

**A Qualitative Analysis of Burden Among Family Caregivers of People with Parkinson's
Disease Psychosis for the Development of a Physician Clinical Education Tool**

by

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Abstract

Parkinson's disease (PD) is one of the leading causes of disability amongst older adults in the United States. PD is of public health significance as it is associated with severe morbidity and quality of life impacts for both the individuals with PD and their family caregivers. Psychiatric symptoms are an underrecognized source of morbidity and caregiving burden in PD, and online resources for those diagnosed with PD often lack sufficient guidance on these symptoms. The purpose of this study is to understand the experience of burden in family caregivers of individuals with PD psychosis (PDP) to inform the development of a physician clinical education tool. Transcripts of nine in-depth semi-structured telephone interviews with caregivers of individuals with PD were qualitatively analyzed and a thematic codebook was developed. The most frequent themes were interpreted as the most salient to the caregiver experience and should be focal points of the education tool. Results revealed that physicians did not routinely ask about psychosis symptoms at appointments, leading to caregivers being unaware of this aspect of PD. Caregivers also expressed the importance of attending caregiver support or other types of supportive groups to manage their mental health, and that they primarily relied on receiving paper resources from their doctor's office to learn about PD. The future development of a physician clinical education tool, informed by the insights from this analysis on the lived experiences and recommendations of caregivers, would educate healthcare providers on what is truly important to their patients with PDP and their caregivers, and enable them to provide more informed and effective care.

Table of Contents

Preface.....	viii
1.0 Introduction.....	1
2.0 Literature Review	3
2.1 Background on Parkinson’s Disease.....	3
2.1.1 Pathophysiology	3
2.1.2 Descriptive Epidemiology	5
2.1.2.1 Diagnostic Criteria.....	5
2.1.2.2 Incidence and Prevalence.....	6
2.2 Parkinson’s Disease Psychosis.....	7
2.2.1 Diagnostic Criteria	7
2.2.2 Progression	9
2.2.3 Risk Factors.....	9
2.2.4 Medication: Risk and Treatment.....	11
2.3 Caregiver Burden	13
2.3.1 Impact of PD Severity and Manifestations on Caregiver Burden.....	14
2.4 Clinical Education Tools.....	16
2.4.1 Guidance on Parkinson’s disease Psychosis	17
3.0 Methods.....	20
3.1 Data Collection.....	20
3.2 Respondents	21
3.3 Analysis.....	21

4.0 Results	23
4.1 Burden	23
4.2 Communication.....	24
4.3 Coping.....	27
4.4 Knowledge	28
4.5 Triggers	29
5.0 Discussion.....	33
5.1 Relevance of Sub-Themes to Design of a Clinical Education Tool	33
5.2 Limitations	36
6.0 Conclusion and Recommendations	38
Appendix A	40
Bibliography	55

List of Tables

Table 1 Frequency of Coded Themes with Heatmap	31
Appendix Table 1 Qualitative Analysis Codebook	40

Preface

Thank you to my advisor, Dr. Albert, for his endless patience with me and for encouraging me to always push on through. Thank you to my parents, Mark, and Chai for their love and support.

1.0 Introduction

Parkinson's disease (PD) is a neurodegenerative movement disorder, characterized by a progressive onset of symptoms that affect motion. PD is caused by the gradual degeneration of the dopaminergic neurons in the part of the midbrain called the substantia nigra, resulting in a loss of the ability to produce dopamine. As a part of the basal ganglia system, the substantia nigra plays an important role in voluntary motor function, cognitive planning, and emotions. PD is distinguished from other neurodegenerative movement disorders by the presence of protein clusters called Lewy bodies within the dopaminergic neurons (Galvan & Wichmann, 2008; Irizarry et al., 1998).

PD is the second most frequent neurodegenerative disease after Alzheimer's disease, and symptom onset typically occurs around ages 65-70, with less than five percent of cases considered to be early onset and occurring before the age of 40. Each year, approximately 10-20 out of every 100,000 people are diagnosed with PD in the United States, with men having a higher lifetime risk of developing the disease than women (Tysnes & Storstein, 2017). The cardinal motor symptoms of PD include bradykinesia (slowed movement), muscle rigidity, a resting tremor, and postural instability. Non-motor symptoms include constipation, fatigue, and Parkinson's disease psychosis (PDP). The lifetime prevalence of PDP is estimated to be over 50% in individuals with PD, and PDP is characterized by the occurrence of at least one of the following symptoms: hallucinations, a false sense of presence, illusions, and delusions (Chang & Fox, 2016; Han et al., 2018). There is a higher prevalence of PDP among individuals with dementia, in those using certain classes of PD medications, and among those on higher doses of dopaminergic medications (Goldman & Holden, 2014; Chang & Fox, 2016).

Informal caregivers can play a significant role in the wellbeing of their loved one with PD. Studies have shown that having a caregiver's support is associated with positive impacts, such as improved morbidity, mortality, and quality of life in the individual with PD, delays in nursing home placement, and increased psychological well-being (Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2006). Alternatively, caregivers report experiencing increased burden when caring for a loved one with PDP. Psychosis symptoms have been found to have a greater impact on caregiver burden than motor symptoms, resulting in negative impacts on the physical, psychological, and social well-being of the caregiver (Mosley, Moodie, & Dissanayaka, 2017; Schrag, 2006).

The intent of this study is to explore the impact of PDP on caregiver burden, and to elucidate aspects of PDP care that are the most salient and important to caregivers. To examine this, transcripts of interviews with nine family caregivers to loved ones with PDP will be analyzed and a codebook will be developed. The results will be used to create recommendations for a future clinical education tool for clinicians to use during their education or continuing clinical practice, to improve care for caregiver burden and reduce the morbidity and negative quality of life impacts in both the caregiver and individual with PD.

2.0 Literature Review

2.1 Background on Parkinson's Disease

Parkinson's disease (PD) is a neurodegenerative disease that affects the central nervous system. It is characterized by a progressive onset of symptoms affecting movement, including (but not limited to) tremors, gait and balance problems, muscle rigidity, and bradykinesia (slowed movement). PD patients can also experience non-motor symptoms, such as constipation, loss of smell, fatigue, and psychosis (Parkinson's Foundation, 2020; The Michael J Fox Foundation). As the disease progresses, symptoms begin to impair a person's ability to independently complete activities of daily living (ADLs), such as using the bathroom or getting dressed, and the person often requires assistance from another person. Caregivers can include family members or friends, or professional care from the nursing field. The increasing burden related to managing the symptoms, treatments, and lifestyle adjustments of PD has a negative impact on the quality of life of the PD patients and their caregivers (Schrag, Jahanshahi, & Quinn, 2000).

2.1.1 Pathophysiology

Parkinson's disease belongs to a group of movement disorders that shares the same clinical symptoms, referred to as "parkinsonism" or "parkinsonian disorders." Other parkinsonian disorders such as multiple system atrophy (MSA) and progressive supranuclear palsy (PSP) present with most or all of the same motor symptoms as PD due to similar underlying pathology in the brain (Dickson, 2012). These disorders are caused by the gradual degeneration of the

dopaminergic neurons in the substantia nigra, and the subsequent loss of dopamine along the neuronal projections from the substantia nigra to the basal ganglia (Galvan & Wichmann, 2008). Located at the top of the brainstem in the midbrain, the substantia nigra's purpose is to supply dopamine along nigrostriatal pathways to the neuron clusters within the basal ganglia, which is the section of the brain that primarily controls movement-related functions (Lanciego, Luquin, & Obeso, 2012).

PD is distinguished from MSA, PSP, and other parkinsonian disorders by the presence of protein clusters called Lewy bodies within the dopaminergic neurons in the substantia nigra. Lewy bodies are circular collections of misfolded proteins that often contain high levels of a protein called α -synuclein (Irizarry et al., 1998). Less than 15% of PD cases are due to genetic causes, with identified mutations attributed to familial inheritance, and a number of those cases have been linked to a genetic mutation to the gene coding for α -synuclein (Stefanis, 2012). Most cases occur in people with no family history of the disease and are thought to be caused by interactions between genes and the environment.

Loss of the dopaminergic neurons takes place over many years, even decades, and attributable motor and non-motor symptoms begin to appear after approximately 50-70% of these neurons have already degenerated (Cheng, Ulane, & Burke, 2010). The reasons for the deaths of these neurons are not exactly known, but scientists have theorized different causes, including increased oxidative stress with aging (Naoi & Maruyama, 1999), vulnerability due to high energy demands from Ca^{2+} channel activity (Mamelak, 2018), or a phenotypic susceptibility to mitochondrial dysfunction (Surmeier, 2018). Regardless of the cause, the subsequent loss of dopamine being transmitted to the basal ganglia is thought to lead to a cascade of neurophysiological changes as the brain adjusts over time, including abnormal neuronal firing

activity and altered responsiveness, which contributes to the presentation of movement symptoms (Galvan & Wichmann, 2008).

2.1.2 Descriptive Epidemiology

2.1.2.1 Diagnostic Criteria

In 1988, the United Kingdom Parkinson's Disease Society Brain Bank (UKPDSBB) published diagnostic criteria for PD that have since been widely used in clinical practice and research (Marsili, Rizzo, & Colosimo, 2018). First, the patient must be diagnosed with parkinsonism, by exhibiting bradykinesia AND at least one other sign from: muscle rigidity, a resting tremor, or postural instability. Second, the patient must not meet an exclusion that could indicate another etiology other than PD, such any history of trauma or medical conditions affecting the head (such as strokes, head injury, encephalitis, tumor, dementia, etc.), oculogyric crisis (prolonged upward gaze in reaction to certain medications), more than one affected family member, unilateral symptoms for three years, or a negative response to dopaminergic therapy. Third, the patient must meet at least three other supporting criteria for a PD diagnosis, such as unilateral onset, a tremor at rest, progressive nature of the disease, persistent asymmetry of the signs, excellent response (70-100%) to levodopa treatment, severe levodopa-induced chorea (abnormal involuntary movements), or a disease course of at least 10 years (Gibb & Lees, 1988). Diagnoses using these criteria have been compared to PD cases confirmed via post-mortem pathological studies, and were found to have an 80-90% accuracy rate (Marsili et al., 2018).

In the decades since the UKPDSBB published their diagnostic criteria, additional sets of diagnostic criteria and guidelines have been added to the knowledge base. All build upon the same cardinal physical characteristics as core diagnostic criteria for PD. One set published in 1999

assigned different levels of diagnostic confidence to the clinical characteristics of the disease as a way to increase diagnostic accuracy, and specified three confidence levels, “Definite,” “Probable,” and “Possible,” with neuropathologic confirmation required for a “Definite” PD diagnosis (Gelb, Oliver, & Gilman, 1999). In 2008, the Movement Disorder Society (MDS) published an updated version of the Unified Parkinson’s Disease Rating Scale (UPDRS), which included non-motor symptoms as part one out of four major diagnostic categories, with the remaining sections relating to motor symptoms (Goetz et al., 2008). And, in 2015, the MDS published another set of criteria building upon their 2008 publication, which included prodromal (pre-clinical) PD as a new diagnostic category of early-stage PD (Postuma et al., 2015). Although identifying a genetic diagnostic category for PD is still a developing field, a 2020 meta-analysis found that approximately 15% of cases are associated with a familial genetic mutation, with several possible genes and gene clusters identified as contributing to familial cases (Tran, Anastacio, & Bardy).

2.1.2.2 Incidence and Prevalence

Parkinson’s disease is the second most frequent neurodegenerative disease after Alzheimer’s disease. Age is a significant risk factor for developing PD. Symptom onset typically occurs around ages 65-70, with <5% of “early onset” cases occurring before the age of 40 (Tysnes & Storstein, 2017). The overall age-adjusted incidence rate of cases is ~10-20/100,000 per year (Tysnes & Storstein, 2017; Van Den Eeden et al., 2003), but when stratified by age group, incidence rates increase with age. In age groups of those less than 60 years old, incidence rates of PD are less than 10 per 100,000 person-years (Van Den Eeden et al., 2003). After age 60, the incidence rates increase rapidly, to approximately 120-135/100,000 in those aged 65-69; 190-330/100,000 in those aged 70-74; 250-550/100,000 in those aged 75-79; 350-815/100,000 in those aged 80-84; and peaking at around 610-970/100,000 in those aged 85+ (Driver, Logroscino,

Gaziano, & Kurth, 2009; Wright Willis, Evanoff, Lian, Criswell, & Racette, 2010). The overall prevalence of PD in the population is ~0.1% but rises to nearly 3% among those ages 85+ (Tysnes & Storstein, 2017; Wright Willis et al., 2010).

Risk and incidence of PD differs by gender, with men affected more than women. At age 40, men have a lifetime risk of developing PD of 2%, whereas women have a 1.3% lifetime risk (Ascherio & Schwarzschild, 2016). Additionally, the age-adjusted incidence rate for men is 19.0/100,000, compared to 9.9/100,000 for women (Van Den Eeden et al., 2003). The data on differences by race are less available, less consistent, and may be largely influenced by sampling frame. However, some data do show that PD may affect Hispanic people at higher rates than other ethnic groups. One research group in Northern California, USA found the highest incidence rates among the Hispanic population (16.6/100,000), followed by White (13.6), Asian (11.3), and then Black populations (10.2) (Van Den Eeden et al., 2003). Another sampled from Medicare beneficiaries aged 65+ in the USA and found that Hispanic people had a 1.07 times higher incidence rate than White people, and both Black and Asian populations had lower incidence ratios than White people (Wright Willis et al., 2010).

2.2 Parkinson's Disease Psychosis

2.2.1 Diagnostic Criteria

Psychosis is a non-motor symptom that can occur during the course of Parkinson's disease. The lifetime prevalence of psychosis in PD is estimated to be over 50%, although due to different data collection and sampling methodologies, the prevalence ranges from 25% - 75% in the

literature (Chang & Fox, 2016; Goldman & Holden, 2014; Ravina et al., 2007). Diagnostic criteria define Parkinson's disease psychosis (PDP) as requiring at least one of the following symptoms: hallucinations, a false sense of presence, illusions, and delusions (Han et al., 2018). Hallucinations are experiences of sensory input without a stimulus, such as visual or auditory hallucinations, and tend to be of people or animals. Visual hallucinations (VH) are the most prevalent in PD, occurring in ~30% of all PD patients, and in ~60% of PD patients who hallucinate. Auditory hallucinations are less prevalent, occurring in ~24% of all PD patients and in ~46% of PD patients who hallucinate, and tend to be of voices or music (Chang & Fox, 2016; Factor, McDonald, & Goldstein, 2017). A false sense of presence is the experience that a person is near when there is nobody there, also known as presence hallucinations. Illusions are visual misperceptions of real objects or stimuli, such as seeing a person where there is actually a lamp. Delusions are falsely held beliefs that persist despite contradictory evidence, and tend to be paranoid in nature, such as the belief that one's spouse is being unfaithful. Delusions are the least prevalent, occurring in ~1-16% of patients with PD, but are considered to be the most serious and disabling of the psychotic symptoms (Chang & Fox, 2016; Ravina et al., 2007).

In addition to exhibiting at least one of the aforementioned psychotic symptoms, a diagnosis of PDP should be considered only if the symptoms began after a diagnosis of clinical PD, and they must reoccur or occur continuously for at least one month. Additionally, any differential diagnoses, such as dementia with Lewy bodies, delirium (due to a drug interaction, infectious disease, etc), or a primary psychotic condition (schizophrenia, bipolar disorder, etc), must have been excluded (Ravina et al., 2007).

2.2.2 Progression

PDP tends to manifest in advanced stages of the disease, sometimes 10 years or greater after the initial diagnosis. VHs, often the first to appear, have been shown to develop in the latter half of the disease process, with only <4% of cases developing this symptom within the first five years of diagnosis (Chang & Fox, 2016). Early on, PD patients are often able to maintain rational appraisal of hallucinations, but due to the progressive nature of the disease, the symptoms tend to recur and worsen over time (Schneider, Althaus, Backes, & Dodel, 2008). Current diagnostic tools assess the progression of hallucinations as a way to measure the overall severity of PD. In the MDS-UPDRS, Part 1: Non-Motor Aspects of Experiences of Daily Living, Section 1.2: Hallucinations and Psychosis, hallucinations are assessed on a scale from “0: Normal” to “4: Severe” that reflect the progression of the severity of this symptom (Goetz et al., 2008). The scores of “1: Slight” and “2: Mild” indicate that the patient is experiencing hallucinations and illusions but is retaining their insight. A patient with retained insight can recognize the experiences they are having as hallucinations. A score of “3: Moderate” and higher indicates that the patient is having hallucinations with a loss of insight and is no longer able to distinguish them from reality. After this point, managing the psychotic symptoms of PD becomes more challenging, for both the patient and their care team.

2.2.3 Risk Factors

There are several factors that can contribute to the risk for developing PDP. Time is an important factor. A more advanced disease duration and higher disease severity have both been shown to positively correlate with increased prevalence of PDP symptoms (Chang & Fox, 2016).

Sleep disturbances from both motor and non-motor causes are also thought to be significantly linked to PDP. Motor symptoms such as stiffness can exacerbate non-motor symptoms of PD, such as nocturia (excessive nighttime urination) or restless leg syndrome (RLS), that lead to poor quality of sleep. Sleep quality can also be affected by sleep disorders such as REM (rapid eye movement) Sleep Behavior Disorder (RBD), which occurs in approximately 30% of PD patients (Chaudhuri, Healy, & Schapira, 2006). In RBD, the normal sleep paralysis that occurs during the REM phase of sleep is lost, and the patient is able to physically and vocally act out their dreams, often with sudden and violent movements (Mayo Clinic, 2018b). In fact, RBD has been found to precede the onset of motor symptoms in PD in ~40% of patients (Chaudhuri et al., 2006).

Visual disorders or otherwise impaired vision can also increase risk for symptoms of psychosis. Cataracts, age-related or disease-related degeneration of visual nerves, or even low lighting at night all can lead to decreased visual acuity. In people with PD, this can increase risk for psychosis, particularly VHS (Chang & Fox, 2016).

Cognitive impairment and decline are also significant risk factors for symptoms of psychosis. PDP is more likely to co-occur with dementia. In one study, 70% of PD patients with dementia reported experiencing visual hallucinations, compared to 10% without dementia (Goldman & Holden, 2014). PD patients with dementia were also more likely to experience delusions, with a prevalence of up to 75% in this group (Chang & Fox, 2016). Additionally, the severity of psychosis symptoms in PD patients with dementia is greater than those without dementia, which suggests a link between psychosis symptoms and future cognitive decline.

2.2.4 Medication: Risk and Treatment

Literature also suggests a relationship between the drugs used to treat the motor symptoms of PD and the development of PDP. The medications used to treat PD work by acting on the dopamine pathways in the brain, which are gradually destroyed as the disease progresses. Levodopa is the most common and most potent treatment for PD, which works by replacing dopamine in the brain. Other drugs act as dopamine agonists, which do not directly replace dopamine in the brain, but they mimic the effects of dopamine and activate the same receptors (Mayo Clinic, 2018a). Studies show that psychosis symptoms increase after the start of dopaminergic drugs and can also be a side effect of long-term dopaminergic therapy (Ravina et al., 2007). In fact, nearly 30% of PD patients who have been chronically treated with dopaminergic drugs develop drug-induced psychosis (Han et al., 2018).

When treating PDP, it is important for clinicians to balance the effectiveness of having their patients maintain optimal physical function with dopaminergic therapies, with the possible side effects of drug-induced psychosis. Treatment should follow a methodical approach. If a PD patient is presenting with hallucinations or other symptoms of psychosis, any possible secondary causes should first be ruled out and treated if applicable, such as acute drug toxicity, dehydration, an infection, or a head injury (Mueller et al., 2018). If possible, the patient should be referred to see other clinicians for other possible health issues, such as an ophthalmologist for any eye or vision issues. If psychotic symptoms still persist, a medication review should occur. Psychosis can be a side effect of interactions between PD medications and other medications, such as antidepressants or benzodiazepines, and doses of these other medications may need to be adjusted, decreased, or discontinued if able (Chang & Fox, 2016). The same adjustments can then also be tried with PD medications, by changing or decreasing the dose, or switching medication types

(such as from a dopamine agonist to Levodopa). If the patient has maintained insight with their psychosis symptoms, different psychological or environmental treatments can be tried to help them cope with hallucinations that may cause distress. These could include attending therapy or support groups, adjusting the lighting in a residence to help with vision problems, or taking steps to create a space that is more conducive to restful sleep.

In a majority of cases, PDP symptoms in patients are resolved after addressing other health and environment issues and adjusting current medications, without further intervention necessary (Chang & Fox, 2016). However, if psychotic symptoms are still not resolved, or persist at a level that causes distress to the patient and/or their care support, an antipsychotic medication can be added. Atypical antipsychotic medications such as clozapine, quetiapine, pimavanserin, rivastigmine, and donepezil have been approved for and have been shown to be successful in treating the symptoms of PDP (Chaudhuri et al., 2006; Han et al., 2018; Mueller et al., 2018). Each drug works with a different mechanism and has different side effects, and so it is important for the clinician to properly monitor the side effects and assess risks such as medical history and concomitant medications before prescribing. One such effect of other atypical antipsychotics, such as risperidone, olanzapine, ziprasidone, and aripiprazole, is that the mechanism of action is through the dopamine D2 receptors, which is the same pathways used by Parkinson's medications to treat the motor symptoms of the disease (Chang & Fox, 2016). If one of those atypical antipsychotics were to be used in a PD patient, it would lessen the effectiveness of PD medications due to competition at the D2 receptors. Another risk is that antipsychotics can increase the mortality risk and incidence of cerebrovascular accidents (CVA), or strokes, in elderly patients, especially those with underlying dementia (Chang & Fox, 2016).

It is important to note that there is not just one risk factor that one can point to as a definite cause of PDP. Research has shown that most of the noted risk factors correlate with incidence and increased prevalence of PDP, but diagnostic tools to pinpoint the exact etiology of the psychotic symptoms do not exist. Instead, careful treatment of health issues, adjustment of medications, and optimization of lifestyle need to occur gradually over time, as a collaborative effort between the clinician, patient, and the patient's care support to find the optimum balance between maintaining the motor and psychotic symptoms of Parkinson's disease.

2.3 Caregiver Burden

“Burden” is a multifaceted construct with many manifestations and perceived impacts that differ from person to person. In the context of caregiving, “caregiver burden” can be defined as the negative effects incurred on a person's wellbeing or functioning as a result of providing care to another person with a disability or an illness (Mosley et al., 2017). These negative effects can be psychological, physical, economic, or social in nature. Understanding and addressing caregiver burden in the context of PD is important, because the well-being of the caregiver can be intricately connected with the well-being of the person with PD.

People with Parkinson's disease often receive care from an informal caregiver, such as a spouse, partner, or child, as opposed to a formal caregiver such as a trained nurse or nursing aide. For a neurodegenerative disease such as Parkinson's disease, the demands of caregiving are likely to increase over time as the disease progresses, and positively correlates with increased caregiver burden (Roland, Jenkins, & Johnson, 2010). Caregiving responsibilities can include direct care and supportive care. Direct care can involve physical and medical aspects of care, such as assisting

a loved one with PD in completing ADLs or administering medications. Supportive care can include coordinating physician appointments, communicating and advocating on behalf of their loved one, or providing psychological, emotional, and social support. It is important to recognize that caregiver responsibilities vary with individual disease severity and needs, the type of relationship between the caregiver and the person with PD, and the amount and type of resources available to the caregiver (Mosley et al., 2017; Shin, Lee, Youn, Kim, & Cho, 2012).

Informal caregivers play a significant role in the physical and psychological well-being of their loved one with PD. Having a caregiver who understands the unique needs of the person with PD can create a comforting, supportive, and secure environment of care. Studies have shown that having a caregiver's support is associated with multiple positive effects, such as better Parkinson's disease outcomes (in both morbidity and mortality), better quality of life in the person with PD, delays in nursing home placement, and increased psychological well-being (Schrag et al., 2006). Caregivers can also find satisfaction and fulfillment in this role, resulting in reduced stress and feelings of burden.

2.3.1 Impact of PD Severity and Manifestations on Caregiver Burden

As Parkinson's disease progresses in severity, it is also very likely that the care needs of the person with PD will also increase. As motor symptoms worsen, the caregiver may need to start dedicating more time and physical effort to help their loved one move from place to place or complete ADLs. Medication regimens may become more complex and require more attention to timing of doses or addressing potential side effects, and they can become financially taxing. The person with PD may need to see multiple specialists to address their increasing healthcare needs. All these factors can take an emotional and psychological toll on the caregiver, which can impact

their ability to be an effective caregiver. Even the most prepared caregiver can experience an increase in burden simply because of the increased care needs of their loved one with PD.

Non-motor symptoms have been found to be the most impactful on increased caregiver burden. In particular, psychological and psychosis symptoms, including depression and hallucinations, have been noted as factors that increase caregiver burden (Schrag et al., 2006). In a meta-analysis of publications addressing giver burden among caregivers of people with PD, psychiatric symptoms were consistently found to have a greater impact on increasing burden than non-motor symptoms (Mosley et al., 2017). In another study sample, caregivers reported greater burden from providing supportive care needs than from the physical aspects of care (Roland et al., 2010).

Caregivers report negative impacts on their own health because of this burden. In one research survey, nearly half of respondents report suffering poorer health due to caring, and over a quarter of caregiver respondents reported that caring has made them physically ill (Schrag et al., 2006). Spousal caregivers may also experience an exacerbation of their own existing health issues, which are more prevalent in an older population. Social relationships are also affected – caregivers report negative impacts on their relationships with other family members, deterioration of their marriage, and overall suffering to their social lives (Schrag et al., 2006). Psychologically, caregiving can result in feelings of depression, which in turn has a significant negative effect on additional caregiver burden, and health-related quality of life in both caregivers and people with PD (Martinez-Martin et al., 2007).

It is clear that the well-being of the caregiver and the person with Parkinson's disease are intertwined. The challenging symptoms of Parkinson's disease, such as Parkinson's disease psychosis, can lead to increased caregiver burden, which in turn negatively impacts the health of

both the caregiver and their loved one with PD. This could result in a positive feedback loop of negative health and QoL outcomes as the disease progresses, which poses a significant concern to healthcare providers and physicians treating the person with PD. This underscores a need for clinicians to consider and address caregiver burden in their overall care of Parkinson's disease.

2.4 Clinical Education Tools

There are many existing resources on the internet about Parkinson's disease, available for anyone to access. A Google search for "Parkinson's disease resources" reveals multiple results dedicated to providing information about the disease, including but not limited to: health care organizations, Universities, the U.S. Government, and foundations such as Parkinson's Foundation (www.parkinson.org), American Parkinson Disease Association (APDA)(www.apdaparkinson.org), and the Michael J. Fox Foundation for Parkinson's Research (MJFF)(www.michaeljfox.org). A quick overview of the three latter PD foundation websites reveals much of the same classifications of information, including what, who, when, and why of PD, testimonials from people living with PD, educational and support resources, information about PD research for both researchers and people with PD, and how one can become involved in the foundation and the broader PD community. The Parkinson's Foundation and APDA both have sections labeled "For Care Partners," which include guidance on becoming a caregiver for a family member or friend with PD and links to additional medical, social, financial, and educational resources. The information on these foundation websites is intended to inform a lay audience about the disease and have likely been thoroughly vetted by experts in the field.

2.4.1 Guidance on Parkinson's disease Psychosis

Symptoms of PDP can have a relatively high impact on the well-being of both the individual with PD and their caregiver. A few downloadable resource guides for caregivers and persons with PD were examined for what guidance is provided on PDP. Downloadable guides were selected because of the possibility that printed or booklet versions could be distributed in doctors' offices or mailed to those who request more information, which makes them accessible to those without computer or internet access.

The APDA has a two-page publication called *Becoming a Care Partner* available for free download on the page of their website specifically curated for care partners. This publication offers tips for caregivers on how to address different medical, social, and emotional challenges that may arise as they begin to care for someone with PD. Care partners are told that the progressive nature of the disease means that symptom onset and severity can be unpredictable and non-linear. Motor symptoms, including tremors, slowness of movement, and poor balance, are mentioned as symptoms to look out for, and there is even a suggestion to record these movements on video for a neurologist's later viewing and appraisal. However, there is no mention of the possible non-motor symptoms that a person with PD could develop, nor of Parkinson's disease psychosis. A section titled, "Preparing for the Future" implores the reader to consider seeking financial and legal planning guidance, but there is no mention of preparing for later-stage symptoms. This publication does not provide guidance to the caregiver about PDP and the psychiatric symptoms of PD and would need to be supplemented with additional resources and conversations (American Parkinson Disease Association, 2018).

On the Michael J Fox Foundation webpage, there is a drop-down menu labeled "Understanding Parkinson's." From this menu, the top two links in the middle column, "The

Parkinson's Journey," were reviewed due to their prominent placement and likelihood of being selected by patients and care partners seeking information on what is to come during the disease. The first resource, *Navigating Parkinson's: Your Guide to the Early Years* is available to download for free. This guide is 32-pages long, and is set up in a question-and-response format with frequently asked questions about the disease, and responses from members of The Michael J. Fox Foundation's Patient Council, who all have PD. Although this guide addresses long-term outcomes of PD in sections such as "What's Going to Happen to Me?", "Will I Die from Parkinson's Disease?", and "How Can I Manage My Symptoms?", a keyword search did not yield a result when searching the term "psychosis." Although there is a general reference to non-motor symptoms, such as cognitive changes and mood or sleep changes, there are no explicit references to psychiatric symptoms (The Michael J. Fox Foundation for Parkinson's Research, 2020).

The second resource available in "The Parkinson's Journey" drop-down menu on the Michael J Fox Foundation webpage is called *Parkinson's 360°*. This 56-page e-book of the same name posits itself as "as candid and relatable guide for patients and families living with Parkinson's" (Dolhun, 2016). Information is arranged into four major sections: 1). Getting to Know Parkinson's Disease, 2). Paving a Path with Parkinson's Disease, 3). Looking Ahead with Parkinson's Disease, and 4). Deep Brain Stimulation. The end of the book covers Parkinson's medications and alternative therapies. Interspersed throughout each of the major sections are personal stories and experiences from four members of the Parkinson's community. This resource has a sub-section dedicated to the non-motor symptoms of Parkinson's disease, and first mentions the term "psychosis" in this section. On page 25, the guide states how hallucinations and delusions are a potential part of the disease process, and it goes on to define these terms as typical indicators of a PD symptom called Parkinson's disease psychosis. In the next section, the guide expands on

PD symptoms that can emerge over time, and states, “Psychosis, if it does occur, is more common in advancing disease and in conjunction with significant cognitive changes” (Dolhun, 2016). It then defines hallucinations, illusions, delusions, and a false sense of presence for the lay audience and identifies these all as aspects of PDP. Finally, *Parkinson’s 360°* takes care to explain that PDP symptoms are treatable, either by adjusting motor symptom medications, or by adding antipsychotic drugs, such as Nuzplazid (pimavanserin), a medication specifically approved to treat hallucinations and delusions due to PDP. More information about Nuzplazid is mentioned on page 47 of the guide (Dolhun, 2016).

Overall, only one of the three reviewed resources specifically mentioned Parkinson’s disease psychosis as a non-motor symptom of PD. Even so, it keeps a general explanation of psychosis symptoms and defines what the symptoms could be but does not go into additional detail about what patients and their caregivers can expect if they are to experience these symptoms. The closest the *Parkinson’s 360°* guide comes to this is in the “Non-Motor Medications” section (page 47) about the antipsychotic Nuzplazid, stating, “When symptoms of psychosis pose safety risks or impact a person’s or their caregiver’s quality of life, medication may be necessary” (Dolhun, 2016). There appears to be a lack of guidance about the psychiatric symptoms of PD for caregivers in these Parkinson’s disease resources.

3.0 Methods

3.1 Data Collection

Data were collected by a study sponsored by the Michael J. Fox Foundation (MJFF), in partnership with the Parkinson's Disease Education Consortium (PDEC) 2019 "Bridging the Communication Gap" research group (The Michael J Fox Foundation, 2019) and Dr. Lana Chahine. Eligible participants were care partners to a family member who had Parkinson's Disease with symptoms of PD psychosis. Participants were screened and recruited by the MJFF via the Fox Trial Finder database (<https://foxtrialfinder.michaeljfox.org>). Verbal informed consent was provided by participants. Nine care partners were invited to complete semi-structured telephone-depth interviews (TDIs).

The TDIs were administered to participants by SSRS, an independent research company.

The interviews followed a standardized discussion guide (SSRS, 2019), proceeding through six sections:

1. Introduction: Welcome, Overview, Ground Rules, Introductions (5 min)
2. Respondent Introduction / Caregiver Role (5 min)
3. Psychosis Description (13 min)
4. Burden Description with Physicians (10 min) & Psychosis Discussions with Physicians (9 min)
5. Coping Strategies (5 min)
6. Sources of Knowledge/Info on Psychosis (3 min)

Each TDI was approximately one hour long in duration. After completion of the interview, participants received an honorarium in the form of a check for their time and contribution to this study.

3.2 Respondents

The nine TDI respondents were between 47 – 72 years old with a mean age (standard deviation [SD]) of 61.4 (8.6) years. All the participants were female, and seven out of nine were caring for their spouse, with one participant caring for her mother and one for her sibling. The participants had been in their roles as care partners ranging from 0.5 – 17 years, with a mean (SD) duration of 8.6 (4.7) years. The care recipients (the individuals with PDP) were between 56 – 95 years old, with a mean (SD) age of 69.1 (12.9) years. Seven out of nine care recipients with PDP were male and had a PD disease duration ranging from 0.5 – 18.5 years, with a mean (SD) disease duration of 9.8 (5.7) years.

3.3 Analysis

The nine TDIs were provided to the author already transcribed and deidentified by SSRS. Participant names were removed from the transcripts, and each participant was assigned a unique identifier. The qualitative coding software NVivo 12 was used to develop a thematic codebook.

The TDIs were analyzed using a directed content analysis approach, with the structured sections of the discussion guide serving as a template for developing key themes (Hsieh &

Shannon, 2005). The author first identified relevant phrases from the discussion guide as primary coding categories, which included Caregiver Burden, Communication (with Physicians), Coping Strategies, and Source of Knowledge (of PDP). The transcripts were then reviewed in an iterative process to identify sub-themes within the primary categories, and to identify emerging themes. The interviews were read and coded by the author, who developed an initial codebook as a single coder. This codebook was then developed iteratively with the project team, with each team member reviewing the transcripts and refining the themes via discussion until a single codebook was agreed upon. One separate coder, a neurologist and movement disorders specialist collaborating with MJFF, developed similar codes in a similar effort. However, no formal reliability study for this set of codes was conducted.

The five major themes are defined in the results section. The three most frequent sub-themes are examined in the discussion section, and the codebook can be found in Appendix A. Quotes from the TDI transcripts were selected to support the identified themes. The most frequent sub-themes were interpreted as topics that are the most salient and universal to the caregiver experience and their needs and were used to formulate recommendations for focal points in a clinical education tool for physicians.

4.0 Results

The five major themes identified in the TDIs are: 1). Burden, 2). Communication, 3). Coping, 4). Knowledge, and 5). Triggers.

4.1 Burden

Each of the caregivers shared information about the amount of time, energy, work, and responsibilities they spent providing care for the care recipient with PDP. Over half (five of nine) of the caregivers stated that they were the sole caretaker for their husband with PDP, and did not have any informal (i.e., a friend or family member) nor paid help for managing their husbands' care. Two of the nine caregivers had other family members help with duties; one woman shared that she and her teenage son are her sister's only family members and have shouldered the entirety of her PD care, and another caregiver has created a care schedule with her sisters to equally divide caring for their mother. The remaining two caregivers shared that they hired formal help; one spouse hired caregivers who come by three afternoons a week while she is at work to drive her husband to his medical appointments and complete menial chores around the house, and another hired an agency to come by two days a week and provide companionship to her husband while she is away. Some of the care responsibilities mentioned included managing medications, grocery shopping, driving to and attending doctor's appointments, household maintenance, and coordinating finances. They also described daily, more intimate tasks, such as helping their loved one shower, get dressed, and preparing meals. Several caregivers described caring for the care

recipient as something they do “24/7,” with one explaining the challenge of balancing her job with caring for her husband who “cannot be unattended at all” as a task that left her “so exhausted I couldn’t even think, much less stay awake and take care of him.”

Caregivers also discussed the emotional labor that they bear. They expressed a need to protect their loved one from feeling guilt or negative feelings. One caregiver stated that “I try to talk about it with [my husband], so he doesn’t feel guilt that he’s ruining my life or that’s keeping me from doing something that I would want to do.” Another expressed the need to use gentle language when discussing her husband’s PDP symptoms with his doctor, because she did not want to hurt his feelings. Similarly, another caregiver described differentiating between her husband and his Parkinson’s disease in her mind because she did not want him to feel guilty for the impact that his PDP symptoms had on her mood and wellbeing. She explained,

“What I have done with my husband is differentiated between my husband and Parkinson’s. I’ve personified Parkinson’s. I have explained to him, if I’m extremely tired in the morning, what happened at night. Because he doesn’t remember it. Yes, he doesn’t remember. I will explain that, ‘This is what happened, this was Parkinson’s.’ Because I don’t want him to feel guilty. He has basically no control over that.”

4.2 Communication

During their interviews, the TDI respondents were asked about various aspects of communication with their physicians, defined as the doctor or specialist who manages the care recipient’s psychosis symptoms. The caregivers shared a variety of communication methods that they employed with the care recipient’s physician(s). Some preferred to send electronic (i.e.

MyChart) or written messages detailing their observations of PDP symptoms rather than discussing within an appointment with their loved one present. Others felt comfortable talking directly with their loved one's care team during the appointment alongside their family member. For example, one caregiver shared that she and her husband would thoroughly document his symptoms before every appointment, stating that "We usually come with a big list of things that we've noticed" to discuss together. This type of preparation for appointments was echoed by most of the respondents. Another caregiver said she would call and speak with her husband's nursing team whenever "something major happens, that he has seen stuff or done stuff," and that the nurses would always get back to her.

The participants also had a variety of responses when asked by the interviewer about their discussions of personal burden and PDP with physicians. Five out of nine caregivers mentioned initiating discussions about the care recipient's psychosis symptoms and how they affect their own life. One caregiver who reported initiating this discussion clarified to the TDI interviewer that "I don't think the psychosis is worse than just the disease," noting that these symptoms hadn't necessarily added to the toll that her husband's PD symptoms had on her life. Several of respondents denied bringing up their loved one's psychosis symptoms and how it impacts them at an appointment. There were three main reasons for this. The first was because their loved one's physician was already aware of and actively assessing for PDP symptoms. Two caregivers explained that had a neurologist who would spend "an hour" to talk with them at appointments who "knows pretty much what's going on," and another two caregivers mentioned that their doctor was in the process of adjusting Levodopa medication doses and were already assessing for PDP as a potential side effect. The second reason was because of a desire to retain a sense of openness and

trust between the caregiver and the care recipient with PD, as to not betray the confidence of the care recipient. As one caregiver explains,

“...my husband is so open with me about things. I feel that that’s really important to keep that openness, so that he can talk to me about things...I feel confident that my husband isn’t keeping things from me...”

The third reason elucidated from the transcripts is because the caregiver is not affected by psychosis symptoms. One caregiver explained that “It didn’t bother me...I just think I roll with it better than some of my sisters do. It’s just, it’s not her, it’s the disease and it’s just part of it...” Others explained that their loved one’s psychosis symptoms were not severe enough to impact neither their nor their loved one’s quality of life but agreed that they would mention PDP symptoms at a doctor’s appointment if psychosis symptoms got worse or became distressing for their loved one.

The most frequently mentioned theme across all caregivers was that their physician did not initiate the discussion of psychosis symptoms at an appointment. Several caregivers appeared to agree that they would have benefitted if the neurologist or movement disorders specialist had mentioned PDP and how it could manifest, earlier on in the disease treatment process. One caregiver explained that she and her loved one with PD were “so unaware of it [PDP] because it had never been brought up in any of our appointments.” This same caregiver also shared that her husband had been experiencing symptoms of psychosis for six months to a year before the doctor asked about them for the first time. Another caregiver theorized that physicians did not ask about psychosis because “A lot of times the doctors don’t want to talk about it either.” One of the other caregivers shared a similar thought and posited that “a lot of his [her husband]’s symptoms are

worse than what the doctors are giving him credit for” because “they’re not spending a whole lot of time with him, especially his neurologist” at appointments.

4.3 Coping

The caregivers shared a variety of strategies that they used to cope with the stressors of being a caregiver to a loved one with PDP. One common theme was a description of resilience and being proactive in managing stress and responsibilities in the face of the disease. As one caregiver described, “...clearing my schedule a little bit so that I wasn’t so stressed was important. I’m proactive on my own behalf.” Another echoed this sentiment and explained her and her husband’s approach as, “We’re sucking up and doing it...This is what needs to happen in order to mitigate the circumstances of this particular disease.” A few of the caregivers mentioned doing different activities to take their minds off their stress, such as listening to podcasts, reading books, watching T.V., and mindfulness meditation.

Additionally, several of the caregivers relayed discussion-based coping strategies, such as talking to family and friends. One caregiver admitted that she “spend[s] a lot of time talking to the dog” to take care of herself. Three out of the nine caregivers stated that they have sought professional help, and have talked to a therapist or social worker, or sought medication to treat their mental health. Four of the caregivers explicitly stated that they have not sought professional support. The most frequently mentioned coping strategy, expressed by seven out of nine caregivers, was group support. These caregivers shared that they were either already involved in a support group specifically for Parkinson’s disease or were seeking to do so, or that they would regularly attend a social group that aligned with their hobbies or interests.

An emerging sub-theme revealed in the interviews was about a psychological way in which the caregivers coped with their stressors. Two of the caregivers referred to Parkinson's disease as a separate entity from their loved one. One of these caregivers explained that this concept was difficult for her to keep in her head when confronted with the symptoms of psychosis that her husband displayed, stating, "I just am in total denial. I cannot make myself say, 'That's Parkinson's, that's not your husband. Your husband is still the loving, kind person you married.'" However, she stated that their physician, as well her husband's other caretakers, "try to remind me that's not your husband, that's the Parkinson's...When they can do that, that usually helps me." The second caregiver admitted to having "personified Parkinson's," and acknowledged that she formed this coping mechanism to assuage any guilt her husband felt due to the impacts his PDP symptoms had on her well-being. In both cases, the caregivers mentally distinguished their loved one's PDP symptoms from the actual person.

4.4 Knowledge

The caregivers shared which source of knowledge they first utilized when seeking information about PD and PD psychosis. About half of the caregivers first received information from an informal social source, including from a friend, family member, the television, or a caregiver support group. A handful of other caregivers sought professional resources and received information from their PCP or neurologist, or from a workshop or presentation. Some of the professional associations mentioned included: the Alzheimer's Association, who hold a yearly day-long conference on Parkinson's disease; and the Parkinson's Foundation. In particular, one caregiver's Parkinson's advocacy work with the MJFF and the Parkinson's Foundation led to

discussions with a pharmaceutical company that produced Nuplazid, a drug approved to treat symptoms of PDP, and therefore she was aware of the symptoms of PDP when her husband started experiencing them.

The majority of the TDI respondents, eight out of nine, described first seeking information from paper materials, defined as brochures, pamphlets, handouts, or books, with seven out of nine also seeking information from the Internet. When asked, “Where did you first learn about PD psychosis?”, one caregiver responded, “Probably in the book Parkinson’s For Dummies.” Another expressed a preference for physical pages, but she acknowledged that “there’s so much out there and so many different things in Parkinson’s that aren’t relevant to (my husband’s) case that I usually start out on a website.” Finally, another caregiver described receiving a “PD packet” from her sister’s neurologist, but it did not mention anything about psychosis. She describes learning about the psychosis piece via “doctor Google,” explaining:

I looked on Google and saw what it was, and I was like, “Oh. Oh. That’s what that is, okay.” That’s when I really understood what was going on and what she was experiencing. It was just like, “Wow!” But it was from googling it, not from anything that anybody gave me.

Although this caregiver expressed finding enough information through the Internet, she goes on to recommend a brochure with information on how to interact with a family member who has PDP, stating that this would be beneficial for other caregivers like her.

4.5 Triggers

A final theme that was ascertained from the transcripts emerged outside of the structured sections of the discussion guide and is about the triggers or circumstances that would lead to

increased instances of psychosis symptoms or episodes. The most frequently mentioned trigger by the caregiver respondents were environmental factors. These caregivers noted that moving to an unfamiliar surrounding or location could trigger their loved one's PDP. One caregiver explained that her husband would, "at a certain time of day, get very, very nervous" and that she "could see the symptoms coming, so to speak." Other triggers of PDP symptoms included "low" or "off" periods of PD medications; troubling moods or emotions; loud noises; being tired; or simply having a bad day. However, most of the caregivers (eight out of nine) admitted that triggers were often, in fact, unexpected or unpredictable, and that sometimes they would not have any clues that their loved ones were experiencing an episode of PDP symptoms.

Table 1 Frequency of Coded Themes with Heatmap

THEMES	TI001	TI002	TI003	TI004	TI005	TI006	TI007	TI008	TI009	Total
1. BURDEN										
1a. BURDEN_ALONE	1	1	1	0	0	0	1	0	1	5
1b. BURDEN_GUILT	1	0	1	1	0	0	0	0	0	3
1c. BURDEN_TIME	1	1	0	0	1	1	1	1	1	7
2. COMMUNICATION										
2a. COMM_CAREMENT	1	1	0	0	1	0	0	1	1	5
2b. COMM_NOCAREMENT	1	3	0	1	1	1	2	0	1	10
2c. COMM_MDMENT	0	1	0	2	2	0	0	4	1	10
2d. COMM_NOMDMENT	4	1	1	2	0	1	1	0	3	13
2e. COMM_METHOD	3	0	1	1	2	0	0	3	1	11
2f. COMM_POS	2	3	0	0	1	1	1	2	0	10
2g. COMM_NEG	0	0	0	2	0	1	1	0	0	4
3. COPING										
3a. COPING_ACTIVITY	0	0	0	0	0	1	0	1	1	3
3b. COPING_ENTITY	0	0	3	0	0	0	0	1	0	4
3c. COPING_FAMFRIEND	3	0	0	3	0	1	0	0	1	8
3d. COPING_GROUP	2	4	2	1	0	0	1	1	1	12
3e. COPING_MED	1	0	0	0	0	0	0	0	0	1
3f. COPING_NONE	0	0	0	1	1	1	3	0	0	6
3g. COPING_PROF	2	1	1	0	0	0	0	0	0	4
3h. COPING_RES	1	2	0	0	0	1	1	0	0	5
4. KNOWLEDGE										
4a. KNOW_FAMFRIEND	1	3	0	0	0	0	0	0	1	5
4b. KNOW_GROUP	1	2	0	0	0	0	0	2	1	6
4c. KNOW_MD	0	2	0	0	2	0	0	0	0	4
4d. KNOW_ONLINE	1	2	0	1	1	0	2	1	3	11
4e. KNOW_PAPER	1	4	0	1	1	2	1	3	1	14
4f. KNOW_PRESENT	1	0	0	0	0	0	1	0	0	2
4g. KNOW_PROF	0	0	0	0	0	0	2	0	0	2
4h. KNOW_TV	0	2	0	0	0	0	0	0	0	2
5. TRIGGERS										

5a. TRIGGER_ENVIRON	0	4	4	2	0	0	0	1	0	11
5b. TRIGGER_LOWMED	1	0	0	0	0	0	0	0	1	2
5c. TRIGGER_MOOD	2	0	1	1	1	1	0	1	0	7
5d. TRIGGER_NOISE	0	0	4	0	0	0	0	0	0	4
5e. TRIGGER_OTHER	0	0	0	1	1	0	0	0	0	2
5f. TRIGGER_TIRED	1	2	0	0	0	0	0	0	0	3
5g. TRIGGER_UNEX	1	0	1	1	1	1	1	2	1	9

5.0 Discussion

Within these major themes, the top three most frequently mentioned sub-themes across all participants were identified (see “Total” column in Table 1). This indicates that these topics are more salient and universal to the caregiver experience and would be the most useful to present as focal points in a clinical educational tool for physicians.

5.1 Relevance of Sub-Themes to Design of a Clinical Education Tool

This study revealed that most of the caregivers reported that their loved one’s physician (neurologist or movement specialist) did not ask them about how psychosis symptoms impacted them at their loved one’s appointments. As a result, the caregivers admitted to being unaware of certain symptoms being a part of PDP, or psychosis symptoms being a part of PD in general, until several months to a year after their loved one had already been experiencing them. As one caregiver disclosed,

“I didn't even realize that that was a part of it, him having the conversation in his head. The paranoia, that's never been brought up. Like I said, when all of this started, I was just thinking hallucinations. Those were the only things I was really thinking were part of it, so the rest of it really hasn't been talked about yet.”

The caregivers also agreed that it would be beneficial for them if their loved one's doctor asked them a simple, "How are you?" or otherwise inquire about their health and well-being at appointments.

Caregivers should be given the opportunity to discuss their experience caring for their loved ones with PDP at the physician's office. As the person who is often spending the most time with their loved one with PDP and is on the "front line" of observing the progression of their loved one's disease, the caregiver should be equipped with the knowledge of what is to come to optimize how they can provide care, as well as the ability to set and adjust expectations of how it will impact their life. However, it appears that there is a communication gap between the physician and caregiver about PDP, about when that information is to be disclosed to or discussed with the caregiver. The proposed clinical education tool should recommend that the physician provide this information to caregivers early in the disease management process and continue to prompt the caregiver throughout the course of care, for the purposes of assessing caregiver burden and to make care recommendations as needed.

Furthermore, when searching some common PD resources on the internet for information about Parkinson's disease psychosis, the information was not readily available. Websites appear to be geared towards people newly diagnosed with PD and their caregivers, who are facing a significant change in their lives and are taking in a lot of new information. To make these resources as accessible as possible, the most common/frequent symptoms are presented. Even with the same disease diagnosis, the individual experience of the disease symptoms and progression can vary, and guidance on less-common symptoms or experiences may simply not be available nor understood. This point is echoed in the analysis results, which indicate that physicians do not consistently give information about psychosis to patients and their caregivers.

When asked about specific coping strategies, a majority of the caregivers reported benefiting from attending a caregiver support group or other type of social group. Some of the caregivers found PD-specific care partners meetings to be beneficial and described them as places where they could engage with other care providers without their loved ones with PD present, discuss various aspects of their loved one's symptoms, and share and their experiences as a caregiver. Other caregivers identified attending groups not specifically about PD as therapeutic, with one saying, "I'm in a Spanish group, and what's lovely is they listen if I want to talk, but we don't necessarily talk about Parkinson's." These results are consistent with the observed benefits within a social support theoretical framework, under which research efforts have shown that social support can reduce general mortality, as well as protect against depression and psychological stress (Veiel, 1985).

The results of this analysis are an in-depth picture of the caregiver experience and how they cope with the burden of caring for a loved one with PDP. An educational tool for physicians should emphasize the importance of group support for the caregiver, and outline steps a physician or clinical practice should take in their community to create these connections. Physicians or clinical practices should identify local and national support groups and non-profit foundations specifically for caregivers of someone with PD, and forge connections with these community group members. With physician input, these groups and foundations can work to develop educational tools, and work to to disseminate group information, contacts, and referrals to caregivers in need. Additionally, physicians or clinical practices could encourage caregivers to join any non-PD social or physical exercise groups, simply for the benefit that the social support could bring to their well-being.

Caregivers overwhelmingly recounted that they first sought out information about PDP from a printed resource, including from a brochure, pamphlet, handout, or book. The clinical education tool should include guidance to keep paper copies of peer- and expert-reviewed informational materials available at the clinic, specifically on PDP and what to expect in the future. These should be distributed to caregivers and their loved one at their initial appointment post-PD diagnosis and should be available at every appointment thereafter.

There is a lot of literature that is distributed by organizations (like the MJFF), but physicians don't really know how caregivers find or receive access to them. This is likely to change as populations age and the "digitally literate" generations age. In the future, clinicians should invest in having both paper and digital versions of information available. This will help prepare for the expanding digital footprint of people with PD and their caregivers, who are likely to find communities of practice or other connections with other caregivers online. Paper versions should still be available for those who cannot access the internet or based on personal preference.

5.2 Limitations

A limitation of this study is that a single coder was used to create the codebook. No formal reliability study for this set of codes was conducted. One additional coder, who is a neurologist in the field, came up with similar codes in a similar effort, but was not involved in creating the codebook for this project. Another potential limitation is the sample size. With only nine caregiver participants in this sample, it is possible that thematic saturation was not reached, and that new themes could have been elucidated with additional interviewees. The nine participants were also in varying stages of their caregiving journey with their loved one, and while this could present a

broader view of the caregiving experience, with a degenerative disease such as Parkinson's, symptoms can vary widely depending on the disease duration, and therefore the caregiver experience.

6.0 Conclusion and Recommendations

Family caregivers of individuals with Parkinson's disease psychosis face a multitude of challenges and pragmatic hurdles as they go through their journey of caring for their loved one with PDP. The significance of this study can be applicable beyond the individual care experience and has potential impacts in the realm of public health. By recognizing the important role of family caregivers and their substantial impact on patient well-being, healthcare systems can allocate resources to where they would be most effective in reducing caregiver and patient burden. Also, legislators at the state and federal levels can advocate for targeted funding and attention to this issue. Addressing burden in family caregivers has the potential to not only improve their well-being, but also the health outcomes and quality of care for the individuals with PDP. Ultimately, addressing the burden and needs of family caregivers should start alongside treatment of the person with PD at the provider-level.

Considering the challenges that family caregivers face caring for a loved one with PDP, having effective coping strategies to mitigate the impacts of this burden are important. A coping strategy has emerged from this analysis that could be a valuable recommendation for caregivers. This approach includes encouraging caregivers to separate the disease process from the individual, as recounted by a few interview respondents. This strategy involves a perspective shift, where the caregiver would acknowledge that the PDP manifestations are a result of the illness and not the care recipient's true nature, which would "de-personalize" the negative experience and possibly lessen the experience of burden. An interventional study of this coping mechanism would be needed to test its effectiveness on reducing caregiver burden.

A future physician clinical education tool should contain resources directly informed by the lived experiences and recommendations of caregivers. These tools can be used by primary or family care physicians and specialized movement disorders neurologists alike. This resource should inform physicians of the importance of asking about psychosis symptoms and informing of their potential impacts on the caregiver's and patient's lives. This should be done at the doctor's appointment early in the disease management process. Physicians should also have information on or recommendations for social support resources readily available, which should be provided to all caregivers of someone with PD, regardless of where they are in the disease process. Furthermore, provider offices should have printed materials curated about the various aspects of PD and PDP, that can be disseminated to caregivers at appointments or at-request.

Further research should be conducted to develop and validate the clinical education tool, which could be completed in a focus group setting to solicit feedback from both the caregiver and clinician perspectives. Additionally, future studies could examine the longitudinal impacts of tailored educational tools on caregiver burden and outcomes of people with PDP. Finally, evaluations could be conducted on the educational curricula for medical students and residents, to assess where to integrate this clinical education tool into education.

Appendix A

Appendix Table 1 Qualitative Analysis Codebook

CODE NAME	DEFINITION	EXAMPLE
1. BURDEN	Explanation of the amount of time, energy, work, responsibilities, etc that the caregivers are providing for care recipient with PD.	
1a. BURDEN_ALONE	Caregiver is sole caretaker for the care recipient with PD	<p>TI002: “Are you the only person who provides care for your husband, or are there others that help? TI002: No, I’m the only one.”</p> <p>TI007: “Are you the only person who provides care for your husband or are there others? TI007: It’s just me.”</p>
1b. BURDEN_GUILT	Mention of need to protect the care recipient with PD from	<p>TI001: “I try to talk about it with him, so he doesn’t feel guilt that he’s ruining my life or that’s keeping me from doing something that I would want to do.”</p> <p>TI003: “I have explained to him, if I’m extremely tired in the morning, what happened at night. Because he doesn't remember it. Yes, he doesn’t remember. I will explain that,</p>

	feeling guilt or negative feelings	<p>“This is what happened, this was Parkinson’s.” Because I don’t want him to feel guilty. He has basically no control over that.”</p> <p>TI004: “If the appointment was somehow compartmentalized and they saw me separately from (my husband), because I really don’t want to hurt (my husband’s) feelings and say, “Boy honey, I think you’re a real loon part of the time.” It just makes him feel so bad.”</p>
1c. BURDEN_TIME	Amount of time the caregiver spends caring for care recipient	<p>TI005: “Outside of work? Pretty much all my hours outside of work. (Laughs).”</p> <p>TI008: “I was doing 18 and a half hour shifts straight multiple times a week. I was so exhausted I couldn't even think, much less stay awake and take care of him. He cannot be unattended at all.”</p>
2. COMMUNICATION	Caregiver communication with the physician or medical staff caring for the care recipient with PD.	

2a. COMM_CAREMENT	Caregiver brings up psychosis symptoms at physician's office	<p>TI008: "Do you ever talk with your doctor about your husband's psychosis symptoms and how they affect you? TI008: Yes. About all of his Parkinson's and how it affects me. I don't think the psychosis is worse than just the disease, the toll it takes on my life."</p> <p>TI009: "How long have the symptoms of psychosis been going on before your doctor asked about them for the first time? TI009: I don't know, six months maybe. A year. It wasn't something that got brought up. We maybe brought it up the first time."</p>
2b. COMM_NOCAREMENT	Caregiver does not bring up psychosis symptoms at physician's office	<p>TI001: "Have you ever brought it up to them? TI001: No, because my husband is so open with me about things."</p> <p>TI006: "Do you ever talk with your doctor about how the psychosis symptoms affect you? TI006: No. Chelle: (27:52) Why not? TI006: I never did. Chelle: (27:56) Why? TI006: It didn't bother me."</p>
2c. COMM_MDMENT	Physician asks about psychosis	<p>TI002: "What have you observed as a caregiver that the doctor might not know about your husband's psychosis symptoms? TI002: He took an hour to basically talk with us. I think that he knows pretty much what's going on."</p>

	symptoms at appointment	TI004: “Try to think back, did you all bring it up first, you, or your husband, or did the neurologist bring it up first? TI004: I think the neurologist brought it up first.”
2d. COMM_NOMDMENT	Physician does not ask about psychosis symptoms at appointment	TI007: “What about your husband’s movement specialist? Do they ever ask you about how it’s impacting you? TI007: No they do not.” TI009: “Anyone ever ask about those? TI009: No. That’s what I said. That’s why we were so unaware of it because it had never been brought up in any of our appointments.”
2e. COMM_METHOD	Method of communication with physician or doctor’s office	<ol style="list-style-type: none"> 1. E-mail: <ol style="list-style-type: none"> a. TI003: “I haven’t brought it up within an appointment, I have MyChart-ed, basically an email, and said, “I’m seeing this.” 2. List/writing: <ol style="list-style-type: none"> a. TI001: “We usually come with a big list of things that we’ve noticed.” 3. Talking in-person: <ol style="list-style-type: none"> a. TI008: “We talk about a lot of these issues. We also talk about how we try to address him, and then he’ll write up something that I can take home so that the other caregivers can help approach him differently to deal with whatever the issue is.” 4. Talking on phone/call: <ol style="list-style-type: none"> a. TI009: “I have called and spoken with her nurses, and then she’ll get back to me. When something major happens, that he has seen stuff or done stuff, I just call and let them know...” 5. Passing notes: <ol style="list-style-type: none"> a. TI004: “I know a couple times it’s like I’ve passed notes through the receptionist to say, “Here, have the doctor read this before we get in there.”

2f. COMM_POS	Note a positive interaction or communication with physician	<p>TI005: “But with my sister’s primary care, she listens to everything I say. She was the one that when I initially told her, she started the ball rolling. She did an assessment and that initially led to the neurologist diagnosing her with Parkinson’s once she was in the hospital. After all this had happened. Yes, I definitely felt heard now.”</p> <p>TI008: “He's an old fashioned guy. He spends an hour with you. He sees my husband when he’s on and when he’s off. He talks to me to make sure I'm doing okay. We can call him on Sunday afternoon to fill up his psychotic meds and he’ll talk to him. He's just wonderful.”</p>
2g. COMM_NEG	Note of negative of unsatisfied interaction or communication with physician	<p>TI004: “I actually think a lot of his symptoms are worse than what the doctors are giving him credit for if that makes sense. Chelle: (33:47) Yes, tell me why you think that. TI004: Because they’re not spending a whole lot of time with him, especially his neurologist.”</p> <p>TI007: “I do think it maybe should be something that doctors do ask about. A lot of times the doctors don’t want to talk about it either.”</p>
3. COPING		Coping strategies used by the caregiver to cope with stresses of being a caregiver/of PD.

3a. COPING_ACTIVITY	Caregiver mentions activities as coping method	<p>TI006: “I listen to podcasts, I read books, I watch TV on my iPad. I dream about buying a house and I keep looking at houses, which I'm never going to buy a house back here, but anyway that's I use myself.”</p> <p>TI008: “What other methods are you using to help you cope? TI008: The one that works the best I haven't been doing lately. It's mindfulness meditation.”</p>
3b. COPING_ENTITY	Referring to PD as a separate entity or personified, distinct from the care recipient.	<p>TI003: “What I have done with my husband is differentiated between my husband and Parkinson’s. I’ve personified Parkinson’s.”</p> <p>TI008: “They try to remind me that's not your husband, that's the Parkinson’s. Actually the people in the house do that too. When they can do that, that usually helps me.”</p>
3c. COPING_FAMFRIEND	Caregiver talks with friends or	TI004: “How about you? How do you take care of yourself? TI004: Spend a lot of time talking to the dog.”

	family members as a coping method	<p>TI004: “Yes. I vent to my older daughter a lot too.”</p> <p>TI009: “Do you ever discuss how PD is affecting you, in general? TI009: Not with a specialist, no, just more with like family and friends.”</p>
3d. COPING_GROUP	Caregiver support group or other supportive group	<p>TI002: “I have started going to a PD care partners meeting. We have a wonderful PD community here in Santa Cruz, and they have these care partner meetings where people meet up without their spouses and talk about these sorts of things just to say, “Oh yes, my husband does that, too.””</p> <p>TI003: “I’m in a Spanish group, and what’s lovely is they listen if I want to talk, but we don’t necessarily talk about Parkinson’s.”</p>
3e. COPING_MED	Prescription of or use of medications for caregiver to cope	<p>TI001: “I said to my doctor, I sought him, and I said, “You know, I think that antidepressant would be a good thing.” We talked about it and I said, “I’m not sure if this would be a long-term thing or if I’ll need to be taking for a long while.” He told me to expect that I might be on them for a while.”</p>

3f. COPING_NONE	Caregiver has not gone to support groups, professionals, etc for coping	<p>TI004: “Have you ever been to a support group to help with psychosis symptoms for you? TI004: No I have not. Chelle: (42:34) Therapist, counselor, psychologist, psychiatrist? None of those? TI004: No.”</p> <p>TI005: “What, if anything, are you doing for yourself to help you cope with your sister’s psychosis symptoms? TI005: Nothing. Chelle: (37:37) Have you ever been to a support group? TI005: (Laughs). No, I don’t like support groups.”</p>
3g. COPING_PROF	Caregiver seeking or considering seeking professional help, such as a therapist	<p>TI002: “Do you think you'll ever go further than the caregiver meetings at this point? Thinking specifically about psychosis. TI002: Yes. I've been playing with the idea of having a therapist that I go to, just somebody to talk to one on one.”</p> <p>TI003: “The social worker helped me with that. She said, “Yes, you have an umbrella of all of these responsibilities that probably will need to be done, but you don’t have to do them all right now. Choose what you think needs to be done right now.” That’s my long-winded comment as to I have talked to the social worker.”</p>

3h. COPING_RES	Caregiver describes resilience or acceptance in face of caring for care recipient with PD	<p>TI001: "...clearing my schedule a little bit so that I wasn't so stressed was important. I'm proactive on my own behalf."</p> <p>TI002: "We're sucking up and doing it. I don't think either of us really likes it. It's like, 'Okay, we've got to. This is what needs to happen in order to mitigate the circumstances of this particular disease.'"</p>
4. KNOWLEDGE	Caregiver's first source of or scope of knowledge about PD/PD psychosis.	
4a. KNOW_FAMFRIEND	Information from a family member or friend	<p>TI002: "I talked to a friend about it and her mother had Parkinson's."</p> <p>TI009: "Not really. My brother-in-law has just sent me a bunch of information on support groups for just the psychosis. I have that information, I just haven't looked into it more."</p>
4b. KNOW_GROUP	Information from group	TI001: "Is that where you first learned about psychosis, PD psychosis? Or was there some other avenue? TI001: I did hear about it before in the caregiver's group first."

	(caregiver support group, etc)	TI008: “As I said, I've taken dementia classes offered by the Alzheimer’s Association and that I found out about once a year there tends to be a day long conference on Parkinson’s disease.”
4c. KNOW_MD	Information about psychosis from physician	TI002: “When he was asking the questions did he tell you a definition of, “Here’s what a delusion is, here's what a hallucination is, here's paranoia,” or did he just run down the examples like I did? TI002: He just ran down the examples. He didn't really go into it too much, but we’re both college educated, we pretty much know that that's an issue.” TI005: “Her PCP called me and asked me a list of questions on, “Have you noticed these things?” Chelle: (27:53) They asked you? TI005: Yes. Yes. I don’t know, I never knew that that was part of Parkinson’s.”
4d. KNOW_ONLINE	Information from internet	TI004: “If it’s really, really relevant then I like the physical pages but there’s so much out there and so many different things in Parkinson's that aren’t relevant to (my husband’s) case that I usually start out on a website.”

		TI005: “When he first laid it on me, she was at the hospital and I did what a lot of people do. I turned to doctor Google. I looked on Google and saw what it was, and I was like, “Oh. Oh. That’s what that is, okay.””
4e. KNOW_PAPER	Information from brochure, pamphlet, handout, book, etc	TI004: “Where did you first learn about PD psychosis? TI004: Probably in the book Parkinson’s For Dummies.”
4f. KNOW_PRESENT	Information from presentations	TI001: “We might say, we might run a list, we get summaries of different workshops or presentations. I’ll read the presentations and then sometimes I say, “That’s really interesting.”” TI007: “Yes, I got more information by actually having the pharmaceutical company come and speak to... Parkinson’s Foundation was really good about bringing the pharmaceutical company in to speak to us when we were there where we could really ask the questions and find out more from them.”

4g. KNOW_PROF	Information due to profession	TI007: “It’s probably more on my radar just because of the advocacy work that I do. I was part of the group that actually helped when they were coming out with Nuplazid and there was such an uproar over that medication when they did their first commercial. I’m on an advisory council for Parkinson's Foundation and we actually met with the pharmaceutical company and talked about why people reacted the way they did to that commercial.”
4h. KNOW_TV	Information from television	TI002: “Well, one of the reasons why we’re here is because (my husband is) having hallucinations and I think we saw this thing on TV that said that there's a new medicine that might deal with that, and maybe he should get on it.””
5. TRIGGERS	Triggers or circumstances that lead to increased instances of psychosis symptoms or episodes.	
5a. TRIGGERS_ENVIRON	Triggers related to time of day, location, environment.	TI002: “I think it's familiar surroundings and expectations of what should be around or whatever. That may be something that triggers the fact that he thinks the boys are here when they’re not.”

		TI003: “He would, at a certain time of day, get very, very nervous. I could see the symptoms coming, so to speak.”
5b. TRIGGERS_LOWMED	Triggers related to low point of psychosis meds	TI001: “I think when he’s tired or his medication’s low.” TI009: “He has his off periods. You know what off periods are. It's definitely worse when he is in those, with everything. With paranoia, yes. With everything, when he has an off period. It's all worse with that.”
5c. TRIGGERS_MOOD	Triggers related to moods or emotions	TI001: “I think it comes along with either troubling memories or worries about something that might be going to happen or something.” TI006: “It was making worse when you did what my father did with her and tried to convince her it wasn't happening, because then she'd get very upset about it.”
5d. TRIGGERS_NOISE	Triggers related to loud noises, lights, machines	[TI003 only] “The CNA came in, happened to be a man, deep voice, loud voice and it triggered a psychotic. Again the similar kind of episode that it’s hard to describe.”

		<p>“and it was the ultrasound and the machine and I wasn’t in the room. There was a curtain and I could see his face becoming more and more agitated and once again it related to machines.”</p>
5e. TRIGGERS_OTHER	Triggers that didn’t fit in another category	<p>TI004: “If he’s having a bad day physically he will also have a bad day mentally. If he’s having a day where he’s freezing a lot, can’t go down stairs, is having trouble rising up out of the chair then that will be a day that he’ll be having trouble, or more hallucinations, more delusions.”</p> <p>TI005: “Yes, I guess when she starts talking about how the job is out to get her, it’s because she’s been looking at something on Facebook and probably looking at coworkers’ posts.”</p>
5f. TRIGGERS_TIRED	Triggers due to being tired	<p>TI001: “are there any triggers that you’ve noticed that either bring it on or make it worse?”</p> <p>TI001: I think when he’s tired”</p> <p>TI002: “It’s much more likely to happen when he’s tired, so around 6:00 on is when they happen. “</p>

5g. TRIGGERS_UNEX	<p>Caregiver describes that they are unable to predict when or why psychosis symptoms are triggered</p>	<p>TI005: “What are your clues that you get that it’s coming on or about to happen, if any?”</p> <p>TI005: Nothing. She’ll just start talking about it.”</p> <p>TI007: “Are there any clues or cues that you get that something like this is going to happen? TI007: No, not really.”</p>
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