Recruitment

**Partners of People with Parkinson's  
Speak Up**

**Partners of people with Parkinson's are in a unique position to provide first-hand information about what it is like to go through the diagnosis of Parkinson's disease with their spouse – and explain what was helpful at the time and what was unhelpful.**

Helen Bradley is completing her thesis as part of a Bachelor of Science (Psychology) Honours under the supervision of Prof Alfred Allan, and is seeking up to 15 volunteers who live in Perth and who are married to or are partners of people with Parkinson's for her study.

**Finding out what is important to partners at this stage will inform more effective services in the future.**

**Would you like to take part in this study?**

You will be required to participate in a one hour individual interview before the end of August (ideally as soon as possible) with the researcher at a convenient location to us both, which may be your home. The researcher may follow up briefly after the interview by phone.

The Edith Cowan University Human Research Ethics Committee, the School of Psychology and Social Sciences Human Ethics Sub-Committee and Parkinson's WA have approved this research.

People interested in participating are invited to contact:  
Helen Bradley 0438899748 or email [hbradle1@our.ecu.edu.au](mailto:hbradle1@our.ecu.edu.au)

Appendix D  
Information Letter

Information Letter  
ECU Letterhead

Contact Details:

Chief Investigator: Helen Bradley

Email: [hbradle1@our.ecu.edu.au](mailto:hbradle1@our.ecu.edu.au)

Supervisor: Prof Alfred Allan

Email: [a.allan@ecu.edu.au](mailto:a.allan@ecu.edu.au)

Information Letter

Dear Participant

Thank you for your interest in this research study. My name is Helen Bradley and I am currently completing my Bachelor of Science (Psychology) Honours at Edith Cowan University. The purpose of my research is to explore the experiences of partners of people with Parkinson's during the initial diagnostic period. I am seeking voluntary participation from partners of people with Parkinson's. My primary aim is to find out what it was like for you and how it could be improved in the future. Your involvement in this research will provide greater awareness of the needs of partners during this time, and assist in informing more effective services for people in this situation in the future. The research has been approved by the Edith Cowan University Human Research Ethics Committee and the School of Psychology and Social Sciences Human Ethics Sub-Committee, and is compliant with the National Health and Medical Research Council of Australia (2007) guidelines.

If you choose to participate in this research, I will request your involvement for one individual interview lasting approximately 1 hour. I will personally conduct the interview at a mutually convenient location, and the interview will be audio recorded. These recordings will not contain any identifiable information. Any information you provide will be recorded under a pseudonym and only my supervisor and I will have access to the information. I may follow up with you after the interview to check my interpretations of what you have said.

Your participation in this research is voluntary, and you may withdraw your consent at any time. If you do withdraw any collected information will be erased and not included in the study. Interested participants will be required to complete and sign an Informed Consent document prior to commencing the interviews.



The interview will give you the opportunity to talk about your experiences during the diagnostic period. In the event that you experience some emotional distress or discomfort, you are under no obligation to continue with the interview. At the time of the interview I will provide you with contact support services and you can contact them to discuss how you feel or receive further support.

If you would like to ask questions regarding the study, please feel free to contact me Helen Bradley (Tel: 0438899748 or my email [hbradle1@our.ecu.edu.au](mailto:hbradle1@our.ecu.edu.au)) or Professor Alfred Allan (Tel: 6304 5536 or email [a.allan@ecu.edu.au](mailto:a.allan@ecu.edu.au)). If you have any concerns with the project or would like to speak to an independent person, you may contact:

Research Ethics Office  
Edith Cowan University  
270 Joondalup Drive, JOONDALUP, WA, 6027  
Phone: 6304 2170  
Email: [research.ethics@ecu.edu.au](mailto:research.ethics@ecu.edu.au)

Yours sincerely  
Helen Bradley  
Chief Investigator

Appendix E  
Informed Consent

## ECU Letterhead

## Informed Consent

I \_\_\_\_\_ understand and agree to the following:

- I have been provided with an information letter explaining the research project.
- I have read and understood the material within the information letter.
- I have been given the opportunity to ask questions about this research, and they have been answered to my satisfaction.
- I am aware that if I have any further questions about the research, I can contact the researcher or supervisor.
- I understand that the research will be a face-to-face interview and will take approximately 1 hour and may include a follow-up conversation by phone of approximately 10 minutes to check what I have said.
- I understand that all information I provide will remain private and confidential, and that my identity will not be disclosed or recorded with my information.
- I understand that I am free to withdraw from this research project at any time without penalty, and I am not required to explain why.
- I agree to participate in this study.

\_\_\_\_\_  
Participant's signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Contact number

\_\_\_\_\_  
Researcher's signature

\_\_\_\_\_  
Date

Appendix F  
Exemplar Journal Extract

## Journal Extract

June 2014

Listening to this participant really made me think about the responsibility we have to ensure that people in this situation have the support they need to manage their own lives and the lives of those in their care.

June 2014

Each person had a little story around how the diagnosis was made. It was very important that they told this story. They needed to put their story in context and so often this included what happened before the diagnosis. That's how they made sense of it.

June 2014

I was thinking about how you as a partner can understand how the other feels when they are ill. What your partner's actually experiencing seems to be very difficult. Reading an article recently on how the symptoms of Parkinson's are experienced by the individual, prompted me to "act" out the description. It occurred to me while doing this, that to begin to understand what someone with Parkinson's is experiencing you need to really get in touch with the problem both physically and emotionally. That takes time and commitment.

June 2014

It seems that I would not have felt like this. I spoke to my supervisor. Is this really what the participant is saying? I was trying not to interpret too much but at times it was difficult. So we went back to the words – what was said.

Appendix G  
Participant Resource Sheet

ECU Letterhead

**List of Counselling Services**

Lifeline: 13 11 14

Mental Health Direct: 1800 220 400

Mental Health Emergency Response Line: 1300 555 788

Australian Red Cross Counselling Service: 1800 052 222

The Samaritans: 9381 5555

Edith Cowan University Psychological Services Centre: 9301 0011

Parkinson's WA: 934607373

For free health advice 24 hours a day call *healthdirect Australia* on 1800022222

**For serious and life-threatening conditions call 000 or visit a hospital emergency department**

Appendix H  
Risk Management Procedures and Incident Report



## **Risk Management and Incident Report**

### **Risks**

#### **Monitoring participant for emotional distress**

The researcher will monitor for evidence of distress in the participant during the interview. In the case of distress the researcher will take immediate steps to sensitively terminate the interview and reschedule or finalise. The participant will not be left in an anxious state. The researcher will listen to the participant and direct the participant to appropriate support services, provided on a prepared resource sheet. If necessary the researcher will contact the supervisor for further advise.

#### **Being alone with participant in their own home**

- (i) Researcher will inform husband via mobile phone prior to, and at the conclusion of, every home visit. If the second call is not received, the family member will phone and make enquiries about the whereabouts of the visiting researcher.
- (ii) The researcher will also advise the supervisor of times and location of interviews.
- (iii) The researcher will access the location on arrival. If the researcher is uncomfortable with the environment, the researcher will sensitively terminate the interview and leave the premises.

### **Incident Report**

All incidents will be documented on an incident report form and provided to the Supervisor.

ECU Letterhead

**Incident Report**

Date: \_\_\_\_\_

Time: \_\_\_\_\_

Name: \_\_\_\_\_

Address of incident: \_\_\_\_\_

\_\_\_\_\_

Description of incident:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Supervisor: \_\_\_\_\_ Date: \_\_\_\_\_

Researcher: \_\_\_\_\_ Date: \_\_\_\_\_