

Literature review:

What is the impact of mindfulness interventions for people with Parkinson's disease?

Research report:

The psychological impact of Parkinson's disease patients' delusions on spouses.

Critical appraisal:

A reflection on the research process from beginning to end to aid future research.

Thesis submitted to the University of Leicester
The Department of Neuroscience, Psychology and Behaviour
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Declaration

The research reported herein is my original work and has not been submitted for any other academic award. The thesis has been checked for completion prior to submission.

The psychological impact of Parkinson's disease patients' delusions on spouses:

A Thematic Analysis

Caroline Joyce Nolan

Thesis abstract

Parkinson's disease (PD) patients suffer from a progressive neurological illness that can affect their mobility and gait. They suffer from tremors and stiffness and can have non-motor symptoms such as hallucinations and delusions. An examination of mindfulness in Part One: Literature review highlights the effects of the PD illness on people and their spouses. It became apparent that there is a lot of stress in PD families and the researcher's focus of study shifted to one aspect of that psychological stress that affects spousal caregivers due to PD delusions. There was insufficient published research papers to merit a separate literature review. Part Two: Empirical Research, looks in particular at the phenomena of delusions which affect a small percentage of the patients as the illness progresses or if the dosage of dopamine agonist medications to treat their PD symptoms is too strong. The empirical research seeks to examine the experiences of spouses living with partners who have had PD related delusions and to determine how it affects them psychologically.

Literature review

A search of four electronic data bases resulted in six studies being selected that met the research inclusion and exclusion criteria. While the six studies looked at mindfulness interventions for people with Parkinson's disease, it became apparent that there is a dearth of studies in this area and in wider psycho-social topics that pertain to psychological and emotional stress on PWP and their spouses.

Research Report

Twelve spouses whose partners had PD delusions were interviewed to capture their experiences and to determine how they were impacted psychologically. Four themes emerged with sub-themes from the thematic analysis of the semi-structured interview transcripts. The results point to significant psychological impact on the caregiver spouses and how it often goes undetected by clinicians because it is under reported by caregiver spouses due to shame and embarrassment. The findings suggest that these issues should be addressed in the clinics for the PD patients for better treatment and care of the patients and their spouses who are their informal caregivers.

Critical Appraisal

The various steps of the research from beginning to end are noted and reflected upon to garner insights into what was helpful for future research.

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Part One: Literature Review

What is the impact of mindfulness interventions for people with Parkinson's disease?

- Literature review

1 Abstract

Parkinson Disease (PD), a degenerative neuro-motor condition, presents with diverse symptoms and is treated predominantly through pharmacological means. Non-pharmacological therapies have more recently been welcomed as complementary ways of treating PD. Amongst those are therapies based on mindfulness, and different studies use various terms for relatively similar approaches with mindfulness such as Mindfulness-Based Stress Reduction Lifestyle Programs (MBSRLP); Mindfulness Meditation (MM); Mindfulness-Based Cognitive Therapy (MBCT). This review examines the research literature studying the impact of mindfulness interventions delivered for people with Parkinson's (PWP).

Method: Four electronic data bases were interrogated in March 2019 (MedLine; PsycINFO; CINAHL; PubMed), along with grey literature via OpenGrey Database and ProQuest Dissertations and Theses (PQDT). From a total of x abstract, eight studies deemed eligible and critical appraisal through the aid of AXIS tool for mixed methods.

Results: A narrative analysis of the studies was conducted. While most studies focus on cognitive impacts in relation to mood, i.e., depression, anxiety and stress levels, studies also find impact on physical symptoms of PD, e.g., gait, rigidity, sleep and even sub-cortical changes. Limitations are that the sample groups in the studies are small. The results are mainly based on self-reporting statements and assessment tools.

Conclusion: While all of the studies record some impact that MBIs have on PWP, the impact wanes after most of the studies conclude. Benefits may be a function of social interaction of PWP in groups that affects their mood, thinking and subsequent behavior rather than the intervention per se. Given the cross sectional nature of these studies, longitudinal studies appear needed to establish causality and understand whether improvements sustain.

Key words

interventions; mindfulness; Parkinson's disease (PD); people with Parkinson's (PWP)

2 Introduction

2.1 Parkinson's disease

Parkinson disease (PD) is a chronic, progressive neurological disorder that affects motor and non-motor functioning. People with PD (PWP), there is psychological distress due to the decline in the patient's well-being and it is visible in the advent or heightened states of depression and anxiety that they experience. While pharmacological treatments are common, patients and their family members as well as medical and health professionals are open to other forms of treatment, e.g., mindfulness.

2.2 Mindfulness

Mindfulness was first introduced to clinical settings by Kabat-Zinn (Kabat-Zinn, 1982) who respected the contemplative practices arising out of Buddhism. He had patients who had chronic pain who undertook mindfulness meditation, with the results revealing a decrease in their self-reported pain levels (Kabat-Zinn, 1982). Mindfulness-based programs (MBPs) after this, began to be integrated as complimentary therapy within medicine to help with stress reduction and cognitive therapy with patients. Mindfulness was embraced by many disciplines because it draws upon the practice of medicine, psychology and education and a person's human experience and awareness of the present moment (Crane et al., 2017). The goal of mindfulness practice is to better regulate a person's behaviour and emotional responses to experiences and situations. It is a practice that is religious and culture free. Mindfulness is about attending to one's experiences in a non-judgmental way with regards to one is feeling (Ludwig & Kabat-Zinn, 2008). The success of mindfulness practice as reported by Kabat-Zinn (Kabat-Zinn 1982) onwards has led to the development of mindfulness-based interventions (MBIs).

Mindfulness has evolved as an adjunct and developed therapy since the advent of Cognitive Behaviour Therapy (CBT). CBT is a psychological treatment that provides empirical evidence of the changes in behavior, thoughts and feelings in people. The focus in the 1950s with Albert Ellis was on behavioural changes. The second wave of CBT in the 1960s focused on how people learned to identify and manage their maladaptive thoughts that affected their emotions and behavior. Mindfulness is considered to be the third wave of CBT. In the early 2000s, it came to the fore in hospital and clinical settings and its therapeutic use focuses on patients' relationships to their thoughts and emotions than on the

content of them, i.e., the focus was on how they thought and not on what they thought (Carvalho et al., 2017; Hayes & Hofmann, 2017).

2.3 Mindfulness Interventions

MBIs can be delivered in diverse forms. Those which have an increased focus on relaxation are often termed Mindfulness Meditation: MM, cognitive that attempt to consider various perspectives (Mindfulness-Based Cognitive Therapy: MBCT); stress reduction sessions (Mindfulness-Based Stress Reduction: MBSR). The MBIs have been offered to PWP as group experiences initially with subsequent direction to practice mindfulness individually, for example, at home (Rodgers et al., 2019 [MBCT]; Advocat et al., 2016 [MBSR]; Cash et al., 2016 [MM]; Dissanayaka et al., 2016 [MM]; Pickut et al., 2013, 2015 [MM]; Son et al., 2018 [MM]). The interventions are usually short, involving group classes for exposure to the methods and are usually delivered over a six to eight week period. The effects of mindfulness practice can be measured through various assessment tools (see table 4 – mental health measure)

Given the apparent effectiveness of MBIs there has been growing interest in their utility for long-term health conditions. Their focus on acceptance and living within the limits of a condition have an intrinsic and therapeutic appeal and fit for those whose health will be challenged lifelong, and whose prognosis may not be positive, such as in the neurodegenerative PD. MBI flexibility is also a strength for PWP as it can involve engagement in groups, or utilizes techniques that can be translated into home environments, a significant consideration as disability increases for PWP. Since anxiety, depression and hopelessness are documented in PWP, these interventions may well address psychological morbidity evident in those living with PD. In order to examine the body of literature to date that may have assessed the impact of mindfulness based interventions on psychological morbidity presented by those with PD, this systematic review was undertaken.

3 Method Data

3.1 Sources and Searches

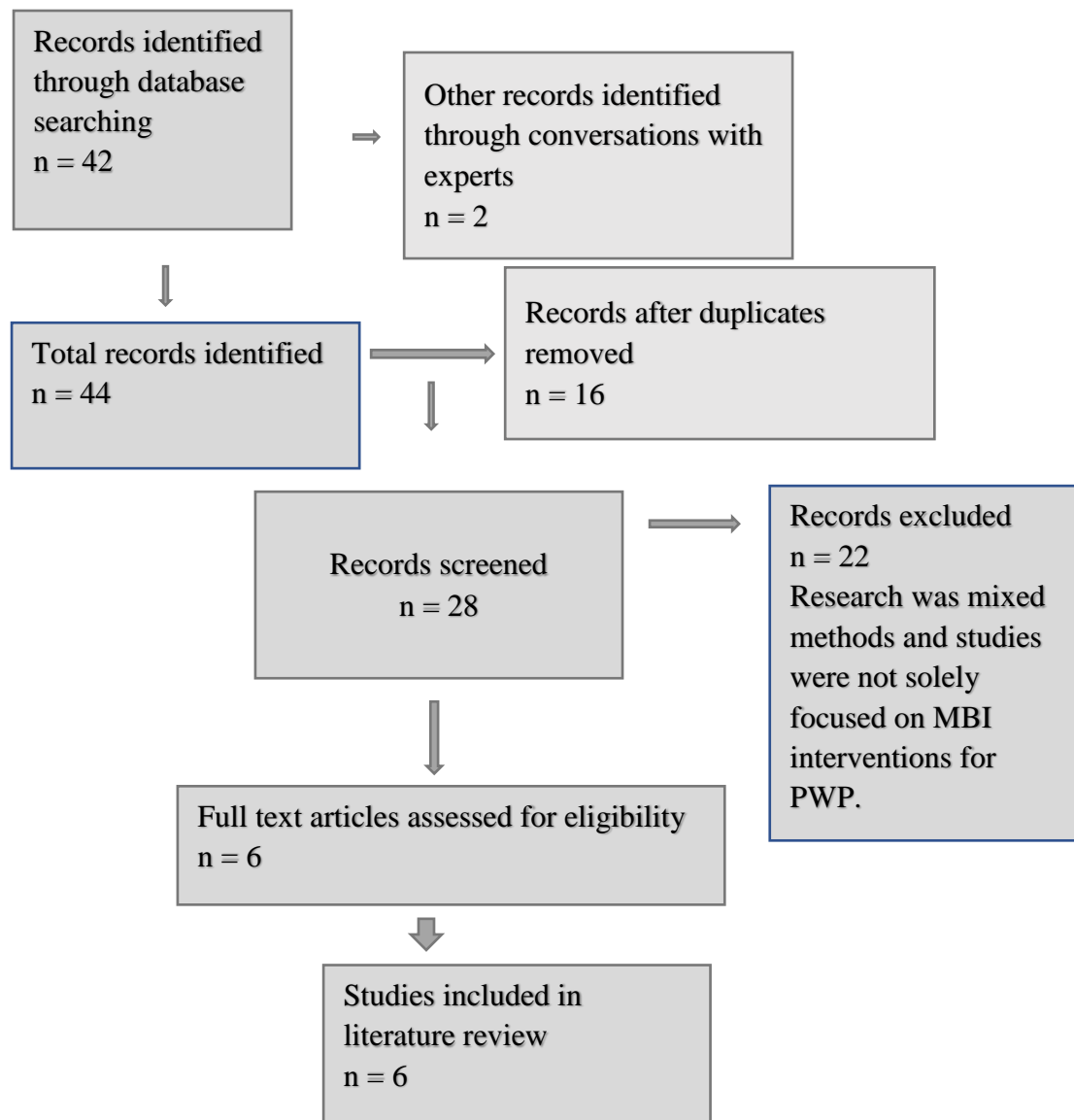
3.3.1 Research question

A systematic search of MBIs and PD was conducted to answer the research question: ‘*What is the impact of mindfulness interventions on people with Parkinson’s disease?*’ The PICO format was used to ensure that the research question was well defined in turn ensuring a focused search of the literature. PICO appraisal tool was located at <https://guides.library.ualberta.ca/catwalk/ask-a-clinical-question>

Table 1. PICO model

<u>P</u> opulation	People with Parkinson’s disease
<u>I</u> ntervention	Mindfulness-based interventions
<u>C</u> omparison	Control groups / Usual care and treatment
<u>O</u> utcome	Improve symptoms of PD

Table 2. Prisma flow chart of records searched for MBSIs with PWP



3.1.2 Eligibility criteria

The studies were considered for eligibility if they were: (1) Written in English; (2) Published in peer reviewed journals and (3) Quantitative. The exclusion criteria: The studies were (1) not focused on PD as the main neurological illness; (2) not focused on MBIs as the main therapeutic intervention and (3) not focused on PD and MBIs as the main focus of research study.

3.1.3 Search

A search of four electronic databases from February 20th to March 7th, 2019 (MedLine; PsycINFO; CINAHL; PubMed), grey literature searched in OpenGrey Database and ProQuest Dissertations and Theses (PQDT). The writer was assisted by a qualified research librarian to ensure that all possible research articles were located within the searched databases.

The ProQuest search found a review by McLean et al., (2017) on MBSI in PD that included two interventions and three papers, that of Cash (2016) and Pikut et al. (2013; 2015). No other published papers were listed and studies in progress were not relevant to the research question. The search was repeated on March 7th 2019 with a librarian from the Knowledge Resource Services (KRS for Alberta Health Services [AHS], Canada) for confirmation of correct search criteria.

The search (for search line details, see Appendix A) contained the following key words: exp Parkinson Disease/; exp Mindfulness/; mindfulness intervention.ti and either Mindfulness or mindfulness intervention.ti with Parkinson Disease for Medline. The same phrases are used for PsycINFO for the explosion of Parkinson Disease and Mindfulness. Within CINAHL the terms are (MH “Parkinson Disease”) and (MH Mindfulness”) and combined as intervention did not yield any different results. Within PubMed the search term was short and consisted of one phrase that produced results that were appropriate for the research question, the search phrase was ‘parkinson disease and mindfulness’.

3.1.4 Search results

The databases, (see table 2 below), yielded 42 abstracts (MEDLINE [7]; PsycINFO [5]; CINAHL [14]; PubMed [16]) with 16 duplicates. Bibliographies of all studies were read by two people. Additional records identified through other sources, e.g., conversations with research and professional experts, yielded a further two records which were, upon examination, duplications of articles scoped through the databases. Fourteen duplicates were removed. Of the remaining 28 abstracts, 22 were excluded because they did not meet the inclusion criteria, i.e., not PD and MBI focused. Six full text articles remained.

3.1.5 Data extraction

A data extraction form was created to include relevant data – see: Appendix B: Data Extraction. It was modified to fit various methodical approaches, e.g., mixed methods

appraisal tool scores (AXIS). It asks for the following information: Reference (First author/ Year/ Journal citation); Topic; Location: Country; Sample size: Intervention population # and the Control population #; Population focus; Quality score; Theoretical framework: Study design type [Interviews; Support Groups; Questionnaires; Other and Interventions and Results. The data extraction form was thorough and helped with gaining clarity with regard to the type of studies, the focus and particular details relative to each study.

3.2 Quality Assessment

The seven studies emerging from the literature search were examined with the appraisal tool AXIS (Downes et al., 2016). AXIS is composed of five sections: (1) Introduction; (2) Methods (3) Results (4) Discussion (5) Other.

<i>Introduction</i>
1 Were the aims/objectives of the study clear?
<i>Methods</i>
2 Was the study design appropriate for the stated aim(s)?
3 Was the sample size justified?
4 Was the target/reference population clearly defined? (Is it clear who the research was about?)
5 Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation?
6 Was the selection process likely to select subjects/participants that were representative of the target/reference population under investigation?
7 Were measures undertaken to address and categorise non-responders?
8 Were the risk factor and outcome variables measured appropriate to the aims of the study?
9 Were the risk factor and outcome variables measured correctly using instruments/measurements that had been trialled, piloted or published previously?
10 Is it clear what was used to determined statistical significance and/or precision estimates? (e.g., p values, CIs)
11 Were the methods (including statistical methods) sufficiently described to enable them to be repeated?
<i>Results</i>
12 Were the basic data adequately described?

13 Does the response rate raise concerns about non-response bias?
14 If appropriate, was information about non-responders described?
15 Were the results internally consistent?
16 Were the results for the analyses described in the methods, presented?
<i>Discussion</i>
17 Were the authors' discussions and conclusions justified by the results?
18 Were the limitations of the study discussed?
<i>Other</i>
19 Were there any funding sources or conflicts of interest that may affect the authors' interpretation of the results?
20 Was ethical approval or consent of participants attained?

The results of the AXIS tool analysis are in Table 3 below. Two raters independently assessed the studies to determine if they met the quality appraisal criteria.

Through discussion and consensus the studies were delegated a positive or negative score to determine if they met the quality expected for inclusion in a narrative synthesis pertaining to the research question.

Table: 3. Quality assessment – AXIS tool for cross sectional studies (see questions in Appendix D).

AXIS	Advocat et al., (2016)	Cash et al., 2016)	Pickut et al., (2013)	Pickut et al., (2015)	Rodgers et al., (2019)	Son et al., (2018)
Q1	Y	Y	Y	Y	Y	Y
Q2	Y	Y	Y	Y	Y	Y
Q3	Y	Y	Y	Y	Y	Y
Q4	Y	Y	Y	Y	Y	Y
Q5	Y	Y	Y	Y	Y	Y
Q6	Y	Y	Y	Y	Y	Y
Q7	Y	Y	Y	Y	Y	Y
Q8	Y	Y	Y	Y	Y	Y
Q9	Y	Y	Y	Y	Y	Y
Q10	Y	Y	Y	Y	Y	Y
Q11	Y	Y	Y	Y	Y	Y
Q12	Y	Y	Y	Y	Y	Y
Q13	N	N	N	N	N	N
Q14	Y	Y	Y	Y	Y	Y
Q15	Y	Y	Y	Y	Y	Y
Q16	Y	Y	Y	Y	Y	Y
Q17	Y	Y	Y	Y	Y	Y
Q18	Y	Y	Y	Y	Y	Y
Q19	N	N	N	N	N	N
Q20	Y	Y	Y	Y	Y	Y

Key: Yes = Y; No = N; Do not know / comment = DNK/C

Table 4. Description of included studies examining mindfulness-based interventions for people with Parkinson's

Author/Year Location	Aims of selected studies' author	Study design + Intervention	Sample size	Population Focus	Measure and Significant Results	QA Score
MBSR Advocat et al., (2016) Australia	The effects of a mindfulness-based lifestyle program for adults with Parkinson's disease	RCT & waitlist <u>Intervention:</u> Mindfulness – 6 weeks (4-6 sessions) + 6 month follow-up	n = 72	PWP – H&Y Stage 2 PD	PDQ-39 showed a small but significant effect size by MBSR participants($\beta = 0.23$) $p = 0.04$ at 6 month follow-up	18
MM Cash et al., (2016) USA	Pilot study of a mindfulness-based group intervention for individuals with Parkinson's disease and their caregivers	Case study <u>Intervention:</u> Mindfulness - 8 weeks	n = 39	PWP and their family members from a movement disorders specialty clinic	Everyday cognition questionnaire:-language subscale $p = .012$; Emotional functioning:-PHQ-9 rating scale) $p = .011$; -FFMQ $p = .001$; -QOL:-emotional functioning $p = .004$; -cognitive functioning $p = .044$; Effects seen in patient sample:-Animals T score $p = .020$; Digit span sequencing SS $p = .048$	18
MM Pickut et al., (2013)	Mindfulness based intervention in Parkinson's disease leads to structural brain changes on MRI.	RCT with Objective Measure (MRI) <u>Intervention:</u>	n = 27	PWP – H&Y Stages 1-3	Increase in GMD from pre- to post MBI. Active versus controls: $p < 0.001$ Amygdala; Hippocampus; Hippocampus/	18

Belgium		Mindfulness - 8 weeks			Parahippocampus; Caudate nucleus; Occipital lobe cuneus; Occipital lobe lingual gyrus; Temporal lobe middle gyrus and inferior gyrus Thalamus; Cerebellum anterior lobe and dentate nucleus	
MM Pickut et al., (2015) Belgium	Mindfulness Training among Individuals with Parkinson's Disease: Neurobehavioral Effects	RCT <u>Intervention:</u> Mindfulness - 8 weeks + 8 week follow-up	n = 27	PWP – H&Y Stages 1-3	UPDRS p < .05 FFMQ p < .01	18
MM Son et al., (2018) Korea	The Effects of Mindfulness Meditation-Based Complex Exercise Program on Motor and Nonmotor Symptoms and Quality of Life in Patients with PD	RCT <u>Intervention:</u> MMBCEP – 8 weeks (6 sessions)	n = 63	PWP – H&Y Stages 1-3	<u>Motor symptoms</u> Chair stand test (time/30 sec) p .015; Shoulder suppleness (cm) p.012; 2.45 m walk test (sec) p <.001; 6-min walk test (m) p <.001 <u>Nonmotor symptoms</u> Depression p <.001; Anxiety – State p <.001; Anxiety – Trait p.006; Cognitive function p.0001 Sleep disturbance p.002; Activities of daily living Quality of life p.006	18
MBCT Rodgers et al.,	Modified Mindfulness-Based Cognitive Therapy for Depressive	RCT & waitlist <u>Intervention:</u>	n = 36	PWP - H&Y	DASS-21 for MBCT participants p = .019 GAI for MBCT participants p = .003	18

(2019)	Symptoms in Parkinson's Disease:	MBCT- 8 weeks				
Australia	a Pilot Trial					

KEY: DASS-21, Depression Anxiety and Stress Scale; DBS, Deep Brain Stimulation; FFMQ, The Five Facet Mindfulness Questionnaire; GAI, Geriatric Anxiety Inventory; H&Y, Hoehn & Yahr ; MB, Mindfulness-Based; MBCT, Mindfulness-Based Cognitive Therapy; MBLP, Mindfulness-Based lifestyle program; MBSR, Mindfulness-Based Stress Reduction; MM, Mindfulness Meditation; MMSE, MMBCEP, Mindfulness meditation-based complex exercise program; PD, OQ-45; Outcome Questionnaire; PDCRS, PD Cognitive Rating Scale; PIGD, Postural instability gait dysfunction; PWP, People with Parkinson's; UPDRS, Unified PD Rating Scale.

3.3 Synthesis of Results

3.3.1 Thematic synthesis

In this thematic synthesis, six quantitative studies met the selection criteria and were examined through the use of the AXIS tool. All questions were answered in the affirmative ‘yes’ apart from questions 13 and 19 respectively, which required a negative ‘no’ response. The papers were deemed to be solid and reputable for the purposes of answering the research question that is the basis of this literature review.

3.3.2 Populations studied

PWP meeting the Hoehn & Yahr Scale of PD between stages 1-3, PWP meeting the Queen square Brain Band criteria for idiopathic PD. Anyone who met these criteria but had dementia or scored less than 24 in the SMMSE or had DBS were excluded.

The studies selected recorded the ages of the participants (see table 4) as being between ages or a mean age. Between ages were reported in Advocat et al., 2016 as 18-75; Rodgers et al., as 40-70; Son et al., 60-69. Mean ages were reported in Cash et al., as 65.6; Pickut et al., 2013 as 61.8 and Pickut et al., 2015 as 62.2. There is a discrepancy between the two studies that were based it would seem on the same cohort of 27 participants. The cohorts in descending numerical order of subject participants (Study participants): Advocat et al., 2016, n = 72; Son et al., n= 63; Cash et al., 2016, n = 39; Rodgers et al., 2019, n = 36; Picut et al., 2013, n = 27; Pickut et al., 2015, n = 27. Five studies stated that the Study participants were in one of the stages numbered 1-3 in the Hoehn & Yahr scale and one just identified the participants as having PD (Rodgers et al., 2019).

3.3.3 The study designs

The studies are quantitative and use a variety of mental health measure tools to evaluate the forms of mindfulness interventions.

Forms of mindfulness interventions

MM - Cash et al., 2016; Pickut et al., 2013, 2015
MBSR - Advocat et al., 2016
MBCT - Rodgers et al. 2019

4 Results

The research literature, (Pickut et al., 2013; 2015) shows corollary evidence that MBIs (Mindfulness-Based Interventions) in PWP lead to structural changes on MRI (Pickut et al., 2013) and neuro-behavioural changes (Pickut et al., 2015). These studies examine how MBIs can affect PWP so that the effects change their brains and how that possibility affects how they behave. The 2013 study of Pickut et al., found increased grey matter density in the areas of the brain that are impacted by regular meditative practices. This study was reviewed along with Pickut et al.'s, later study in 2015 and that of Cash et al., 2016, as part of a systematic review of MBSR in PD by McLean et al., 2017. The systematic review found only limited evidence that MBSRs can be useful to PWP due to small sample sizes. Only one of the studies used a control group that received 'usual care'. McClean felt that the reasons for study participants dropping out from the studies were not reported in either Pickut et al., (2013; 2015) study and that of Cash et al., 2016. McLean et al., 2017, argue for more information regarding the participants, e.g., their socio-economic status, and they felt that the follow up interventions were too short to gather more information that may point to the effectiveness of MBIs on PWP.

An important addition to MBI literature is an Australian study (Advocat et al., 2016) demonstrating that early interventions like MBLPs (Mindfulness-Based Lifestyle Programs) improve QOL of PWP and have durable effects. The DASS-21 and PDQ-39 scores (see table 4) convey how the MBLP helped to diminish the severity of the PD symptoms such as depression, anxiety and stress. Mindfulness, it seems from this study, was sustained for PWP

post group work and by extension could be practiced independently by volunteers as part of plan to manage PD symptoms. The more mindful PWP were as measured by regularity and length of practice, the more likely they were to report improvements in their emotions and general mental health as is evidenced by the lack of improvements by the non-MBLP/control group. The knowledge of mindfulness techniques was key in giving the PWP a tool with which to work with for the betterment of their lives while living with a chronic illness, i.e., PD. Along with positive changes in their well-being, psychologically, PWP who engaged in mindfulness, according to the findings of the study (Advocat et al., 2016), also noted improved motor functioning.

An American study (Cash et al., 2016) looked at MBIs to evaluate their impact on PWP. The studies show many cognitive benefits as well as improved motor functioning as a result of the MBIs. The American study (Cash et al., 2016) found that the MBI lead to an improvement in depression, language functioning, mental flexibility and complex attention as well as reduced emotional and cognitive symptoms of PD.

A study from Korea, (Son et al., 2018), taught PWP MMBCEP (Mindfulness-meditation-based complex exercise program). They also had the study participants assessed with the Korean version of the GDS and K-MoCa along with STAI, PDSS and they assessed their ADL and QOL. The improvements reported increased motor functioning [lower and upper extremity] and a decrease in non-motor symptoms, i.e., depression, anxiety, cognitive functions and sleep disturbances. Participants also reported enhanced ADL and QOL. MMB practice is said to stimulate of the parasympathetic nervous system through the deep breathing of the Study participants (Son et al, 2018). They assert that meditation has a positive impact on a person's ability to concentrate and regulate emotions. The study design is pragmatic in which the variables are not set. There was the risk of bias due to the sample of Study participants that was convenient, SP activity in their homes was not monitored and a post-intervention examination was not documented to determine whether mindfulness-meditation benefits were prolonged or sustained.

The most recently published study from Australia, Rodgers et al., 2019, focused on mindfulness-based therapy, in this case MBCT. It reports a decline in depressive symptoms in the participants. However, there was no change in the levels of anxiety or QOL at the group level but there was a reduction for individuals who were in the MBCT group. There was a control group, a waitlist group, for the study. While the study does show some benefits from the MBCT, Rodgers et al., 2019, note that the Study participants had low levels of depression and anxiety at baseline. A bigger sample and one that had higher measures of emotional and mental health stressors may have produced data that would better substantiate the findings. The researchers' findings suggest that modified MBCT for PWP suffering from depressive symptoms may hold promise as an intervention, but they doubt its efficacy as a tool to address the impacts of anxiety and the QOL for PWP.

5 Discussion

The articles on mindfulness interventions for PWP spanned 2000-2019 with the introduction of the third wave of CBT of which stand-alone mindfulness practices were being used as complimentary therapy for PWP within hospital / clinical settings (Hayes & Hofmann, 2017). Note that OVID only introduced the keyword 'Mindfulness' into its data base in 2014. Before this, the term used was 'cognitive therapy'. Given the scope of 'cognitive therapy' this review does not include it in the search on MBIs in PD and this study is not focused on waves 1 and 2 of CBT. This may limit the number of articles retrieved but it also shows that there was a shift in understanding of Mindfulness from the 2000s onwards with the introduction of the 3rd wave of CBT and with its specific introduction to databases as in the example of Ovid's insertion of it in 2014. However, searches from the four data bases using 'Mindfulness' do track studies from 2013 up to 2019 which are included in this review. While every aspect of the terms pertaining to MBSIs were used, there may be articles that were not caught in the search.

Deeper examination of study design, conduct and analysis reveals high variability in study quality. There are several gaps in the literature, including: the reasons for participant drop-out; incomplete study questionnaire completion despite completion of an intensive

course. There is no indication that the quality of the MBSIs were equal across the studies including: therapist experience, ratio of therapists to volunteers in group settings, school of philosophy of the intervention therapist, therapeutic effectiveness, what domains of the therapeutic intervention were most helpful for volunteers. Some studies within the research literature can be more specific about the content of the Mindfulness practice (e.g., Goodrich et al., 2015). The delivery of a course will differ according to the facilitator. Many studies do not provide the content of the courses. It would appear that at times there was confusion initially for study participants regarding what was involved or required of them. There was no way to monitor how the study participants behaved post class settings and whether or not they give more time to mindfulness practice in between therapeutic sessions. The variables differed widely and most of the data relied on self-report measures regarding how mindfulness was indeed changing the study participants' moods and thoughts. The study samples were small overall. More study regarding the benefits of MBSIs for PD patients is merited. This review demonstrates the necessity for further studies using validated tools, more descriptive detail regarding how MBSRs are taught, therapeutic effectiveness and which domains of therapeutic effectiveness are most impactful for PWP. Methods to encourage continued use of mindfulness techniques should be explored.

6 Recommendations for future research and clinical practice

Therapies that include alternatives to pharmacological interventions are gaining popularity for PWP and for those suffering from other neurodegenerative diseases (Li et al., 2016). Research is necessary, MBIs have long been associated with positive outcomes for cancer and cardiac patients (Petricone-Westwood et al., 2018), but this review would point to benefits for PWP. With the advancement in technological, and the introduction of new and diverse psychological interventions (e.g., relaxation training such as Yoga (Justice et al., 2018) and counseling (Benge et al., 2018) are becoming possible through remote delivery (Swalwell et al., 2018). MBIs are perfectly suited for transmission via telehealth and over the phone. There is also the possibility today of apps and computer programs (brain games and exergaming, Benge et al., 2018). It would be important for researchers to consider the standard of MBIs regarding their content and efficacy. What constitutes a solid and therapeutic MBI? Do

teachers need a quick course or should they be grounded in knowledge regarding the challenge of a PWP. If PWP are experiencing tremors at the time of their MB class or session, how do they relax and become mindful, is it the same as for a non-PD sufferer? What are the criteria for MBIs? How does a study qualify a practice that relies on self-reporting? While the benefits of MBIs were clear from the various studies, it would suggest that the practice of MBI was short overall, with a few continuing it after their study finished. Longitudinal studies may elicit more data and having bigger sample sizes and participants with higher baseline scores pertaining to levels of depression, anxiety and stress so that the true effects of MBIs can be measured more accurately.

7 Conclusion

The dearth of studies on MBIs points to the challenges around the assessment of their efficacy in the treatment of PD patients. While the studies do not equivocally show sustained or, in many cases, significant benefits, mindfulness was demonstrated to increase white matter which in turn may imply improved connectivity. Further, mindfulness can improve self-regulation in PWP benefitting anxiety, depression and hopelessness. Mindfulness is low-to no risk intervention compared to the majority of treatments for PWP. Mindfulness can be cost effective, portable and adaptable. Having to attend to the activities of daily life that are necessary, carving out time for mindfulness can seem like one extra thing to do, even if remembered. It would seem from the quantitative data from the mood and cognitive tools that the study participants did benefit somewhat from the various MBIs and how they may serve as complimentary therapies for PWP and their family members living and coping with PD as well.

8 References

1. Advocat, J., Enticott, J., Vandenberg, B., Hassed, C., Hester, J. et al., (2016). The effects of a mindfulness-based lifestyle program for adults with parkinson's disease: A mixed methods, wait list controlled randomised control study. *BMC Neurology*, 16, 1. doi:10.1186/s12883-016-0685-1 [doi]
2. Advocat, J., Russell, G., Enticott, J., Hassed, C., Hester, J. et al., B. (2013). The effects of a mindfulness-based lifestyle programme for adults with parkinson's disease: Protocol for a mixed methods, randomised two-group control study. *BMJ Open*, 3(10), 003326. doi:10.1136/bmjopen-2013-003326 [doi]
3. Bengt, J.F., Roberts, R. L., Kekecs, Z. & Elkins, G. (2018). Brief report: Knowledge of, interest in, and willingness to try behavioral interventions in individuals with Parkinson's disease. *Adv Mind Body Med*. 32(1), 8-12.
4. Bogosian, A., Hurt, C. S., Vasconcelos E Sa, D., Hindle, J. V., McCracken, L. et al., (2017). Distant delivery of a mindfulness-based intervention for people with parkinson's disease: The study protocol of a randomised pilot trial. *Pilot and Feasibility Studies*, 3, 4. eCollection 2017. doi:10.1186/s40814-016-0117-4 [doi]
5. Carvalho, S., Martins, H., Almeida, S., Silva, F. (2017). The evolution of cognitive behavioural therapy – The third generation and its effectiveness. *European Psychiatry*, 41: 773-774. <https://doi.org/10.1016/j.eurpsy.2017.01.1461>
6. Cash, T. V., Ekouevi, V. S., Kilbourn, C., Lageman, S. K. (2016). Pilot study of a mindfulness-based group intervention for individuals with Parkinson's disease and their caregivers. *Mindfulness*, 7:361-371.
7. Crane, R., Brewer, J., Feldman, C., Kabat-Zinn, J., Santorelli, S., Williams, J. & Kuyken, W. (2017). *PsycholMed* 47(6) 990-999. doi: 10.1017/S0033291716003317
8. Downes, M. J., Brennan, M. L., Williams, H. C. & Dean, R. S. (2016). Development of a critical appraisal tool to assess the quality of cross-sectional studies (AXIS). *BMJ Open*, 6(12). doi:10.1136/bmjopen-2016-011458

9. Duggleby, W., Holtslander, L., Kylma, J., Duncan, V., Hammond, C. & Williams, A. (2015). Meta-synthesis of the hope experience of family caregivers of persons with chronic illness. *Qualitative Health Research* 20(2) 148-158. DOI:10.1177/104973230935329
10. Ghaffari, B. D. & Kluger, B. (2014). Mechanisms for alternative treatments in Parkinson's disease: Acupuncture, Tai Chi, and other treatments. *Curr Neurol Neurosci Rep.* 14:451. doi: 10.1007/s11910-014-0451-y
11. Goodrich, E., Wahbeh, H., Mooney, A., Miller, M., Oken, B. (2015). Teaching mindfulness meditation to adults with severe speech and physical impairments: An exploratory study. *Neuropsychological Rehabilitation*, 25(5), 708-732.
12. Hayes, S., Hofmann, S. (2017). The third wave of cognitive behavioral therapy and the rise of processed-based care. *World Psychiatry*, 16(3), 245-246.
13. Justice, C., Cheung, C. & Samson-Burke, A. (2018). Development and evaluation of a yoga intervention program for Parkinson's disease. *Int J Yoga Therap.*, 20(1), 113-122. doi: 10.17761/2018-00015R2.
14. Kabat-Zinn J. (1982) An outpatient program in behavioral medicine for chronic pain patients based on the practice of mindfulness meditation: theoretical considerations and preliminary results. *Gen Hosp Psychiatry.* 4(1):33-477042457
15. Li, S., Dong, J., Cheng, C., Weidong, L. (2016). Therapies for Parkinson's diseases: alternatives to current pharmacological interventions. *J Neural Transm* 123, 1279-1299. doi: 10.1007/s00702-016-1603-9.
16. McLean, G., Lawrence, M., Simpson, R., & Mercer, S. W. (2017). Mindfulness-based stress reduction in parkinson's disease: A systematic review. *BMC Neurology*, 17(1), 4. doi:10.1186/s12883-017-0876-4
17. Ludwig, D., Kabat-Zinn, J. (2008) Mindfulness in medicine. *JAMA* 300(11) 1350-1352. doi:10.1001/jama.300.11.1350

18. Petricone-Westwood, D., Jones, G., Mutsaers, B., Séguin Leclair, C., Tomei, C., Trudel, G., Dinkel, A. et al. (2018). A systematic review of interventions for health anxiety presentations across diverse chronic illnesses. *International Journal of Behavioral Medicine*. doi:10.1007/s12529-018-9748-6.
19. Pickut, B. A., Van Hecke, W., Kerckhofs, E., Marien, P., Vanneste, S., Cras, P. et al. (2013). Mindfulness based intervention in parkinson's disease leads to structural brain changes on MRI: A randomized controlled longitudinal trial. *Clinical Neurology and Neurosurgery*, 115(12), 2419-2425. doi:10.1016/j.clineuro.2013.10.002 [doi]
20. Pickut, B., Vanneste, S., Hirsch, M. A., Van Hecke, W., Kerckhofs, E., Marien, P. et al. (2015). Mindfulness training among individuals with parkinson's disease: Neurobehavioral effects. *Parkinson's Disease*, 2015, 816404. doi:10.1155/2015/816404 [doi]
21. Rodgers, S. H., Schutze, R., Gasson, N., Anderson, R. A., Kane, R. T., Starkstein, S. et al. (2019). Modified mindfulness-based cognitive therapy for depressive symptoms in parkinson's disease: A pilot trial. *Behavioural and Cognitive Psychotherapy*, 1-16. doi:10.1017/S135246581800070X [doi]
22. Swalwell, C., Pachana, N. & Dissanayaka, N. (2018). Remote delivery of psychological interventions for Parkinson's disease. *International Psychogeriatrics*, 30(12), 1783-1795.
23. Sandelowski, M., Barroso, J. (2007). *Handbook for Synthesizing Qualitative Research*. New York: Springer.
24. Son, H. G., & Choi, E. O. (2018). The effects of mindfulness meditation-based complex exercise program on motor and non-motor symptoms, and quality of life in patients with parkinson's disease. *Asian Nursing Research*, doi:S1976-1317(17)30511-X [pii]

Appendix A: Systematic search strategy (7th March 2019)

Table A1(a). MEDLINE

Search	7 th March 2019	Results
1	exp Parkinson Disease/	60936
2	exp Mindfulness/	2249
3	mindfulness intervention.ti	68
4	2 or 3	2283
5	1 and 4	7

Table A1(b). PsycINFO

Search	7 th March 2019	Results
1	exp Parkinson Disease/	21098
2	exp Mindfulness/	8524
3	1 and 2	5

Table A1(c). CINAHL

Search	March 7 th 2019	Results
S3	S1 AND S2	14
S2	(MH “Parkinson Disease”)	17784
S1	(MH “Mindfulness”)	3387

Table A1(d). PubMed

Search	March 7 th 2019	Results
1	parkinson disease and mindfulness	16

Appendix B. Data Extraction Form *

- Reference (First author / Year / Journal citation)
- Topic
- Location:
 - Country
- Sample size:
 - Intervention population sample (#)
 - Control population sample (#)
- Population focus:
- Quality score:
 - AXIS tool

Theoretical framework

- Study design type:
 - Interviews
 - Support Groups
 - Questionnaires
 - Other (write-in)
- Interventions:
- Results:

* a modified sample data extraction form – see: Data Extraction: Prisma item 10, Ebling Library, Health Sciences Learning Center, University of Wisconsin, Madison, WI, USA.

Appendix C. Appraisal tool AXIS for cross-sectional studies (Downes et al., 2016)

Answers to the questions were one of the three: Yes; No; Do not know/ comment

Introduction

- 1 Were the aims/objectives of the study clear?

Methods

- 2 Was the study design appropriate for the stated aim(s)?
- 3 Was the sample size justified?
- 4 Was the target/reference population clearly defined? (Is it clear who the research was about?)
- 5 Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation?
- 6 Was the selection process likely to select subjects/participants that were representative of the target/reference population under investigation?
- 7 Were measures undertaken to address and categorise non-responders?
- 8 Were the risk factor and outcome variables measured appropriate to the aims of the study?
- 9 Were the risk factor and outcome variables measured correctly using instruments/measurements that had been trialled, piloted or published previously?
- 10 Is it clear what was used to determine statistical significance and/or precision estimates? (eg, p values, CIs)
- 11 Were the methods (including statistical methods) sufficiently described to enable them to be repeated?

Results

- 12 Were the basic data adequately described?
- 13 Does the response rate raise concerns about non-response bias?
- 14 If appropriate, was information about non-responders described?
- 15 Were the results internally consistent?

- 16 Were the results for the analyses described in the methods, presented?

Discussion

- 17 Were the authors' discussions and conclusions justified by the results?
18 Were the limitations of the study discussed?

Other

- 19 Were there any funding sources or conflicts of interest that may affect the authors' interpretation of the results?
20 Was ethical approval or consent of participants attained?

Appendix D: PRISMA-P 2015 Checklist

This checklist has been adapted for use with protocol submissions to *Systematic Reviews* from Table 3 in Moher, D. et al., (2015). Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic Reviews* 2015 4:1.

Section/topic	#	Checklist item	Information reported		Line number(s)			
			Yes	No				
ADMINISTRATIVE INFORMATION								
Title								
Identification	1a	Identify the report as a protocol of a systematic review	<input type="checkbox"/>	<input type="checkbox"/>				
Update	1b	If the protocol is for an update of a previous systematic review, identify as such	<input type="checkbox"/>	<input type="checkbox"/>				
Registration	2	If registered, provide the name of the registry (e.g., PROSPERO) and registration number in the Abstract	<input type="checkbox"/>	<input type="checkbox"/>				
Authors								
Contact	3a	Provide name, institutional affiliation, and e-mail address of all protocol authors; provide physical mailing address of corresponding author	<input type="checkbox"/>	<input type="checkbox"/>				
Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review	<input type="checkbox"/>	<input type="checkbox"/>				

Section/topic	#	Checklist item	Information reported		Line number(s)
			Yes	No	
Amendments	4	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments	<input type="checkbox"/>	<input type="checkbox"/>	
Support					
Sources	5a	Indicate sources of financial or other support for the review	<input type="checkbox"/>	<input type="checkbox"/>	
Sponsor	5b	Provide name for the review funder and/or sponsor	<input type="checkbox"/>	<input type="checkbox"/>	
Role of sponsor/funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol	<input type="checkbox"/>	<input type="checkbox"/>	
INTRODUCTION					
Rationale	6	Describe the rationale for the review in the context of what is already known	<input type="checkbox"/>	<input type="checkbox"/>	
Objectives	7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)	<input type="checkbox"/>	<input type="checkbox"/>	
METHODS					
Eligibility criteria	8	Specify the study characteristics (e.g., PICO, study design, setting, time frame) and report characteristics (e.g., years	<input type="checkbox"/>	<input type="checkbox"/>	

Section/topic	#	Checklist item	Information reported		Line number(s)
			Yes	No	
		considered, language, publication status) to be used as criteria for eligibility for the review			
Information sources	9	Describe all intended information sources (e.g., electronic databases, contact with study authors, trial registers, or other grey literature sources) with planned dates of coverage	<input type="checkbox"/>	<input type="checkbox"/>	
Search strategy	10	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated	<input type="checkbox"/>	<input type="checkbox"/>	
<i>STUDY RECORDS</i>					
Data management	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review	<input type="checkbox"/>	<input type="checkbox"/>	
Selection process	11b	State the process that will be used for selecting studies (e.g., two independent reviewers) through each phase of the review (i.e., screening, eligibility, and inclusion in meta-analysis)	<input type="checkbox"/>	<input type="checkbox"/>	
Data collection process	11c	Describe planned method of extracting data from reports (e.g., piloting forms, done independently, in duplicate), any	<input type="checkbox"/>	<input type="checkbox"/>	

Section/topic	#	Checklist item	Information reported		Line number(s)
			Yes	No	
		processes for obtaining and confirming data from investigators			
Data items	12	List and define all variables for which data will be sought (e.g., PICO items, funding sources), any pre-planned data assumptions and simplifications	<input type="checkbox"/>	<input type="checkbox"/>	
Outcomes and prioritization	13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale	<input type="checkbox"/>	<input type="checkbox"/>	
Risk of bias in individual studies	14	Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis	<input type="checkbox"/>	<input type="checkbox"/>	
DATA					
Synthesis	15a	Describe criteria under which study data will be quantitatively synthesized	<input type="checkbox"/>	<input type="checkbox"/>	
	15b	If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data, and methods of combining data from studies, including any planned exploration of consistency (e.g., I^2 , Kendall's tau)	<input type="checkbox"/>	<input type="checkbox"/>	

Section/topic	#	Checklist item	Information reported		Line number(s)
			Yes	No	
	15c	Describe any proposed additional analyses (e.g., sensitivity or subgroup analyses, meta-regression)	<input type="checkbox"/>	<input type="checkbox"/>	
	15d	If quantitative synthesis is not appropriate, describe the type of summary planned	<input type="checkbox"/>	<input type="checkbox"/>	
Meta-bias(es)	16	Specify any planned assessment of meta-bias(es) (e.g., publication bias across studies, selective reporting within studies)	<input type="checkbox"/>	<input type="checkbox"/>	
Confidence in cumulative evidence	17	Describe how the strength of the body of evidence will be assessed (e.g., GRADE)	<input type="checkbox"/>	<input type="checkbox"/>	

Appendix E: Key to abbreviations

AD, Activities of daily life
ANOVA, analysis of variance
BDI, Beck Depression Inventory
DASS-21, Depression Anxiety and Stress Scale
DBS, Deep Brain Stimulation
FFMQ, The Five Facet Mindfulness Questionnaire
FMI, Freiberg Mindfulness Inventory
GAI, Geriatric Anxiety Inventory
HDRS, Hamilton Depression Rating Scale
H&Y, Hoehn & Yahr
HBQ, Health Behaviours Questionnaire
K-MoCA, Korean-Montreal Cognitive Assessment
LOC, Locus of control
MAAS, Mindful Attention Awareness Scale
MB, Mindfulness-Based
MBCT, Mindfulness-Based Cognitive Therapy
MBLP, Mindfulness-Based lifestyle program
MBSR, Mindfulness-Based Stress Reduction
MM, Mindfulness Meditation
MMSE, Mini-Mental State Examination
MMBCEP, Mindfulness meditation-based complex exercise program
NHMRC, National Health and Medical Research Council
PD, Parkinson's Disease
PD, OQ-45; Outcome Questionnaire
PDCRS, PD Cognitive Rating Scale
PDSS, Parkinson's Disease Sleep Scale
PDQ, Parkinson's Disease Questionnaire
PDQOL, PD Quality of Life Questionnaire
PWP, People with Parkinson's
SMMSE; Standardised Mini-Mental State Examination
STAI, The State-Trait Anxiety Inventory
UPDRS, Unified PD Rating Scale
VBM, Voxel Based Morphometry

Part Two: Research Report

The psychological impact of Parkinson's disease patients' delusions on spouses:

A thematic analysis.

Caroline Joyce Nolan.

1 Abstract

Introduction: Whilst there is a growing cadre of research reporting on carers' experiences of living with those with PD, to date there has been little systematic exploration of how carers are affected by bizarre and illogical thoughts expressed in PD delusions. This study sought to explore how caregiver spouses are affected by their delusional partners, in both private and public domains.

Method: Semi-structured, qualitative interviews were undertaken with spouses whose partners were being seen at a Movement Disorders Clinic in Western Canada, and had reported PD related delusions. Interviews sought to establish how spouses experienced and managed the delusions and their impact on them. The data was subject to thematic analysis.

Results: Twelve spousal carers were interviewed, with analysis of data eliciting four themes – Managing incredulity: experiencing shock and trying to make sense of delusions' content; Hyper-vigilance: constant alertness to bizarre and threatening discourse; Defensive strategizing: anticipating delusions and addressing potential consequences; Concealing and Exposing: ambivalence about disclosing impact of delusions yet wishing for support.

Conclusion: Spouses reported significant impacts to their emotional well-being and marital relationships. They described reactive coping strategies and challenges to an orderly, predictable life, constantly monitoring potential threat, and re-evaluating marital bonds. Spouses reported reluctance to share their experiences to mitigate a sense of emotional betrayal of their spouses and to avoid feelings of shame. Findings suggest services should be more attuned to the impact of delusions on spousal carers and strategies to facilitate disclosure to enable delivery of appropriate support.

Keywords:

Caregivers
Coping
Delusions
Parkinson's Disease
Spouse

2 Introduction

2.1 Overview of Parkinson's Disease

Parkinson's Disease (PD) is a chronic, progressive neurological disorder that affects motor and non-motor functioning. Motor issues include tremor, stiffness, impairments to gait and speech and non-motor issues include psychological problems, e.g., cognitive decline (Barken, 2014, Hounsgaard et al., 2011) and psychosis, i.e., thoughts, feelings or sensory experiences not based in reality. Although less often reported, psychosis is a common symptom that affects approximately 50% of those living with PD (Divać, N., Stojanovic, Savić Vujović, Damjanović, Prostan, 2016). Psychosis is a term that covers both hallucinations [auditory and visual] and delusions.

2.2 PD delusions and research

Delusions (fixed false beliefs of spousal infidelity, intruders breaking into the family home and thoughts of people stealing from them) affect about 16% of the PD population (Minton, Perepezko, Pontone, 2016). Delusions are focused on in this research because the presence of delusions can be less overt and obvious to those interacting with the delusional individuals because they are often rooted in plausible phenomena (spousal infidelity). Without prior awareness of the phenomena, spouses will not initially recognize the symptoms of the PD illness and delay clinical reporting. The content of delusions psychologically impacts the marital relationships and mental health of caregiver spouses.

To date much of the research conducted on psychotic phenomena in PD has focused on biological underpinnings (Friedman & Chou, 2004; Timmers et al., 2017). Recent work examines psychosocial topics, e.g., sexuality (Petra, 2017) and marital relationships (Tanji et al., 2008; Karlstedt, M., Fereshtehnejad, S., Aarsland, D., Lökk, J. 2017), through predominantly quantitative methodologies. Research on caring for a family member with PD is sparse but a metasynthesis out of England (Theed, Eccles & Simpson, 2017) is particularly relevant. It looks at the following topics of spousal experiences of PD and the challenges experienced by middle aged spouses and their coping mechanisms (Habermann, 2000); the impact of PD on the couple

relationship (Hodgson, 2004); how PD is experienced and how palliative care may be of help to the PD population (Hudson, 2006); how PD affects daily living from the patient and relative perspective and what factors can facilitate their daily living (Wressle, 2007); the experience of living a partner with PD and psychotic symptoms and their coping mechanisms (Williamson, 2008); how PD patients and their family members experience the healthcare system who have lived with the palliative stage of PD (Giles & Miyasaki, 2009), former carers' experiences of palliative and end-of-life care (Hasson et al, 2010); experiences of informal carers of people with PD (McLaughlin et al., 2010), factors that people perceive to be important for quality of life in PD (Den Oudsten et al., 2011), how families perceive their caregiving experiences, their needs and what leads to the institutionalization of relatives with PD (Abendroth et al., 2012), and the coping experiences and general well-being of caregivers of people with PD (Tan, 2012).

Focus on delusions has been largely considered in relation to their emergence as a corollary of dopaminergic medication which can alleviate tremor and stiffness, but elevates risk of perceptual problems. Indeed a review of dopamine agonists' association with delusional thinking, paranoia and jealousy, hallucinations and problems of impulse control such as hyper-sexuality, gambling and grandiose ideas, revealed significant detriment to quality of life (Burn & Jarhanshahi, 2013). A systematic review of published PD cases related to delusions is also available (Warren, N., O'Gorman, C., Hume, Z, Kisely, S., Siskind, D., 2018) that examines whether or not PD delusions are associated with disease progression and cognitive impairment. It finds there is unexpected heterogeneity amongst cases of delusional psychosis that is not explained by existing models of PD psychosis.

Whilst the presence of psychotic phenomena has been noted, little work has examined their psychosocial impact. A study on delusions from a PWP (person with Parkinson's) perspective has been done (Todd, Simpson & Murray, 2010) and it further confirms the importance of this research to explore the topic further from the perspective of spouses who are caring for them.

A circumscribed but growing body of qualitative research has sought to explore how partners and caregivers of PWP are affected by their loved ones' PD (Barken, 2014; Carter et al., 2012; Hounsgaard et al., 2011; Martin, 2015; Mercer, 2015; Secker & Brown, 2005; Tan et al., 2012;

Turney & Kushner, 2017; Williamson et al., 2008). However, very little research has attended specifically to the experience and impact of PD psychotic phenomena on family members (Turney & Kushner, 2017; Williamson et al., 2008). Indeed, the review contained herein found that only one paper explicitly alludes to delusions' impact on the caregiver (Williamson et al., 2008). Whilst the practical aspects of addressing psychotic phenomena are addressed, there is a need for further exploration of how PD psychotic phenomena are understood and their psychological impact on spouses. The psychological impact and emotional changes within SPs and their marital relationships are not examined. While the research (Williamson, Simpson & Murray, 2008) highlights the uncertainty and search for understanding experienced by wives with husbands with PD psychosis, it focuses more on how psychosis can change the identities of those with PD rather than the in-depth emotional implications for their spouses. The gap in the literature is the lack of reporting or analysis of the internal psychological ramifications on spousal caregivers of PWP with delusions. There are lacunae in the research regarding the internal dialogue within spouses of how they are thinking, feeling and doing in relation to the raw and intimate nature of the delusional content and how it affects the marital bond and spousal relationship.

In reports of frank psychosis unrelated to PD, a cadre of studies reveals that such phenomena affect emotions and appraisals of family carers, as well as how coping can be enabled and facilitated if there is support to process experiences such as anger, lowered mood, stress, loss of social networks and diminished self-esteem (Kuipers, Onwumere & Bebbington, 2010). Hence the burden of undertaking informal care of a psychotic family member significant correlates with mental health problems and relational problems (Flyckt, Löthman, Jörgensen, Rylander & Koernig, 2013). Given potential for adverse impacts for carer well-being and quality of life and the potential for isolation conferred by psychotic symptoms, I sought to gain a deeper understanding of how partners and carers experience such phenomena presented by their loved ones, what impact this has on carers and their marital relationships and their capacity to sustain care. Qualitative research would allow participants to provide more nuanced information and potentially lead to the development of strategies for coping with delusional thoughts and resulting behaviour. By speaking with spouses of PWP delusions, the experiences can be recorded and examined. An analysis of the content that has come directly from those who live or

have lived (if the case that PWP has passed away or resides in long term care), through an episode or episodes of their partners' being delusional not only benefits the caregiver spouses, but also other caregivers and health and medical team members who care for the PWP.

The content of PD delusions is often intense and intimate, e.g., delusions around marital infidelity. It refers to aspects of people's lives and in particular their marriages and relationships. What is normally personal and private can be aired in public by the PWP when delusional. The events that occur due to delusions by the PWP while often remaining within the home setting, are at times mentioned albeit briefly in clinic visits. The implication of having to share or report delusional thoughts has ramifications for the spouse of the PWP and the PWP. What exactly is the psychological impact on the spouses? Is it temporary or ongoing? Does it impact the care given to the PWP by the spouse? These are questions that precipitated the initiation of this study. It is clear from studies done to date on people with PD, on their experiences of delusions and the effect on those caring for them (Williamson et al., 2008; Todd, Simpson & Murray, 2010), that there is a need for further exploration of delusional experiences. The studies also illustrate how qualitative research is an approach that is able to extract data that is not always measurable through quantitative tools of analysis. A qualitative approach involves the aggregation of information through the careful and assiduous analysis of first hand experiences. With the extraction of themes and relevant subject issues, significant data is available for clinicians and other health professionals who are involved in the care of PWP to study and consider when treating or working with people with PD and their spouses.

3. Method

3.1 Design overview

A thematic analysis was advanced using the guidelines of Sandelowski and Barroso (2007) for synthesizing qualitative research. The approach herein sought to undertake detailed examination of transcribed data elicited from semi-structured interviews, focusing on experiences of informal caregiver spouses, i.e., the Spouse Participants [SPs], of PWP with PD related delusions. The format of interviewing and analyzing the content is acceptable within the field of qualitative analysis.

3.2 Position of the researcher

Working in the Movement Disorder Program at the University Hospital Out-Patient Clinic gave me the experience of the population that formed the core focus of this research. I have bi-weekly clinical visits with people with PD and their spouses. This gave me the background and the familiarity to launch into this investigative work with unknown study participants. I was used to hearing about issues and was equipped to listen carefully and to ask questions that were open to encourage the responses from the caregiver spouses around their psychological experiences of coping with partners who had or have PD related delusions. The data was recorded and transcribed and the themes were enumerated subsequently that corroborate that they were representative of the concrete reality of what it is to be married to someone with PD and had delusions.

3.3 Methodological approach

Individual semi-structured interviews were undertaken (mean interview time 40 minutes). Eight of the interviews were face to face and four were over the telephone. The interview protocol was developed prior to recruiting the SPs. It was a useful instrument to ensure that the specific aim and goal of the research question were being answered by the SPs. The language used was colloquial and at a Grade 8 reading level to allow for SPs of all educational levels to understand the questions. No medical or clinical words were used except for the words, Parkinson's disease and delusions. The questions were open ended to encourage descriptive answers and to ensure that each participant was asked the same questions and that each interview had the same scope and focus in relation to what information was being sought. The qualitative interview process was set up to extract the experiences of the SPs, to record and capture their articulated feelings and thoughts in relation to what they were being asked in the interviews about living with a spouse who has PD and who was or had been delusional. The initial questions focused on: the age of the SP; the length of time since the spouse's diagnosis with PD; the request for examples or evidence of delusional thinking; their awareness of PD delusions prior to incidents; what was helpful for coping; the SP's own sense of his/her personality; what could be added to assist caregiver spouses in similar situations; a question soliciting any other information they would like to include and a chance to ask any questions that they had resulting from the interview

process. The interview protocol was read and assessed as part of the U of A ethics application. It was passed as being suitable for use. It was used in all of the interviews (face to face; telephone). The interviews were all audiotaped and transcribed by a trained transcriber who signed a confidentiality agreement despite no real names being mentioned in the audio recordings.

Transcriptions were coded using MAXQDA 2018, a qualitative analysis software package. Based on this analysis, themes were identified and coded until saturation, and an analysis of emergent themes was carried out to inform understanding of spousal experiences of delusions in PD.

3.3.1 Reliability and Validity

Attentive to the debate around evaluating qualitative methods (Angen, 2000; Creswell, 2013; Ludvigsen, Hall, Meyer, Fegran, Aagaard, Uhrenfeldt, 2016) and to optimize qualitative validity and qualitative reliability the following steps were taken:

- A reading and re-reading the transcripts to ensure a full understanding
- A process to ensure there was a clear definition of each code was established and examples provided (included in memo sections within MAXQDA 2018)
- Numerous meetings with a second coder to discuss coding, the findings and the analysis of findings
- There was a lengthy cross-checking of the coding with two other researchers to assess and compare results of the primary and secondary coders
- Then there was the engagement of external readers without familiarity of the SPs or the interview data for independent review
- The codes that finally emerged after the steps above were then aggregated and the findings were grouped and presented as thematic summaries in keeping with the guidelines for quality qualitative research (Creswell, 2009).

It should be noted that the literature review also guided some of the thematic triangulation because it highlighted that there were already stressors for couples coping with PD within their marriages.

3.4 Participant recruitment

Potential SPs, accessed via a Movement Disorders Program providing services to urban and rural populations in Alberta, Canada, were approached by their consultant Movement Disorders Program's neurologist or psychiatrist to participate in the research study if the SPs had previously reported some unusual ideas or actions of the PWP during previous consultations and if the physicians identified them as having been delusional.

Due to only nine SPs being recruited via the Movement Disorders Program, a poster was created and passed by the U of A Ethics Committee to further recruit from the Parkinson Association of Alberta. Seven people responded but only three had spouses who had been delusional. The other five had spouses who had had hallucinations. While they were aware of psychosis, the respondents to the poster were unable to distinguish the differences between the presentation or manifestation of hallucinations and delusions.

After screening the potential SPs from the Parkinson's Association, those who fulfilled the inclusion criteria were added to the list of those from the Movement Disorders clinic. They were all provided with the consent form, to read and review privately. If they wished to proceed, the subjects provided informed consent prior to the interview process. The inclusion criteria required that SPs were spouses of a PD patient with, or who had, delusional thoughts related to PD, no age restriction, male and female, fluent in English and able to consent to research. The data elicited from interviews was raw and immediate from SPs. It was delivered orally. This was the most accurate way to extract the information because SPs could clarify what was expected of them or they could be re-directed to give more focused responses. The SPs were made aware that they could withdraw their interview data up to a specific date. They were also made aware of resources should they require emotional support during or after the interview.

3.5 Data analysis

The transcribed interviews contained words of both interviewer and SPs. Each script was identified as a subject number (e.g., Subject 1, Subject 2) and then exported as a Word document to a MAXQDA 2018 project file, and each subject file was then given a pseudonym to ensure participant anonymity. Following the steps established by Creswell (2009), the first author familiarised herself with the whole data, exploring for initial concepts and recurring themes. Codes were developed which included numerous examples of what they represented, and were examined by two independent coders. The final themes and sub-ordinate themes were reviewed by those coding to ensure there was consensus of meaning. Numerous meetings with full texts of the transcripts and the coding markers were held to ensure that the data was accurately analysed and was an accurate account of the themes that emerged from the SPs' interviews. The data was then presented as charted summaries based on the emergent themes which permitted transparent theme and case-based comparisons.

3.6 Quality issues

To address reflexivity, all twelve interviews were undertaken by the first author, a practising psychologist with three years' experience in working with clients with neuro-degenerative conditions. All potential SPs were alerted to the study's focus (partner experiences of their spouses' PD-related delusions) through information sheets. Ideas and reflections on the research were documented from inception to conclusion of the research process. Monthly, formal supervision meetings helped clarify approaches, methodology and validity of research.

The involvement of experienced clinicians (bi-weekly meetings with neurologists within the Movement Disorder programme and clinician peers) and service users were key to pursue what Creswell (2009) advocated for, i.e., the extraction of independently derived data in qualitative studies from (1) detailed discussion of research processes merits; (2) the identification of strengths and weaknesses as they unfolded; (3) the cross-checking of codes; (4) the clarification of code definitions to ensure that there was not a shift in meaning with the addition of new transcript material.

3.7 Ethical considerations

This study was reviewed and approved by the University Ethics Review Committee, University of Leicester, UK and by the Health Research Ethics Board, Health Panel, University of Alberta, Alberta Health Services and Covenant Health, Canada (ref: Pro00070834) and by NACTRC (Northern Alberta Clinical Trials Research Centre) for interviews within the Kaye Edmonton Clinic.

4 Results

Twelve spouses participated aged between 62-82 years old, 8 women and 4 men. Years since the diagnosis of partners' PD ranged from 3-24 years.

Table 1: Research SPs' demographic data (to maintain anonymity, pseudonyms are used)

Participant #	Participant's Name	Gender	Age	Years since PD diagnosis
1	Eva	F	73	8
2	Nora	F	74	23
3	Lucy	F	62	18
4	Julia	F	64	16
5	Jane	F	74	8
6	John	M	66	13
7	David	M	80	10
8	Tom	M	79	3
9	Ann	F	80	6
10	Mike	M	82	24
11	Karen	F	62	16
12	Liza	F	70	18

4.1 SPs' interview demographics

SPs agreed to be interviewed, eight face to face and four by telephone. Those utilising telephone interviews lived more remotely. All the SPs were content with the location of the interviews and expressed comfort and willingness to participate. Eight of the SPs' spouses lived at home, three were in long term care and one had died a year earlier.

4.2 Identified codes and themes from interview transcripts

The initial coding process resulted from reading the interview transcripts of the SPs and giving attention to what they were reporting as being their experiences. Attention was given to their emotions and what they perceived to be important to them in relation to hearing, responding and coping with their partners' PD delusions.

Examples of the coding of the transcripts are given in *Appendix L*. Various emotions were noted and highlighted. If an SP noted how they were anxious, a particular colour was assigned to that emotion. Once codes were established, a re-reading of the material was necessary to re-assess and evaluate whether or not a theme was present or best suited in the coded section it was in. The coded sections have sub-sections which captured different nuances in regard to what the data exhibited in relation to the SP's. At the end of the coding process, colours were evaluated and what themes they represented. Then an independent coder assessed the coding and discussions ensued as to whether the data was allocated to the best code set. A review of the data and codes was undertaken again. The amount of codes designated whether there was a significant theme that was occurring in multiple transcripts. Some codes called for an amalgamation of them to form a new code label.

See Table 2 below for the final codes, i.e., four main codes, each code encapsulated facets of how spousal carers of those with PD experience partners' delusions.

Table 2: Codes and sub-codes

Codes	Sub-codes
Spouses' emotional responses to their partners' expression of delusions	angry; anxious; despairing; depressed; embarrassed; frustrated; honest; hopeless; hurting; searching; surprised
Spouses' behavioural responses to what was happening due to their partners' delusions	afraid; alert; cautious; frozen watchfulness; protecting

Spouses' cognitive responses to what was happening due to their partners' delusions	agreeing; coping with changes; coping with loss; defensiveness; preparedness; seeking meaningful connections; survivalist
Spouses' ambivalence with regard to sharing their experiences	conflicted; contradictory; guilty; incongruent; lonely

All SPs indicated that their participation in the study was motivated by their emotional reactions to, and broad ranging impact of, their spouses' delusions. Some codes were amalgamated in further analysis due to conceptual overlap with 11 sub-codes emerging [angry; anxious; despairing; depressed; embarrassed; frustrated; honest; hopeless; hurting; searching; surprised] capturing spouses' reports of their emotional responses to delusions.

Behaviour of carer spouses in response to their partners PD delusions was another topic articulated in all interviews and was designated as a key code. All of the SPs spoke about a change in their behavior as a necessary and self-preservation response to what was unfolding in their lives. Five states of continuous ways of being emerged and were coded under 5 sub-codes [afraid; alert; cautious; frozen watchfulness; protecting].

SPs talked about how they had to be constantly alert to what their ill partners were saying and doing. This vigilance was needed for their own safety and that of their partners. There were always two aspects to be considered: how they were and how their partners were in terms of safety.

SPs were also able to articulate their cognitive responses to what was happening for them as they lived and dealt with their delusional partners. They described a need to be creative and devise appropriate ways to cope with challenges to previous closeness in relationships, to learn how to cope with the changes, to defend themselves in the face of accusations and anticipate what might (unpredictably) yet come.

SPs sought to maintain calm by acceding to their partners' delusions even when these clearly challenged reality. SPs noted their striving to continue meaningful connections with their

partners and with others outside the home. This was noted by all to be difficult. The thought processes of what SPs reported were coded and arranged under the following 7 sub-codes [agreeing; coping with changes; coping with loss; defensiveness; preparedness; seeking meaningful connections; survivalist].

SPs all alluded to their ambivalence about disclosing certain aspects of their partners' thoughts and behaviours. Some SPs explicitly expressed guilt about revealing how their ill partners made them feel or how they had to respond to their partners in an effort to protect each other. The interviewer noted that some SPs offered contradictory or incongruent statements which was understood as attempts to mitigate and minimize their partners' behaviour.

Content of the PD delusions was described as embarrassing and shameful for many of the SPs. And was often elided with reports of isolation, yet a real desire to share the delusions' impact. SPs reported that their core sense of self and values was shaken both by the delusions and unwelcome dilemmas about what disclosure might be, i.e., a betrayal of their marriage vows. Codes related to these issues were coded and 5 sub-codes [conflicted; contradictory; guilty; incongruent; lonely] emerged under the key code 'Spouses' ambivalence with regard to sharing their experiences'. With further readings of the selected data with codes and sub-codes, super-ordinate and sub-ordinate themes emerged. Each key theme is listed (Table 3) with the corresponding sub-themes that were considered in the pulling together of the major themes that were emerging from the data.

Table 3: Identified super-ordinate themes and sub-themes

Super-ordinate themes	Sub-ordinate themes
Managing incredulity when faced with bizarre thoughts of PWP	<ul style="list-style-type: none"> • Making sense of bizarre thoughts of PWP • Breach of faith and hurt due to breakdown of the marital bond due to delusions of PWP

Hyper-vigilance due to delusional thoughts and bizarre behaviour of PWP	<ul style="list-style-type: none"> • New state of being due to the stress of living with a delusional spouse • Real risk of violence for the SP due to the PWP's delusions • Dual protection of SP and PWP due to delusional thoughts and behaviour
Defensive strategizing to minimize PWP's delusional thoughts and actions	<ul style="list-style-type: none"> • The challenges of controlling and limiting delusional PWP for the sake of safety • Adapting emotions when living with a spouse who has PD delusions
Concealing and exposing what it is like to live with spouse with PD and delusions	<ul style="list-style-type: none"> • Putting on a 'game' face before people outside of the marriage • Shame and guilt for the SP when talking about the marriage or PWP • Approach and avoidance of help when living with a spouse with PD related delusions

4.3 Theme 1: Managing incredulity when faced with bizarre thoughts of PWP

Most spouses reported their partners' delusions as surprising and shocking, and an unexpected facet of PD. The sudden onset of delusions upset the homeostasis of the marriage with content that was unimaginable like spousal infidelity.

David: "First I said, 'Don't be silly', and pointed out that we were together every day, all day, aside from maybe 15 minutes that I'd watch the news. I did that because it was a busy time of the night getting my wife ready for bed and that was my 15 minutes of collapse".

Making sense of the bizarre was challenging. SPs understood that the delusions caused their partners to say and do things that had no bearing on the truth of how they were living and relating. Yet, they created doubt and uncertainty regarding the entirety of their marriage and its

meaning. Many spouses defaulted to how many years they had been together and chose to use this as a measure to weigh against the strange things that were being said.

Tom: “Well, we’ve known each other since we were about seventeen. We’ve been married going on to fifty-eight years now. So we tolerate each other and we know that we’re not perfect. We do the best we can”.

4.3.1 Making sense of bizarre thoughts of PWP

Partners’ opinions, statements and responses were initially construed as having a meaning based in reality. Some said they initially believed what their spouses were saying. However, when the content of the delusions was attacking or offensive, it was felt as a personal affront, especially if the spouses had been very solicitous in caring for their partners who had PD.

Karen: “In the beginning it’s hard to distance yourself from that and not internalize it.”

Lucy: “At first it was, “How dare you! What did I do to deserve this?” And then it’s like, “OK, we’ve got to remember he’s not well. This isn’t normal. Let’s talk about it in the morning and see what happens”.

SPs reported being surprised by the onset of PD delusions and how it caught them off guard. They recounted how they sought to correct or make sense of the delusions as part of their own emotional responses to them.

Liza: “I think everybody thinks with Parkinson’s that you’re going to physically fail, and I was prepared to sort of handle all that. It’s quite a sideways glance to find out that there’s an emotional trigger to this”.

Karen: “I’m constantly telling him how much I love him and so on. What bothers me more for some reason is him thinking that I’m having an affair than thinking I was a prostitute”.

Nora: “He always thought I was a party girl for some reason. I wasn’t but he assumed for some reason that I was always out with somebody and being really rotten and unfaithful. This went on and on that was very, very hurtful. We constantly lived together, so I can’t imagine when I would have had the time to do this, but that’s what a lot of his thoughts were”.

The responses from SPs above illustrate the ways in which they had to work out and come to some sense of what their partners were saying. Despite their attention and steadfastness to their partners, they were thought of as a prostitute, a party girl and that they were cheating on them by having affairs. They ruminated over what their partners said and tried to understand how their thoughts could even be plausible. They entered into mental games for which there could be no logical answers as to how or why their partners would even come up with the thoughts that they had about their relationship and marital fidelity.

4.3.2 Breach of faith and hurt due to the breakdown of the marital bond due to delusions of PWP

Spouses reported frequent and intense hurt by what their delusional partners said, describing a breach of faith in their marital bond.

Nora: “It really hurt because we’ve always been very devoted. It was such a shock as a friend came in one day and my husband said to him ‘Well, I guess I have to tell you we’re getting separated.’ This was the first I realized that he took it like he wasn’t going for care, but that he was being kicked out”.

David: “Just puzzled why she would think that. There were other comments about when I was going to leave because of the stress of looking after her and she would say things that I hadn’t said about leaving her”.

The hurt arising from accusatory delusions was felt by SPs and it increased their sense of isolation and despair.

Karen: “Oh, it was very sad. I had to go on antidepressants because I saw no hope anymore . . . I felt really alone. Like he’s gone, he’s not coming back.”

Ann: “I lost hope. I remember going through a good year or so of being terribly sad, just feeling so very alone”.

Mike: “It’s kind of like you get a little punch in the gut”.

SPs struggled because of their long-term commitment to their partners and the caring ‘contract’. After all their time together, their devotion to their ill partners’ care, SPs felt attacked in their own homes. A safe environment could be undermined in a moment’s comment undoing the trust built over years of fidelity and mutual allegiance.

SPs sought ways of coping with accusations and strange comments around the topics of trust, infidelity, and leaving the marriage. They reported examining ways to accept that they were now in a different and undesired phase of the marital relationship. Some utilised humour but for others it was very demanding:

Tom: “I spent a lot of time in town and when I came back home she says ‘Okay, who’s that woman you’re going with?’ Stuff like that. I just kind of laughed it off, it was nobody. She had little instances like that. Suspecting me of having an affair with someone. Little things like that I kind of just shrugged off. I laughed it off, wasn’t too concerned about it”.

John: “Her delusions changed our life . . . she would talk about me not realizing it was me she was talking about”.

Liza: You can’t be the primary caregiver and be vilified at the same time. It’s really a quite impossible task.”

The character of the ill partners was reported as often changed by the PD delusions. Spouses sought the partner they had once committed to and were left ruminating over the ‘new’ one and the rationale of what was being said by them. Some of SPs tried to adapt how they felt by remembering who their spouses were before the onset of the PD delusions. Review helped them to cope in the present challenging circumstances. Spouses recognized how they were hurt while trying to look after them, and survived by recalling the times when their partners were loving and kind. They made excuses for them in an effort to protect their ill partners but also to soothe themselves. They reported being mindful in the present, yet seeking memories to extract happy recollections of when times were good. Those memories helped to sustain them so they could continue to look after their partners and to remain dedicated and faithful spouses.

Nora: “You have feelings you know, and they don’t mean to hurt your feelings, but they often, often do. I guess because he was always such a loving person. He was the kind of person who brought you flowers just because it was Monday, it didn’t matter. It makes you sad. There’s not much you can do about it. You just always put it off – they can’t help it. They don’t know what they’re saying anymore.”

Jane: “You’ve got to remember how much you loved this person because that’s who they really are”.

4.4 Theme 2: Hyper-vigilance due to delusional thoughts and bizarre behaviour of PWP

The unexpectedness of the delusions in the partner with PD created a new state of being within SPs. They became hyper-vigilant. SPs reported how bizarre thoughts left them perpetually unsettled, preparing for the next potential attack or accusation. They reported uncertainty and little mental rest for themselves due to a need to be alert, ready for the unthinkable and the unimaginable. Despite precautionary preparation spouses still felt they were caught off-guard, and utilised a frozen watchfulness, waiting for the next incident or event.

4.4.1 New state of being due to the stress of living with a delusional spouse

The onset of PD delusions had a volatility to it that greatly impacted SPs' sense of well-being and safety.

Julia: "I didn't expect it to come that soon, so I probably wasn't completely ready for it".

Eva: "It catches you off guard because it's nothing and then there it is. It starts. I didn't have any sense that that was going to start happening."

Liza: "I had to be really careful that I didn't trigger something that would upset him because he would become very upset".

Lucy: "I'm just putting my guard up and waiting and trying to be as calm as I can with the situation".

Spouses reported making profound changes to their domestic routines and activities, notably monitoring all aspects of how and what they did and said. They reported greater self-consciousness of their own behaviour and expressions, mindful that apparently innocuous actions might provoke partners' suspicion or paranoia. They had to adopt a calm exterior and pretend that everything was okay, and described editing aspects of their lives to ensure that nothing tipped the balance in the relationships. This new hyper-vigilant state of being left them with physical and emotional exhaustion. Even recalling and talking about their experiences was difficult.

Ann: "It's got me nervous, upset, just thinking about it again".

4.4.2 Real risk of violence for the SP due to PWP's delusions

Sub-themes of danger and violence were raised frequently. SPs emphasized how their delusional partners' outbursts often induced fear within them.

Ann: “There was a paranoia, a feeling that he was going to be potentially violent. It was terrifying because I didn’t know what he was going to do to me. I could picture him coming into my bedroom with scissors in his hand and killing me. That’s how terrifying he was. He never did, and he never came at me with anything, but it was that scary to me”.

A participant described the reality of having little time to process how events were unfolding, particularly when delusions appeared potentially dangerous. SPs reported a reactive self-protection with the help of various defense mechanisms, e.g., thinking on the spot.

Julia: “It was happening so quickly that honestly I didn’t have much time to think about myself. I was just acting on what was coming because it was one thing after another. He saw the house on fire. Then he started thinking we were flooding. Then he ran away from the house”.

4.4.3 Dual protection of SP and PWP due to delusional thoughts and behaviour

Spouses reported protective strategies, particularly mindful of what might unfold in the form of threats or challenging behaviour of their spouses.

Lucy: “I know it’s probably going to happen again. So, let’s see what we can do to avoid or stay on top”.

SPs reported that they had the difficult dual task of needing to protect themselves and at the same time, they needed to protect their partners from harm, notably trying to mitigate the potential for violence or of emotional over-reaction.

Julia: “That was the scariest moment, I would say, because I didn’t know first what to think about it or what to do. The good thing about this was that I learned that I’m capable of physically restraining him . . . Of course, I learned what to do, but there was a moment that I didn’t brace

myself properly, so he was able to shake me, not violently. I don't want this to sound like I was in any kind of danger. I wasn't."

Ann: "Trapped in my own house, trapped everywhere . . . the doctor told me to get out of there and go over to spend the night with my friend. So that's what I did. He went looking for me, but I hid my car".

SPs reported witnessing the effects of the delusions on their partners, but they also recounted personal impact on themselves. They undertook extra measures at their own expense to alleviate their partners' situation, readily adopting some of the traditional roles of their partners to ensure that their partners were not further challenged. They were self-sacrificing and emphasised anything that would lessen the suffering of their partners.

Jane: "They called me at one o'clock in the morning and I went over and said, 'Oh, you're fine, you're just in hospital. They're doing all they can for you'. And he said, 'Well why was it like jail?' He took off and went down into the stairwell, so I suppose that's what it looked like to him. So, then I crawled into bed with him at the hospital and just laid there until he went to sleep and then I got up and went home".

4.5 Theme 3: Defensive Strategizing to minimize spouses' delusional thoughts and actions

The theme of defensive strategizing captures SPs' creative strategies to manage their delusional partners. SPs reported a need to take control of a situation and had to accommodate and adapt their usual lifestyle patterns in order to cope and still care for their partners. At times, their way to control was to not control.

4.5.1 The challenges of controlling and limiting delusional PWP for the sake of safety

Eva: "As long as I can control where he's at. I can control the people he's with. I work very hard to make them understand what changes have

happened, so they are watching for them, so that he doesn't get into any kind of trouble".

John: "Living with her delusional, I will be direct with her but if she is confrontational, I won't continue. I've to learn not to over control the situations but I do need to manage her daily living because she will put the milk in the microwave and the cheese in the freezer".

Lucy: "You've got to pick your battles and you've got to let go".

SPs had to be practical in their responses to what was happening at home, reporting the importance of managing what was going on around them. They also had to recognize that they could only oversee and control so much. They had, at times, to concede and accept that there were some things they could not change or would require too much effort. SPs had to re-evaluate what was imperative for them and what was less important to them. They reported compromising on and what had to be negotiated within themselves since their partners were unable to help with their discernment of needs. SPs were alone in the process of making decisions that affected both them and their partners. SPs had to be considerate of the limitations of their spouses and they had to find ways to cope with their own feelings about how things were, about what they could control and what was out of their control.

4.5.2 Adapting emotions when living with a spouse who has PD delusions

The interviewed spouses revealed how they had many self-defence coping mechanisms as part of their defensive strategizing. They endeavored to adopt a positive stance so that they themselves could push through the chaos and the sorrow of their lives that were forever changed.

Karen: "He's just a shell of the person that I once knew and yet I struggled to still try to be very much involved. I guess I still somewhere look for glimpses of the old guy and the rare time there he will be, so it keeps me open for the next one. For the most part I make light of it, but not in the

sense that I make fun of it or anything. I just realize that I can't internalize any of that because that's just not him, that wasn't him".

There was always a dual tension in them as they 'tried' and 'struggled' to view things more positively and to make light of things. SPs had to actively work at adapting their emotions to ensure that they could maintain their marital bonds and perform their informal caregiver duties.

4.5.3 Marital fidelity and spousal relationship in the wake of PD delusions

SPs also had a sense of duty and loyalty to their marital promises that sustained their caring for their delusional partners.

Ann: "I'm just that kind of a person that would not walk out on somebody like that. I might have had to take a break if he had been violent. I might have had to do something then, but it was scary enough that had I not been the type of person I am, I would have gone".

Julia: "So, I stopped explaining things when he tells me something that isn't real. I just go along with him and don't try to explain things to him. Until he starts talking about it and I know that he is kind of with me, then we go through it and I tell him that it wasn't happening".

SPs had to negotiate what would be helpful or not to their partners and they had to adapt their behaviour to best meet both of their needs because they were still very committed to their marriages and maintaining as best they could their spousal bonds. They loved their partners and didn't wish to upset them or leave them uncared for, even when they had to engage in practices for self-care, e.g., going on vacation or being strategic with resources, e.g., hiding phones and car keys, as is evidenced in the respective quotes below.

Nora: "I'm going to go to Ireland. We were going to do that together one day but of course now he can't. So, I won't tell him until probably the

week or few days before I go. Otherwise it'll be every day 'When it is happening? When's it happening?' Then I'll arrange for people to make sure that they come and visit him while I'm gone so he isn't alone a lot".

Ann: "I was being sneaky. Only because that was the only way I could contact my family. I ended up hiding the phones on him every night when I went to bed. All the phones I had to hide. I had to hide the car keys because I didn't know where he was going to go if he went out. It was a holy terror. I just can't explain how bad it was".

SPs found an inner-strength within themselves and became quite resourceful as part of their strategizing. Despite that, SPs expressed a need for something extra, e.g., support from others. SPs had to be willing to open their private experiences to those around them, despite the fact that it might expose their marriage and themselves as caregivers and how they measured up in the eyes of health professionals and their family members, relatives and friends.

4.6 Theme 4: Concealing and exposing what it is like to live with a spouse with PD and delusions

The theme 'concealing and exposing' captures opposing forces and tensions within the interviewed spouses. SPs reported a drive to protect their partners, to be good wives and husbands and to be seen as good caregivers. To present as capable caregivers and dutiful and committed spouses, they needed to put on a 'game' face before they engaged with people outside the home.

4.6.1 Putting on a 'game' face before people outside of the marriage

Spouses felt societal pressure to present before the public or health professionals as competent and committed. Most described a tension between wanting to hide their delusional partners' comments and behaviour and a desire to share their experiences. Many SPs reported that they had donned a mask of some sort.

Liza: “That’s just normal – to put on the best face. That’s what you do and then you expect him to do that too”.

Karen: “I lost hope and yet you try to put your game face on and adapt and adjust to all the irregularities of his thoughts and his actions”.

In an effort to protect their partners and themselves, they had to accept the changes in their lifestyles and they had to play the survival game of self-defence.

John: “My life is gone. It is spent now sitting blocking the shots”.

4.6.2 Shame and guilt for the SP when talking about the marriage or PWP

SPs articulated considerable guilt when they talked about considering disclosing their partners’ delusional behaviours and the trials of remaining loyal.

David: “I’m a bit uncomfortable because some of it seems a bit disloyal to my wife and I want to be careful with that. I don’t want, even between us, for there to be a negative image of her. She’s a very lovely person”.

Liza: “You live the life you’re in. I can’t get ready for him to go off the deep end. I have to live the life I’m in so if something happens, you have to think, ‘ok is this unusual?’ So when something is unusual . . . well . . . there’s the support in the loyalty part. You want your husband to look good”.

John: “I feel guilty speaking about her because she likes privacy and always said ‘don’t tell the family’”.

The dilemma experienced by spouses was palpable in the interviews; they would tear up or speak with inflection that denoted intense emotions relating to delusions. Disclosure was desired but would engender shame and a sense of betraying partners. The content of the delusions (alluding

to sex, prostitution and extra-marital affairs) and ensuing problems pertaining to their private lives, their levels of intimacy and their mutual fidelity was described as shaming for many of the interviewed spouses. As a cohort of older adults they appeared unused to openly discussing issues that they found to be awkward and embarrassing.

Nora: “It’s just something, I guess at my age, you just don’t bring up and discuss. We weren’t used to discussing that kind of stuff in public . . . sexual things out in public. Not like now. You see it on TV and it’s very common”.

4.6.3 Approach and avoidance of help when living with a spouse with PD related delusions

SPs were very aware of what they had to do as caregivers but they also reported needing outside supports or validation from those who might understand what was going on for them. It was important that people really knew what the reality was like for them to live with someone with PD delusions.

Liza: “Well, I only shared it with my friend that my husband was accusing her husband. I would never have shared it with anyone else. She was my friend and a nurse. She kind of knew that something was amiss. It’s good to have friends. I’m lucky that I have lots of friends. That changes how you react to this. It would be quite lonely to be with someone if you didn’t have the support system”.

Jane: “I’m a talker so I don’t keep everything inside. When I go to the care partners’ group, I say it like it is. My daughter and my son, we talk it out and they know what I deal with every day. And then it’s like, “Can I help you Mom? Can I chat with Dad for a while?” I don’t keep things.”

Many spouses described a profound sense of loss and loneliness, both from a transformed marital relationship or the fact that many family members had pulled away.

John: "Friends have left us".

Karen: "Well, I don't want to be a burden to those that are close to me so that they stop being as close as they are to me. So many friends have gone by the wayside through all of this and I just want to go out and laugh again. I want to have 'a good belly laugh' as they say. I want to wake up and not feel the weight of the world . . . because people don't want to be around somebody who is sad all the time".

Eva: "You just don't know where to go. I have tried to talk to people, but they're not involved, and they don't want to be involved . . . They all say what they have to say, but they are getting away from you as fast as they can. They don't really want to hear it".

Spouses emphasised a need for community resources. Many felt that these could facilitate sharing more of their lives and experiences and convey the impact of PD related delusions to the wider public. SPs were always engaged in a process of searching and seeking more information for themselves to help them cope more or to understand what is going on.

Julia: "Not everybody has access to information and not everybody wants to know. If somebody would explain to the person who takes care of the ill person that those are the things that will be happening and there is no purpose to avoid them".

Ann: "About my feelings . . . I don't even know if I had any because I was numb. I had to figure out how to help him, even to the point where I was calling the nurse in those desperate times".

SPs reported how they sought to be open and honest that things were difficult for them, but there appeared to be significant internal emotional conflict within them that prompted them to conceal what was going on.

Nora: “Well, I don’t know. I’ve always been very truthful with my husband and lately I can’t tell him the truth because he has so many anxiety issues that you don’t tell the truth. I’ve never been a liar and it upsets me not to be able to tell the truth”.

SPs revealed in their interviews that there was far more happening for them psychologically than was visible to the public. They all experienced inner turmoil requiring individual solutions.

Lucy: “With me it’s always, ‘Oh, come on, there’s a brighter side to this. Just think of this, just think of that.’ I’ve always been that way so maybe that’s where I can separate more and just say, ‘OK, I’m not going to worry about that part. That’s probably part of who he is or who he has become now, what the disease has made him become’”.

Behind the exterior presentation to the health professionals and public was a sense of shame and guilt along with sadness, hopelessness and loneliness that thwarted their approach, and led to avoidance of help.

Tom: “I was kind of hoping for this discussion and I didn’t have any assumptions about what you would do.” Interviewer: “How has the interview been for you?” Tom: “Oh, I’m comfortable with it! You haven’t asked anything that was too personal”.

The solace and support they craved came only when they were willing to let their masks drop temporarily and to openly talk about what it had been like for them to be married to someone with PD delusions.

5 Discussion

Analysis and synthesis of interview data elicited themes capturing the psychological impact for those interviewed, of living with a partner who has PD delusions.

5.1 Summary of main findings

Spouses were adversely impacted psychologically by their partners' delusions. They reported shock and emotional pain as they tried to comprehend bizarre and attacking comments. They experienced intense hurt by what their partners believed to be true.

SPs had to adopt new ways of being as a result of becoming hypervigilant for their own safety and that of their partners. They reported defensive strategizing which encompassed adapting their emotions to cope with the unexpected and with the hurt that ensued. They had to examine the extent of what they could control and the limits to their control, as well as their own sense of marital fidelity and the spousal relationship. SPs communicated a perpetual tension, a push-pull state of existence, putting on a socially sanctioned persona as a committed carer whilst feeling shame about what their partners were saying and guilt about their own wishes to disclose impacts.

Healthcare researchers tend to focus on patient experiences perhaps contributing to the near total neglect of the caregiver experiences of delusions in PD. While there exists literature on related topics such as the effects of gender differences in sexual behaviors of Alzheimer disease or intimacy issues due to dementia (Harris, Adams, Zubatsky, White, 2011; Davies, Sridhar, Newkirk, Beaudreau, O'Hara, 2012; Hayward, Robertson, Knight, 2013); the high prevalence of physical and sexual aggression to caregivers in advanced PD and experiences in palliative care (Miyasaki, 2016), there is no specific body of research addressing this paper's research question. Other angles from which to review the literature were also considered, e.g., an exploration of patterns of coping with partner violence (Al-Modallal, 2012; Foster, 2015) and caregivers living or being around someone with frank psychosis (Kuipers, Onwumere, Bebbington, 2010).

The findings of this research suggest changes in, and significant challenges, to the psychological health of spouses of PWP who present with PD delusions. Experiencing violence and emotional abuse is not uncommon for caregivers looking after people with Parkinson's (Miyasaki, 2016). Intimate partner violence has been recorded in the general body of research literature pertaining to marriage (Wong, 2016), as have topics that address ways of coping when loved ones have dementia (Mullin, Simpson, Froggatt, 2013). The common element, as suggested by the findings, is the suffering of spouses due to the illness or behaviour of their partners.

The study SPs revealed how they had been psychologically affected by their partners' delusional thoughts. There was a change in their lives that was deeply intimate and personal and rarely discussed outside the family unit. There was a breach in the spousal relationship due to the PD psychotic symptoms that hurt SPs as they attempted to remain faithful and helpful as life partners and informal caregivers.

As a result of the PWP having delusions, the relationship between the spouses is affected. There appears from what was reported by many of the spouses, a lack of trust, intimacy and love which are the core elements of relationship. Things become one way with the SP having to do everything or most things for the PWP and this inevitably consumes and overshadows the marital relationship. The healthy spouses have to force themselves to continue to be the care-givers. They are pressured to be care-givers despite not being professionally trained for that role. They find themselves in a 'job-like' position that they did not sign up for. Many SPs reported that they did remain in their marriages because they did see the need to remain in them to honour their marital commitments despite the cost to themselves and the dire consequences to their physical, mental and emotional health.

The marriage is now for the SPs possibly just something that belongs to the past. They can only now reminisce about how it was and what has been lost. They are lonely and quite often very isolated, emotionally and physically, from others and the PWP.

For a few SPs, there is some hope beyond hope in a miracle that might come about from the medical world that could potentially address the PWPs' health conditions to restore them and the

marriage to what was. For all of the SPs, they report for the moment just co-existing with the PWP in quiet lives of desperation. For the SP, their needs cannot be met and they try to live and cope within limitations to the marriage that were not of their choosing.

5.2 Limitations and future directions

Table 4: Limitations and future directions

Interview	Each participant was interviewed once
Interview mode	Face to face (8 interviews); By telephone (4 interviews)
Interview protocol	General questions to encourage discussion of experiences
Length of interview	30-60 minutes
Setting of interview	Movement Disorders Clinic Room (Face to face); Home (Telephone)
Participant's ages	62, 66 (x2), 70, 73, 74 (x 3), 79, 80 (x2), 82
Familiarity with psychosis	Confusion between hallucinations and delusions
Other sources that may have been helpful	Adult children Other caregivers

The SPs after consenting to participating in the research were only interviewed once between 30 – 60 mins, and it was the first time that they had met with the interviewer. This may have hindered open and flowing conversation. They may have needed more time to become comfortable before having to delve into the topic as determined by the interview protocol.

The interview protocol did not provide any explanation or examples of the information that the interviewer was seeking. The SPs were unfamiliar with being asked about their feelings and thoughts. They were familiar only with talking about how their spouses with PD were experiencing the illness. There is evidence within the interview data that SPs were not always able to distinguish or know the difference by what is meant by the term hallucination versus delusion. There was a conflation of psychotic symptoms for many of the SPs. This slowed

down the interview process when the interviewer had to tease apart the information to clarify what was being asked for and recorded.

There was no evidence within the data that the face to face interview data differed from that retrieved through telephone interviews but the setting of each may have hindered more revealing insights. The clinic setting may not have been the most comfortable for people to come and talk about their private experiences and for those interviewed over the telephone, while situated at home, they were talking to an unseen interviewer and again expected to talk about their private lives in relation to when their spouses had been ill with PD related delusions.

Given the nature of the delusions around issues like emotional and sexual fidelity, it is possible that the responses of the SPs may not be as developed had there been more than one interview. The SPs were also senior citizens, the majority of them being elderly. Due to their advanced ages, there was a lack of familiarity in discussing their marital experiences openly and with a stranger.

There was evidence in the interview data of shame and embarrassment regarding the subject matter. There was also a feeling of guilt reported by many of the SPs because they felt that their spouses had been good people. They felt that talking about their PD psychotic ideas and bizarre behaviour, in an interview with someone unfamiliar with their spouses, was dishonouring them and so while answering it appeared that they also sought to protect them. This may have changed the depth or type of responses.

While the SPs sought to please interviewees, they were unsure of what the interviewer was really looking for. This was due to an unexpectedness of what would be asked. While the letter with a description of the study had been issued with the consent form, the SPs did not seem to really understand the purpose and nature of the study fully. They may have benefitted from a personal explanation rather than a written one. It was clear from the interviews that the SPs had not prepared their answers or had sat and recollected what life had been like during the period of time their spouses were delusional.

All of the SPs reported that it was the first time they had experienced focused discussion about the delusions and consequences for them. Prior conversations had been with professionals limited to pharmacological issues, e.g., change in dosage of Levodopa or another dopamine agonist medications. It would have also been helpful to ask or learn more about what their adult children experienced as well. Was the experience the same or different? They too like spousal caregivers are silent voices in the literature regarding how PD delusions affect the family unit. The input of other caregivers may also have been a good resource for a thorough examination of the research question.

5.3 Implications for clinical practice

Table 5: Implications for clinical practice

Education of person with PD and spouses	Family physician conversations Brochures Education session
Education of health professionals	‘Lunch and Learn’ Talks for Movement Disorder interdisciplinary team members Development of education literature (e.g., for family physician) Educational seminars (in clinic and community settings) Training for screening of psychosocial issues (e.g., ZBI -12) Training for use of approved assessment tools (BDI –II; BAI)
Access to health professionals and community resources	Neurologists; Psychiatrist for Movement Disorders; Social Worker; Chaplain/Spiritual Health Practitioner; Psychologist; Community Counsellors; Nurses; Other allied health professionals; Parkinson’s Association

Spouses and their partners should be exposed to the topic of delusions, at minimum through a brochure but at best through an educational session that could be delivered in Movement Disorder clinics and promoted through family physicians or local/regional Parkinson’s Association. Knowledge about potential delusional states can be frightening but it is a risk of PD

illness and like all risks, it is better, for some spouses to feel prepared than blindsided, e.g., Lucy: “No one told us about delusions, I think they should have warned us”. But some participants felt it would have been too much, e.g., Julia: “not everybody wants to know”. The education of medical and health professionals is essential for the deliverance of accurate and helpful information to people with PD and their spouses. ‘Lunch and Learn’ talks given to medical and allied health professionals in hospital and community contexts would also help a wider group of people become aware of PD issues that may manifest when a PWP is admitted to acute care hospitals or placed in long-term care.

Screening is an important pre-clinical element that needs to be enhanced. All of the SPs had been through the Movement Disorders’ clinic or had been seen by a community Neurologist. None of the SPs had received literature or education pertaining to PD delusions. It would seem that future couples coming for PD health care would benefit from being asked about various aspects of their home lives and their marriages/relationships. The separation of couples for the purposes of assessment would be advisable. It might be helpful to ask the husbands and wives to fill out some approved clinical inventory tools e.g., Zarit Burden Interview (ZBI -12) to determine the level of caregiver burden relating to cognitive and other issues of spouses and to use this as a way to delve deeper into what was recorded and noted. The use of other tools such as BDI –II (Beck Depression Inventory II) and/or BAI (Beck Anxiety Inventory) with quick and easy Likert scaling may also reveal issues going on for the accompanying spouse of the person with PD.

The availability of resources, both within Movement Disorder clinics and within the community is important. It might have benefitted the SPs to have had a psychologist or counsellor to talk to that focused on broader issues than just changes to PD drugs that may have been causing or exacerbating the PD delusions, e.g., Karen “I would have liked someone to talk to, to confide in about the kinds of delusional things he was saying”. Many of the SPs were also familiar with the Parkinson’s Association of Alberta as an educational and supportive resource. The findings of this research suggest that improved connection to what is being discovered in clinical settings be imparted to organizations such as the PD association so that they can devise educational information and provide educated facilitators to lead support groups. Having a dedicated group

to caregivers coping with PD psychosis would be helpful for providing good care to the carers by addressing their common feelings of isolation, shame, embarrassment and guilt.

6 Conclusion

Qualitative approaches capture the raw experiences of people and aid in the gathering of data that is rich and accurately describes and records these experiences. Qualitative data enhances the body of research when looking at the research question of the psychological impact of PD delusions on spouses. The research findings show that issues resulting from PD delusions impact the spouses psychologically in many ways. The challenges and problems are often under reported due to perceived stigma and embarrassment, e.g., Karen: “I didn’t say anything to anyone at the time because I was mortified by what he was thinking, that I was a prostitute”. Spouses might benefit from some information, the concentration of which could be decided by the primary health provider regarding the potential for PD delusions for each individual patient case, i.e., depending on how the spouse of the PWP presents and seeks information and queries the potential trajectory of PD for their partner.

7 References

1. Aarsland, D. (Ed), Cummings, J., Weintraub, D., Chaudhuri, K. (Eds.). (2013). *Neuropsychiatric and cognitive changes in Parkinson's disease and related movement disorders*. Cambridge: Cambridge University Press.
2. Abendroth, M., Lutz, B., Young, M. E. (2012). Family caregivers' decision process to institutionalize persons with Parkinson's disease: A grounded theory study. *International Journal of Nursing Studies*, 49, 445-454.
3. Al-Modallal, H. (2012). Patterns of coping with partner violence: experiences of refugee women in Jordan. *Public Health Nursing*, 29(5), 403-411.
4. American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC.
5. Angen, M. (2000). Evaluating interpretive inquiry: reviewing the validity debate and opening the dialogue. *Qualitative Health Research*, 12: 1338-1352.
6. Apaydin, H., Benbir, G. (2014). Capgras syndrome during the course of Parkinson disease dementia. *The Journal of Neuropsychiatry and Clinical Neurosciences*, 26 (3), E46-E46.
7. Barken, R. (2014). Caregivers' interpretations of time and biography: The experiences of caring for a spouse with Parkinson's disease. *Journal of Contemporary Ethnography*, 43 (6), 695-719.
8. Boland, A., Cherry, G., Dickson, R. (Eds.). (2014). *Doing a systematic review – a student's guide*. London: Sage.
9. Booth, A., Sutton, A., Papaioannou, D. (2016). *Systematic approaches to a successful literature review* (2nd ed.). London: Sage.
10. Burn, D., Jarhanshahi, M. (2013). *Hallucinations and delusions*.
<https://www.Parkinsons.org.uk/information-and-support/hallucinations-and-delusions>
11. Cannas, A. et al. (2009). Othello syndrome in Parkinson disease patients without dementia. *The Neurologist*, 15 (1), 34-36.
12. Carter, J., Lyons, K., Lindauer, Malcom, J. (2012). Pre-death grief in Parkinson's caregivers: a pilot survey-based study. *Parkinsonism and Related Disorders*, 18, S15-S18.

13. Creswell, J. (2013). *Qualitative Inquiry & Research Design: Choosing among five approaches*. California: Sage.
14. Cummings, J. (1991). Behavioural complications of drug treatment of Parkinson's disease. *Journal of American Geriatric Society*, 39, 708-716.
15. Davies H., Sridhar S., Newkirk L., Beaudreau S., O'Hara R. (2012). Gender differences in sexual behaviors of AD patients and their relationship to spousal caregiver well-being. *Aging Ment Health*, 16(1):89-101.
16. Davis, K. (2011). Formulating the evidence based practice question. *Evidence Based Library and Information Practice*, 6 (2), 75-80.
17. Den Ousten, B., Lucas-Carrasco, R., Green, A. The WHOQOL-DIS group. (2011). Perceptions of person with Parkinson's disease, family and professionals on quality of life: An international focus group study. *Disability and Rehabilitation*, 33, 2490-2508.
18. Divač, N., Stojanovic, Savić Vujović, Damjanović, Prostan (2016). The efficacy and safety of antipsychotic medications in the treatment of psychosis in patients with Parkinson's disease. *Behav Neurol* 4938154:1-6.
19. Dixon-Wood, M. et al. (2007). Appraising qualitative research for inclusion in systematic reviews of quantitative and qualitative comparison of three methods. *Journal of Health Services Research & Policy*. Jan Vol 12 (1), pp.42-7.
20. Duggleby, W., Holtslander, L., Kylma, J., Duncan, V., Hammond, C., Williams, A. (2015). Meta-synthesis of the hope experience of family caregivers of persons with chronic illness. *Qualitative Health Research* 20 (2) 148-158.
DOI:10.1177/104973230935329.
21. Elliott, B. (2015). Survivors' coping with intimate partner violence: insights and limitations. *Families, Systems, & Health*, 33(3), 295-296.
22. Flicker, S, Cerulli, C., Swogger, M., Talbot, N. (2012). Depressive and posttraumatic symptoms among women seeking protection orders against intimate partners: Relations to coping strategies and perceived responses to abuse disclosure. *Violence Against Women*, 18(4), 420-436.
23. Flyckt, L., Löthman, A., Jørgensen, L., Rylander, A., Koernig, T. (2013). Burden of informal care giving to patients with psychoses: A descriptive and methodological study. *International Journal of Social Psychiatry*, 59(2), 137-146.

24. Foster, E. L., et al. (2015). Coping with intimate partner violence: qualitative findings from the study of dynamics of husband to wife abuse. *Families, Systems, & Health*, 33(3), 285-294.
25. Friedman, J. (2013). *Making the connection between brain and behavior*. New York: Demos.
26. Friedman, J., Chou, K. (2004). Sleep and fatigue in Parkinson's disease. *Parkinsonism & Related Disorders*, 10, 27-35.
27. Giles, S., Miyasaki, J. (2009). Palliative stage Parkinson's disease: Patient and family experiences of health-care services. *Palliative Medicine*, 23, 120-125.
28. Grant, M., Booth, A. (2009). A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Information and Libraries Journal* (26):91–108. DOI: 10.1111/j.1471-1842. 2009.00848.x
29. Habermann, B. (2000). Spousal perspective of Parkinson's disease in middle life. *Journal of Advanced Nursing*, 31, 1409-1415.
30. Harris S., Adams M., Zubatsky M, White M. (2011). A caregiver perspective of how Alzheimer's disease and related disorders affect couple intimacy. *Aging Ment Health*, Nov;15(8):950-960.
31. Hasson, F., Kernohan, W., McLaughlin, M., Waldron, M., McLaughlin, D., Chambers, H. et al. (2010). An exploration into the palliative and end-of-life experiences of carers of people with Parkinson's disease. *Palliative Medicine*, 24, 731-736.
32. Hayward L., Robertson N., Knight C. (2013). Inappropriate sexual behaviour and dementia: an exploration of staff experiences. *Dementia*, 12(4):463-480.
33. Hodgson, J., Garcia, K., Tyndall, L. (2004). Parkinson's disease and the couple relationship: A qualitative analysis. *Family Systems & Health*, 22, 101-118.
34. Hounsgaard, L., Pedersen, B., Wagner, L. (2011). The daily living for informal caregivers with a partner with Parkinson's disease – an interview study of women's experiences of care decisions and self-management. *Journal of Nursing and Healthcare of Chronic Illness*, 3, 504-512.
35. Hudson, P., Toye, C., Kristjanson, L. (2006). Would people with Parkinson's disease benefit from palliative care? *Palliative Medicine*, 20, 87-94.

36. Karlstedt, M., Fereshtehnejad, S., Aarsland, D., Lökk, J. (2017). Determinants of dyadic relationship and its psychosocial impact in patients with Parkinson's disease and their spouses., *Parkinson's Disease*. Doi.org/10.1155/2017/4697052
37. Kuipers, E., Onwumere, J., Bebbington, P. (2010). Cognitive model of caregiving in psychosis. *The British Journal of Psychiatry: The Journal of Mental Science*, 196(4), 259-265.
38. Kyrtos, C., Stahl, M., Eslinger, P., (2015). Capgras syndrome in a patient with Parkinson's disease after bilateral subthalamic nucleus deep brain stimulation: a case report. *Case Reports in Neurology*, 7(2), 127-133.
39. Ludvigsen, M., Hall, E., Meyer, G., Fegran, L., Aagaard, H., Uhrenfeldt, L. (2016). Using Sandelowski and Barroso's meta-synthesis method in advancing qualitative evidence. *Qualitative Health Research*, 26 (3), 320-329.
40. Lyons, K., Stewart, B., Archbold, P., Carter, J. (2009). Optimism, pessimism, mutuality, and gender: predicting 10-year role strain in Parkinson's disease spouses. *The Gerontologist*, 49 (3), 378-387.
41. Martin, C. (2015). Psychosocial challenges experienced by partners of people with Parkinson disease. *Journal of Neuroscience Nursing*, 47 (4), 211-313.
42. Mercer, C. (2015). The impact of non-motor manifestations of Parkinson's disease on partners: understanding and application of chronic sorrow theory. *Journal of Primary Health Care*, 7 (3), 221-227.
43. McLaughlin, D., Hasson, F., Kernohan, W., Waldron, M., McLaughlin, M. Cochrane et al. (2010). *Palliative Medicine*, 25, 177-182.
44. Minton, L., Perepezko, K., Pontone, G. (2016). *Psychosis: A mind guide to Parkinson's Disease*, Florida: National Parkinson Association.
45. Miyasaki, J. (2016). High prevalence of physical and sexual aggression to caregivers in advanced Parkinson's disease. Experience in the palliative care program. *Parkinsonism and Related Disorders*, 24, 141-142.
46. Mullin J, Simpson J, Froggatt K. (2013). Experiences of spouses of people with dementia in long-term care. *Dementia*, 12(2):177-191.
47. Noblit, G., Hare, R. (1988). *Ethnography: Synthesizing Qualitative Studies*. London: Sage.

48. Sandelowski, M., Barroso, J. (2007). *Handbook for Synthesizing Qualitative Research*. New York: Springer.
49. Secker, D., Brown, R. (2005). Cognitive behavioural therapy (CBT) for caregivers of patients with Parkinson's disease: a preliminary randomized controlled trial. *J Neurol Neurosurg Psychiatry*, 76:491-497.
50. Sullivan, T. P., Weiss, N. H., Price, C., Pugh, N., Hansen, N. B. (2018). Strategies for coping with individual PTSD symptoms: experiences of african american victims of intimate partner violence. *Psychological Trauma: Theory, Research, Practice, and Policy*, 10(3), 336-344.
51. Tan, S., Williams, A., Morris, M. (2012). Experiences of caregivers of people with Parkinson's disease in Singapore: a qualitative analysis. *Journal of Clinical Nursing*, 21, 2235-2246.
52. Tanji, H. et al., (2008). Mutuality of the marital relationship in Parkinson's disease. *Movement Disorders*, 23 (13), 1843-1849.
53. Timmers, E. et al. (2017). Non-motor symptoms and quality of life in dopa-responsive dystonia patients. *Parkinsonism and Related Disorders*, 45, 57-62.
54. The Joanna Briggs Institute (2014). *Joanna Briggs Institute Reviewers' Manual*. Adelaide, South Australia: The Joanna Briggs Institute.
55. Todd, D., Simpson, J., Murray, C. D. (2010). An interpretative phenomenological analysis of delusions in people with Parkinson's disease. *Disability and Rehabilitation*, 32(15), 1291-1299. <https://doi.org/10.3109/09638280903514705>
56. Turney, F., Kushner, B. (2017). The experience of the spouse caring for a partner with Parkinson's Disease. *Nursing Praxis in New Zealand*, 33 (1), 7-16.
57. van Hees, Petra J. et al. (2017). Discussing sexuality with patients with Parkinson's disease: A survey among Dutch neurologists. *J Neural Transm*, 124(3):361-368.
58. Warren, N., O'Gorman, C., Hume, Z., Kisely, S., Siskind, D. (2018). Delusions in Parkinson's disease: A systematic review. *Neuropsychology Review*, 28:310-316.
59. Williamson, C., Simpson, J., Murray, C. (2008). Caregivers' experiences of caring for a husband with Parkinson's disease and psychotic symptoms. *Social Science & Medicine*, 67, 583-589.

60. Wong, J. et al. (2016). Problem-focused coping mediates the impact of intimate partner violence on mental health among Chinese women. *Psychology of Violence*, 6(2), 313-322.
61. Wressle, J., Engstrand, C., Granerus, A. (2007). Living with Parkinson's disease: Elderly patients' and relatives' perspective on daily living. *Australian Occupational Therapy Journal*, 54, 131-139

Part Three: Critical Appraisal

1 Critical appraisal

The following eight sections contain elements of my notes and my reflection on the research process from start to finish. The review of the various aspects of the doctoral process may be helpful for those interested in engaging in similar research.

1.1 Choosing a research topic

I began searching for a university in which to do my doctorate in psychology. Many doctoral programmes were very focused on research, but the University of Leicester PsyD stood out for me because of its focus on students who were already working in the field of clinical psychology. At the time of my application, the Department of Psychology was aligned with the School of Medicine. The intersection of Psychology and Medicine was attractive to me. I wanted to conduct research that would hopefully yield good clinical pointers and findings to help patients, their family members and clinicians.

I realized at the time that there are new areas opening up for research, e.g., Medical Assistance in Dying (MAID) which became legal in Canada in February 2015. Due to changes in the criminal code, Canadian adults were free to request MAID (Supreme Court of Canada, 2015). I considered researching the area of emotional bias in those choosing MAID. I discussed some of my ideas with Dr. Wendy Johnson, Director of the ALS clinic, Dept of Medicine, University of Alberta, and she was very interested and encouraged for me to pursue the topic. I looked at the faculty of the University of Leicester and I was particularly drawn to the hospital-based research by Prof. Noelle Robertson. I discussed with her my possible topic and applied for the PsyD programme. As a few months passed, I found my own exposure to MAID, primarily with ALS and other neurological patients with a terminal diagnosis, to be a dark emotional area for me. I was more torn between understanding why some patients chose MAID, but I felt more comfortable with those who chose the more natural route to death with the aid of palliative care. As a result of how I felt, I didn't really want to delve into research in this area for my doctoral work.

As time went on, I decided that I would like to consider another topic if I could come up with one that might have more hope within it, at least for me emotionally and practically. I like to be

productive and feel I make a difference in work. At this time, I was counselling many spouses of Parkinson's patients who said that they appreciated the sessions and wondered why they didn't have a counselling resource sooner. I listened to their accounts of their experiences at home with their ill partners and I felt that there might be something I could address if I could somehow capture the experience. I had initially thought 'mindfulness' would be the focus of my empirical research and that was the focus of my literature review. However, from what I gleaned thematically I realized that while 'mindfulness' can be helpful to PWP and their spouses too, there were some fundamental themes that I was encountering clinically but not in the literature. Scanning the research body of literature, I found there was nothing on the psychological impact of Parkinson's patients' delusions on spouses. Before examining how mindfulness might help them I decided I needed to do primary research into this area of PWPs' delusions and the ramifications for their spouses. Mindfulness as an approach to help the spouses is something that has yet to be explored due to my findings, the richness of the topic pertaining to delusions more than suffices for this PsyD research thesis and the effectiveness of practices of mindfulness have yet to be explored with this study participants' population, i.e., spouses of delusional PWP.

My initial steps to research: I had not yet enrolled for the PsyD programme officially when I consulted with Dr. Janis Miyasaki, Director of the Movement Disorder Clinic, Dept of Medicine, University of Alberta, and she was very enthusiastic and supportive of the topic areas related to PD that I was interested in. Then I discussed it with Prof. Robertson and to my delight she had engaged in and supervised research on other neurological illness, e.g., Huntington's Disease. So a research topic was born at least as a tentative area that was certainly interesting to me, but I had yet to do a more in-depth literature search, all the while hoping that my topic wasn't covered too extensively.

1.2 The literature review

The initial search began with me trundling through the data bases (e.g., MEDLINE via OVID, CINAHL, PsycInfo) that I could access through Alberta Health Services. I was able to find articles on PD but I found that they were too broad. I enrolled in a few Knowledge Resource Courses: Knowledge Resource Service (KRS) Orientation; Search Skills 1 – Speedy Searching; Search Skills II – Searching Fundamentals; Search Skills III: Advanced Literature Searching;

Introduction to Grey Literature; Finding Full Text Articles. The searching techniques all seemed easy enough and intriguing when watching the librarians visually on screen, typing, clicking and finding articles. However, I soon discovered it was way more intricate and confusing when I attempted the searches myself. All of the extra aspects of knowing how things like “and”, “or”, “*”, “S1 and S4” could change the outcome was frightening. I enlisted the help of the librarians to double check my scoping of the data bases. I was afraid that I would miss key studies on my topic of interest. The librarians helped me at times to refine my searches. As I read through some of the studies, more aspects came to light, so I had to determine what my inclusion and exclusion criteria to narrow the scope of the review to make it relevant to my research area. This literature review process took a few months. Some full text articles were available immediately and some had to be retrieved through other libraries, courtesy of the KRS staff responding to my requests for the articles. What I found to be interesting was the KRS staff’s enthusiasm and interest in my topic. The staff were located in Edmonton, Calgary and Red Deer. It was eye-opening and positive for me that the topic was being well received. A few of the staff told me that they had relatives with PD and were asking me to contact them if I needed any more research into the topic, they were more than willing to try and root out anything from the databases that may help my research.

One of the other discoveries that I made during this time, was in a conversation about my initial doctoral work with a researcher on one of my clinical units in the hospital. She asked me about my literature search process and she asked me what reference software package I was using. I was at a loss – what software package? She mentioned something called *RefWorks* and told me to look it up. When I did, I was astounded by *RefWorks*’ capabilities. I, having done most of my academic studies in the 1990s, had to type up references and bibliographies one key at a time. *RefWorks* showed me how times have changed and how much easier it is now, less typing for starters. Between database literature searches and *RefWorks*, I realized while there are some great e-tools today, but there is also much more pressure to ensure that there is nothing missed.

Something else that was new to me was Grey Literature. I was lucky to be working with world renowned neurologists who are very active on the international conference circuits. I was working one day a week at the Kaye Edmonton Clinic (KEC) as part of the Complex Neurology

Symptoms Clinic (CNS), Dept of Medicine, University of Alberta, which is part of a research project between the University of Colorado Hospital (UCH), Denver, USA and the University of California San Francisco (UCSF), San Francisco, California, USA. With my access to experts at my own site, University of Alberta Hospital (UAH) and the KEC and those at UCH and UCSF. I put out my topic of interest and waited with bated breath to see if the neurologists and psychiatrists, chaplains and other health professionals, e.g., clinic nurses had any work done on this topic. After much time and assiduous attention to the literature that existed, I extracted six articles that best helped me build an argument for my ability to examine the research literature to determine the focus of my empirical research.

1.3 Methodological decisions

Qualitative research was new to me. Monthly discussions with my supervisor directed me to various articles that were qualitative. I was exposed to many methods and read up on various approaches. At one point I went to see Dr. Alex Clark, Chair of the International Institute for Qualitative research (IIQM), University of Alberta and discussed with him my literature review findings. I was looking for pointers as to the best way to proceed with the qualitative research piece that would form part two of my doctoral programme. We discussed computer coding software packages. I told him that I would like to use the German software package called MAXQDA and I was trying to figure out why most universities use NVIVO. I talked about what I liked in the MAXQDA system and he suggested I take a course in NVIVO and in MAXQDA and then to make a case for the German one if I still thought it was better. So, I enrolled in an NVIVO course that was given by someone in Sydney, Australia and in a MAXQDA three half-day on-line seminar from Vancouver, British Columbia, Canada. Hands down for me, MAXQDA seemed much more evolved and it allows coders to switch between PC and Mac platforms.

As a result of that hour session at the IIQM, Dr. Clark referred me to a colleague of his at the Faculty of Nursing, University of Alberta, to discuss with him what methodological approaches are welcomed within the University of Alberta Hospital and Kaye Edmonton Clinic. We discussed things like grounded theory, its merits and usefulness for research. With Prof. Robertson we had looked at other approaches, e.g., phenomenological, interpretative and

ethnographic. With some more reading, I settled on a narrative approach but by the time my first couple of interviews were done, I realized that the thematic approach would most likely be the best fit to achieve my research goals. At the end of twelve interviews, themes were apparent and began to be saturated, i.e., no new themes were emerging, so I concluded the recruitment process and notified all concerned at the Kaye Edmonton Clinic and at the Parkinson Association of Alberta. The themes were clear to me and with verification from three other people, I felt confident in the assertion that four themes were present in all of the twelve interviews with the spouses of the PD patients who had delusions.

In preparing for the interview process I looked to see what recording devices were being used in Alberta Health Services and the protocols for the University of Alberta re: the recording of research participants and the transfer of electronic files. At this time, I also consulted an IT specialist regarding the transfer of files from the *Philips* Digital Recorder and their placement onto USB sticks for the transcriptionist.

The transcriptionist was a casual administrative assistant within Alberta Health Services and had done some work for the Department of Psychology at the University of Alberta Hospital. She was very pleased to be asked to transcribe, on her own time, the interviews for an area of research that she thought was fascinating. Funding was provided to pay for the transcription of the interviews thanks to the Dr. Janis Miyasaki Parkinson's Disease Research, University of Alberta Hospital Foundation.

The interviews took quite some time to happen. I had thought I could do them all one after another. But I found it was harder to recruit participants despite the neurologists' and psychiatrist's attention to possible study subjects at clinical visits to the KEC as part of the Movement Disorders Clinic. The transcriptionist had finished typing up the first few and then she and her husband moved to the states. Luckily, she was still open to transcribing and I just had to figure out how to get the USB sticks to her. Due to the challenges recruiting and having participants available for interviewing, the interviews spanned a year. The transcriptionist had returned to Alberta for a few family functions with her adult children who still reside here. This facilitated an easy transfer of the new and accumulated interviews on USB sticks.

1.4 The ethics and approvals process

The submission for ethics approval was similar within U of A and UOL but the U of A process was very long and complex. I would submit the paper work to the U of A and then get emails via the neurologist that I was working with that there had to be changes, e.g., if a document didn't have a project identifier number or it did not have headed paper, or it was not compliant with a template etc. Then I may notice a typo and would have to upload and re-submit a document that seemed to take forever with the Research Ethics Management Online (REMO) tool. Eventually, in what seemed an unending process, the REMO administrator, deemed the application to be ready to be sent on to the ethics committee. One of the elements that I found interesting was despite it being my research project, I wasn't named as the principal investigator because I didn't hold a faculty position within the Department of Medicine. I think this was a bit cumbersome for the process because while I was still happy to be named as a co-investigator, all of the administrative or reviewers' comments or even the announcement of the ethics committee's approval and the call for the annual renewal, still went to the principal investigator who had to then let me know. Fortunately, I had a good relationship with the named principal investigator, Dr. Janis Miyasaki, who was very supportive of my work and had lots of input with regard to PD from a medical perspective and her prolific research work in the area of Movement Disorders, primarily PD.

The application of the UOL ethic's application was a dream in comparison to the U of A's application process. But the latter had prepared me and probably made it easier. I found that the biggest element was if you wanted to make changes, it was arduous in both systems. I realized for any future research, it would be important to be as thorough and aware, as to what extent a research project might be before an ethics application is begun. I appreciate though, despite criticisms, the importance of an ethics approval application. Having it challenging made me more aware of the necessity to stay within the scope of what was approved and sanctioned.

1.5 Recruitment and interviews

The interviews went well. The only negative, for me, was that they were spaced out over a year. It was not as easy to set up times because I had to wait for most of the participants to be in the city for their partners' clinical appointments. Many had to travel vast distances, e.g., between 50

to 1000 kilometers to attend the clinic. Participants came on time and they were eager to participate. After reading the information letter and having signed the consent forms, they were interviewed. A few of the participants, who lived more than 50 kilometers from the city, chose to be interviewed over the phone. They too were ready for their telephone interviews.

The participants had been informed about the research study by their neurologist, clinic psychiatrist or nurse and were invited to contact me if they were interested in participating. Those that contacted me were screened to see if they met the inclusion criteria. As time went on, I had to submit an amendment to the ethics board and had to ask the Parkinson Association of Alberta to put up a poster to try and get some more participants. That was an interesting process. I had an influx of calls from extremely enthusiastic spouses, but I found that most of their partners did not have delusions. Upon talking to the spouses, it was apparent that their partners had suffered with hallucinations or general denial of their PD diagnosis and most of the spouses did not know the difference between hallucinations and delusions. Most did not really understand what delusions were and that was something that had to be teased out further in the interviews. I did get four participants from the Parkinson Association that met with the inclusion criteria.

One other note about the interview process, I realized after the first couple of interviews that I really had to emphasize at the start of the interviews and with gentle reminders during them that I was primarily interested in the spousal experiences themselves, how they thought, felt and behaved and not focusing as much on their partners with PD. The spouses were so used to being asked about their ill partners, they found it was a new and welcome experience to be asked about how they had been coping emotionally and psychologically. I found that those from rural communities tended to be very practical and task orientated so this made the interviews a little trickier as I tried to get the right wording or disposition to get their comments on emotional experiences etc., but they responded well to my probing questions and positively embraced the interview process overall.

1.6 The analysis

This section of the research process was by far the most exciting. I read and re-read the interview transcripts and I was surprised by their content. It was heartening to realize that there was far more content in the scripts than I had thought there was while engaged in the interviews. I had always felt that I wasn't getting enough information or the depth of self-reflection that I had wanted from the spouses. It had been challenging to get them to talk 'psychology' in ways. However, it was with close attention to the articulated words of the participants that I realized they had in fact said a lot. The material was very rich, and it was at this point that I felt that the whole long process of the doctorate and research requirements for UOL and U of A were worth it. I eagerly began a cursory coding and then followed up with more in-depth coding. Then I re-named or moved codes and sub-codes for best fit and eventually came up with four main codes. Then I re-coded the documents with the new schema to see if what I had detected was in fact present in the majority of the interviews. I found that the four themes were present in all twelve interview transcripts and I was able to extract pieces of text to confirm, validate and ratify the findings.

The use of MAXQDA as the computer software was very helpful for the analysis. It uses lot of colour and is very user friendly. I had started using MAXQDA 12 for my literature review and a new version of MAXQDA 2018 for the analysis of the transcripts. The newer version has more labels over the icons and that makes it more helpful for making different decisions re: codes, insertion of memos, access of visual tools etc. which all helped the analytical process move along smoothly.

When I was relatively content with the emergent themes and sub-themes, I had a colleague, Nathram Jagnanan, help with the verification of my coding. He read the transcripts and examined the codebook and we ensured there was consensus. Then as an extra measure, I would read out the highlighted and coded textual components and we would further discuss if it met the code criteria. This was a tedious process, but it was fun, we both found it interesting to discuss the topics and it was one that forced me to re-think and re-evaluate what I had coded. Then my supervisor, Prof. Robertson, oversaw my coding selections and helped me to come up with more accurate overall titles or sub-titles or to leave things as they were. I also presented the thematic

findings to Dr. Janis Miyasaki to get her comments on the findings and to test them against her clinical experience and knowledge of the PD population and their family members. She too was very pleased with the themes that emerged and felt that they were of paramount importance for the advancement of PD related treatment and patient and family care.

1.7 Report writing and dissemination

Prof. Noelle Robertson felt that this work should be presented at a conference and would also like to see it published in a mental health journal such as *Aging and Mental Health*. Dr. Janis Miyasaki too was very ardent in saying that the work deserved to be read and published in a neurological journal, her suggestion was, *Parkinsonism and Related Disorders*. I will have to consider what might be the best fit for the content and for my target audience. I will do this after I submit my doctoral work and await feedback from the examination committee which I understand will be about a six to ten weeks.

For starters, my work, after it is accepted by the UOL, will be available to any of the participants who would like a copy. One has requested a copy already and I think she will be pleased with it. I think it will be helpful for her to see what other people said because it was similar. Some members of the Parkinson Association of Alberta have also expressed an interest in having me come to give a talk to the members in the new year. I think this would be a great opportunity to help people understand more about PD delusions and it would make me feel that my research is not just an academic pursuit, but a real contribution to the education and support of those who have PD or who live with someone with PD.

On the work front, one of the neurologists, Dr. Richard Camicioli, has asked me to present my work to the neurologists within the Movement Disorder program. His suggestion was before I defend my thesis, which might be a neat opportunity and help in my preparation. However, this also feels a little scary because it is always, perhaps, more daunting to present as a non-physician in front of physician colleagues. However, it would be interesting to see what comments they would have that might help me for the next stage, i.e., selecting aspects of my work and formatting them according to the publisher's guidelines to make it an acceptable article for publication. Its format, as it stands, fits with *Aging and Mental Health* but the audience that I

would like to have would be neurologists and that is why *Parkinsonism and Related Disorders* would be excellent, however, their full-length article is 3,000 words maximum which would mean I would have to put participants' quotes from the thematic sections into tables to exclude the word count and really present the study and its findings very succinctly which, I would think, might be challenging.

1.8 Professional and personal learning points

I had never seen a meta-synthesis prior to engaging in this doctoral programme. It was challenging, and it took me some time to grasp the purpose and point of it all. However, I realize it is the format and language of my medical colleagues and allied health professionals. Now that I have done one, I could foresee myself being able to do another one with less hassle. The use of MAXQDA for the coding of the articles and the extraction of themes prepared me for my own empirical research project. The discipline of being very precise in the meta-synthesis brought a skill that was re-usable when it came to the analysis of the interview transcripts, the coding process and identification of themes.

While it may seem that many topics have been covered in research, I was surprised by the dearth of literature pertaining to my own area of interest, i.e., PD delusions and nothing on the psychological implications of them on spouses. This shows me that clinicians always have to question and query if there are in fact things we can research or read about in the literature and implement them in our practice. As my own research will hopefully have a good article impact factor, I trust that the information will be considered by neurologists and related clinicians around the world. If that is the case, the work and the account of it, contained herein, will have been valuable and a solid contribution to the fields of medicine and psychology for the betterment of clinicians, patients and family members.

2 References

1. Government of Canada (2018, September 30). Medical assistance in dying. Retrieved from <https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html>
2. International Institute for Qualitative Methodology (2018, September 30). Retrieved from <https://www.ualberta.ca/international-institute-for-qualitative-methodology/>
3. Parkinson Association of Alberta (2018, September 30). Retrieved from <http://parkinsonassociation.ca/>
4. Supreme Court of Canada. 2015. Carter v. Canada (Attorney General), SCC 5.
5. Parkinsonism and Related Disorders (2018, September 30). Guide for authors. Retrieved from <https://www.elsevier.com/journals/parkinsonism-and-related-disorders/1353-8020/guide-for-authors>



STUDY PROTOCOL

Study Title: The Psychological Implications of Parkinson's Patients' Delusions on their Spouses – A Narrative Study.

Principal Investigator:

Dr. Janis Miyasaki
Director of Movement Disorder Program
Dept. of Medicine, University of Alberta
Email: miyasaki@ualberta.ca
Tel: 780.248.1798

Co-Principal Investigator:

Caroline Nolan, R. Psych
Complex Neurology Symptoms Clinic
Kaye Edmonton Clinic
Email: caroline.nolan@ahs.ca
Tel. 780.407.8441

Dear Physicians/Health Team Member of the Movement Disorder Program:

We, the named principal investigators named above are conducting a narrative approach qualitative data analysis study on the psychological implications of Parkinson's Patients' delusions on their spouses. We are hoping that you may be able to help us recruit some participants for the research.

Purpose of Study

The purpose of this study is to understand what it is like to live with someone who has Parkinson's Disease and associated delusions. This research seeks to speak with the spouses of your patients who may wish to volunteer in this study.

Method

Volunteers will be approached with information about participating in the study by you the physician or health team member of the volunteer's spouse. If they are interested in participating in the study or want more information they will be given contact information to contact Caroline Nolan.



Selection Criteria for Participants

The spouse of a Parkinson's patient who was with the patient prior to the diagnosis of Parkinson's disease. The Parkinson's patient must also have suffered from or is experiencing delusions associated with Parkinson's treatment/condition. The patients are not part of the study. It is only their spouses' whose first language must be English and they must be cognitively healthy to the best of your knowledge.

Study Procedures

The first part is recruitment: the volunteer will be asked to participate in a study by the physician of their spouse. If they agree, they will be given contact information for Caroline Nolan. Once the volunteer has contacted Caroline Nolan, Caroline will make an appointment to review the study and obtain informed consent. Study activities will only occur after informed consent is completed.

Benefits

The spouses' participation in the study will greatly help the investigators to study the psychological implications of Parkinson's Patients' delusions on the spouses and it will hopefully, through publication in due course, be of benefit to many other spouses of Parkinson's patients, to other care-givers and health teams locally, nationally and internationally.

Risk

There are no known risks to this study but should the researchers become aware of any, you will be alerted immediately. The benefits are thought to outweigh the risks involved.

The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.



University of Alberta Seeking Participants for a Parkinson's Care Research Study

The impact of Parkinson's Patients' Delusions on their Spouses

The University of Alberta in conjunction with Alberta Health Services and the University of Leicester, UK, is conducting a research study to examine the impact of Parkinson's patients' delusion on their spouses/care-partners.

Spouses/care-partners are invited to participate in a study about the impact of Parkinson's Patients' Delusions on them. This study, if you would like to be in it, will take 1 hour, at a time that is good for you.

Purpose of Study

The study looks at what it is like to live with someone who has Parkinson's disease and has had unusual thoughts/delusions, either currently or in the past. There are no studies reporting the impact of delusional thoughts on spouses of people with Parkinson's disease. So, the results of this study will better inform healthcare professionals to help spouses and the families of those with Parkinson's disease who have delusional thoughts.

You may be able to participate in this study if you meet all of the following criteria:

- You are a fluent English speaker
- You have a spouse/partner who has a diagnosis of Parkinson's Disease and has or had Parkinson's related delusions
- You live in Alberta

What will happen when you come?

- The study visit will last 1 hour and take place at the Kaye Edmonton Clinic.
- The interviewer will be Caroline Nolan, Pastoral Counselor, AHS.
- During the 1 hour visit, Caroline Nolan will ask questions about your thoughts, feelings and reactions to your spouse's delusions or unusual thoughts.
- This interview will be audiotaped and then typed out and examined later by the interviewer. The report will not identify you, your spouse or family members.

If you are interested in participating or require more information, please contact:

Caroline Nolan

caroline.nolan@ahs.ca

780.9653101

Pro00070834 - Jan 26th 2018

Appendix H: Participant Information Letter



Movement Disorders Program

INFORMATION LETTER and CONSENT FORM

Study: The impact of Parkinson's Patients' Delusions on their Spouses.

Principal Investigator

Dr. Janis Miyasaki
Director of Movement Disorder Program
Dept. of Medicine
University of Alberta
Email: miyasaki@ualberta.ca
Tel: 780.248.1798

Co-Principal Investigator:

Caroline Nolan
Pastoral Counsellor – Movement Disorder Program
1H1.26 Walter McKenzie
University of Alberta Hospital
Edmonton, AB, T6G 2B7
Email: caroline.nolan@ahs.ca
Tel: 780.407.8441

Dear Study Participant:

You are invited to participate in a study about the impact of Parkinson's Patients' Delusions on their Spouses. This study, if you would like to be in it, will take 1 hour, at a time that is good for you.

Purpose of Study

The study looks at what it is like to live with someone who has Parkinson's disease and has had unusual thoughts/delusions either in the past or right now. You will be asked questions about your thoughts and feelings about your spouse's thoughts and beliefs that are not based in real time (delusions). There are no studies reporting the impact of delusional thoughts on spouses of people with Parkinson's disease. So, the results of this study will better inform healthcare professionals to help spouses and the families of those with Parkinson's disease who have delusional thoughts.

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What will happen when you come?

The study visit will last 1 hour and take place at the Kaye Edmonton Clinic, 4C. The interviewer will be Caroline Nolan, Pastoral Counselor, AHS. During the 1 hour visit, Caroline Nolan will ask questions about your thoughts, feelings and reactions to your spouse's delusions or unusual thoughts. This interview will be audiotaped and then typed out and examined later by the interviewer. The report will not identify you, your spouse or family members.

What will you get?

You will not get anything directly from being a part of this study, but you may understand better your reactions to your spouse's thoughts. Your information will help us understand your experiences and will help others like yourself. We plan to share this information study in a good healthcare journal.

Risk

You may become upset or have uncomfortable feelings when talking about your spouse. If you feel very upset and uncomfortable at any point, you can ask to finish the interview immediately. Also, if you wish, Dr. Miyasaki can speak with you and your family doctor to organize support on an ongoing basis outside of the study.

Free Participation

Your participation is completely free. You can withdraw from the study up to two weeks after your interview. If you decide to stop being part of the study, your information can be removed and destroyed immediately. Your spouse's care will not be affected by your decision to participate or not participate in the study.

Confidential

The information in this study is confidential unless there is risk that you might harm yourself or others or there was evidence of child abuse. We will do our best to get help for you or your family if you need it.

Information will be stored in password protected files and kept safe for at least 5 years after the study ends. You are welcome to have a report of the study findings at the end of the study if you are interested in reading it.



If you require further inform contact:

Principal Investigator – Director of Movement Disorder Program, Dept. of Medicine, University of Alberta: Dr. Janis Miyasaki
Email: miyasaki@ualberta.ca
Tel: 780.248.1798

Co-Principal Investigator: Pastoral Counsellor, University of Alberta Hospital: Caroline Nolan
Email: caroline.nolan@ahs.ca
Tel: 780.4078441

The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

Appendix I: Informed consent form



Movement Disorders Program

CONSENT

Title of Study: The psychological impact of Parkinson's patients' delusions on their spouses
Principal Investigator(s): Dr. Janis Miyasaki (780.248.1798) & Caroline Nolan (780.407.8441). Study **Coordinator:** Dr. Janis Miyasaki

	<u>Yes</u>
Do you understand that you have been asked to be in a research study?	<input type="checkbox"/>
Have you read and received a copy of the attached Information Sheet?	<input type="checkbox"/>
Do you understand the benefits and risks involved in taking part in this research study?	<input type="checkbox"/>
Have you had an opportunity to ask questions and discuss this study?	<input type="checkbox"/>
Do you understand that you are free to leave the study up to two <u>weeks</u> afterwards without having to give a reason and without affecting your (future medical care/employment, or without penalty)	<input type="checkbox"/>
Has the issue of confidentiality been explained to you?	<input type="checkbox"/>
Do you understand who will have access to the information you provide?	<input type="checkbox"/>
Who explained this study to you? _____	
I agree to take part in this study:	
Signature of Research Participant _____	
(Printed Name) _____	
<u>Date:</u> _____	
I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.	



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Movement Disorders Program, Kaye Edmonton Clinic, 4C Neuroscience
11400 University Avenue, Edmonton, Alberta, Canada, T6G 1Z1. Tel. 780-407.5465 Fax. 780-407.8969
www.albertahealthservices.ca

PROTOCOL FOR INTERVIEW WITH PD PATIENTS' SPOUSES

Name

Age

What's your education level?

What's your cultural background?

How has your mental and physical health been over the last 10 years?

Can you tell me a little bit about your childhood? Your relationships with your parents, your siblings, friends, school and community?

When did you meet your spouse and how did you meet?

Could you say something about your relationship before you got married? The kinds of things you did?

How long has your spouse been diagnosed with PD?

How has your relationship been since his/her diagnosis?

How would you describe yourself in general? Your personality?

Has there been any unusual thoughts regarding you or anyone else? (give examples)

Can you describe the content of his/her delusions? Be as specific as possible with examples of what he/said.

Are you able to recall any aspect of a delusion that affected you maybe more than others?

Did you know straight away that your spouse was delusional?

Can you remember and recount when your spouse was delusional:

- (a) any thoughts you had at the time?
- (b) how you felt then? What emotions did you have?
- (c) were you fearful of him/her talking to others about the false thoughts or embarrassed by them disclosing the false thoughts?
- (d) what your outward reaction was?

Did you speak to anyone about this?

If yes – who did you speak to and how was that?

If no – was there some reason that prevented you from talking about it?

Do you think spouses should talk to someone, like a health professional, about the experience?

Did you at any point wonder about how he/she was affected by the false thoughts?

Can you talk a little about your whole experience of being with someone with PD and delusions?

How do you feel about the whole experience of caring for someone with PD and delusions? Your thoughts, your feelings and anything else that comes to mind?

What do you think is important for health teams to consider in relation to PD patients with delusions and their spouses?

Anything else you would like to mention?

Appendix K: Transcriber confidentiality agreement

Confidentiality Agreement

Project title – The psychological implications of Parkinson’s patients’ delusions on their spouses

I, _____, the _____ (specific job description, e.g., interpreter/translator) have been hired to _____

I agree to -

1. keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format (e.g., disks, tapes, transcripts) with anyone other than the *Researcher(s)*.
2. keep all research information in any form or format (e.g., disks, tapes, transcripts) secure while it is in my possession.
3. return all research information in any form or format (e.g., disks, tapes, transcripts) to the *Researcher(s)* when I have completed the research tasks.
4. after consulting with the *Researcher(s)*, erase or destroy all research information in any form or format regarding this research project that is not returnable to the *Researcher(s)* (e.g., information stored on computer hard drive).
5. other (specify).

(Print Name) (Signature) _____
(Date)

Researcher(s)

(Print Name) (Signature) _____
(Date)

The plan for this study has been reviewed for its adherence to ethical guidelines and approved by Research Ethics Board (*specify which board*) at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

Appendix L: Coding examples

Document Browser: John

11 S: I felt sad and I did feel mad. You feel sorry for yourself. I wanted her back. There was so much loss which made me feel very sad. I kept looking for her hoping the real her would come back.

12 S: When she got excessively startled by me in the house, when it appeared to her that I was sneaking up on her, I had to start knocking/tapping the wall as I came by as a warning for her. It would annoy me when she got startled, so that helped, the tapping.

13 S: With the Respiridone, she became dozy, sleepy, blank. She had a blank face. She was like a zombie. But when we went to a seminar with Dr. X, he said that the Respiridone is no longer a common treatment. So we have started weaning her off and she has had no side-effects. It's been a week and a half now. She is beginning to be more alert again, but the delusions are coming back. But I have to live with them. I'd rather them than the blank zombie.

14 S: What's helped are the support groups with the Parkinson's Association. I am learning more and wished I'd gone sooner. No one had told us about the cognitive issues.

15 S: Living with her delusional, I will be direct with her but if she is confrontational, I won't continue. I've to learn not to over control the situations but I do need to manage her daily living because she will put the milk in the microwave and the cheese in the freezer.

16 S: My life is gone. It is spent now sitting blocking the shots. It gets lonely. I have liked talking to you because I don't talk to my family. I feel guilty speaking about her because she likes privacy and always said "don't tell the family" about things. Friends have left us. It is a fulltime job caring for her. But I'm optimistic, I like to see her return again now after being flat for so long. I feel guilty that I asked them to take the delusions away. I am moving forward with hope and thankful that the Parkinson's Association gave me the information about this study today and that I could come and meet with you and talk about this stuff.

17

Defensive Strategizin

Defensive Strategizin

..Searching

Defensive Strategizin

Defensive Strategizin

..Lonliness

Hypervigilant

Code System	Eva	Jane	Nora	Lucy	Julia	John	David	Tom	Ann	Mike	Karen	Liza	SUM
humour								1					1
how it felt to be interviewed and talk at									1				1
Defensive Strategizing	1	1	1	1	3	4	4	5	2	2	2	1	27
Defensiveness							5	2			1		8
Relief and Acknowledgement						1							1
Personal limitations							1						1
Change/Lament											1		1
seeking meaningful connections										2			2
Loss						1					1		2
Prepared											1		1
Agreement		1											1
Hypervigilant	1		1	2	2	1							7
denial													0
Sudden onset					1								1
Protector		2	2	1	1				1		1	1	9
Fear/Afraid									2				2
Danger									2				2
Managing Incredulity	1	2	1	1	2		2	2					11
Searching						3							3
Hurt			4							1	3	1	9
Depressed/Hopeless											1		1
Despair												1	1
frustration/anger							3					1	4
Anxiety												1	1
Honest											1		1
Depression												1	1
conflicted												1	1
Embarrassment			1										1
Surprise												1	1
Clueless						1							1
Exposing and Concealing	1	1	1	1	1		1			1		1	8
Loneliness						1			1		2	1	5
Need to disclose								1	1		1		3
SUM	4	7	11	6	10	12	16	11	10	6	15	11	119

Ann - Protector													Coded segments	
Code System	Eva	Jane	Nora	Lucy	Julia	John	David	Tom	Ann	Mike	Karen	Liza		
humour													<p>I didn't really want my family to know which was probably dumb. I didn't want my daughter to know. She lives ½ hr away. I didn't want anybody to think worse of my husband, but I've been that way all my life. I'd been married for 14 years before I met my husband and I didn't want anybody in the family to know what he was really like so I kept it to myself.</p> <p>C: So it was a little bit to protect him and to protect our relationship?</p> <p>S:Right, with family, with friends, yes.</p>	
how it felt to be interviewed and talk at														
Defensive Strategizing														
Defensiveness														
Relief and Acknowledgement														
Personal limitations														
Change/Lament														
seeking meaningful connections														
Loss														
Prepared														
Agreement														
Hypervigilant														
denial														
Sudden onset														
Protector														
Fear/Afraid														
Danger														
Managing Incredulity														
Searching														
Hurt														
Depressed/Hopeless														
Despair														
frustration/anger														
Anxiety														
Honest														
Depression														
conflicted														
Embarrassment														
Surprise														
Clueless														
Exposing and Concealing														
Loneliness														
Need to disclose														

Appendix M: U of L ethics approval letter

From: ethicsapp@leicester.ac.uk [mailto:ethicsapp@leicester.ac.uk]

Sent: 17 April 2017 21:55

To: Robertson, Noelle <nr6@leicester.ac.uk>

Subject: Ethical Approval System: Application Approved

Dear Noelle Robertson,

The Reviewers have approved the following application.

Applicant: Caroline Nolan (cjn15)

Title: The psychological implications of Parkinson's patients' delusions on their spouses - A narrative study.

Application Reference: 11139-cjn15-neuroscience,psychologyandbehaviour

Principal Investigator: Nolan, Caroline (cjn15)

Title of Research: The psychological implications of Parkinson's patients' delusions on their spouses - A narrative study.

You can view this application by going to the Ethical Approval System at:

<https://ethicsapp.le.ac.uk/ethics/applications.aspx?app=w/UdHjIgp4TVPSr6DOiFbg==>

Ethical Approval System Admin (ethics@le.ac.uk)

Appendix N: U of A approval letter



RESEARCH ETHICS & MANAGEMENT ONLINE (REMO)
OFFICE OF THE VICE-PRESIDENT [RESEARCH]

Caroline Nolan | My Home | Logout

Home/Help
Human > Impact of Parkinson's Patients' Delusions on Spouses > Impact of Parkinson's Patients' Delusions on Spouses

Current State
Approved

My Activities
☐ Send Email to REB Coordinator

Post Approval Activity: Impact of Parkinson's Patients' Delusions on Spouses
Description:
The psychological implications of Parkinson's patients' delusions on their spouses - A narrative study.

Principal Investigator: Janis Miyasaki
PAA #: Pro00070834_AME1
Type: Amendment
Date Created: 24/01/2018 12:24

Letter of Approval: [View](#)
Original Study ID: Pro00070834
Date Submitted: 24 January 2018

History **Change Log**

Activity	Author	Activity Date
REBA Send Approval to Study Staff	Kabatoff, Charmaine Natalie	30/01/2018 10:01
REBA Approved as Administrative Change	Kabatoff, Charmaine Natalie	30/01/2018 10:01
SS Submit Changes	Nolan, Caroline Joyce	30/01/2018 08:56
0 Changes Logged.		
REBA Changes Requested By REB Administrator	Kabatoff, Charmaine Natalie	24/01/2018 14:28
0 Reviewer Notes Logged for Amendment/Renewal. 0 Reviewer Notes Logged for Study. 1. Update section 4.3 of the main application to reflect the use of posters. 2. Add the UofA Ethics ID (Pro) to the poster. (This is a new requirement of all recruitment and consent materials).		
PI Submit for REB Review	Nolan, Caroline Joyce	24/01/2018 12:32
Flyer for recruitment for approval. Thank you.		
Created Post Approval Activity	Nolan, Caroline Joyce	24/01/2018 12:24



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Privacy Policy

Health Research Ethics Board

308 Campus Tower
University of Alberta, Edmonton, AB T6G 1X8
p. 780.492.9724 (Biomedical Panel)
p. 780.492.0302 (Health Panel)
p. 780.492.0459
p. 780.492.0639
f. 780.492.0420

Notification of Approval (Renewal)

Date: February 20, 2018
Amendment ID: Pro00070834_REN1
Principal Investigator: [Janis Miyasaki](#)
Study ID: MS2_Pro00070834
Study Title: The psychological implications of Parkinson's patients' delusions on their spouses - A narrative study.
Sponsor/Funding Agency: University Hospital Foundation

Project ID	Project Title	Speed Code	Other Information
View RES0032537	Dr. Janis Miyasaki Parkinson's Disease Research	ZG327	

Approval Expiry Date: Tuesday, February 19, 2019

Thank you for submitting this renewal application. Your application has been reviewed and approved.

This re-approval is valid for another year. If your study continues past the expiration date as noted above, you will be required to complete another renewal request. Beginning at 30 days prior to the expiration date, you will receive notices that the study is about to expire. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

All study related documents should be retained so as to be available to the Health REB upon request. They should be kept for the duration of the project and for at least 5 years following study completion.

Sincerely,

Anthony S. Joyce, PhD.
Chair, Health Research Ethics Board - Health Panel

Note: This correspondence includes an electronic signature (validation and approval via an online system).



308 Campus Tower
University of Alberta, Edmonton, AB T6G 1K8
p: 780.492.0724 (Biomedical Panel)
p: 780.492.0302 (Health Panel)
p: 780.492.0459
p: 780.492.0639
f: 780.492.9429

Notification of Approval - Amendment

Date: January 30, 2018

Amendment ID: Pro00070834_AME1

Principal Investigator: [Janis Miyasaki](#)

Study ID: MS1_Pro00070834

Study Title: The psychological implications of Parkinson's patients' delusions on their spouses - A narrative study.

Sponsor/Funding Agency: University Hospital Foundation

RSO-Managed Funding:	Project ID	Project Title	Speed Code	Other Information
	View RES0032537	Dr. Janis Miyasaki Parkinson's Disease Research	ZG327	

Approved Consent Form: Approval Date
3/22/2017

Approved Document
[Information + Informed Consent Letter](#)

Approval Expiry Date: Wednesday, March 21, 2018

Thank you for submitting an amendment request to the Health Research Ethics Board - Health Panel. The following has been reviewed and approved on behalf of the committee:

- Use of a recruitment poster at the Parkinson's Association of Alberta.
- Recruitment Flyer (1/29/2018)

Note: Approval for an amendment does not change the original approval date.

Sincerely,

Charmaine Kabatoff
Senior REB Coordinator, Health Research Ethics Board - Health Panel

Note: This correspondence includes an electronic signature (validation and approval via an online system).



Appendix O: Chronology of the research process

Research proposal	February 2017
Submission of U of A Ethics form	February 2017
Ethics approval from U of A	February 2017
Submission of UOL Ethics form	March 2017
Ethics approval from UOL	April 2017
Literature review	March 2017 – December 2017
Participant recruitment	April 2017 – April 2018
Interviews and data collection	April 2017 – April 2018
Data analysis	May 2018 – June 2018
Research report	July 2018 – August 2018
Submission	Sept 2018
Write up/submission to peer-reviewed journal	Within 4 months



PARKINSONISM & RELATED DISORDERS

Official Journal of the [International Association of Parkinsonism and Related Disorders](#)

AUTHOR INFORMATION PACK

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ISSN: 1353-8020

DESCRIPTION

Parkinsonism & Related Disorders publishes the results of basic and clinical research contributing to the understanding, diagnosis and treatment of all **neurodegenerative syndromes** in which **Parkinsonism, Essential Tremor** or related **movement disorders** may be a feature.

Regular features will include: Review Articles, Point of View articles, Full-length Articles, Short Communications, Case Reports and Letter to the Editor.

Topics covered will include:

- Molecular biology
- Neuroanatomy
- Neurophysiology/electrophysiology
- Neuroparmacology
- Neuropsychology
- Neuroimaging
- Neurotoxicology
- Clinical phenomenology
- Surgical and pharmacological treatment
- Transplantation studies
- Relationship with aging
- Epidemiology/environmental impact factors
- Rehabilitation

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AUDIENCE

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