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Knowledge, Attitudes and Behaviors to Dietary Management of Parkinson's Disease

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KNOWLEDGE, ATTITUDES AND BEHAVIORS TO DIETARY MANAGEMENT OF PARKINSON'S DISEASE

BY

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ABSTRACT

Background: Levodopa is the most commonly used medication to improve motor sequelae in persons with PD (PwPD). However, levodopa and dietary protein compete for absorption in the gut and blood brain barrier. Dietary proteins are essential for growth and physical functioning, which generally deteriorate with PD progression. Informal caregivers (ICG) often assist PwPD with meal and medication management, but have reported information deficits regarding dietary and medication management for PwPD.

Objective: To obtain qualitative information related to dietary knowledge and attitudes, and quantitative data on dietary behaviors from PwPD and their ICG.

Methods: Cross-sectional, mixed-methods study. A semi-structured interview was used to collect qualitative data. Quantitative data was collected through use of, two 24-hour dietary recalls and the Dietary Screening Tool.

Results: Ten dyads completed this study. All PwPD were found to be at possible nutrition risk, and consume an average protein intake above recommended values. The dyads reported misinformation, and limited knowledge surrounding medication and meal management. Emerging qualitative themes included *Reliance on Caregiver for Buying and Preparing meals*, *Reduced Enjoyment of Foods and Meal Times*, *Barriers to Dietary Intake*, *Lack of Nutrition Knowledge*, *Barriers to Medication Management*, *Management of Symptoms*, and, *Access to Medication Information*

Conclusion: There is a lack of nutrition and medication knowledge, and a need for more awareness of the protein-levodopa interaction and strategies to attenuate the fluctuations that may occur within the dyads. Interdisciplinary teams for PwPD could help to improve health and delay progression of PD if followed early in diagnosis.

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PREFACE

This thesis was written to comply with the University of Rhode Island graduate school Manuscript Thesis Format. This thesis contains one manuscript: *Knowledge, Attitudes and Behaviors to Dietary Management in Parkinson's disease.* This manuscript has been written in a form suitable for publication in *Disability and Health Journal.*

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Knowledge, Attitudes and Behaviors to Dietary Management of Parkinson's disease

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ABSTRACT

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Results: Ten dyads completed this study. All PwPD were found to be at possible nutrition risk, and consume an average protein intake above recommended values. The dyads reported misinformation, and limited knowledge surrounding medication and meal management. Emerging qualitative themes included *Reliance on Caregiver for Buying and Preparing meals*, *Reduced Enjoyment of Foods and Meal Times*, *Barriers to Dietary Intake*, *Range of Nutrition Knowledge*, *Barriers to Medication Management*, *Management of Symptoms*, and, *Access to Medication Information*

Conclusion: There is a lack of nutrition and medication knowledge, and a need for more awareness of the protein-levodopa interaction and strategies to attenuate the fluctuations that may occur within the dyads. Interdisciplinary teams for PwPD could help to improve health and delay progression of PD if followed early in diagnosis.

Key Words: Parkinson’s disease, protein, levodopa

INTRODUCTION

Parkinson's disease (PD) is a progressive neurodegenerative movement disorder that currently affects over 900,000 Americans, and is expected to double by 2030[1-3]. While the etiology of PD is not well understood, it involves death of dopamine producing neurons in the substantia nigra, resulting in loss of sensorimotor control, balance, gait, mood, cognition, communication and swallowing[1, 4-6]. These PD sequelae (consequences of pre-existing conditions) lead to time-intensive and expensive management strategies including visits to health professionals, medications, surgeries, and complementary health approaches ranging from $10-14 thousand dollars per person annually[7]. In addition to public health costs, there are also costs on the informal caregivers (ICG) who spend 39^{+} hours a week on management for people with Parkinson's disease (PwPD)[8].

Levodopa is the most common dopaminergic medication used to improve motor function, quality of life, and reduce morbidity and mortality in PwPD[9]. However, consumption of dietary protein and levodopa compete for absorption at the gut and blood brain barrier[9, 10]. Dietary proteins are essential as they promote muscle mass retention, growth, and physical functioning[2]. Previous research shows that PwPD consume more protein then recommended (0.8g/kg), and a higher protein intake is associated with a higher daily levodopa dose over time[10]. This relationship may be partially attributed to protein-levodopa interaction (PLI), leading to higher doses of levodopa which can be ineffective in reducing motor sequelae[10, 11]. Therefore, it is recommended that levodopa be consumed between 30-120 minutes before or after a protein food[5, 12, 13]. In addition to medication timing, a low-protein diet (LPD) or protein redistributed diet (PRD) diet have been recommended to minimize the PLI and reduce motor fluctuations in PwPD[14, 15]. A

LPD restricts total daily protein intake to 0.5g/kg/day[14], while a PRD limits protein intake to 7-15g before the dinner meal with a goal protein intake of 0.8g/kg/day[10, 14, 16-18]. However, there are inconsistent recommendations for PwPD and their ICG on how to adequately manage this food-drug interaction[14, 16, 19].

Informal caregivers (unpaid family member or friend) [20-22] often assist PwPD with many care issues including meal and medication management, which become more complex as the disease progresses[22, 23]. Medication management is a "high-level", medically related task, in the caregiver literature[22], and ICG have reported information deficits regarding dietary and medication management for PwPD, all contributing to the feelings of stress surrounding caretaking[19, 22-29]. Therefore, the purpose of this study was to obtain qualitative information related to dietary knowledge and attitudes, and quantitative data on dietary behaviors from PwPD and their ICG. It was hypothesized that PwPD and their ICG will report limited knowledge, and/or misinformation but a positive attitude towards education in regards to dietary management. Also, PwPD will be at increased nutritional risk and not adhere the nutrient intake recommendations. This data will provide insight to what PwPD and their ICG believe about diet and levodopa management for healthcare professionals.

METHODS

Participant Recruitment

The current cross-sectional, mixed-methods study was conducted from October 2017 to January 2018. People with PD and their ICG were recruited as dyads from PD health clinics and rehabilitation centers throughout Rhode Island. All participants were community-dwelling adults aged 18 and older, who had access to a telephone. The PwPD self-reported their disease stage based on the Hohn-Yahr (HY) scale (stages 1-4)[30] and reported adherence to taking at least one levodopa-containing medication. Participants with PD were excluded if they received calories from enteral/parenteral nutrition, or scored ≤18 on the Telephone Montreal Cognitive Assessment (T-MoCA). This study was approved by the University of Rhode Island Institutional Review Board.

Data Collection

Data were collected during 3 assessments, which included two-telephone calls and one home visit. The first assessment was a screening phone call to review inclusion criteria, administer the T-MoCA, and complete the informed consent process. Assessment #2 was a second telephone call where the dietary screening tool (DST), and the first 24-hour dietary recall (24HR) were completed. For the DST, a total score from 0-105 was calculated and categorized with one of three nutritional risk levels; (<60) at risk, (60-75) possible risk, and (>75) not at risk[31]. The Nutrition Data System for Research was used to collect 24HR data by use of the multiple-pass interview approach and, distribution of the foods amount booklet for adequate recall[32]. Assessment #3 was a home visit to the dyad, where anthropometric assessments (height, weight and calculated BMI), a past medical history questionnaire, the second 24HR, and a 21-question semi-

structured interview were completed.

Moderator Guide

Semi-structured interview questions were created by the research team to explore 3 domains, 1) Eating Environment, 2) Dietary Intake and, 3) Medication Management (**Table 1**). Questions were piloted with 3 PD dyads with similar inclusion criteria to determine content validity and understandability of the interview. All interviews were audio-recorded, transcribed verbatim and coded using thematic qualitative content analysis[33]. Structural coding, using questions and key phrases from the moderator guide was used to categorize the data into codes, then the codes were systematically reviewed. The primary author and an undergraduate researcher reviewed and coded the transcripts separately, then discussed their findings to identify the most common themes, and generated the final themes together. Qualitative content was summarized and direct quotes were used to illustrate the perspectives of the participants (**Table 2)**. Participants with PD and their ICG are identified in the text as "PD", or "ICG", followed by a number that was assigned sequentially as surveys were completed.

Data Analysis

Descriptive statistics and data from the questionnaires and 24HR were analyzed using SPSS Version 25 (IBM Corp, New York). Normality was assessed using skewness and kurtosis. Categorical variables are reported as numbers and percentages, and continuous variables are reported as mean ± standard deviation. All data collected from the moderator guide was analyzed using NVivo 11 QSR (International Pty Ltd, Victoria Australia).

RESULTS

Demographics

Ten PwPD and their ICG participated in this study. **Table 3** displays all demographic data. Mean ages of the participants were, 68.7±8.5 years (range 50-82 years) for the PwPD, and 69.4±5.6 years (range 57-78 years) for ICG. Seventy percent of the PwPD and, 30% of were ICG were males. All of the PwPD and 90% of the ICG were retired. All of the PwPD and 60% of the ICG had at least an associates degree. PwPD had been diagnosed with PD for 11.4±4.9 years (range of 8-19 years) and had been taking levodopa for 6.9±3.84 years (range 2-15 years). Mean scores on the T-MoCA was 20.30±1.56. The qualitative results are presented according to the moderator guide domains. Additional themes are incorporated within each of those domains.

Dietary Intakes

This domain covered knowledge of recommended dietary intakes and attitudes about food and nutrition since the diagnosis of PD. Two emerging themes came from this domain **(Table 2a)**. In the *Barriers to Dietary Intake* theme, all of the participants explained some barriers related to PD sequelae that has affected dietary intake. The ICG explained digestive issues that pose as a barrier to the types of foods that they buy and prepare. Another barrier was the modifications of foods. Many participants reported no difficulty with chewing and swallowing but, when asked what kind of dietary changes they have made since being diagnosed with PD, the answers related to changes due to swallowing difficulties that have affected the foods they consume. Other participants described how the motor sequelae as a result of PD act as a barrier because they impact the way they get the foods into their mouths. Despite the barriers, a majority of the PwPD

reported consuming a healthy diet, however they reported an inclusion of sweets due to the decreased taste of foods, and sweet foods containing a stronger flavor.

The other emerging theme was, *Range of Nutrition Knowledge for PD,* where many PwPD and their ICG reported some knowledge, but confusion about the PLI. Some were not aware that dietary proteins compete with levodopa or, recently learned about this interaction. The participants were also unaware of the PRD and LPD that may help decrease some of the motor fluctuations they experience. Due to the range of knowledge surrounding the protein altered diets, many participants spoke about the challenges that they would have following these diets. Despite this range of nutrition-related knowledge the majority of the participants reported that they would be very interested in learning "anything you have" about the medication-meal management.

Eating Environment

This domain included two items, which addressed PwPD and their ICG attitudes around food and some of the behaviors they exhibit during the mealtime process **(Table 2b)**. In the *Reliance on ICG for Buying and Preparing Meals* theme, participants reported that ICG play a large role in buying and preparing foods in the home. For approximately half of the dyads, the PwPD helped plan what foods to buy but the ICG do most of the purchasing and preparation, especially for foods requiring more advanced preparation. Also, in the *Reduced Enjoyment of Foods and Meal Times* theme, both PwPD and ICG described a decreased enjoyment in the eating experience and an avoidance of going out to eat because of PD progression.

Medication Management

This domain gave insight into self-reported behaviors around medication intake, three themes emerged **(Table 2c)**. The first theme, *Barriers to Medication Management,* showed that in most of the participants, the responsibility of managing medication was on the PwPD. However, many PwPD described challenges remembering to take the medication at the right time due to busy schedules. Many used of devices and strategies to help overcome their challenges to taking their medication but even those could result in their own problems. Another theme that arose was, *Management of Symptoms,* despite some barriers to taking the medication, when asked about how the medication manages daily PD symptoms all of the participants discussed a positive effect if the medication was working that day. Finally, the theme, *Access to Medication Information,* described how the participants accessed medication information. A majority mentioned that they would find information online or talk with their peers. Most described that they would not feel comfortable contacting their doctor or a health care professional because they are not readily accessible, and some of the information provided is not easily understood. Although many participants had means of accessing medication information, most recognized the importance of staying up-to-date with information and expressed positive attitudes toward learning.

Dietary Data

In addition to the qualitative data about diet and medication management within this population, dietary assessments were used to better understand results in relation to the qualitative and quantitative data. Mean score on the DST was 66.4±13.9, which categorizes this population at possible nutrition risk and further investigation found that 30% of PwPD were not at nutrition risk, 40% were at possible risk, and 30% were at

nutrition risk. Mean BMI for the PwPD was 27.1±4.7 (overweight) with 30% classified as normal weight, 50% as overweight and 20% obese. All dietary data is displayed in **Table 4**. Participants consumed an average of 1955.7±678.2 calories, at 4.5±1.4 eating times per day. Eighty percent of the PwPD consumed their medication and meals within 30 minutes of each other. Timing of meals and levodopa intakes are in **Figure 1**. Average protein intake per kg of body weight was 0.9±0.2, the recommendation is 0.8g/kg/day, and in this sample 30% were below and 70% were above this recommendation.

DISCUSSION

The goal of this study was to explore the knowledge, attitudes, and behaviors of dietary management in PwPD and their ICG through dyadic interviewing and dietary assessments. The major findings of this study were the range of knowledge related to food-medication management and, not adhering to protein recommendations for this population. PwPD and their ICG have received little information related to the PLI and were confused about meal and medication timing, which is consistent with a qualitative dyadic study by Shin et al[19], that revealed participants feeling stress and uncertainty related to medication and diet management[19]. In addition to the qualitative data found, dietary intake information confirmed the lack of adherence to protein-levodopa timing. Participants took their medications less than the 30-120 minutes recommended prior to consuming a meal (80%), and more protein than the RDA (0.9g/kg), with more grams of protein during the day than at night. These findings are also consistent with a previous PD dietary studies which found that, 75% of PwPD consumed protein with their levodopa and more protein during the daytime[10, 34].

Levodopa is the most effective medication to control PD motor sequelae[9], therefore it is important to identify possible interactions and barriers to compliance so PwPD can receive the greatest symptomatic benefits. All of the participants reported difficulties talking to their healthcare providers about medication and most resorted to the internet or peers, which may not provide valid information. Registered dietitians (RDs) are trained in managing food-drug interactions and can help provide reliable information to PwPD and ICG. However, RD's are often excluded from the management of PD.

Therefore, future research should further investigate the use of RDs in the management of PD, and ways to increase access to PD health information.

The PwPD in this sample were responsible for managing their own medication, which is inconsistent with previous research which indicated that ICG are highly involved in medication management[22]. This could be attributed to the study participants being highly educated and screened for cognitive impairments. Regardless, the PwPD reported that levodopa has positive effects on their motor sequelae when it is "working". Due to the reported range of knowledge about the PLI and the medication fluctuations, PwPD may benefit from a LPD or PRD as both have been effective in reducing motor fluctuations and total levodopa dosag[17, 18].

The ICG took on the majority of the food purchasing and preparation in this sample, which is consistent with previous literature, where ICG have been found to become the primary food provider when food and food-related work become a problem[35]. The PwPD experienced decreased enjoyment around food and the eating environment which can be contributed to PD sequelae like, decreased taste, gastrointestinal (GI) distress, taste and motor flucutations. Person's with PD described a loss of taste that affected their enjoyment of foods; previous research has shown a decreased desire for most foods, except for those with strong tastes, such as ice cream[36]. In addition to taste, GI distress decreased eating enjoyment due to decreased gastric emptying rate which will increase abdominal distention, discomfort, nausea and early satiety and bloating in PwPD[5].

Other sequelae that decreased food enjoyments included, chewing and swallowing and motor functioning. Previous research has found that the prevalence of dysphagia in

PwPD varies (35-80%) due to the majority of PwPD self-reporting no swallowing difficulties, but showing evidence on a bedside swallowing test[37]. While this study did not directly assess swallow function, symptoms associated with dysphagia were identified and affected the foods participants consumed. Additionally, the reported difficulties in using utensils while eating show the need for an occupational therapist (OT) however, only 13-25% of PwPD have utilized OT services because most patients are not referred to their services until the later stages of the disease, when it may already be too late[38]. Therefore, the inclusion of a multidisciplinary team of RDs, SLPs and OTs early in PD diagnosis could allow PwPD to maintain more activities of daily living as the disease progresses and deter some of these barriers to dietary intake.

The second aim was to identify the nutritional risk status and dietary intakes of PwPD through two dietary assessments. Optimal nutritional status is difficult for PwPD to maintain due to cognitive decline, gastrointestinal issues, difficulty swallowing, and PLI[1, 5, 6]. In the current sample, PwPD were found to be at possible nutrition risk, which is consistent with previous research[39]. **Table 5** compares DST and NDSR data to show quality and variety of the participants diets. While there are no formal dietary guidelines for PwPD our findings show participants are not meeting the general recommendations for the Dietary Guidelines for Americans (DGAs), or those that are specific for PwPD[5,40]. While this population was meeting the recommendations for macronutrient and calorie intakes, on average they did not meet the 30-35g recommendation of fiber per day to alleviate constipation[5], or the vitamin D, calcium, magnesium and potassium recommendations for muscle and bone health[40]. Meeting the recommendations for all nutrients is important to improvement in nutritional status and slow disease progression[5].

The large standard deviations of the results, exhibit the heterogeneity of PwPD which makes standardized intakes difficult to quantify, therefore all dietary recommendations should be individualized to fit the needs of PwPD[40]. The DGAs may be utilized early in the diagnosis but once levodopa therapy is introduced, protein intake may need to be altered so the medication absorption can be improved[5]. Additionally, when educating PwPD, health professionals should be aware of cognitive deficits when presenting information to PwPD and should present information multiple times and provided written materials.

In the current study, PwPD and their ICG showed a range of knowledge, and misinformation about dietary recommendations for PwPD but showed a positive attitude towards receiving education in regards to managing dietary protein intake and levodopa. Also, this population's dietary behaviors showed them to be at possible nutrition risk and consuming more than the RDA for protein, which may call for future dietary research to explore diet quality and variety in PwPD. However, due to the small, homogenous sample size this information cannot be generalized to a larger population of PD. Additionally, this sample included mostly white and highly educated participants which is common in the PD literature, future research should focus on targeting other races and education levels. Also, due to the cross-sectional, descriptive design of the study, only one-time point was obtained and more longitudinal approaches should be considered for this population. All of the dietary data is based on self-reports which may affect the accuracy, but in order to increase some validity, food amount booklets were sent to all participants and referred to, and the multiple pass methods was utilized during the 24HR. However, despite these limitations, this study is unique because it included both PwPD

and their ICG to gather mixed methods data which will be beneficial for interdisciplinary teams working with this population. This research could be modified to attenuate to additional neurological disorders which affect 1 in 7 households[3].

CONCLUSION

Current findings confirm lack of nutrition and medication knowledge and the need for nutrition education around food-drug interaction and managing disease sequelae's impact on dietary intake. Overall, the results of the study identify areas for education that have the potential to attenuate motor fluctuations secondary to medication intake and maximize management of disease symptoms overtime. Future research should focus on interdisciplinary teams for PwPD could help to improve health and delay progression of PD if followed early in diagnosis.

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TABLES AND FIGURES

Table 1: Qualitative Domains

Eating Environment:	1. *Describe the most challenging aspects of preparing and eating meals since the diagnosis of PD* 2. *Who is responsible for buying and preparing food in your home?*
Dietary Intake:	1. *How has your diet changed since being diagnosed with PD? Prompt: are there any foods that you have stopped or increased eating due to your diagnosis?* 2. *How would you describe your current diet?* 3. *Who have you spoken with about your diet and what have they told you?* 4. *Is there anything you would like to know about the foods that you eat or your daily nutrition in general? Prompt: what questions or concerns do you have about your daily eating or about the foods you eat in general?* 5. *What is your understanding of a PRD or LPD? Prompt: the PRD limits protein during the day and includes more protein at dinner, the LPD limits all protein during the day and at dinner* 6. *What challenges would you anticipate if you were following a PRD or LPD?* 7. *What difficulties do you have chewing or swallowing your food or beverages? Prompt: what fluids do you have difficulties consuming? How often do you cough during meals? How much more time does it take you to eat than before the diagnosis?* 8. *Do you modify the textures or consistencies of your foods or beverages? Prompt: Do you consume ground meat instead of whole pieces? Do you soften or puree your vegetables? Do you use products like "Simply Thick" to thicken the fluids you consume?*
Medication Management:	1. *Describe your greatest challenges to taking your levodopa medication as prescribed by your doctor?* 2. *How you do cope or overcome the challenges to taking your levodopa medication as prescribed by your doctor?* 3. *What is your daily levodopa schedule?* 4. *What information have your doctor and/or pharmacist provided bout the timing of your medication?* 5. *How do you time your food and medication intakes?* 6. *How do you obtain information about your levodopa medication?* 7. *How well does levodopa manage your daily symptoms? Prompt: do you ever feel shaky, unsteady or sluggish after consuming your medication?* 8. *What do you know about the food-drug interaction between levodopa and protein?* 9. *What information would you like to know about your medication management? Prompt: how interested are you in learning more?* 10. *Do you rely on your caregiver to receive your levodopa medication?*

Table 2: Qualitative Themes

a. Dietary Intake	
-Barriers to Dietary Intake	"It's a Mediterranean diet with cookies and stuff like that." –PD8
	"We eat a lot of fish and chicken, occasionally red meat and my worse thing is cookies, and chips occasionally." –PD9
	"My taste has gotten worse over the years, I think I eat foods by the memory of what they taste like." –PD3
	"I have noticed some foods don't have as much taste, (my doctor) said it's understandable that I like to eat chocolate because it has a strong flavor." –PD2
	"There are some digestive concerns every once in a while. Sometimes spaghetti and meatballs can make his stomach a little acidic so I have to be careful about what we eat and how it will affect him." –ICG1
	"(He stopped eating) anything tomato because he has that burning tongue syndrome." -CG3
	"I like to eat salads but I am concerned because once I did have choking." –PD1
	"I'm more conscious in how I eat food, I cut smaller pieces, especially meat or something, lettuce or salad I cut into small pieces." -PD1
	"Certain kinds of lettuce seem to be harder, mostly what I use is the heart of romaine, tomatoes, cucumbers, things you can feel going down. I think I was putting spinach in a salad, trying to use that, and the spinach became a choking hazard. I had already also put spinach in meatloaf and he said I can't swallow parts that have spinach, so I don't anymore." –ICG1
	"I've had trouble consuming fluids… water or juice, but very rarely, it's not a problem." –PD1
	"Sometimes I choke on water of coffee, so I take smaller sips." –PD5
	"I don't have a lot of difficulty except a couple of times I was eating autumn soup and I aspirated a little on the soup and choked really bad." –PD6
	"I initially had trouble with things like crackers and pretzels so I stopped eating those really dry things. I've reintroduced a lot of that overtime just being more mindful and having liquid nearby." –(PD8)

-Range of Nutrition Knowledge for PD	"I don't modify the textures, if there is something like steak or a pork chop I cut it up into much smaller pieces than he used to have." –ICG4 "Sometimes when you drink water, something that's very crumbly, he will have difficulty, start coughing, so he has to drink water after it. And every once in a while, when he swallows water or diet coke or something he'll cough, but not very often." –ICG4 "Sometimes water tends to go down the wrong hole. I cough on occasion, now and then." –PD3 "I stay away from beef because it's too difficult to slice it sometimes…" –PD3 "Using utensils, like gripping them and getting food into my mouth without it falling in my lap. I take smaller bites and it takes me longer to eat" –PD5 "I went through a period of difficulty getting it (food) into my mouth but that was before the dosage of carbidopa/levodopa that I'm taking now." –PD6 "I have seen (diet information) online, I read things from the APDA, I saw that mentioned once that it may be some help in the absorption of the dopamine but I don't recall it being something that they necessarily were recommending it just was sort of mentioned" –ICG1 "I am interested in trying to time the medication and the protein consumption to see it we could make it happen that the sinemet goes in a half-hour before the meal is consumed and see is that makes a difference or does it have to be an hour before or two hours after. I would be very interested in knowing those things –ICG1 "I didn't know and I don't know how bad it is and I still don't know how long I should wait when I eat" –PD6 "The doctors don't give you information about anything" –PD8 "I get concerned when I take my Sinemet pill, is that supposed to compete for absorption with fats and so it's best if you don't take it with a heavy mean anyway but it also makes you nauseous that's why I start with crackers in the morning." –PD2

	"I know that too much protein slows down the carbidopa but other than that no. I never really experienced that though, I know about it." –PD5 "I was never told anything, until recently about protein being a hindrance to absorbing dopamine, so I've been a little concerned about when I am eating meals and when I am taking medications, should I be waiting a half hour or should I be waiting an hour? This is one issue I've been worrying about." –PD6 "Well the question that I have and have always had, and people always give me answers but they're not really answers is the interaction between protein and Sinemet, carbidopa/levodopa is confusing and really challenging because 99% of the food that I eat has protein in it and some sources say that even a trace amount of protein can interfere with the carbidopa/levodopa. That is the only medication that is having an effect on my brain and helps me be in more control." –PD8 "My understanding is that any amount of protein in the body at the same time that carbidopa/levodopa is in the body prevents is from entering the brain, it's just a block- no sinemet allowed here." –PD8 "Because he actually requires more protein now, he has the protein supplement, because of the energy level, because of the PD, muscle support for sure, so a low protein diet would be something that I am not keen on." –ICG1 "I think he would get tired and be rather listless and the other part would be trying to figure out having low protein during the day and then why at night? He's not going to do anything then, that's when we settle down. I'd rather say high protein in the morning and decrease it during the day but even that makes the meals off balanced." –ICG1 "Yeah, I think it would be challenging. You'd have to start and think about when you took your pills, when you ate, how much protein you could have, so yes it would be challenging." –ICG4 "That I'm getting enough protein –PD5 "I don't want my wife to have to make two meals. I'll eat whatever she eats so that would be a challenge." –PD6 "It would be really challenging for me because I like to eat small amounts of food a lot." -PD8

b. Eating Environment *-Reliance on ICG Buying & Preparing Foods* *-Reduced Enjoyment of Foods & Meal Times*	"She's taken over. Yeah, I used to do it all, I used to do a quite a bit of cooking too." –PD3 "He doesn't prepare the meals, he can throw together a sandwich if he needs to but I'm the cook." –ICG1 "I used to like to experience and enjoy many foods of different kinds (of food), now most foods don't have much of a taste and I also have to force myself to eat to put weight on." –PD1 "He doesn't have his taste buds as good as they were so he doesn't enjoy a lot of stuff. I would say the things he enjoys the most is probably sweets." –ICG3 "We don't go out to restaurants anymore because it's too much of a hassle." –ICG5 "I am just not interested (in eating) anymore." –PD11
c. Medication Management *-Barriers to Medication Management*	"Frequently what we have is a therapy sometime like today when we came home it was about 12:15 and he was hungry, I was starving so we had lunch right away, but he was due for a pill at 12 so he had the pill, he ate lunch within that half hour before it would have been fully absorbed." –ICG1 "When you're retired your day ought to be empty but ours winds up having a lot of going to the YMCA for exercise classes and Doctors visits and I wind up in a position where I pretty much have to take the pill very close to a meal or put it off longer than is appropriate." -PD 2 "My greatest challenge, taking it on time –PD11. Taking it on time and taking it throughout the day, you stop when you know you're not doing anything so –CG11. Yeah like if I'm home, I tend not to take it –PD11. I try to remind her because I see the signs when she runs out –CG11. Yeah like it bothers him more than it bothers me, I don't mind being off my meds, I just move slower, but he says my face looks different and I just move differently –PD11. "I use an alarm in my phone to remind me when to take the 1:00pm and 6:00pm pills. It's not uncommon for me to be in a seminar when it would have gone off, and I've got my phone turned off and I forget to take it until later." -PD2

-Management of Symptoms	"I had a cell phone all set up but he won't carry a cell phone so that has been a real problem, I am trying to come up with an apparatus that he will use and carry." -CG 4 "I have pill box that I have in the drawer that has my vitamins in it too, but then for lunch I would forget to take it if it wasn't out." -PD 7 "We try writing down each time I take a dosage. So, if I take carbidopa-levodopa every 4 hours, 4 times a day, if I start at say 8am, I write 8am and know my next dose is due at 12 then 4. If I don't write it down it's like, did I take it at 7 yesterday because I was up earlier or did I sleep in and take it at 9? - PD10. "The impact of levodopa is pronounced it's just a question of how long it takes" –PD1 "I guess it controls some tremors, my jaw used to shake a lot more visibly than it does now but it's pretty successful" –PD2 "I think it helps a lot, I'd say maybe 50-60%." –PD3 "There are days that I think I'm just as well off without pills, but if I do that I realize that the pills really are doing some good" –PD4 "If he takes them every four hours on time they make a huge difference." –ICG4 "If she misses a dose she will feel it if it goes past the four hours." –ICG5
-Access to Medication Information	"When it's working it works pretty well. I can walk without any assistance, I walk with a can though because I have a problem with my left hip. When I'm not doing well I will use a walker and even that is a struggle" –PD6 "I couldn't manage my life without it. I notice sometimes feeling a little more sluggish or stuck, frozen is the term they like to use so it's really challenging to be at my best without taking the medication." –PD8 "If you have high protein, it just feels like you're not medicated –PD11 When (she's) on the medication most people can't even tell she has Parkinson's." –CG11 "I would ask my doctor but he's kind of hard to get a hold of so we look it up." –PD2

	"Absolutely none from the doctor, just how many times he could take it but that's all, not when" –ICG1 "Look online and the handouts you get at the pharmacy." –PD5 "I look online but the sheet comes with my medication, I get 2-3 pages of information and I scan it, I mean I read it when I first got it but now I scan it in case there is something different." –PD7 "Online but probably more so on the information from the pharmacy. You know how CVS sends 3-4 pages of stuff you can't understand, that I can't understand. Usually that or medical journals they have good information. And here at the gym they post things that are pertinent, groups and surveys" –PD10 "Well I've spoken about it with my peers in the support groups and LOUD Crowd." –PD8 "Online and talking to other people with Parkinson's." –PD11 "We'll sit in the cafeteria when the guys are in LOUD, they'll talk about the down time, who has down time, who doesn't. I find a lot of information when I sit with the ladies -ICG3 "You just have to educate yourself and have a great support group which we have at URI, we are so lucky. That is a blessing that is worth so much and I think it's a constant battle but it's also you have to keep educating yourself on all the new stuff and it never lets up- ICG4

Table 3: Participants Demographics

	PwPD	ICG
Age	68.7±8.5	69.4±5.6
Gender %(n)		
Men	70(7)	30(3)
Women	30(3)	70(7)
Working Status %(n)		
Working	0(0)	10(1)
Retired	100(10)	90(9)
Highest level of education %(n)		
Some college	0(0)	40(4)
Associates degree	10(1)	10(1)
Bachelor's degree	30(3)	40(4)
Master's degree	30(3)	10(1)
Doctoral degree	30(3)	0(0)
Other health issues		
Diabetes	10(1)	
Hypothyroidism	10(1)	
Hypertension	10(1)	
Heart condition	20(2)	
BMI %(n)	27.1±4.7	
Normal	30(3)	
Overweight	50(5)	
Obese	20(2)	
Height (in)	67.2±3.0	
Weight (kg)	78.9±16.5	
Years since diagnosis	11.4±4.9	
Years on levodopa	6.9±3.8	
Levodopa dose/day (n)	3.9±1.0	
T-MoCA	20.3±1.6	
DST %(n)	66.4±13.9	
Not at risk	30(3)	
At possible risk	40(4)	
At risk	30(3)	
Eating times/day (n)	4.5±1.4	
Meals/day	2.9±0.3	
Snacks/day	1.8±1.4	
Protein intake (g/kg)	0.9±0.2	
Protein pre-dinner (g)	39.8±19.0	
Protein post-dinner (g)	32.5±7.8	

Table 4: Nutrient Breakdowns

	PwPD Intakes	Range	DGA Male	DGA Female
Calories	1955.6±678.2	905.5-3214	2,000	1,600
Total water (ml)	1884.9±791.2	819.7-3372	3700	2700
Carbohydrate (g)	232.2±79.8	98.7-308.6	130	130
Fiber (g) **Soluble** **Insoluble**	23.2±9.4 6.3±2.9 17.3±7.7	6.5-29.7	28	22.4
Fat (g) **Monounsaturated** **Polyunsaturated**	84.2±43.5 (38%) 32.3±20.2 17.8±9.6	24-179	20-35%	20-35%
Protein (g) **Animal** **Vegetable**	72.3±20 44.2±12.3 17.8±9.6	43.6-106.3	56	46
Vitamin D (mcg)	377±296	28.9-1042	600	600
Thiamine (mg)	1.6±0.5	0.6-2	1.2	1.1
Riboflavin (mg)	1.9±0.6	0.7-2.7	1.3	1.1
Niacin (mg)	21.3±6.8	11.4-29.5	16	14
Vitamin B6 (mg)	1.8±0.7	0.6-3.1	1.7	1.5
Vitamin B12 (mcg)	4.2±2.5	1.5-10.1	2.4	2.4
Folate (mcg)	415.1±186.9	154.5-712.5	400	400
Calcium (mg)	839.6±410.3	266-1066.5	1,000	1,200
Iron (mg)	14.8±8.2	5.7-33.1	8	8
Magnesium (mg)	324.5±179.5	132.5-762	420	320
Potassium (mg)	2599.8±977.5	1715-3540.5	4,700	4,700
Sodium (mg)	2544.5±715.2	1253.5-3493	2,300	2,300

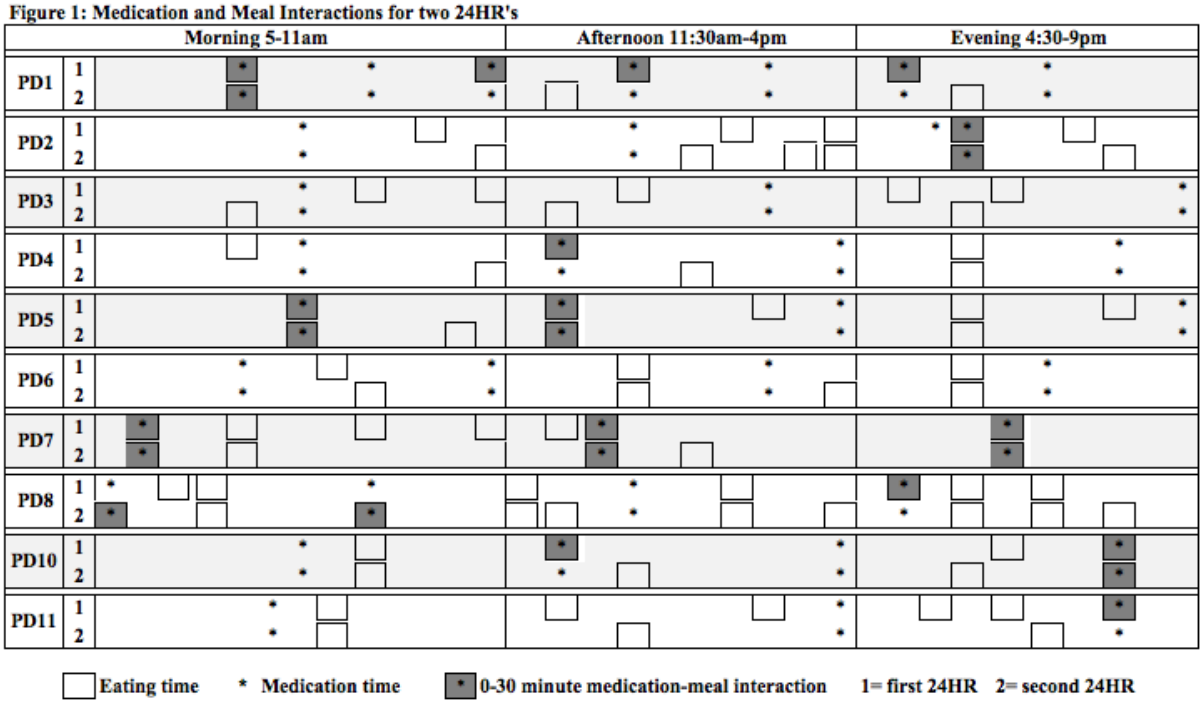
Table 5. Comparison of Dietary Groups between 2 Dietary Assessments

	DST (points)	NDSR (servings)
Fruits	11.2 (15)	2.2 (2 cups)
Vegetables	11 (15)	3.7 (3 cups)
Whole Grains	10.4 (15)	1.7 (3.5oz.)
Lean Proteins	7.5 (10)	5.9 (6oz.)
Added Fats, Sugars & Sweets	11.9 (25)	5.8[a]
Dairy	4.5 (10)	1.3 (3 cups)
Processed Meats	7.5 (10)	0.7[a]
Supplements	50%	50%[b]

[a]= There are no specific DGA recommendations for number of servings

[b]= Percentage of participants using supplements

Figure 1: Medication and Meal Interactions for two 24HR's



APPENDICES

Appendix A: Review of Literature

I. Introduction

Parkinson's disease (PD) is a progressive neurodegenerative disorder that affects over 900,000 Americans and by 2030 the prevalence is expected to double[1-3]. Parkinson's disease causes motor and non-motor sequelae (consequences of pre-existing conditions), such as resting tremors, slowness of movement, cognitive decline, depression, sensory changes, difficulty swallowing, and gastrointestinal issues, all of which can negatively impact dietary intake and nutritional status[1, 5-7]. The motor sequelae are commonly managed with levodopa therapy to improve motor function, quality of life, and reduce morbidity and mortality in persons with PD (PwPD) [10]. Informal caregivers, those who provide the majority of care without monetary compensation, assist PwPD in managing the disease sequelae and levodopa medication[23, 24]. Additionally, caregivers are involved with all aspects of dietary management such as menu planning and food purchasing and preparation, since PD sequelae reduces the PwPD's ability to complete these tasks[24, 30]. Dietary protein is essential as it promotes muscle mass retention, growth, and physical functioning, which generally deteriorate with PD progression[1, 2, 11]. However, dietary protein competes with levodopa for absorption, therefore timing of levodopa and protein intake needs to be managed properly[11, 20]. Dietary management is critical for PwPD as they are at increased risk of poor nutritional status[39], and need to minimize the protein-levodopa interaction (PLI)[17]. Although dietary modifications exist for PLI management, PwPD and their caregivers report misinformation regarding which dietary modifications are optimal[20]. The purpose of this review is to investigate the sequelae associated with PD,

and the treatments currently available to help PwPD and how their caregivers contribute to a large amount of management of sequelae.

II. Parkinson's Disease

Parkinson's disease is most prevalent in the fastest growing US population, adults aged 65 and older[3], and affects 1-2% of the population, globally[4]. The etiology of PD is not well understood, but involves neuronal call death from the brain stem to the cerebral cortex that result in loss of sensorimotor control, balance, gait, autonomic function, mood, cognition, communication and swallowing[1, 4-7]. The disease often presents with presents with the loss of dopamine-secreting neurons within the sunstantia nigra and the presence of Lewy bodies[41]. Therefore, there is a decrease in the amount of dopamine, a neurotransmitter that regulates movement and emotional response. When there is not enough dopamine present, non-motor and motor sequelae will occur. Early signs of the disease include tremor, postural instability and bradykinesias, which prompt a visit to the neurologist but, often go untreated as these sequela are often attributed to the normal aging process[4]. The most common type of PD is idiopathic, which presents in 90% of PwPD[4], and often includes a young onset and, akinetic and tremor predominance but each PwPD will present with their own set of sequela. Due to the heterogeneity of PD, and the widespread pathology of PD the onset, progression and etiology of most sequelae are not understood[1].

Parkinson's disease is often staged according to motor sequelae[1, 31], by the five stages of the Hoehn and Yahr (H&Y) scale with stage 5 being most advanced[31]. These scores are assigned by the neurologist and can fluctuate as the disease progresses and medications are altered. Scores are evaluated as the disease stage from 1, "unilateral

disease", 1.5 "unilateral plus axial involvement", 2 "bilateral disease without impairment of balance", 2.5 "mild bilateral disease with recovery on pull test", or, 3 "mild to moderate bilateral disease, some postural instability, physically independent", 4 "severe disability, but still able to walk or stand unassisted", and 5 "wheelchair-bound or bedridden unless assisted"[31]. These stages will fluctuate with disease progression and overall management of the disease, but give PwPD a guide as to where they stand in the progression of their disease.

Management of PD is time-intensive and expensive management strategies including doctors' and other health professional appointments, medications, surgeries, and complementary health approaches ranging from $10-14 thousand dollars per person annually[8]. Due to the neurodegenerative nature of PD, a caregiver will be warranted to take over all activities of daily living (ADLs) as the disease progresses[42]. Pharmacological management is the most frequently used management in PD, and often presents with the most confusion and difficulties in compliance among PwPD and their caregivers according to qualitative research[23].

III. Pharmacological Management of PD

The neurodegenerative, movement disordered mature of PD causes motor and non-motor sequelae result in an increased burden on PwPD and their caregivers, which effect physical, social, emotional and nutritional statuses[9]. In order to uphold overall quality of life, and slow progression of disease, there have been pharmacological treatments studied and recommended to treat the sequelae[41]. Recommendations are based on the individual due to the heterogeneity of PD[41].

a. *Motor Sequelae Management*

Medications used to treat the motor sequelae associated with PD act on the neurological interactions in the striatum[41]. Recommendations are to initiate medication when patients begin to experience functional impairment or social embarrassment from their symptoms[41]. The choice of initial medication depends on the patient's specific age and what symptoms they are experiencing[41]. The three most typical medications used for PwPD are 1) monoamide oxidase type B inhibitors (MAOBIs), 2) dopamine agonists and 3) levodopa[41]. These three produce dopaminergic effects; dopamine agonists and levodopa work to bind to and activate dopamine receptors, while MAOBIs inhibit the breakdown of dopamine. Additional drugs that may be used include beta-blockers, anticholinergic and amantadine drugs[41], which act to block postsynaptic receptors for other neurotransmitters in the striatum, therefore making dopamine more available.

In the early stage of PD, when motor sequela are generally mild, MAOBIs, anticholinergic, beta-blockers, or amantadine drugs are typically the first line of treatment[41]. However, there has been inconclusive evidence on the overall effectiveness of these drugs[41]. In a recent meta-analysis of MAOBIs in early PD, there was only a small but significant symptomatic benefit shown with rasagilin[43, 44]. Anticholinergic medications like, trihexyphenidyl, benztropine and procyclidine, have been shown to improve some motor fluctuations compared to placebos in clinical trials but, have not been shown to significantly help tremors[44, 45]. The beta-blocker, propanol is the most effective when controlling tremors in PwPD[44, 46-49]. Additionally, The International Parkinson and Movement Disorder Society recommends the use of amantadine's, unspecified for motor system management as mono- and adjunct therapy, despite the mixed evidence supporting its treatment for PD[44, 50]. These drugs are known to be

effective in the early stages of the disease but as motor sequelae become more pronounced, or they are diagnosed earlier, stronger medications are warranted[41].

Dopamine agonists (carbidopa), and/or levodopa are typically prescribed as PD progresses and motor sequelae become more prominent and activities of daily life are impaired[41]. Dopamine agonists may be prescribed before levodopa in a more advanced stage of PD, or as a first line of treatment if the patient is under 60 years of age. Dopamine agonists result in less negative side effects than levodopa, and are typically tried first in young on-set PD. However, dopamine agonists have been shown to cause compulsive behaviors in PD, especially compulsive eating, which can result in overweight and obesity and has a negative impact on health status[41]. Therefore, it may only be an effective treatment for a short time, before a full-levodopa treatment is warranted.

Levodopa therapy has shown to provide the greatest symptomatic benefit for PD including, less freezing gait, daytime drowsiness, edema, hallucinations and risk of impulse control disorders. Levodopa is quickly metabolized in the plasma and has a short half-life of 1.5 hours[51, 52]. Upon administration, levodopa crosses the blood-brain barrier in order to be converted into dopamine, replacing the neurotransmitter deficient in PD. Most PwPD start levodopa at 50mg one time per day, and then three to four times per day equaling 100-200mg[53]. Levodopa is commonly combined with a dopamine agonist (carbidopa) so there is an increase of levodopa in the central nervous system which will improve one's ability to tolerate the drug by reducing adverse side effects like nausea, from peripheral decarboxylation[51]. There are several ways levodopa therapy can be administered such as, immediate-, controlled and co-administration.

Immediate-release (IR) medications combine carbidopa and levodopa to inhibit metabolism in the periphery and allow an increase in central nervous system (CNS) availability[10]. The IR formulas have short half-lives and therefore need to be taken more frequently[44, 52, 54, 55]. Because of the increased frequency in taking IR formulas, overtime there is a shortening of clinical response and higher, more frequent dosing to compensate for the change in pharmacodynamics[44, 52, 54, 55]. These changes due to chronic levodopa use, increases the probability of over and under dosages which lead to motor complication. Motor sequelae have occurred as early as 5-6 months after levodopa treatment[56]. After 2 years only 20% of patients experience sustained benefits[57], and after 5 years, 70% experience on-off fluctuations and dyskinesia's[58, 59]. As time on IR levodopa increases, wearing off becomes more frequent, levodopa doses need to be given in increasing frequency.[10]

Controlled-release (CR) medications are degradable polymer matrices that slow the release of levodopa into the gut[10]. These medications produce less "off" time and more "on" time[10]. Although levodopa levels are more stable, the absorption of CR levodopa is delayed, making symptom relief less predictable[60]. Research has shown that in the long-term (5 years), there is no difference in degree of motor fluctuation and dyskinesia's between CR and IR medications in patients with moderate to severe motor fluctuations[49].

Co-administration strategies of IR and CR have also been tried in PwPD in order to increase effectiveness of levodopa therapy. This strategy has shown to increase total exposure of IR by 30-40% and prolongs levodopa half-life to 2.4 hours[10]. This combination inhibits peripheral levodopa metabolism and allows more levodopa to enter

the CNS[10]. This strategy has been shown to produce levodopa plasma profiles similar to CR but with higher levodopa fluctuations[61]. However, the scheduling of this formula may increase the burden or complexity of the medication schedule as the first dosage needs to be taken early in the morning and restricts the CR at night[10].

Levodopa is the most effective medication to control PD motor sequelae in, independent of patient age and severity that will be prescribed depending on onset of PD and degree of sequelae. However, there is other issues associated with consumption. People with Parkinson's should talk with their healthcare providers on which treatment would be most beneficial for them and their lifestyle. It is also important to take nutritional status into consideration when discussing levodopa therapies as long-term use of this medication can negatively impact nutritional status which has been shown to already deteriorate with PD progression. Specifically, one major nutritional concern is the contraindication with protein, which will be discussed in greater detail later.

b. *Non-motor Sequelae Management*

Close to 100% of PwPD present with one or more of the non-motor sequelae. Non-motor sequelae can be broad, like depression or cognitive impairment, or narrow, like hallucinations, orthostatic hypotension, or sialorrhea (increase in saliva) [41, 62-64]. Non-motor sequelae may present as part of disease, or as a side effect of a PD medication used to treat the motor sequelae (described above) and both, the sequelae and the medication will fluctuate as the disease progresses[41]. It is important to consider the pharmacological management of these sequaela as they may affect overall nutritional status, dietary intake and quality of life in PwPD.

A common broad non-motor sequelae is depression that often occurs throughout

the disease course and may worsen as the disease progresses[41]. In 2013 a systematic review[65], and two meta-analyses[66, 67], reviewed antidepressants effect on depression and found no statistically significant superior antidepressant compared with a placebo, but tricyclic antidepressants were more effective than selective serotonin receptor inhibitors (SSRIs) and dopamine agonists (mirapex). The AMA suggests that SSRIs and selective serotonin norepinephrine reuptake inhibitors (SNRIs) can be effective in managing depression despite the little evidence found in PwPD[41]. Despite the positive effects, tricyclic antidepressants are not frequently recommended due to the adverse effects that may occur in older adults who are cognitively impaired[41]. Dopamine agonists are also an option to target depression as it can improve motor symptoms as well[41]. The use of antidepressants in PwPD is very common to treat depression and 13-22% of those who are community-dwelling, and 50% of those who are institutionalized use antidepressants[68], which also an effect on cognition and quality of life (QoL), and can lead to a decreased nutritional status. Therefore, it is crucial to identify eating patterns in PwPD.

There have been few studies that have assessed the treatment of cognitive impairment in PwPD. The most studied class of drugs have been cholinesterase inhibitors in five placebo-controlled trials[69, 70], that have shown improvements in global assessment scale scores, cognitive function, behavioral disturbance and ADLs ins patients with Parkinson's disease dementia. However, with these drugs, the AMA believes that meaningful clinical benefit of these drugs is variable and unpredictable in PwPD, and research into other drugs to help with this non-motor sequelae needs to be conducted[41]. Cognitive impairment has shown to decrease nutritional status, performance in activities

of daily living[31, 71, 72], quality of life, and increase caregiver burden[26]

The narrow non-motor sequelae, hallucinations, orthostatic hypotension, and sialorrhea may also occur as a part of normal disease sequelae or may be a side-effect of a PD medication[41]. Hallucinations, perceptions of things that are not present, have been treated with clozapine, but there is a risk of leukopenia, which will require frequent blood monitoring[41]. Also, for those with dementia, rivastigmine has shown to reduce hallucinations[73], while donepezil has shown to reduce hallucinations in those without dementia[74]. Domperidone, has been recommended by the AMA to control dopamine agonist- and levodopa- induced, hypotension especially when the medications are introduced together[41]. The use of anticholinergic drugs for the treatment of sialorrhea has been recommended by the AMA, however, these are not well tolerated in older adults with cognitive dysfunction[41]. Glycopyrrolate may be very effective and better tolerated due to limited blood-brain barrier penetration, and botox injections can be effective and well tolerated, but with more injections, the risk of adverse effects like dysphagia may limit use[41].

Pharmacological management strategies for motor and non-motor sequelae are often the first line of treatment for PwPD[41]. It is important to consider all medications that the PwPD is taking, and be aware of the adverse effects that may impact nutritional status, dietary intake and quality of life. Other approaches to compliment pharmacological management of non-motor sequela may include dietary or occupational health measures like, increasing salt and fluid consumption, elevating the head of the bed, and quickly drinking 2, 8-oz glasses of cold water in the case of orthostatic hypotension[41]. For more broad motor or non-motor sequelae, surgeries and ancillary

services are recommended to be used in conjunction with pharmacological management for better health outcomes[75]

IV. Non-Pharmacological Management

Parkinson's disease is a progressive disease that causes decline in motor, cognitive and nutritional functioning. Pharmacological management is often started at disease onset and will be monitored and altered throughout its progression. In addition to pharmaceuticals, there are potential non-pharmacological management strategies like, surgeries and ancillary services recommended for symptom management and to slow disease progression[76]. The most common surgery for PwPD is Deep Brain Stimulation (DBS), while the most common services for PD include physical and exercise therapies, occupational therapy, speech therapy, and a growing need for nutritional therapy[77]. There is currently no cure for Parkinson's disease so, the recommended medications, surgeries and services will all work in combination to manage the disease progression[76].

a. *Deep Brain Stimulation*

Deep brain stimulation (DBS) has recently emerged as an effective treatment for PwPD who no longer receive symptomatic relief from medications[76]. Worldwide, there are over 100,000 PwPD who have undergone DBS, and more are expected to receive the treatment[76, 78]. An electrode implanted in the brain sends an electrical current to a neuro-stimulator in the chest, which blocks dysfunctional signals that cause motor fluctuations[79]. Research conducted on the benefits of DBS have shown profound improvements related to motor and speech sequelae[79-81]. A recent meta-analysis of 6-randomized controlled trials found that DBS improved motor functioning while off medication[79]. Schupbch et al[80] found significant and sustained motor sequelae five years

after surgery. Another study compared speech one year before and after in one group who was treated with DBS, and another who was only treated with medication[81]. Only those who received DBS experiences a significant decrease in speech intelligibility, strained voice and stuttering, only from those who received DBS[81]. While DBS may impact speech, it is an effective treatment option for managing overall disease sequelae[76]. However, because this is not the first line of treatment, and is only utilized in a small population of PwPD, the use of ancillary services is recommended with the use of pharmacological management, whether DBS was preformed or no to reduce side effects and optimize symptoms outcomes[76].

b. *Ancillary Services*

The American Academy of Neurology recommends regular utilization of physical, occupational and speech therapies for PwPD[82]. These therapies have been shown to improve quality of life, dysarthria and hypophonia in PwPD[38, 83-85]. The positive effects of rehabilitation services slowing disease progression in PD have been well documented. However, a recent study showed that only 25% of US Medicare beneficiaries with PD received rehabilitative therapies in a 3-year period[86], potentially due to poor dissemination and implementation of PD research. Therefore, it is important for PwPD to have a multidisciplinary team where primary care doctors and neurologists recommend these rehabilitation services for better management of PD progression. Regular attendance at these rehabilitation services, or one-on-one sessions has shown improvements in motor function, activities of daily living, speech volume, cognition and quality of life[86].

Physical and Exercise Therapies

Physical activity in the management of PD was first introduced in 1950[87]. It was not until three decades later that experimental studies were used to recognize the benefits that physical and exercise therapies had on motor fluctuations in people with Parkinson's disease (PwPD) [88, 89]. Physical and exercise therapies are the most utilized rehabilitation service for PD and randomized controlled trials show its significant impact on improving motor and non-motor sequelae, activities of daily living (ADL), speech volume and QoL[90]. Common physical and exercise therapies include resistance training, tai chi, water exercises, robotic gait training, dance, virtual reality, aerobic training, boxing, Nordic and downhill walking[91, 92]. As most of these exercises serve to improve physical mobility and functioning, activities such as dancing, water exercises, virtual reality training, and Nordic walking have also allowed PwPD to enjoy greater health and wellbeing[91, 92].

Many studies have demonstrated that older adults enjoy different activities that are not typical exercises because they add enjoyment. Tai chi has shown to provide the most improvement in postural stability, movement function and gait in people with mild to moderate PD[93-95]. These improvements can be maintained into the long-term (3 months) and still prove to be beneficial as the disease progresses[93-95]. Also, dancing is a complex motor skill that involves postural stability, weigh shifting, inter-limb coordination, single leg-stance activities and trunk rotation[96]. Older adults have been identified as a population to enjoy dancing as a form of physical activity[97-99]. In PwPD, this exercise has shown benefits in body function, disease severity and QoL[99].

More traditional exercises like resistance and aerobic training, walking, boxing and water exercises. Resistance training which may include exercise machines, has resulted in improved lower limb muscle strength, balance and motor symptoms[100].

Aerobic training through use of a cycle ergometer was used as aerobic training, improvements in functional mobility, ADL, balance, disease severity and walking[101]. Different types of walking training, Nordic and downhill have both been tested and show benefits in functional mobility, gait, QoL and improvements in walking, respectively[102, 103]. Boxing is becoming a common activity for PwPD because there have been improvements in functional mobility, ADL, gait and balance in PwPD[104]. Water exercises have been thoroughly tested in older adult literature as the effects of buoyancy and hydrostatic pressure of water has contributed to a decreased risk of falls[105]. For PwPD, the aquatic environment may enhance balance, reduce freezing or gait and fear of falling and increase movement of amplitude and speed[96, 106, 107].

In addition to traditional physical activities, there have been many technological creations to exercise to complement physical activities. Robotic gait training involves a large device where one's legs are strapped into a machine and moved on a treadmill[108, 109]. This type of complementary exercise has improvements in functional mobility, balance, disease severity, gait[108, 109]. Virtual reality and exercise gaming have also been proposed to complement and practice to exercise therapy in those with neurological disorders[110, 111]. With this technology, there improvements have been shown in functional mobility, ADL, gait, QoL, balance and movement disorders[110, 111]. A final technology, the whole-body vibration, transits energy into your body, forcing your muscles to contract and relax each second, which can provide modest improvements in the short term for mobility, gait, balance and disease severity[112]. Although these new therapies can improve motor functioning, when compared to physical therapies the improvements are not as

positive and it is suggested that these technologies are used in conjunction with additional physical activities[91].

Occupational Therapy

Occupational therapists are trained to help PwPD maintain their usual level of self-care, work and leisure activity for as long as possible[113]. Possible interventions may include re-organizing the daily routine, learning new skills for alternative or adaptive ways to carry out activities, providing or advising on specialized equipment or resources and patient education (like devices to increase mealtime experience) [113]. Multiple studies have examined the use of an occupational therapist and results have shown that only 13-25% of PwPD have utilized their services[113-115]. Most patients are not referred to an occupational therapist until the later stages of the disease where the occupational therapist helps to reduce daily stress, minimize disability and improve quality of life despite the natural increase in impairment[113].

Speech Therapy

Over 89% of PwPD will have a speech disorder and/or dysphagia throughout the progression of their disease which will require pharmacological and nonpharmacological management strategies[86]. Communication and speech deficits are often apart of the disease sequelae, and are difficult to manage with medications or DBS alone[4], which will require the specialty of a Speech Language Pathologist (SLP) to provide ancillary services. The most common treatments for communication deficits include, the Lee Silverman Voice Treatment (LSVT), or effort-based therapy, speech and voice therapy and musical therapy[4]. The best outcomes have been shown with LSVT, which focuses on increasing vocal loudness, voice quality, speech ineligibility, articulation[116-118], and more

evidence has been found surrounding positive changes in facial expression[119] and swallowing[120]. This treatment is time-intensive as it includes 16, 1-hour long sessions, delivered over 4 weeks[119], but has been tested in an 8-week time period with the same positive results[121].

Treatments for dysphagia are patient-dependent and will depend upon the physiology of the swallowing for the safest approach[4]. Often, modification of textures and consistencies of foods and liquids with thickeners will depend on barium swallow testing. Honey-thickened liquids have been shown to result in the fewest aspiration events, but for patient QoL purposes, the chin-down feeding approach was better accepted[122]. Exercise programs like, expiratory muscle strength training (EMST) have also been used to improve cough, swallow function, penetration/aspiration scores, and hyolaryngeal function[123, 124].

Parkinson's disease sequelae will progress overtime and warrant the need for ancillary services. While it would be beneficial for ancillary services to be started early, most will not start until later. The motor (tremors and rigidity) and non-motor (dysphagia and altered gastric emptying) sequelae can be managed with DBS, physical, speech and occupation therapies and pharmacological therapies. However, these sequelae may contribute to a larger issue of under/over-nutrition which will call for nutritional services to be a part of the interdisciplinary team.

V. Dietary Management

Optimal nutritional status is difficult for PwPD to maintain as cognitive decline, weight fluctuations, difficulty swallowing and gastrointestinal issues contribute to inadequate dietary intakes[1, 5-7]. Poor dietary intake result in poor nutritional status and

risk[39]. Currently, there have not been any nutrition assessment tools that have been validated in PwPD. However, the Dietary Screening Tool (DST) and Mini Nutrition Assessment (MNA) are reliable and validated tools to identify severity of nutritional status and risk in older adults, and have been used to identify PwPD with impaired nutritional status and at nutritional risk[32, 39, 125]. There have been dietary recommendations suggested that address PD sequelae and medication interaction[17], however no person with PD is alike and all will require a nutritional assessment for individualized dietary recommendations. Therefore, the review will address several nutritional issues that relate to PD that should be taken into consideration when caring for a patient with PD.

Cognitive Decline

Dementia, the most common cognitive symptom, occurs in 40% of PwPD and is associated with an accelerated progression of disease and risk for institutionalization[29, 126, 127]. Cognitive decline has shown to affect interest in food through loss of taste and smell senses, and eating habits in PwPD[128, 129]. The memory loss associated with cognitive decline affects ones' ability to remember to eat, placing the feeding on the caregiver, if applicable[130]. Also, over the last few years there has been evidence of the gut-brain axis that links the gut to the source of PD pathology that eventually progresses to neurodegeneration[131]. The inclusion of phytochemicals and antioxidants from berries, wine, caffeine have been suggested to have neuroprotective effects and may slow progression of PD[132].

Weight Changes

Weight status in PD will vary based on disease stage and severity. Studies have shown that the prevalence of obesity among PwPD is 50% higher than the general population[133]. Obesity is associated with impaired glucose control, hypertension, dyslipidemia, and cardiovascular disease, all of which will further effect PwPD, aside from typical disease sequelae[133]. If the PwPD is not obese at diagnosis, they may become obese preceding initial diagnosis due to an increase in energy intake, or the initiation of DBS or a dopamine agonist medication, all of which will increase energy intake[134, 135]. Although weight and energy intake may increase during these times, a major sequela of PD is weight loss and eventual undernutrition, [5, 136] partly due to rigidity and dyskinesia (~400kcals/day) [137-140]. Weight loss is associated with increased energy expenditure, early satiety due to decreased gastrointestinal motility, olfactory impairment, bulbar dysfunction and decreased baseline dopaminergic stimulation of central reward systems[135].

Additionally motor sequela have an negative effect on activities of daily living related to food intake like, shopping, preparing, and cooking which may also reduce food intake[141]. A 3-year longitudinal study showed that increasing energy intake to compensate for the increased expenditure was not effective in preventing weight loss, suggesting that the idea of progression weight loss in PD may be related to other factors like malabsorption[125]. Weight fluctuation is a major concern in PD due to muscle wasting which can impact cognitive functioning and ability to carry out activities of daily living, which will increase caregiver burden[5].

Dysphagia

Difficulty swallowing (dysphagia) is a common sequela that presents in up to 80% of PwPD[142-144]. Tremors and rigidity occurs in the head and neck regions with PD, therefore chewing and swallowing can be effected[145, 146]. There are functional changes in the oropharyngeal and esophageal motility of the neck which impair peristalsis and low sphincter activity to further disrupt gastric functioning[147, 148]. Assessment of dysphagia includes clinical parameters like, changes in BMI, HY-scale, food and drink retention, and questionnaires addressing self-reported perception of swallowing[149]. Dysphagia is believed to play a role in weight loss in PD, because it results in prolonged feeding periods, mealtime interruptions, and avoidance of certain foods, specifically solid foods [145, 146 150, 151]. Liquid foods are usually associated with dehydration and risk for aspiration due to dry oral organs (dry mouth) [150, 151]. Both textures can all lead to nutrient deficiencies. Texture-modified diets and the use of thickened whole-formulations and ready-to-eat foods are often recommended for use as they can be safer to swallow in PwPD[5]. Dietitians and SLPs should work together to identify the best texture for the individual and if it is meeting their nutrient needs. If nutrient needs are not able to be met, a gastrostomy may be indicated[5].

Gastrointestinal Issues

Impaired gastric emptying rate is a severe motor sequelae that increasingly occurs with PD progression[152]. Changes in gastric motility (ex. reduced absorption related to dopaminergic activity) play a large role on small intestine transit, through enhanced production of bacteria and malabsorption due to alterations of the enterocytes[153, 154]. Impaired gastric emptying in PwPD is that it may prolong the exposure of levodopa to the decarboxylase enzyme in the gastric mucosa, delaying absorption in the guts and its

overall efficiency in reducing motor fluctuations[153, 154]. Decreased gastric emptying rate will increase abdominal distention, discomfort, nausea and early satiety and bloating, which may reduce the enjoyment of eating and energy intake in PwPD[5]. Constipation is the most commonly reported gastrointestinal sequela for PwPD, and impacts nearly 60% of PwPD throughout the course of their disease[5]. Increased transit time and gut dysbiosis are factors that contribute to constipation, and are contraindicated in PwPD as this will highly degrade their levodopa medication and reduce its availability[5]. Dietary strategies to address constipation include increase in fiber and water intakes. People with PD have been shown to consume adequate fiber to alleviate their constipation however, this population has also been shown to consume less water, which negatively effects stool consistency and bowel habits[11]. Therefore, when education PwPD on how to alleviate constipation, increases in water and fiber must be discussed in unison[11].

a. *General Recommendations for Dietary Intake*

Nutrition assessment is critical for PwPD as the associated motor and non-motor sequelae can negatively impact dietary intake and nutritional status and vice versa. However, there is a lack of specific dietary recommendations for PwPD to manage sequelae. People with PD will need to monitor nutrients like protein, water, fiber, calcium, vitamin D and B6 and folate. It has been recommended that PwPD should consume at least 1.5L of water per day and consume a minimum of 30-35g of fiber per day[5]. The dietary guidelines for Americans (DGAs) may be used to form a base for recommendations in this population as they promote a balanced and nutritious diet that includes fruits, vegetables, protein, grains and dairy[40]. The recommendations for this diet include 10-35% of calories from protein sources, 45-65% of calories from carbohydrates

and 20-35% of calories from fats with <10% of calories from added sugars and saturated fats, but all breakdowns and items from food groups should be individualized to fit the needs of the person with PD[40]. The Mediterranean diet has been studied within this population and is associated with reduced PD incidence and later age of diagnosis[5]. It is typically 50-60% carbohydrates, 12-15% protein and 25-30% fat, which is a small change from the DGAs[5]. The Mediterranean diet focuses on fruits, vegetables, nuts, seeds, fish and other lean protein, including fish high in DHA and EPA like salmon, tuna and swordfish that have been shown to improve neuronal health and slow PD progression [132]. The DGAs or Mediterranean diet may be utilized early in the diagnosis but once levodopa therapy is introduced, protein intake may need to be altered so the medication absorption can be improved[5].

b. *Dietary Protein Patterns*

Dietary protein is essential as it promotes muscle mass retention, growth, and physical functioning[1, 2, 11]. However, all dietary protein can interfere with absorption of levodopa-containing medication in the gut, blood brain barrier, and the peripheral nervous system[19, 155]. Specifically, the large neutral amino acids, phenylalanine, tyrosine, and tryptophan, which are commonly found in protein foods like dairy products, nuts, seeds, salmon and turkey, will have the most competition. Therefore, it is recommended that levodopa be consumed anywhere from 30-120 minutes before or after a protein-containing meal or snack[11]. Persons with PD consume up to 50% more protein than the Recommended Dietary Allowance (RDA), 1.2g/kg vs. 0.8g/kg respectively, and a higher protein intake is associated with a higher daily levodopa dose over time, due to the contraindication of protein and levodopa[11].As stated above the higher doses of levodopa

can be ineffective in reducing motor sequelae[11, 12]. Also, studies have shown that 22% (n=364)[156] and 38% (n=52)[155] of their participants alter the timing of their dietary protein intake to reduce motor fluctuations. There have been PD-specific dietary recommendations, the LPD and PRD, that aim to reduce PLI experienced by PwPD but both may not maintain a healthy diet[11, 15, 16, 18, 19].

The American Academy of Neurology recommends a LPD or PRD to minimize PLI and reduce motor fluctuations in PwPD [15, 16]. A LPD restricts total daily protein intake to 0.5g/kg/day[15]. Low protein diets in conjunction with levodopa have been tested in randomized clinical trials in an attempt to reduce motor sequelae in PwPD. Two studies have reported on the effectiveness of motor fluctuations with levodopa on five protein altered diets ranging from 10g/day (0.15g/kg/day in 70kg person) to 2g/kg/day[18, 19]. The most control on motor symptoms occurred in the diets providing 0.5g/kg, also, as protein intake increased to 2g/kg, there was a decrease in symptom control. Participants in these studies continued to follow the 0.5g/kg protein diet 2-12 months after the study ended and were able to reduce their levodopa dosage from 20-42%[18, 19]. The results from these studies suggest that restricting protein is effective in controlling PD sequelae and may reduce the dependence on levodopa therapy. However, although participant acceptance was shown, other studies have not and this may not be the best option due to outcomes changes like lean body mass, muscle strength and ADL's which were not measured in the present studies, but all may be impacted by low protein intake, especially in the aging population[1, 2, 11].

The PRD may be a better option for aging adults with PD as it focuses on reducing dietary protein prior to the evening meal, and consuming an unlimited amount

of protein at the evening meal[11, 15, 17-19]. This diet does not limit total protein and most studies have tested between 7-15g of protein before the evening meal with a goal of 0.8g/kg of protein daily (70kg body weight= 41-48g at dinner) [157-160]. In a case-controlled study that investigated 600 PwPD, overall daily protein intake influenced levodopa-related motor complications[11]. A daily dietary protein intake 10 grams over the individual's recommendation of 0.8/g/kg (70kg body weight= 66g) was predictive for an increase in levodopa dose by 0.7mg/kg/day (70kg body weight =~50mg additional levodopa/day). A multivariate regression analysis determined an inverse association between PRD and motor fluctuations (p=0.046)[11]. From this study, it can be speculated that levodopa dosage may increase at a slower rate, may be effective for a longer time and therefore help with motor fluctuations for a longer time, if the PRD with protein intake at 0.8g/kg/day is practiced.

There are multiple studies that support the use of Mediterranean and modified protein diets for PwPD[5, 11, 15, 17, 19]. Also, the use of low-protein supplements may be used to meet dietary recommendations[157]. Other dietary patterns such as, the consumption of dairy products (milk, cheese, ice cream and yogurt), canned fruits and vegetables, diet sodas (due to the aspartame), fried foods, beef have shown to negatively affect PD progression, but have not been as extensively studied and have shown inconclusive results[132]. The conflicting dietary evidence may add to the confusion that PwPD and their caregivers already experience with the disease[20, 29].

VI. Caregivers

Parkinson's disease is the second most prevalent neurodegenerative disease that affects the ability to perform ADLs, participate in social activities and access medical

care[42]. Additionally, dementia, the most common cognitive symptom, occurs in 40% of PwPD and is associated with an accelerated progression of disease and risk for institutionalization[29, 126, 127]. Therefore, PwPD often require formal (paid) and informal (unpaid) caregivers are necessary to provide physical, psychosocial and cognitive support for PwPD[42]. The scope of this review will focus on informal caregivers which spend up to 39 hours of care per week and, the costs of caregiving have shown to incur the second largest economic burden on a family[9].

It is estimated that 80% of caregivers for PwPD are informal and, are typically a spouse/partner or other immediate family member[161]. Informal caregiving for those with neurological disorders has been extensively studied and has showed improved health outcomes, treatment adherence, quality of care and decreased risk of institutionalization for the PwPD[162-165]. However, the time and efforts put into caregiving have negative effects on the caregivers' quality of life, especially if a woman is caring for a male with PD[42]. The burden associated with caregiving for this population is often due to the many medications, therapies, doctor's appointments and overall decline in functional ability that are associated with PD which the caregiver must take on[25]. Through the use of qualitative, quantitative, and mixed-methods studies, caregivers often report an information deficit regarding dietary and medication management for PwPD, all contributing to the feelings of stress regarding care of PwPD[20, 23-30].

Caregivers are highly involved in medication management in PD[23]. A qualitative study by Shin et al[20] investigated the challenges and strategies to medication adherence in 16 PwPD and 5 caregivers. In this patient-caregiver dyad study, the participants' main concerns were increased cost of medication, medication compliance and decreased

levodopa response overtime. Specifically, the dyads reported feeling stress and uncertainty about the timing of levodopa and meals[20]. The reported information deficit regarding PLI in this study affirms the need to identify the specific knowledge and attitudes regarding dietary protein, levodopa management and overall dietary habits in PwPD as is has not been the aim of qualitative research thus far. It is important to include caregivers in dyadic studies when assessing PwPD because caregivers often shoulder the burden of PD progression as the cognitive status of the PwPD may be compromised due to disease sequelae[24, 25, 29, 39, 126, 127].

VII. Conclusion

There is often confusion within the PwPD-caregiver dyad for effective dietary protein modification when taking levodopa-containing medications[15, 17, 20]. Persons with PD should limit protein when consumed concurrently with levodopa during the day to attenuate motor fluctuations[19, 155, 166, 167]. However, consistent recommendations are not available; various protein levels, and timed delays between medication and meal consumption exist[11, 20]. Informal caregivers help manage daily tasks for PwPD including medication and meal management because PD sequelae typically decreases the ability to function independently[23, 25]. As PwPD have been identified as a population at possible nutrition risk, caregivers should be cognizant of foods that promote optimal health and attenuate PLI. The purpose of this cross-sectional, mixed methods study is to obtain qualitative information related to dietary knowledge, attitudes, and behaviors in regards to PLI as reported by PwPD and their caregivers, and to assess nutritional risk and daily dietary intake within PwPD. This data provide insight to what PwPD and their caregivers believe about diet and levodopa management for healthcare professionals.

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Appendix B: Extended Methodology

Methods:

This cross-sectional, mixed-methods study was conducted from October 2017 to January 2018 when approval was granted from the University of Rhode Island (URI) Institutional Review Board (IRB). People with Parkinson's disease and their ICG were from, posting of flyers and personal visits to, PD health clinics and rehabilitation centers, and hospitals and universities throughout Rhode Island. In order to participate, all participants needed to be community-dwelling adults aged 18 and older and have access to a telephone. The PwPD needed to self-reported their disease stage based on the HY scale (stage 1-4)[31] and adherence to taking at least 1 levodopa-containing medication. All ICG needed to be informal, meaning they were an unpaid family member/friend who provides the majority of care to the PwPD[21-23]. Participants were excluded if they received calories from enteral/parenteral nutrition, reported a HY stage ≥5, or scored ≤18 on the T-MoCA. The sample size for this mixed-methods study included 10 dyads, with 10 interviews total which has shown to be an appropriate number for data saturation in this population[20, 28, 168-170] .

This study was completed in 3 assessments, two-telephone calls and one home visit. The first assessment was a screening phone call with the primary author where the PwPD completed the T-MoCA and all participants reviewed inclusion criteria. The informed consent process was then conducted over the telephone. Assessment #2 was another telephone consisted of the DST and the first 24HR. All participants completing the 24HR recall were mailed a food amount booklet for estimating portion sizes. Assessment #3 was a home visit with the primary author, where the past medical history

(PMH), a second 24HR and a 21-question semi-structured interview were completed. Dyadic interviewing (inclusion of two people in one interview) was used during the second and third assessments, as this method has shown to provide insight to strengths and strategies for coping with sequelae[171]

Qualitative Methods

Ten dyads were interviewed for this study (10 PwPD and their 10 caregivers). This sample size is consistent with past qualitative research to provide sufficient theoretical saturation (the point at which there is no significant new data) and yield sufficiently dense data with diverse experiences and perspectives[20, 28, 168-170]. Semi-structured interview questions were created by the research team to explore Eating Environment, Dietary Intake, and Medication Management. The questions were piloted to 3 dyads prior to the start of this study in order to determine content validity and understandability of the survey. Based on these pilots, questions were formatted to be more directed to the PwPD, for example "How has your diet changed since you have been diagnosed with PD" these changes allowed more insight from the PwPD. Also, in order to identify where the knowledge gap is within the dyad, questions were formatted to be more open-ended, "Is there anything you would like to know about the foods you eat or your daily nutrition in general?" This question gave us great insight to the PLI the PwPD experienced as most addressed this concern during the interview. In the original interview, there was not a question about how long the PwPD have been on levodopa or how many times per day they take the medication, so this was added.

The interviews were conducted face-to-face at the participant's home with the PwPD and their informal caregiver and primary author present. All interviews were

audio-recorded, transcribed verbatim and coded using thematic qualitative content analysis[34]. The primary author and research assistant reviewed and coded the transcripts separately, then discussed their findings to identify the most common themes from each interview, and generated the final themes together. The two researchers then used nVivo 11 QSR (International Pty Ltd, Victoria Australia) to code for final key themes as it is shown to be useful for enhancing the analytical capacity of qualitative data[172]. The final key themes for coding were: 1. Barriers to Dietary Intake, 2. Lack of Nutrition Knowledge for PD, 3. Reliance on ICG Buying and Preparing Foods, 4. Reduced Enjoyment of Foods and Meal Times, 5. Barriers to Medication Management, 6. Management of Symptoms, and 7. Access to Medication Information. Qualitative content was summarized and direct quotes were used to illustrate the perspectives of the participants. Participants with PD are identified in the text as "PD" followed by a number that was assigned sequentially as surveys were completed. The participants who were caregivers are identified in the text as "CG" followed by a number that was assigned sequentially as surveys were completed.

Quantitative Methods

Nutritional risk status through use of the DST[32] and nutritional intake through use of the Nutrition Data System for Research (NDSR). The DST is a 25-item questionnaire that identifies dietary patterns and nutritional risk. The sub components are: whole fruit and juice, vegetables, lean proteins, added fats, sugars and sweets, dairy and processed meats, and use of dietary supplements. A total score ranging from 0-105 was calculated and categorized with one of three different nutritional risk levels; (<60) at risk, (60-75) possible risk, and (>75) not at risk[32].

Two 24HR were collected using NDSR. Dietary intake data was gathered by the multiple-pass interview approach[33], which included a respondent-driven 5-step process: 1) Quick List to collect a list of foods and beverages consumed the previous day, 2) Forgotten Foods to probe for forgotten foods, 3) Time and Occasion to collect the time and eating occasion for each food, 4) Detail Cycle to collect a detailed description of each food including amount and additions, and review the 24HR day, 5) Final Probe to probe for anything else that has been consumed[173].

Additional Measures

Anthropometrics. Height was measured in cm by use of stadiometer (Detetco, Webb City Missouri), and weight will be measured in kg using a scale (Tanita BF-556, Arlington Heights, Illinois). Body mass index (BMI) was calculated by kg of body weight/height in meters^2, and classified according to predetermined categories: underweight= <18.5kg/m^2, normal weight= 18.5-24.9kg/m^2, overweight= 25-29.9kg/m^2 and obese ≥30kg/m^2 [174].

Disease Staging. Self-reported HY scores were assessed as the disease stage from 1, "unilateral disease", 1.5 "unilateral plus axial involvement", 2 "bilateral disease without impairment of balance", 2.5 "mild bilateral disease with recovery on pull test", or, 3 "mild to moderate bilateral disease, some postural instability, physically independent"[31].

Past Medical History. PwPD completed a medical history questionnaire to identify current and prior health-related conditions of PwPD. The topics addressed in this questionnaire included neurological, endocrine and cardiovascular health.

Cognitive Functioning. The T-MoCA is a valid telephone test of cognition includes 8 subtests that consist of digit span, attention, calculation, repetition, verbal fluency, abstraction, recall and orientation[175]. Total possible score on this assessment is 22.

Statistical Analysis

Data from the questionnaires and home visits was analyzed using SPSS Version 25 (IBM Corp, New York). Normality was assessed using skewness and kurtosis. Pearson's correlations were used for the normally distributed data, and Spearman's correlations were used for the data that was not normally distributed. Categorical variables are reported as numbers and percentages. Frequencies were used to determine which participants are at nutritional risk, possibly at risk and not at risk based on DST scores. Continuous variables are reported as mean ± standard deviation. The DST will be a continuous variable to identify the number and percent of participants found at nutrition risk, possible risk and not at nutrition risk. Data from the 24HR recalls is reported as mean macronutrient intake and g/kg protein consumed. Level of significance was set at a p-value of <0.05.

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Appendix C: Consent forms for Research

Knowledge, attitudes and behaviors for the dietary management of Parkinson's disease Oral Consent Script for Research Consent for Caregiver

"Before we begin, I want to review a few things with you.

- **Can you fluently speak English?**
- **Are you 18 years or older?**
- **Do you live at home?**
- **Are you an unpaid caretaker of a person with Parkinson's disease?**
- **Do you have access to a telephone?**
- **We will be completing a short questionnaire that will require you to recall words, identify letters and numbers, subtract, repeat phrases and make similarities (T-MoCA)".**

BACKGROUND

The purpose of this research study is to describe dietary knowledge, attitudes, and behaviors in regards to the protein-levodopa interaction as reported by people with Parkinson's disease and their caregivers. Additionally, to better understand dietary quality and intake of people with Parkinson's disease, nutrition risk status and dietary intake will be examined. This data will provide insight to healthcare professionals about what people with Parkinson's disease and their caregivers understand and do about diet and levodopa management.

You are being invited to take part in a research study. Before you decide to participate, it is important for you to understand why the research is being done and what it will involve. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you want to volunteer to take part in this study.

STUDY PROCEDURE

This study will be completed at three Time Points that will all occur one month of each other. The first two Time Points will take place via telephone call, and the final will be a home visit. The total study time is expected to take three and one-half hours depending on how much you want to speak about each item on the questionnaires. The three time points are described below. Your participation in this interview is completely voluntary; you may choose not to participate. If there are any questions you do not wish to answer, just let me know and we can skip it. You can stop the interview at any time. **Our conversation will be kept completely confidential and your responses will remain confidential.** I am in a private office and will be using a speakerphone. No one else will be in the room with me. If you agree, our conversation will be tape-recorded in order to document your exact words. The tapes will be destroyed at the end of this project. The transcripts will be numbered and will not contain your name or any identifying information.

Time Point #1 (~35 minutes) _

- This will be completed on the phone.

- Review of inclusion and exclusion criteria.
- Complete the informed consent process.

Time Point #2 (~55 minutes)

- This will be completed on the phone.
- The inclusion of you and your caregiver in one interview (dyadic interviewing) will be used from this time point on, but, all dietary assessments (24- hour dietary recall and dietary screening tool) will be completed for people with Parkinson's only as the scope of this study is the knowledge, attitudes and behaviors of people with Parkinson's in regards to dietary recommendations, especially concerning protein due to the prominent food-drug interaction people with Parkinson's may experience.
- Complete the Dietary Screening Tool. The Dietary Screening Tool is a 25-item questionnaire that asks participants to report how frequently they consume various types of food and will detect dietary patterns.
- Complete the first 24-hour. A 24-hour recall is a way to characterize nutritional intake and consists of 5- steps to collect all of the foods and beverages that you have consumed in the past 24 hours. The caretaker will be mailed a food amount booklet for estimating portion sizes after the first Time Point.

Time Point #3 (~120 minutes)

- This will be completed in-person – a study staff member will complete it as a home visit.
- Complete the past medical history questionnaire. This questionnaire will identify current and prior health-related conditions. The topics addressed in this questionnaire will include neurological, endocrine and cardiovascular health.
- Complete the second 24-hr dietary recall.
- Complete the 21-question semi-structured interview. The study staff has designed this interview. You and your caretaker will be asked to answer questions about your eating environment, dietary intake, and medication management.

RISKS

The risks of this study are minimal.

BENEFITS

We cannot promise any direct benefit for taking part in this study. However, possible benefits include customized dietary recommendations for your caretaker based on their 24-hour recalls and the dietary screening tool answers. The recommendations will be generated by study staff and reviewed by the Principal Investigator and the doctoral nutrition student, who are registered dietitians, and sent to you approximately 1 month after Time Point #3.

CONFIDENTIALITY

We will keep all research records that identify you private to the extent allowed by law. You will be assigned a participant number that will be kept with your responses from the questionnaires, interview and dietary recalls. In publications, you will be identified as "participant #".

VOLUNTARY PARTICIPATION

Research studies include only people who choose to take part. You can tell us that you don't want to be in this study. You can start the study and then choose to stop the study later. This will not affect your relationship with the investigator or any groups you may be involved in at the University of Rhode Island or related to Parkinson's disease, and there will be no penalty of loss of benefits to which the participant is otherwise entitled.

COSTS AND COMPENSATION TO PARTICIPANTS
You will not receive any compensation for your time in this study.

CONTACT INFORMATION
If you have any additional questions about this study please feel free to contact the principal investigator, Dr. Ingrid Lofgren at 401-874-5706. You may also contact the Vice President for Research and Economic Development at 401-874-4576.

CONSENT
I will be turning on the tape recorded now.
What questions do you have about the information that I have provided?
Do you consent to participating in this research study?

Knowledge, attitudes and behaviors for the dietary management of Parkinson's disease Oral Consent Script for Research

Consent for Person with Parkinson's disease

"Before we begin, I want to review a few things with you.

- **Do you fluently speak English?**
- **Are you 18 years and older?**
- **Do you have Parkinson's disease with a Hoehn-Yahr staging of 1-4?**
- **Do you live at home?**
- **Are you currently taking 1 levodopa containing medication?**
- **Do you have access to a telephone?**
- **We will be completing a short questionnaire that will require you to recall words, identify letters and numbers, subtract, repeat phrases and make similarities (T-MoCA)".**

BACKGROUND
The purpose of this research study is to describe dietary knowledge, attitudes, and behaviors in regards to the protein-levodopa interaction as reported by people with Parkinson's disease and their caregivers. Additionally, to better understand dietary quality and intake of people with Parkinson's disease, nutrition risk status and dietary intake will be examined. This data will provide insight to healthcare professionals about what people with Parkinson's disease and their caregivers understand and do about diet and levodopa management.

You are being invited to take part in a research study. Before you decide to participate, it is important for you to understand why the research is being done and what it will involve. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you want to volunteer to take part in this study.

STUDY PROCEDURE

This study will be completed at three Time Points that will all occur one month of each other. The first two Time Points will take place via telephone call, and the final will be a home visit. The total study time is expected to take three and one-half hours, depending on how much you want to speak about each item on the questionnaires. The three time points are described below. Your participation in this interview is completely voluntary; you may choose not to participate. If there are any questions you do not wish to answer, just let me know and we can skip it. You can stop the interview at any time. **Our conversation will be kept completely confidential and your responses will remain confidential.** I am in a private office and will be using a speakerphone. No one else will be in the room with me. If you agree, our conversation will be tape-recorded in order to document your exact words. The tapes will be destroyed at the end of this project. The transcripts will be numbered and will not contain your name or any identifying information.

Time Point #1 (~35 minutes) _

- This will be completed on the phone.
- Review of inclusion and exclusion criteria. This will include a short cognition test.
- Complete the informed consent process.

Time Point #2 (~55 minutes)

- This will be completed on the phone.
- Complete the Dietary Screening Tool. The Dietary Screening Tool is a 25-item questionnaire that asks participants to report how frequently they consume various types of food and will detect dietary patterns.
- Complete the first 24-hour dietary recall. A 24-hour recall is a way to characterize nutritional intake and consists of 5- steps to collect all of the foods and beverages that you have consumed in the past 24 hours. You will be mailed a food amount booklet for estimating portion sizes after the first Time Point.
- Your caregiver may participate with you at this time point but, all dietary assessments (24- hour dietary recall and dietary screening tool) will be based on your diet and typical food consumption as the scope of this study is the knowledge, attitudes and behaviors of people with Parkinson's in regards to dietary recommendations, especially concerning protein due to the prominent food-drug interaction people with Parkinson's may experience.

Time Point #3 (~120 minutes)

- This will be completed in-person – a study staff member will complete it as a home visit. This visit will include you and your caregiver.
- Complete the past medical history questionnaire. This questionnaire will identify current and prior health-related conditions. The topics addressed in this questionnaire will include neurological, endocrine and cardiovascular health.
- Complete the second 24-hr dietary recall.

- Complete the 21-question semi-structured interview. The study staff has designed this interview. You and your caregiver will be asked to answer questions about your eating environment, dietary intake, and medication management.

RISKS
The risks of this study are minimal.

BENEFITS
We cannot promise any direct benefit for taking part in this study. However, possible benefits include customized dietary recommendations based on their 24-hour recalls and the dietary screening tool. The recommendations will be generated by study staff and reviewed by the Principal Investigator and the doctoral nutrition student, who are registered dietitians, and sent to you approximately 1 month after Time Point #3.

CONFIDENTIALITY
We will keep all research records that identify you private to the extent allowed by law. You will be assigned a participant number that will be kept with your responses from the questionnaires, interview and dietary recalls. In publications, you will be identified as "participant #".

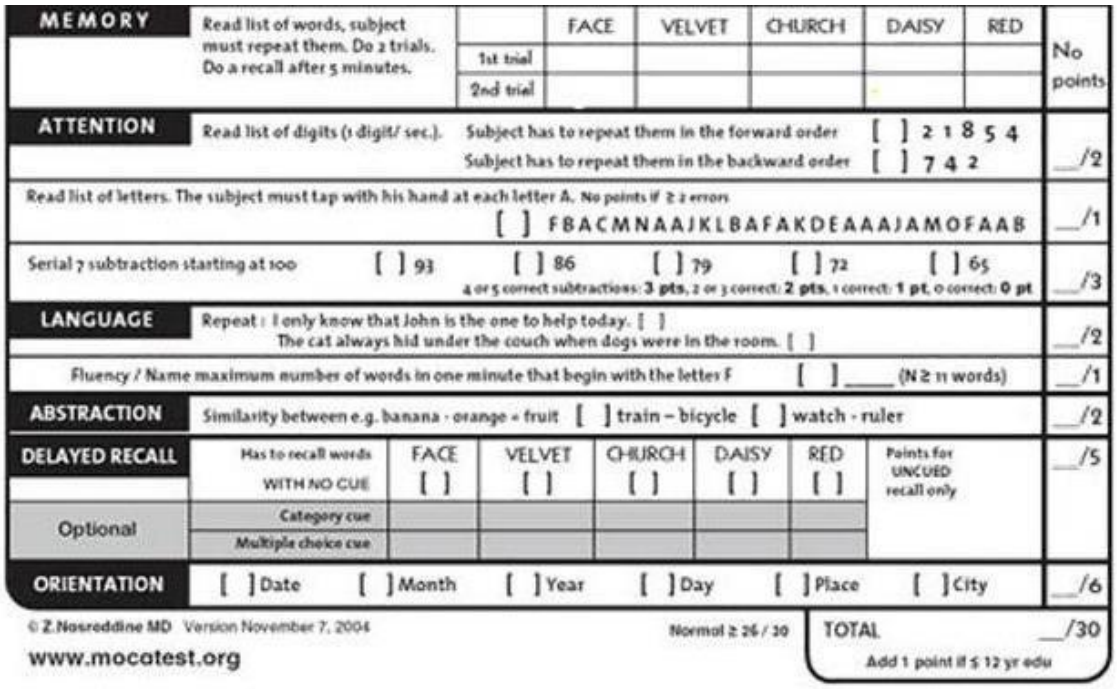
VOLUNTARY PARTICIPATION
Research studies include only people who choose to take part. You can tell us that you don't want to be in this study. You can start the study and then choose to stop the study later. This will not affect your relationship with the investigator or any groups you may be involved in at the University of Rhode Island or related to Parkinson's disease, and there will be no penalty of loss of benefits to which the participant is otherwise entitled.

COSTS AND COMPENSATION TO PARTICIPANTS
You will not receive any compensation for your time in this study.

CONTACT INFORMATION
If you have any additional questions about this study please feel free to contact the principal investigator, Dr. Ingrid Lofgren at 401-874-5706. You may also contact the Vice President for Research and Economic Development at 401-874-4576.

CONSENT
I will be turning on the tape recorded now.
What questions do you have about the information that I have provided?
Do you consent to participating in this research study?

Appendix D: Assessment Materials



MEMORY	Read list of words, subject must repeat them. Do 2 trials. Do a recall after 5 minutes.		FACE	VELVET	CHURCH	DAISY	RED	No points
		1st trial						
		2nd trial						
ATTENTION	Read list of digits (1 digit/ sec.).	Subject has to repeat them in the forward order [ ] 2 1 8 5 4						
		Subject has to repeat them in the backward order [ ] 7 4 2						/2
Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors [ ] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B								/1
Serial 7 subtraction starting at 100 [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65 4 or 5 correct subtractions: 3 pts, 2 or 3 correct: 2 pts, 1 correct: 1 pt, 0 correct: 0 pt								/3
LANGUAGE	Repeat : I only know that John is the one to help today. [ ] The cat always hid under the couch when dogs were in the room. [ ]							/2
Fluency / Name maximum number of words in one minute that begin with the letter F [ ] ____ (N ≥ 11 words)								/1
ABSTRACTION	Similarity between e.g. banana - orange = fruit [ ] train – bicycle [ ] watch - ruler							/2
DELAYED RECALL	Has to recall words WITH NO CUE	FACE [ ]	VELVET [ ]	CHURCH [ ]	DAISY [ ]	RED [ ]	Points for UNCUED recall only	/5
Optional	Category cue							
	Multiple choice cue							
ORIENTATION	[ ] Date [ ] Month [ ] Year [ ] Day [ ] Place [ ] City							/6
© Z.Nasreddine MD Version November 7, 2004 www.mocatest.org							Normal ≥ 26 / 30	TOTAL /30 Add 1 point if ≤ 12 yr edu

Participants will complete two 24-hour recalls (24HR). The first 24HR will be done over the phone (assessment #2) b and the second 24HR will be done in-person during a home visit (assessment #3). A 24HR is when a person is asked to list and describe all the foods they ate the previous day. Since people consume different foods and beverages, different questions are asked during each 24HR. Participants will be encouraged to have labels of foods they eat available during the assessments so exact information can be entered. This project will be utilizing the Nutrition Data System for Research from the University of Minnesota to collect the dietary data. Information on the program is attached.

For the most part, all participants will be asked the following questions. Many of these questions will be asked multiple times.

- At what time did you get up yesterday?
- What was the first thing you had to eat or drink after getting up yesterday?
- What else did you have to eat with that (insert food or beverage)?
- What was added to that beverage?
- What else did you have at that meal?
- Was the (insert food or beverage) eaten plain or did you put something on it?
- What did you eat after that meal?
- What did you have for snacks yesterday?
- What was the brand of (insert food or beverage)?
- How many cans/bottles or juice/soda/water did you have at that time?

- What was the last thing you ate and drank yesterday?
- What did you snack on after you last meal?
- Did you get up during the night and eat anything?
- About what size was the (insert food or beverage)?
- Was the (insert food or beverage) an original product or was it modified in anyway? For example, was it low sodium, low fat, cholesterol free, etc.?
- When was the first time you took your levodopa or levodopa containing medication?
- When was the next time you took your levodopa or levodopa containing medication? Did you have anything to eat at this time?

Depending on dietary intake, these additional questions may be asked. Many of these questions could be asked multiple times.

- Did you add any cream, milk, milk substitute to the coffee or tea?
- Did you add any sugar or sugar substitute to the coffee or tea?
- How much of the (insert food or beverage) did you eat?
- Were you able to finish all of that (insert food or beverage)?
- Was this (insert food) prepared with fat? If so, what type of fat?
- When preparing (insert food) was salt added?
- Was there frosting on the (insert food)?
- If so, about how much frosting?
- What was the flavor/color of the frosting?
- Did you add any condiments to (insert food)?
- If so, what condiments and how much of each?
- Was there ice in the (insert beverage)?
- Was the cake a single, double, or triple layer cake?
- Were there any seeds on the bagel?

Dietary Screening Tool

DIRECTIONS: Please check one response to each question that best describes how you eat.

How often do you usually eat fruit as a snack?

____ Never
____ Less than once a week
____ 1 or 2 times a week
____ 3 or more times a week

How often do you usually eat whole grain breads?

____ Never **or** less than once a week
____ 1 or 2 times a week
____ 3 or more times a week

How often do you usually eat whole grain <u>cereals</u>?

____ Never **or** less than once a week
____ 1 or 2 times a week
____ 3 or more times a week

How often do you usually eat candy or chocolate?

____ Never
____ Less than once a week
____ 1 or 2 times a week
____ 3 or more times a week

How often do you eat crackers, pretzels, chips, or popcorn?

____ Never
____ Less than once a week
____ 1 or 2 times a week
____ 3 or more times a week

How often do you eat cakes or pies?

____ Never
____ Less than once a week
____ 1 or 2 times a week
____ 3 or more times a week

How often do you eat cookies?

____ Never
____ Less than once a week
____ 1 or 2 times a week
____ 3 or more times a week

How often do you eat ice cream?

____ Never
____ Less than once a week
____ 1 or 2 times a week
____ 3 or more times a week

How often do you eat cold cuts, hot dogs, lunchmeats or deli meats?

____ Never **or** less than once a week
____ 1 or 2 times a week
____ 3 or more times a week

How often do you eat bacon or sausage?

_____ Never **or** less than once a week
_____ 1 or 2 times a week
_____ 3 or more times a week

How often do you eat carrots, sweet potatoes, broccoli, or spinach?
_____ Never
_____ Less than once a week
_____ 1 or 2 times a week
_____ 3 or more times a week

How often do you eat fruit (not including juice)? Please include fresh, canned or frozen fruit.
_____ Never **or** Less than once a week
_____ 1 or 2 times a week
_____ 3 to 5 times a week
_____ Every day or almost every day

How often do you eat hot or cold breakfast cereal?
_____ Never
_____ Less than once a week
_____ 1 or 2 times a week
_____ 3 to 5 times a week
_____ Every day or almost every day

How often do you drink some kind of juice at breakfast?
_____ Never **or** Less than once a week
_____ 1 or 2 times a week
_____ 3 to 5 times a week
_____ Every day or almost every day

How often do you eat chicken or turkey?
_____ Never **or** less than once a week
_____ 1 or 2 times a week
_____ More than 3 times a week

How often do you drink a glass of milk?
_____ Never **or** Less than once a week
_____ 1 or 2 times a week
_____ 3 to 5 times a week
_____ Every day or almost every day
_____ More than once every day

Do you usually add butter or margarine to foods like bread, rolls, or biscuits?

____ Yes
____ No

Do you usually add fat (butter, margarine or oil) to potatoes and other vegetables?

____ Yes
____ No

Do you use gravy (when available) at meals?

____ Yes
____ No

Do you usually add sugar or honey to sweeten your coffee or tea?

____ Yes
____ No

Do you usually drink wine, beer or other alcoholic beverages?

____ Yes
____ No

How often do you eat fish or seafood that <u>IS NOT</u> fried?

____ Never
____ Less than once a week
____ Once a week
____ More than once a week

How many servings of milk, cheese, or yogurt do you usually have each DAY?

____ None
____ One
____ Two or more

How many different vegetable servings do you usually have at your main meal of the day?

____ None
____ One
____ Two
____ Three or more

Which of the following best describes your nutritional supplement use.

_____ I don't use supplements
_____ I use supplements other than vitamins and mineral
_____ I use a multivitamin/mineral preparation (e.g. Centrum)

INTERVIEW

Knowledge, attitudes and behaviors for the dietary management of Parkinson's disease

Ingrid Lofgren, PhD, Principal Investigator
Leslie Mahler, PhD, CCC-SLP, co-Investigator
Version 1: 7-3-13

Participant Name:_____ Initials: ___ ___ ___ ID#: _____

Name of Interviewer:_____
Date:_____

Emergency contact name and address & phone:

_____

_____

DIRECTIONS: Read the following questions out loud to each prospective volunteer and record the answers. Any answers that require clarification should be written in the space below the question or on the back of the sheet. Indicate whether any follow-up is necessary or if any referrals are appropriate.

What is your neurological diagnosis? _____

When were you diagnosed? _____

What were your symptoms at that

time?_____

_____

____

What are your symptoms now?

_____

_____

_____

What is your communication

like?_____

_____

_____

What is your diet like?

_____

What is your physical activity like?

_____

Does your speech sound clear to other people?

_____

If not, how does it sound?

_____

Can you think of the words that you want to say?

_____

If you do have trouble, how often does it happen?

_____

Are you experiencing any symptoms of a swallowing disorder?

_____

If yes, what is the problem with your swallowing?

_____

_____

_____

What would you say is your most significant problem with speech or swallowing today?

_____

_____

Did you experience any changes in your speech or swallowing *before* your diagnosis?

_____

_____

_____

Does medication affect your speech or voice or swallowing? _____ If yes, in what way?

_____

Speech

How many hours of speaking do you do in a day?

_____

What is a typical day of communicating like for you?

_____

_____

_____

Do you pronounce your words clearly?

_____

Do people ask you to repeat yourself?

_____

Do people have a hard time understanding you?

_____

What do you do when you want to be as easy to understand as possible?

_____

_____

_____

What percent of your speech do you think is understandable?

_____

Has your neurological diagnosis caused you to talk less?

_____

If so, how much less? _____ Why?

_____

_____

_____

Swallowing

Do you have any difficulty with swallowing? _____

Do you cough during mealtimes? _____

If yes, do you cough more with water or solid food?

_____

Do you have difficulty making the food go down (need to swallow twice)?

_____

Does it take you longer to finish a meal than before your neurological diagnosis?

_____

Have you experienced any unintentional recent weight loss? _____

Have you ever been diagnosed with pneumonia? _____ If yes, when?

_____

Have you changed your diet since your neurological diagnosis? _____

If yes, what did you modify? _____

Musculoskeletal system:

Has your doctor ever told you that you have: (circle all that apply)

- Osteoarthritis or degenerative arthritis
- Rheumatoid arthritis
- Osteoporosis
- Ankylosing Spondylitis
- Unknown or other type of arthritis
- Any other disease of joint or muscle:
- Comments:_____

Cardiovascular system:

- Has any family member had a heart attack prior to the age of 55?
    - If so, how are they related to you?
- Have you ever had frequent cramping in your legs while resting?
    - If yes, is it a current problem? _____
- Have you ever had pain or cramping in your legs while walking?
    - If yes, is it a current problem? _____

- If yes, is this pain relieved by rest or by discontinuing walking?
- Have you ever been told that you have high blood pressure
    - If yes, what was the date of onset? _____
    - Were you given any medications? _____
- Did a doctor ever tell you that you had a heart problem?
    - If yes: What was the date of onset? _____
- What did the doctor call it? _____
    - Were you given any medications? _____
- Do you have any history of high cholesterol in your blood as evidenced by a previous blood lipid tests?

  _____

Comments:_____

Endocrine system:

Have you ever had any of the following: Thyroid problems, adrenal problems, diabetes mellitus?

- _____

- If yes to diabetes, which type? Type 1 or Type 2

  Date of onset- _____

  Are/were you on any medication, or is it diet controlled?

_____

Neurological system:

- Do you have any significant problems with your memory? (circle all that apply)
    - When answering the telephone, do you recall what you were doing before it rang?
    - Can you give the directions to your house/apartment?
    - Can you keep appointments without a reminder?
    - Can you remember what clothes you wore yesterday?
- Any problems with vision other than corrective lens changes?
    - If yes, which of the following conditions- Blindness, temporary loss of vision, double vision, glaucoma, cataract, macular degeneration or others.

      _____

__

Do you have and of the following?: (circle all that apply)

- Vertigo (a feeling of spinning, or unsteadiness)
- Seizure or convulsions?
- Migraine or severe headaches?
- Paralysis of arm or leg?
- A head injury with loss of consciousness?
- Pain, numbness or tingling in your limbs?
- Pain in your lower back?
- Do you have pain in any part of body including headaches while exercising?

- Have you been told that you have a peripheral neuropathy?
- Tremors?
- Problems with walking? If yes,
    - Do you fall frequently?

- Is your walking problem related to pain, weakness or loss of balance?

- Have you ever had an operation on skull or brain?

- Have you ever had meningitis or Brain fever?

Comments:_____

Previous Treatment

Have you had previous speech or swallow treatment, occupational therapy or physical therapy? _____

If yes, please describe (when, what)

_____

_____

____

Was it beneficial?

_____

If yes, what changes did you notice?

_____

_____

____

Employment

Are you employed?

_____

Type of employment

_____

How much speaking do you do at your job?

_____

_____

____

Other

Have you noticed any difficulty with your memory? _____

Have you experienced any changes in your mood?

_____

Is it difficult for you to pay attention long enough to finish a task?

_____

Do you have any difficulty reading? _____

Do you have any difficulty writing? _____

Do you have any other health problems or conditions that would affect communication, nutrition or physical activity?

_____

_____

_____

_____

Semi-Structured Interview Questions
Eating Environment: 1. Describe the most challenging aspects of preparing and eating meals since the diagnosis of Parkinson's disease. 2. Who is responsible for buying and preparing food in your home? ***Dietary Intake:*** 1. How has your diet changed since being diagnosed with Parkinson's disease? Prompt: Are there any foods that you have stopped or increased eating due to your diagnosis? 2. How would you describe your current diet? Prompt: Are you following any special diet? 3. Who have you spoken with about your diet and what have they told you? Prompt: What instructions have you been given and by whom? 4. Is there anything that you would like to know about the foods that you eat or your daily nutrition in general? Probe: What questions or concerns about your daily eating or about the foods you eat in general? 5. What is your understanding of a Protein Redistribution diet or a Low Protein diet? Prompt: The Protein Redistribution diet limits protein during the day and includes more protein at dinner; the Low Protein diet limits protein during the day and at dinner. 6. What challenges would you anticipate if you were following a Protein Redistribution or Low Protein diet? 7. What difficulties do you have chewing or swallowing your food or beverages? Prompt: What fluids to you have difficulty consuming? How often do you

cough during meals? How much more time does it take you to eat than before the diagnosis?

8. Do you modify the textures or consistencies of your foods and beverages? Prompt: Do you consume ground meat instead of whole pieces? Do you soften or pureed your vegetables? Do you use products like "Simply Thick" to thicken the fluids you consume?

Medication Management:

1. Describe your greatest challenges to taking your levodopa medication as prescribed by your doctor?
2. How do you cope or overcome the challenges to taking you levodopa medication as prescribed by your doctor?
3. What is your daily levodopa schedule?
4. What information have your doctor and pharmacist provided about the timing of your medications?
5. How do you time your food and medication intakes?
6. How do you obtain information about your levodopa medication?
7. How well does levodopa manage your daily symptoms? Prompt: Do you ever feel shaky, unsteady or sluggish after consuming your medication?
8. What do you know about food-drug interactions between levodopa and protein?
9. What information would you like to know about your medication management? Probe: How interested are you in learning more?
10. Do you rely on your caregiver to receive your levodopa medication?

Final Questions

1. Is this anything else about maintaining a healthy diet that works with your Parkinson medications that you want to share?
2. Is there anything else you would like to share regarding your journey with Parkinson's that you would like to share?