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## TAILORING DIGITAL HEALTH TO IMPROVE THE NUTRITION AND HEALTH OF PEOPLE WITH PARKINSON'S DISEASE

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TAILORING DIGITAL HEALTH TO IMPROVE THE NUTRITION AND  
HEALTH OF PEOPLE WITH PARKINSON'S DISEASE

BY

DARA LYN LOBUONO

A DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT OF THE  
REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY IN  
BIOLOGICAL AND ENVIRONMENTAL SCIENCES

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2020

DOCTOR OF PHILOSOPHY IN BIOLOGICAL AND ENVIRONMENTAL  
SCIENCES

OF

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2020

## **ABSTRACT**

Parkinson's disease (PD) is an incurable, neurodegenerative movement disorder, impacting nearly one million Americans. By 2030 the number of people with PD (PwPD) is expected to double and with this growing population, informal caregiver responsibility will also increase. Nutritional status worsens as PD progresses, which impacts cognition, body composition, ability to perform activities of daily living (ADL) and quality of life (QOL), and increases caregiver burden. Nutritional screening and intervention for PwPD can improve health outcomes, but are often excluded from PD treatment plans.

Given the negative impact of PD on mobility and increased caregiver burden, digital technology could improve access to health care services for PwPD and their caregivers, making them excellent candidates for digital health. Digital health services (i.e. wearable devices, videoconferencing, phone apps) are used in PD management across many health disciplines, but have not been implemented for nutritional management of PD. Understanding how nutritional status changes overtime for PwPD, and including PwPD and their caregivers in the formative stage is critical to developing effective digital health services. The aim of this body of research is to: 1) describe how the nutrition status of PwPD changes overtime, 2) describe the diet quality and self-reported nutrition concerns of PwPD and their informal caregivers, 3)



collect formative data around digital health to manage nutrition for PwPD and their caregivers through dyadic interviewing.

The first chapter focuses on tracking the nutritional status of eight PwPD over four years and examines how disease sequelae, conditions that result from PD, may influence nutritional status. Findings reveal that the majority of PwPD were either at “possible-” or “at nutrition-” risk throughout the four years. There was a modest decrease in weight and body mass index. Findings suggest that PwPD can benefit from ongoing nutrition screening throughout the course of PD.

Chapter two evaluates the diet quality via Healthy Eating Index (HEI)-2015 scores and self-reported nutrition concerns identified from qualitative interviews of twenty PwPD and their informal caregivers. This chapter also explores if a consistent pattern existed between nutrition concerns coded and diet quality scores of PwPD and caregivers. Mean HEI-2015 scores of PwPD and caregivers translate to an F letter grade and both PwPD and caregivers have intake inconsistent with the Dietary Guidelines for Americans. Participants also have low HEI-2015 component scores for whole grains, fatty acid ratios, and greens & beans. Qualitative themes specifically around dietary concerns related to PD sequelae include: change in appetite, amount eaten and/or weight, gastrointestinal issues, food-medication management, chewing/swallowing issues, change in taste/smell. No consistent pattern between HEI-2015 scores and self-reported nutrition concerns were detected.

Findings suggest this population could benefit from nutrition services to better health outcomes.

Chapter 3 examines twenty PwPD's and their caregivers' perception and acceptance of digital health for managing nutrition and health through semi-structured dyadic interviews and questionnaires. This study also evaluates the participants' level of digital competence. Phrases from interviews related to perceptions of digital health were sub-coded into three categories: Perceived Usefulness, Perceived Ease of Use and Awareness of Digital Health. Phrases related to Acceptance of digital were sub-coded into Accept, Neutral or Reject. An Average Dyadic Acceptance Rate for digital health was obtained through averaging the percent of phrases coded as Accept from each interview transcript. To integrate the two data sets, qualitative codes were transformed into variables and compared to digital competence scores. Twenty-five (62.5%) participants used the internet for at least 5 health-related purposes. The Average Dyadic Acceptance Rate was 54.4%. Dyads rejected digital health devices if they did not see the added benefit. The majority of phrases coded revealed participants found digital health useful, but hard to use, and about half of the phrases coded indicate dyads needed education about existing digital health mediums. Findings suggest dyads are accepting of technology but are not utilizing technology to its full potential. Perceiving technology as hard to use and digital competence scores, implies education is warranted prior to providing a digital nutrition service.

This body of research supports the need for nutrition screening and services among both PwPD and caregivers, who present with poor diet quality. Findings from this study also suggest more research is needed to figure out how to increase acceptability of digital health among this population. However, low diet quality scores, current technology usage, and perceived usefulness of digital health suggests technology may be a way to increase access to nutrition professionals among the PD community to promote better health outcomes.

## **ACKNOWLEDGEMENTS**

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## **DEDICATION**

This dissertation is dedicated to my grandmother, Lena Largo (5/17/1926-12/16/2019), and to my good luck charm, Leanna Rae Ippoliti.

## PREFACE

This dissertation is presented in manuscript format and contains three chapters that are from two different studies through the University of Rhode Island. Upon completion of the final dissertation submission, three manuscripts will be submitted for publication to the specified journal highlighted on each manuscript title page. Chapter one will be submitted to *Movement Disorders*, chapter two will be submitted to the *Journal of the Academy of Nutrition and Dietetics*, and chapter three will be submitted to *Health and Social Care in the Community*.



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## CHAPTER ONE

### A Comprehensive Longitudinal Nutrition Assessment of People with Parkinson's Disease Over Four Years

By

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will be submitted to: *Movement Disorders Journal*

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# A Comprehensive Longitudinal Nutrition Assessment of People with Parkinson's Disease Over Four Years

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## Abstract

**Background:** Parkinson's disease (PD), a neurodegenerative disease, results in motor and non-motor changes that can impact nutritional status. How nutrition assessment markers change longitudinally has not been examined. The purpose of this study was to track the nutritional status of people with Parkinson's disease (PwPD) over time.

**Methods:** This study was an observational, longitudinal study examining people with PwPD with assessments analyzed at baseline, year 2 and year 4. The assessments included: the dietary screening tool (DST), height and weight to calculate body mass index (BMI), fasting glucose and lipid profiles, and blood pressure. A one-way repeated measures ANCOVA compared outcomes variables over time.

**Results:** Eight PwPD were assessed. The baseline age was  $67.1 \pm 4.0$  years and time since diagnosis was  $8.1 \pm 7.5$  years. There was no change in mean DST scores overtime ( $64.0 \pm 13.8$  vs.  $66.4 \pm 8.8$  vs.  $64.3 \pm 13.2$ ) and majority of participants were at possible or at nutrition risk at each assessment.

Participants experienced weight declines ( $176.3 \pm 29.7$  lbs vs.  $169.0 \pm 25.5$  lbs,  $\eta_p^2=0.01$ ) and BMI ( $27.6$  kg/m<sup>2</sup> vs.  $26.6 \pm 2.2$ ,  $\eta_p^2=0.02$ ) from baseline to year 4. The number of PwPD with elevated glucose ( $\geq 100$  mg/dL) increased from one to four, but the number of PwPD with suboptimal HDL-C decreased from four to two.

**Conclusion:** The presence of nutrition risk, experienced weight loss, and changes in biochemical and clinical values, suggest that interdisciplinary intervention strategies may need to be designed and tested in this population.

**Key words:** Parkinson's disease, nutritional status, diet quality, longitudinal study, cardiometabolic risk

## Introduction

Parkinson's disease (PD) is an incurable, progressive neurodegenerative disease that traditionally occurs in the second half of life.<sup>1</sup> Over 900,000 Americans are diagnosed with PD<sup>2,3</sup>, and that number is expected to double by 2030.<sup>3</sup> People with PD (PwPD) typically live about 15 years after diagnosis and just recently researchers are investigating what post one year from diagnosis.<sup>4</sup> Parkinson's disease-specific sequelae, conditions that result from PD, impact motor and non-motor function<sup>5</sup> and worsen as the disease progresses.<sup>5</sup> Common motor sequelae (slowness of movement, tremors, and balance issues), and common non-motor sequelae (changes in smell and taste, gastrointestinal issues and difficulty swallowing), are all associated with compromised nutritional status.<sup>6-8</sup> Monitoring these changes overtime provides how nutrition health outcomes among PwPD change overtime in light motor and non-motor sequelae.

While PD sequelae tracking is a part of normal care, comprehensive nutrition assessment have not been incorporated, and this impairs the ability to provide effective, critical nutrition intervention.<sup>9</sup> To our knowledge, this is the first study to track sequelae while concurrently completing a nutrition assessment. Nutritional and weight status in PwPD varies over the course of the disease.<sup>8</sup> These fluctuations can occur due to decline in cognitive and physical functioning.<sup>8</sup> Fluctuations in weight and nutrition status can further compromise body composition, biochemical and clinical levels, cognitive and physical functioning,<sup>7,10,11</sup> quality of life (QOL), and are associated with longer



hospital stays.<sup>12,13</sup> The purpose of this longitudinal, observational study was to track the nutritional status of PwPD over four years. A secondary aim of this study was to describe changes in PD sequelae, as these sequelae may help explain the possible changes in nutritional status that occur. It was hypothesized that change in motor and non-motor sequelae overtime can influence nutrition status and dietary intake, which in turn can impact health outcomes measured by biochemical, anthropometric and clinical data (Figure 1).

## **Methods**

This was an ancillary study of a five-year observational, longitudinal study assessing the nutritional, cardio-metabolic, cognitive and physical function status of PwPD and acquired brain injury (ABI) (Longitudinal Study of Communication, Nutrition and Physical Activity). To be eligible for the original study, persons recruited via flyers, word-of-mouth, and announcements in support groups, had to be between 18-85 years of age and one-year post-PD or -ABI diagnosis; for this study, we only used data from PwPD. Participants completed assessment visits (~3 hours each) at the University of Rhode Island's Speech and Hearing Clinic every six months for five years. Specifically, for this study, PwPD's were assessed at baseline, years two and four. The University's Institutional Review Board approved this study (IRB HU1314-006) and subjects provided written consent in accordance to the Declaration of Helsinki before enrolling.

### ***Assessments.***

Nutrition assessment includes the examination of anthropometric measures, biochemical markers, clinical data, and dietary intake.<sup>14,15</sup> Comprehensive nutrition assessments examined change in nutrition status overtime. This included assessments of diet quality, biochemical, anthropometric, and clinical data. To assess diet quality, participants completed the dietary screening tool (DST), a 25-item questionnaire validated and used to identify dietary patterns and nutritional risk in older adults.<sup>16</sup> A total of 105 points can be achieved and scores can be categorized as: at risk (<60), possible risk (60-75), and not at nutrition risk (>75). Serum total cholesterol, low-density lipoprotein cholesterol (LDL-C), high-density lipoprotein cholesterol (HDL-C), triacylglycerol, and glucose were obtained using a finger stick (Cholestech<sup>®</sup> LDX system, Hayward, CA) after a 12-hour fast. Blood pressure was measured using an automatic blood pressure machine. Height and weight were measured in duplicate and used to calculate body mass index (BMI, kg of body weight/height in meters<sup>2</sup>). The following criteria were used to characterize suboptimal assessment markers: 1) BMI >28 kg/m<sup>2</sup>;<sup>17</sup> 2) systolic >130 mmHg and diastolic blood pressure >80 mmHg; 3) total cholesterol (TC) >200mg/dL; 4) high-density lipoprotein cholesterol (HDL-C) <40mg/dL; 5) low-density lipoprotein cholesterol (LDL-C) >100mg/dL; 6) triacylglycerol (TAG) >150mg/dL; 7) fasting glucose  $\geq$ 100mg/dL.

The following assessments were used to describe change in disease sequelae. The short physical performance battery (SPPB)<sup>18</sup> assessed

physical functioning. The Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) <sup>19</sup> assessed cognitive function; scores <80 were indicative of cognitive impairment. Both the Swallowing Quality of Life (SWAL-QOL) Survey<sup>20</sup> and a timed swallow test (ml/s) <sup>21</sup> assessed swallow function. A SWAL-QOL score of <75% and a time swallow speed of <10ml/s was considered suboptimal. Finally, a medical history questionnaire is used to identify health-related conditions and changes in health conditions at each assessment visit.

**Statistical Analysis.** Data were analyzed in SPSSv26. Categorical variables are represented as numbers and percentages and continuous variables are reported as mean±standard deviations. Data were assessed for normality and non-normally distributed data were transformed (square root or reflect and square root) for analyses, mean±standard deviations of variation before transformation are reported. A repeated measures analysis of covariances was used to examine change overtime among outcome variables. Time since diagnosis was used as a covariate. A Bonferroni adjustment was made for multiple comparisons. Analyses were 2-tailed and a p<0.05 indicates statistical significance. Participants were then individually analyzed for suboptimal scores across each outcome variable and the frequency of sub-optimal scores were reported.

## **Results**

Eight PwPD were analyzed over four years. At baseline, the mean age was 67.1±4.0 years and ranged from 62-72 years. The average time since

diagnosis was  $8.1 \pm 7.5$  years, ranging from 1-23 years. Six out of eight participants were male (75%). All participants identified as Caucasian. One participant reported attending some college, another had a college degree, and six achieved a post-baccalaureate degree. At baseline, two participants identified as smokers but quit during the first two years of the study. Three participants had deep brain stimulation, and one participant had the diagnosis of PD with Lewy Body Dementia. Two PwPD had thyroid conditions, and one PwPD had a history of a myocardial infarction.

**Nutrition Assessment Markers.** There was no significant change in nutrition assessment markers overtime (Table 1). At baseline and year 2, seven participants were at possible- or at nutrition- risk, while six participants were at possible- or at- nutrition risk at year 4. Three PwPD had BMI scores  $>28\text{kg/m}^2$  at baseline, which decreased to two PwPD at years 2 and 4. For one PwPD height and weight could not be measured at year 4 due to functional decline. Over the four years, four participants experienced a ten pound or greater weight loss. One PwPD remained within one pound of their baseline body weight, and one PwPD experienced a six-pound weight gain.

The number of PwPD with elevated systolic blood pressure (SBP) increased from four to seven overtime, but the number of PwPD with elevated diastolic blood pressure (DBP) decreased from five to two overtime. Only one participant had elevated total cholesterol at baseline, two participants had elevated total cholesterol at year 2 and one participant had elevated total cholesterol at year 4. At baseline three participants had elevated LDL-C, while

four PwPD had elevated LDL-C at year 2 and three at year 4. Four participants presented with low HDL-C at year 1, which decreased to two participants at years 2 and 4. At baseline, three PwPD had abnormal fasting TAG levels, while one PwPD at year 2 and two PwPD at year 4 had elevated fasting TAG levels. One PwPD had elevated fasting glucose levels at baseline and year 2, however four participants had elevated levels at year 4. All participants had at least one suboptimal lab value or blood pressure reading at each visit.

***Disease Sequelae.*** Outcome variables used to describe disease sequelae at each time point are summarized in Table 2. At baseline all participants had RBANS scores indicative of normal cognitive functioning. At year 2 (37.5%, n=3) had RBANS scores <80 and 50% (n=4) had RBANS scores <80 at year 4. Three PwPD (37.5%) had SPPB scores <10 at baseline, while four (50%) had SPPB scores <10 at years 2 and 4. At baseline two PwPD had SWALQOL scores <75%, while four participants had suboptimal scores at year 2, and two PwPD at year 4. Two participants had suboptimal timed swallow speeds (<10 seconds) at baseline, and four participants had suboptimal timed swallow speeds at years 2 and 4.

### ***Discussion***

Findings indicate most PwPD were at nutrition risk overtime, experienced weight loss and presented with multiple cardiovascular risk factors. While there was no significant mean change in outcome variables related to cognition, physical functioning or swallowing, many participants exhibited decline in these areas over time.

**Nutrition Related Outcome Variables.** Throughout this study most PwPD were at possible or at nutrition risk. Previous research has found up to 63% of PwPD to be categorized as with malnutrition or at risk for malnutrition<sup>22</sup>, however there is limited research regarding the overall diet quality of PwPD. The current study adds to previous research regarding weight status among PwPD. Previous research has found over 50% of PwPD to experience weight loss but present with elevated waist circumference.<sup>8,22</sup>

This study also adds to the body of research on biochemical and clinical assessment markers that may help not only assess nutritional status, but also cardiometabolic status. Our sample presented with multiple cardiometabolic risk factors throughout the course of the study despite the modest decline in weight. Overtime there was an increase in HDL-C levels among PwPD, while not significant, there was large effect size. Additionally, the number of PwPD with low HDL-C levels decreased by year 4. Previous research suggests a cardiometabolic protective effect of PD and theorizes that optimal HDL-C levels among PwPD may explain this theory.<sup>23</sup> While improvements in HDL-C levels were observed, the number of participants with elevated fasting glucose and triglycerides increased. This may be attributed to the change in taste PwPD experience, as an affinity for sugar and sweets is common<sup>8</sup>, which can impact glucose and triglyceride levels.

**Disease Sequelae Outcome Variables.** The increase in the number of PwPD with suboptimal cognition, physical functioning, and swallowing is consistent with the literature.<sup>24</sup> At year 4, 50% of PwPD in this study had

suboptimal assessment markers related to cognitive, physical, and swallow function. Past research has found a relationship between physical activity level and/or physical functioning with cognition and well-being measures among PwPD.<sup>25,26</sup> The decline in swallow function among participants may help explain the presence of weight loss and consistently poor diet quality among PwPD. Previous research has found PwPD with dysphagia are more likely to experience unintentional weight loss and to avoid foods that can be part of a nutritious diet, such as fruits and vegetables.<sup>10</sup> Current findings, along with this previous research, support the need for an interdisciplinary treatment approach for managing PD to promote health-related QOL.

***Study Strengths and Limitations.*** This is the first study to evaluate the change in nutritional status among a cohort of PwPD over four years in conjunction with change in motor and non-motor sequelae. This study provides subjective and objective data that provides a holistic picture of how the nutrition and health status of PwPD can change overtime. Finally, the interdisciplinary nature of this study can help inform future screenings and the care management of PwPD. Study results can be incorporated into the World Health Organization International Classification of Functioning, Disability, and Health (ICF) model has been used a framework to assess PwPD's health, health related function and QOL.<sup>25</sup> The ICF model consists of five domains that cover all aspects related to a person's health status and human function and include: 1) body functions and structures, 2) activities, 3) mental health factors, 4) environmental factors, and 5) personal factors.<sup>25</sup> Future should can

expand upon this interdisciplinary assessment of PwPD to also screen for mental health factors.

While this study is novel, it is not without limitations. Our small sample size warrants tracking of a larger cohort of PwPD overtime. To see significance differences in DST scores, a total of 28 participants would have been needed to achieve a power of 0.80 and a large effect size ( $\eta_p^2=0.25$ ). Based on our sample size of eight participants a power of 0.05 was achieved. The generalizability of study findings is limited by the fact that the majority of our participants were highly educated, white, male, and recruited from the University's Speech and Hearing Clinic. However, epidemiological studies have reported the majority of American PwPD are white, and this could be due racial and socioeconomic disparities in receiving treatment for PD.<sup>27</sup> Additionally, one participant's physical functioning had declined so much from baseline that a height and weight was not obtained at year 4. However, inability to complete certain assessments sheds light onto the progression and realities of PD. Future research should track a larger, more diverse sample of PwPD to better understand how nutritional status changes throughout the course of PD and explore if a synergetic relationship exists between nutrition, cognition, physical functioning, and disease progression.

## **Conclusion**

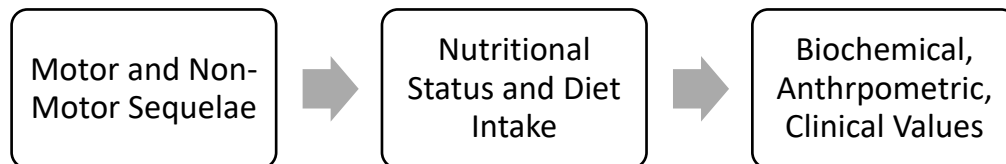
This study adds to the body of literature finding PwPD to have poor nutritional status and diet quality.<sup>9,28</sup> Participants in this study experienced weight loss and changes in biochemical and clinical values, which supports



the need for routine, interdisciplinary assessment for PwPD to identify and treat disease sequelae and promote health-related QOL. Future research should explore the efficacy of interdisciplinary interventions. This interdisciplinary team should include nutrition professionals, such as registered dietitians. Additionally, due to the observed decline in cognitive and physical functioning among PwPD research should also consider including informal caregivers whose role around buying, preparing, and serving nutritious foods may increase as PD advances.

### **Chapter 1 Table and Figures**

**Figure 1:** Propose Mechanism of How Disease Sequelae Impact Nutrition Status Which May Further Impact Health Outcome



**Table 1: Nutrition Assessment Markers Among PwPD Over 4 Years**

	Baseline	Year 2	Year 4	p	$\eta_p^2$
DST	64.0±13.8	66.4±8.8	64.3±13.2	0.8	0.04
Weight (lbs.) <sup>a</sup>	176.3±29.7	169.0±29.2	169.0±25.5	0.9	0.01
BMI (kg/m <sup>2</sup> ) <sup>a</sup>	27.6±3.4	26.6±3.1	26.6±2.2	0.9	0.02
SBP (>130 mmHg)	141.4±22.4	140.3±17.2	144.1±14.5	0.06	0.38
DBP (>80 mmHg)	81.1±10.4	78.8±14.2	80.1±12.4	0.9	0.46
TC (>200mg/dL)	175.1±25.2	165.1±33.2	163.9±22.0	0.6	0.07
LDL-C (100mg/dL)	104.0±22.6	93.75±30.9	87.4 ±36.2	0.99	0.0
HDL-C (<40mg/dL)	44.1±17.4	49.0±17.7	48.1±12.4	0.53	0.1
TAG (>150 mg/dL)	134.9±68.3	112.9 ±45.7	143.0±80.4	0.88	0.02
GLU (>100mg/dL) <sup>a</sup>	89.0±9.4	89.2±7.2	95.0±12.2	0.66	0.07
Statin Medication (n(%))	6(75)	6(75)	6(75)	NA	NA
BP Medication (n(%))	4(50)	4(50)	3(37.5)	NA	NA

<sup>a</sup>n=7; effect size 0.01=small, 0.06=moderate; 0.14=large. Abbreviations: DST=dietary screening tool, BMI=body mass index, SBP=systolic blood pressure, DBP=diastolic blood pressure, TC=total cholesterol, LDL-C=low-density lipoprotein cholesterol, HDL-C=high density lipoprotein cholesterol, TAG=triacylglycerol, GLU=glucose, BP=blood pressure

**Table 2: Change in Disease Sequelae (Cognition, Physical Function, Swallowing) Among PwPD Over Four Years**

	Baseline	Year 2	Year 4	p	$\eta_p^2$
RBANS	93.0±13.3	88.6±22.4	81.6±24.2	0.4	0.1
SPPB	9.9±1.8	8.8±2.1	8.4±3.3	0.8	0.03
SWALQOL	77.3±12.4	72.5±12.2	75.6±16.1	0.3	0.2
Swallow Speed (ml/secs)	15.7±9.8	15.01±11.1	13.5±10.6	0.8	0.03

<sup>a</sup>n=7;  $\eta_p^2$  values can be interpreted as: 0.01=small effect, 0.06=moderate effect, 0.14=large effect. Abbreviations: RBANS=Repeatable Battery for the Assessment of Neuropsychological Status; SPPB=short physical performance battery; SWALQOL=swallowing quality of life

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## CHAPTER TWO

### Diet Quality and Nutrition Concerns of People with Parkinson's Disease and Their Informal Caregivers: A Mixed Methods Study

By

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Diet Quality and Nutrition Concerns of People  
with Parkinson's Disease and Their Informal Caregivers: A Mixed Methods  
Study

By

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**Abstract**

**Background:** People with Parkinson's disease (PwPD) are often at nutritional risk. Limited research exists regarding the diet quality or nutritional concerns of PwPD and informal caregivers. Using patient-caregiver dyads is an innovative model to assess nutrition and understand dietary needs.

**Objective:** Data collected from dyads were used to evaluate the diet quality and describe self-reported nutrition concerns of PwPD and their caregivers. Whether or not there was a consistent pattern between nutrition concerns and diet quality among PwPD and caregivers was also explored.

**Methodology:** A mixed-methods study design assessed 20 PwPD-caregiver dyads. During home visits, semi-structured, dyadic interviews were audio-recorded for qualitative data and anthropometrics and questionnaires were collected. Two phone 24-hour recalls were completed to collect dietary intake. Dietary data was assessed for diet quality using the Healthy Eating Index (HEI)-2015 scoring metric.

**Statistical Analyses Performed:** Diet quality descriptives for PwPD and caregivers were reported as mean±standard deviation. Qualitative data was analyzed in NVivo and inter-coder reliability was >90%. Qualitative data was charted into framework matrices and reported as frequencies to quantify codes. A side-by-side comparison of themes and HEI-2015 scores for each participant was conducted.

**Results:** Mean participant age was 68.1±11.2 years. Mean HEI-2015 scores for PwPD was 58.3±12.4 and 58.1±10.6 for caregivers, translating to an F letter grade. Dietary concerns related to PD sequelae included: change in appetite or amount eaten, gastrointestinal issues, food-medication management, chewing/swallowing issues, and change in taste/smell. A large amount of variation between HEI-2015 scores and self-reported nutrition concerns were detected.

**Conclusions:** Poor diet quality may be attributed to self-reported nutrition concerns. Presence of poor diet quality and nutrition concerns among dyads suggests including both nutrition professionals and caregivers to promote nutritional health among PwPD. Future research should examine the number of nutrition concerns to help identify readiness to make dietary changes among dyads.

**Keywords (5 key words minimum):** Parkinson's disease, caregivers, nutrition, dietary intake, mixed methods, diet, food and nutrition



## ***Introduction***

Parkinson's disease (PD) is a progressive neurodegenerative movement disorder that impacts nearly one million Americans.<sup>1,2</sup> Disease stage and sequelae (conditions that result specifically from PD), physiological factors and treatments and associated side effects of PD can compromise dietary intake and quality.<sup>3,4</sup> Disease sequelae impact motor (slowness of movement, shuffling/freezing gait, muscle rigidity<sup>5,6</sup>) and non-motor (fatigue, cognitive changes, difficulty swallowing, change in taste and smell, gastrointestinal issues<sup>3,7-9</sup>) function, which can worsen overtime and impact dietary intake, nutritional status, and body composition<sup>3</sup>. Suboptimal weight status and body composition can further impact physical function and cognition<sup>10-12</sup>, quality of life (QOL), and health outcomes.<sup>13</sup> Consequently, informal caregiver responsibilities increase as PD progresses,<sup>14</sup> and caregivers are typically responsible for performing the majority of activities of daily living (ADL) for people with PD (PwPD),<sup>15</sup> including assisting with or doing the buying, preparing, and consuming meals and snacks.<sup>16,17</sup>

Nutrition is integral in managing PD.<sup>3</sup> However, there is limited research related to diet quality among PwPD and caregivers, populations who are at risk for poor dietary quality. To help improve dietary patterns in at-risk populations, understanding food choices and exploring acceptable sources of nutrition advice and support is essential.<sup>18</sup> The Healthy Eating Index (HEI)-2015 is a diet quality index that assesses the compliance with the Dietary Guidelines for Americans (DGAs).<sup>19</sup> The DGAs are evidenced-based

recommendations informed by diet quality's impact on health outcomes, such as weight status, diabetes, cancer and cardiovascular disease.<sup>19,20</sup>

Adhering to the DGAs could help PwPD meet the requirements for what are several nutrients of concern, such as fiber<sup>21</sup>, fluid<sup>21</sup>, vitamin D<sup>22</sup>, vitamin E<sup>23</sup>, omega-3 fatty acids<sup>23</sup>, and protein<sup>22</sup>. These nutrients can be obtained through an adequate diet that aligns with the dietary guidelines. However, research has found that PwPD have poor diet quality inconsistent with dietary patterns that promote health, such as the DGA or the Mediterranean Diet Pattern.<sup>24,25</sup> Findings warrants the exploration of differences in overall dietary patterns between PwPD and their informal caregivers.<sup>26</sup>

It is particularly important to assess the diet quality of caregivers, as caregiver stress and burden can adversely affect caregiver's psychosocial and physical functioning, which can compromise care provided and the health of the patient-caregiver dyad<sup>27,28</sup>. Research has examined the nutrient intake of PwPD and their spouses<sup>26</sup>, but has not specifically analyzed the diet quality in the context of the patient-caregiver dyads. Additionally, exploration of nutrition concerns of these dyads and how these concerns compare to diet quality have not been explored. Compared to the general population, caregivers for PwPD are more likely to have depression, anxiety, decreased health status<sup>27</sup>, and/or poorer QOL<sup>29</sup>, which may impact diet quality. Additionally, given the later onset of PD, most caregivers are older and have their own medical conditions that may require dietary modifications.<sup>30</sup>

Qualitative work is needed to explore PwPD's and their caregivers' views on dietary intake and decisions that impact that intake. Such nutrition research has been used in similar populations, like older adults and their informal caregivers, to better understand factors impacting dietary choices and inform appropriate and acceptable services.<sup>31,32</sup> This qualitative work has also been conducted to better understand various aspects of care among PwPD and their caregivers, such as coping with the disease<sup>33,34</sup>, managing cognitive changes<sup>35</sup>, and QOL.<sup>36</sup> However, such an approach has not been used to understand the nutrition concerns of this population.

Understanding the diet quality and the nutrition concerns of both PwPD and their caregivers can inform nutrition services for managing PD, and how best to facilitate dietary management from patient perspective. Additionally, gathering this information can help identify general services required to facilitate the process of learning to live with PD.<sup>37</sup> As a result, to effectively design a nutrition intervention for PwPD and caregivers, assessing dietary quality as well as collecting qualitative information related to their nutrition concerns is vital to develop an effective and sustainable nutrition service. The main purposes of this study were to: 1) evaluate the diet quality among PwPD and their informal caregivers; 2) describe the self-reported nutrition concerns among PwPD and their informal caregivers; and 3) explore if there was a consistent pattern between self-reported nutrition concerns and dietary quality of PwPD and informal caregivers.

## Methods

A concurrent mixed-method design<sup>38</sup> was used to assess diet quality and nutrition concerns of PwPD and their informal caregivers. This mixed-methods design was chosen to gain a more complete understanding of nutritional needs of PwPD and caregivers through comparing and synthesizing both quantitative and qualitative data.<sup>38</sup> Data was collected over four assessments completed between November 2018 and April 2019. Participants were recruited from support groups throughout New England, New York, and New Jersey via announcements and flyers at community centers, via healthcare providers, and through popular press coverage from the University.

Assessment 1 was an informational phone call during which participants were screened for eligibility and informed about the study protocol. Both the PwPD and their informal caregiver were required to participate and needed to be community-dwelling, English-speaking, and  $\geq 18$  years old. Participants also needed to score  $\geq 18$  on the Telephone Montreal Cognitive Assessment (T-MoCA), a cognitive screening tool.<sup>39,40</sup> At the beginning of Assessment 2, which was an in-person visit, the study protocol was reviewed and both PwPD and their informal caregiver completed the informed consent process.

Participants completed a timed-swallow test, questionnaires, and a semi-structured, dyadic interview. Assessments 3 and 4 were phone calls during which participants completed two 24-hour recalls. Findings from this study were a part of a larger study seeking to inform features of a digital health nutrition intervention. Approval from the University of Rhode Island's

Institutional Review Board (HU1819-001) was obtained.

### ***Data Collection***

Nutrition assessment data are highlighted in Table 2. The two 24-hour recalls included one week and one weekend day, and were conducted using the gold-standard, multiple-pass interview method.<sup>41</sup> Participants received a food amounts booklet to help estimate and report accurate portion sizes. The 24-hour recalls were entered into Nutrition Data System for Research Software 2017 (NDSR, University of Minnesota, Minneapolis, MN) and analyzed for total energy and nutrient intake. The NDSR data were assessed for diet quality using the HEI-2015 scoring metric.<sup>42</sup> Outputs from NDSR were used to calculate HEI-2015 component scores derived using SAS codes.<sup>42</sup> Total HEI-2015 scores are based on 1-100; the higher the score, the better the diet quality. A graded approach was used to categorize HEI-2015 scores (A=90-100, B=80-89, C=70-79, D=60-69, and F=0-59).<sup>42</sup>

During Assessment 2, height was measured using a stadiometer (Seca, Birmingham, UK) to the nearest 0.5 cm in duplicate and then averaged and weight was obtained using a calibrated scale (Tanita HD351 digital scale, Arlington Heights, IL) to the closest 0.1 kg and in duplicate and then averaged. These values were used to calculate body mass index (BMI, kg of body weight/height in meters<sup>2</sup>). A foot-to-foot bioelectrical impedance analysis device (Tanita BF-556, Arlington Heights, IL), estimated body fat percentage.<sup>43</sup> Body fat was not obtained for participants with implanted medical devices. Waist circumference was measured at the top of the hip bone using Gulick

anthropometric tape (Fabrication Enterprises Inc. White Plains, NY) in duplicate and averaged.<sup>44</sup> Finally, participants also completed a medical history and demographic information (age, gender, race/ethnicity, education level, employment status) survey.

Semi-structured, dyadic interviewing was used to capture information related to dietary intake and nutrition concerns using a pre-prepared moderator guide (Appendix A). The research team developed the moderator guide with reference to previous literature.<sup>3,37,45</sup> Twenty-four opened- and closed-ended questions were used that fit into one of three main domains: PD and Diet, Accessibility of Nutrition and Health Information, and Digital Health for PD. Semi-structured dyadic interviews also contained three closed-ended questions which provided insight into PwPD's and caregivers' perceptions of healthy eating and its usefulness for managing disease. Interviews were conducted in the participants' homes by a doctoral candidate who was also a registered dietitian (DL) and audio recorded using a digital recorder. The mean length of interviews were approximately 39 minutes and interviews lasted from 21 to 64 minutes in length.

### ***Data Analyses***

***Quantitative data analyses.*** Quantitative data was analyzed using SPSS v26 (IBM Corp, Summers, NY). Descriptive statistics are reported as mean±standard deviation for continuous variables and percentages and frequencies for categorical variables. Outliers were identified using boxplots (points that extend more than 1.5-box lengths from the edge of the box)

among the following HEI-2015 variables: HEI-2015 Total Scores, Protein, and Refined Grains component scores. To explore differences between PwPD and caregivers, independent samples t-tests were used for all normally distributed continuous variables and Mann-Whitney U tests examined differences between non-normally distributed continuous variables. Finally, the percent and frequency of PwPD and caregivers who met >80% of adequacy and moderation HEI-2015 components scores were calculated. A p-value of <0.05 indicated statistical significance.

***Qualitative Data Analyses.*** Qualitative data was analyzed using the framework analysis method<sup>46</sup> and Colaizzi's Strategy in Descriptive Phenomenology.<sup>47</sup> The following steps were taken to analyze transcripts. Recordings were transcribed verbatim and DL checked transcripts for accuracy. Transcripts were analyzed by DL and a trained research assistant (KS). The analyses focused on five questions from the moderator guide related to diet and nutrition.

Before coding individually, KS and DL read through all of the transcripts and developed a list of initial impressions and themes within three categories: Dietary Concerns Related to PD Sequelae, Other Nutrition Concerns, and Perceptions of Diet (Figure 1). Dietary concerns were coded deductively while themes that emerged from the transcripts were coded inductively and fell into the category of Other Nutrition Concerns or Perceptions of Diet. Both DL and KS coded one transcript from each batch independently and met to compare and reconcile coding. Then DL and KS created a working analytical

framework and agreed upon codes to use for analyzing the remaining transcripts. The transcripts were uploaded to NVivo12 (QSR International Pty Ltd, AU) and coded separately by DL and KS. An inter-coder reliability was calculated, with an agreement  $\geq 93\%$  achieved.<sup>48</sup>

DL and KS compared codes and reconciled differences between codes, until a consensus was reached, and codes were finalized. To ensure information related to dietary intake was not overlooked in other sections of the transcripts, DL went through all of the transcripts and coded the remaining sections. KS reviewed the codes to verify coding structure, and added additional codes when needed, and DL and KS discussed differences in coding and collapsed themes. The larger research team and DL met to further collapse and finalize themes.

***Data Integration.*** The research team reviewed both data sets and considered the qualitatively-coded themes in conjunction with the findings from the statistical analyses of the HEI-2015 scores. Qualitative data was charted into framework matrices and reported as frequencies using NVivo12 to quantify codes within the over-arching category of Dietary Concerns Related to PD Sequelae. This frequency data derived from the qualitative themes and a side-by-side comparison of themes were compared with individual HEI-2015 Scores for each participant. Data was interpreted and connections were explored between HEI-2015 scores and frequency of self-reported Dietary Concerns Related to PD sequelae from PwPD and their caregivers.



## Results

Twenty dyads were assessed. Participant characteristics are summarized in Table 1. All participants identified as Caucasian and one PwPD identified as Hispanic. Sixteen of the twenty dyads lived together. Ninety percent of PwPD were taking levodopa-containing medication, ranging from 3-7 times per day.

To help describe our study population and support the research aims, Table 2 highlights diet assessment data of PwPD and caregivers. Both PwPD and caregivers had near optimal percent body fat and waist circumference though BMI scores indicated both groups were overweight. Dyads were consuming slightly below the acceptable macronutrient distribution range (AMDR) for carbohydrates, slightly above the AMDR range for fat and within the AMDR range for protein. People with PD consumed  $0.9\pm 0.4$  g/kg body weight protein per day and caregivers consumed  $0.9\pm 0.2$  g/kg body weight per day. While dyads were below the dietary reference intake for most vitamins and minerals, the majority were taking supplements. There was no difference in nutrition assessment variables between PwPD and caregivers.

### ***Dietary Quality Among PwPD and Caregivers.***

Total HEI-2015 and component scores for PwPD and caregivers are summarized in Table 3. Low HEI-2015 scores indicates poor diet quality consistent with the national average.<sup>49</sup> Fifty-five percent of PwPD and 65% of caregivers had total HEI-2015 scores that translates to an F letter grade.<sup>42</sup> Examination of HEI-2015 and component scores for PwPD and caregivers are

summarized in Figure 2 and highlights the number of PwPD and caregivers who achieved  $\geq 80$  of maximum scores for total HEI-2015 scores and component scores.

### **Qualitative Results: Self-Reported Nutrition Concerns**

**Dietary Concerns Related to PD Sequelae.** There were 182 phrases coded into the category Dietary Concerns for PD Sequelae (Table 4). The major themes related to PD Sequelae are highlighted in Figure 1. Phrases where dyads described how PD impacted mealtime and eating ability were coded as Mealtime Related Issues. The major areas discussed around these meal-time related issues included three-major sub-themes: Chewing and Swallowing; The Time it Takes to Cook or Consume a Meal; and Physical Sequelae. Phrases where participants reported cutting up their food smaller, modifying textures to consume foods, coughing during meals, or taking more effort to chew their food, were coded as Chewing and Swallowing.

- *“He has been advised to cut things into small pieces often, and to drink fluids as you eat” –CG17*

Many participants also described how physical changes related to PD impacted their ability to eat certain foods and mealtime. Phrases were coded as Physical Sequelae when dyads described how tremor and other physical changes impacted their ability to consume certain foods.

- *“Primarily, the tremor affects my ability to get soup or things on a fork up to my mouth” – PD2*

Another sub-theme within Mealtime Related Issues was the Time It Takes to Cook or Eat a Meal. Several participants described how the length of time to

prepare a meal or consume a meal could diminish their appetite or impact meal enjoyment.

- *“I’m done and the dishes are already done, but I’m waiting for his dish”*  
– CG14

Phrases related to a Change in the Amount Eaten, Appetite, or Weight Status were coded when participants described an increase, decrease or no change in appetite, amount of foods consumed and/or change in weight status. Most of the phrases coded described a decrease in appetite. However, some participants did notice they were eating more than they used to.

- *“My appetite is less than it used to be, there is no doubt about it.”* – PD6
- *“I’ve always been able to eat a lot and consume the calories very well. Parkinson’s you just have to eat.”* – PD17

Only in four interviews did participants describe change in weight status. One participant reported an increase in weight due to the medications. Two participants reported that their weight decreased. Another reported that their weight stayed the same since being diagnosed.

- *“I’m kind of grateful you’re losing weight in that when and if you fall, I’m gonna have to help you get back up, and the more you weigh, you know I’m better off if you don’t weigh as much.”* - CG14 to PD14

Phrases where dyads described managing issues such as constipation, diarrhea, and nausea were coded as Gastrointestinal Issues; most of these phrases coded were constipation-related.

- *“A little bit of constipation...I try to eat a lot of salad lately, try to compensate a little.”* – PD18
- *“I think for myself sometimes I tend to overcorrect, so then it’s you know, say my stool has been running loose, then I overcorrect, and then I’m in a constipation phase.”* – PD10

Phrases where dyads discussed issues with spacing levodopa containing medication and high protein meals or where dyads described side-effects of medication that impacted dietary intake were coded as Managing PD Treatment and Diet.

- *“I found online that milk is one of the worst proteins to have with my medications, so I have been spacing out having my milk more than an hour from when I take my meds. I used to mix the MiraLAX with milk, but now I will mix it with Gatorade... I noticed that my medication lasts 45 minutes longer.”* – PD01
- *“The first medication that I was on for Parkinson's increased my appetite and caused insomnia. And of course, if you are awake, you are going to pick on food items, so I wound up putting on some weight for about a year.”* - PD7

Phrases were coded as Taste and Smell when participants described how loss of taste and/or sense of smell impacted their food choices and ability to enjoy foods. Many reported a higher affinity for sweet tasting foods such as ice cream and desserts, while others reported trying to decrease their sugar intake.

- *“I've come to love ice cream, I have it every single night almost, I didn't used to do that...”* - PD16
- *“I lost my sense of smell in 1992...way before my Parkinson's diagnosis, yes, but I think they relate loss of smell to Parkinson's. So, it took some of the enjoyment of food...”* - PD05

Phrases where dyads described trying to increase their fluid intake or recognizing they needed more fluids in their diet were coded as Fluid and Thirst.

- *“We're trying to increase the amount of water weight that I drink”* - PD13 about fluid intake and managing low blood pressure.

**Other Nutrition Concerns.** Five themes emerged within the category of Other Nutrition Concerns (Figure 1). In total, 143 phrases were coded related to Other Nutrition Concerns. Phrases around Understanding Nutrition Claims were coded in 19 out of 20 interviews. Phrases were coded as Understanding Nutrition Claims when dyads expressed a desire to better understand healthy eating, nutrition claims, nutrition for overall health, or nutrition claims for managing PD.

- *“As I spoke to you earlier, the difference between good cholesterol and bad cholesterol, so that I’m making better choices.” – PD19*
- *“Probably for my dad in particular it would be if for Parkinson’s, do they recommend a higher protein, lower fat, lower carb diet? Or do they recommend complex carbs with protein? Maybe he could eat a healthier diet than he does.” – CG07*

Within the theme Managing Life were three sub-themes: Managing Other Conditions with PD, Managing PD and Life, and Managing Diet and Life. Besides managing Parkinson’s disease, many PwPD had other health conditions they were dealing with, including: musculoskeletal issues, weight management, endocrine issues, gastrointestinal issues, cardiovascular issues, and brain disorders.

- *“Well one thing we’ve learned, because he does have a tendency to [get] gout, there’s certain vegetables to avoid that will contribute to uric acid forming in the joints.” – CG17*
- *“I sort of have breakfast, but don’t really have lunch, and then at dinner I eat a lot...I think it’s more my Concerta wears off, and then um, because it’s considered an appetite suppressant, and then I’m just really hungry.” – CG12*

Within the Managing Life theme was also the sub-theme, Managing PD and Life. Participants described challenges with overcoming life events and challenges and managing PD.

- *“Well Parkinson’s definitely makes you more emotional. I’ve always been an emotional person. I cried when we got married.” – PD14*

A few participants described day-to-day and life events that could impact their dietary intake, such phrases were coded as Managing Diet and Life. One participant felt dealing with personal matters impacted their dietary choices but felt PD did not.

- *“People who don’t think you’re just going through a fad or trying to be effected by something, when really you’re just trying to eat healthy, especially for a medical condition, you know, ‘oh well she’s on one of those diets or she’s being one of those people’” – PD10*
- *“I have been not watching what I eat over the past 18 months, but it does not have to do with Parkinson’s, it has to do with stress... stress eating - not feeling good and eating the wrong foods.” – PD20*

Many participants described how they were currently involved with complimentary care services to help manage PD. Phrases where participants described partaking in exercise programs, acupuncture, dietary changes, or support groups were coded as Alternative Practices or Medicine.

- *“There was a cleanse that was put out by Kripalu, the yoga center, it’s like a 3 week cleanse to purge your body of various toxins, you know it’s hard, but once you get into it its really good, you feel really healthy and vibrant” –PD11*
- *“My acupuncturist, who I respect and think is bright, tells me ‘don’t eat peanuts’ and I love peanuts...I asked her why she said something I didn’t understand, but I stopped eating peanuts, and same thing with milk, she said stop eating dairy so I stopped eating yogurt and milk.” – PD05*

When discussing food intake and dietary choices, many participants were not sure that their dietary intake changed as a result of having PD. Some did not feel having PD impacted their food intake, dietary choices or preferences. Several participants could not distinguish if changes they experienced with food were a result of having PD or just a natural part of the aging process.

- *“I generally felt better on the Keto diet because I lost a little weight, but, um, as far as Parkinson’s symptoms I’m not aware.” –PD02*
- *“No, I don’t eat a lot, but I don’t know if that’s Parkinson’s or not. Indirectly it probably is, because I don’t have my smell” –PD16*

The final theme related to the category Other Nutrition Concerns was Dietary Needs of Caregivers. Several interviews revealed caregivers had their own dietary concerns that may differ from the PwPD or were managing their own health conditions that required dietary modifications, including neurological conditions such as multiple sclerosis and essential tremor. Many caregivers were also the ones buying and preparing foods or impacted by their loved one’s dietary challenges.

- *“I feel really badly for [him] because he has got nothing to eat because just being in the kitchen thinking about food is awful but he’s not wasting away, so...” -PD15*
- *“I mean I call him almost every day ‘got any ideas for dinner?’, but I think for the most part it all falls on me. I think that he really does think that if he ate better, he might feel better, so again it’s on me.” –CG18*

**Perceptions of Diet.** In total 113 phrases were coded within the category Perceptions of Diet. Phrases coded as Perceptions of Diet fit into three sub-themes (Figure 1). Of the 72 phrases coded as Perceived Usefulness of Diet for Managing PD, 73.6% of these phrases described how dyads thought

dietary choices were useful for Managing PD, while 19.4% of phrases coded described how dyads were not sure or neutral regarding the role diet plays for managing PD. Only 6.9% of phrases coded described how participants thought a healthy diet was not useful for managing PD. As a result, there were mixed perceptions as to how useful diet can be for managing PD. The following quotes are examples of responses to the question, “How important is it to follow an eating plan for managing PD.”

- *“It’s very important, I don’t know if you would call it an eating plan, but it’s important to know what you are going to eat and when you are going to eat it and figure out how to back up from what time it is now and to dinner and when you should start taking your medicines and put it in proper order.” -PD12*
- *“I think more science needs to be done there, I think there needs to be some things that they find that [some foods] are especially good...some fruit that comes from Asia somewhere.” –CG16*

For the sub-theme, Perceived Usefulness of Diet for Managing Health, 85% of phrases coded indicated participants found following a diet useful for managing overall health and only 15% of phrases coded indicated participants found following a diet to be useless for managing overall health.

- *“I don’t count calories. I eat what I eat.” –PD04*  
*“But you need to! We need to be more cognizant of the caloric intake because it affects how much you weigh, and if you lost 15 pounds, your core would be much more manageable. As would mine be! ...one isn’t independent as each other. So caloric intake does count! You just don’t think it does.” -CG04*

A third theme within the category of Perceptions of Diet was Perception of Own Diet Quality. Of the 21 phrases coded, 76% of phrases coded described participants who perceived they had good dietary quality, while 14%



of phrases coded were linked to participants who perceived they had poor diet quality. Only 2 interviews and 9.5% of the phrases coded reflected that participants recognized that their diet could be improved or that they were interested in making improvements in their diet quality; these phrases were coded as Neutral.

- *“Only that I know that I should have more fruits and vegetables.”-PD15*
- *“We need a healthier diet. We do eat like fish once a week at least, but we also eat like pizza, you know... But yeah I think we need to eat healthier, we definitely need to eat healthier. He tries to, he’s a lot better at it than I am.” –CG18*

### ***Integration of Quantitative and Qualitative Data***

The frequency of themes coded within the category Dietary Concerns Related to PD Sequelae were compared with HEI-2015 scores to detect if any pattern between self-reported concerns and diet quality existed. Given the large variation between HEI-2015 scores and Self-Reported Nutrition Concerns Related to PD sequelae. Several PwPD reported a change in taste, including a preference for sweeter foods. However, about 50% of participants had high added sugar moderation scores, indicating that their diets are low in added sugar. Sodium scores indicate excess salt intake may be a concern for PwPD and caregivers. Higher salt intake may be attributed to change in taste as well as the intake of convenience and processed foods.

### **Discussion**

This study is the first to examine PwPD’s and caregivers’ diet quality in conjunction with self-reported dietary concerns related to managing PD. Findings from this study indicate PwPD and caregivers have poor diet quality

as well as nutrition concerns regarding PD sequelae and their own nutrition literacy. Qualitative analyses revealed dyads also believe that a healthy diet may be important for managing PD and overall health. However, there was no pattern between HEI-2015 scores and Nutrition Concerns Related to PD Sequelae. Findings from this study can be used to provide tailored nutrition counseling and inform nutrition interventions among PwPD and caregivers.

This study adds to the body of literature of dietary quality and PD management by providing objective dietary quality data which is scarce. Our study supports the caregiver as an integral part of the care provided to PwPD and without including caregivers' dietary management for PD may be incomplete. Total HEI-2015 scores of both PwPD and their caregivers was comparable to the average HEI-2015 scores for Americans of 59, or an F.<sup>50</sup> Compared to the national HEI-2015 component for Americans, dyads scores indicate PwPD and caregivers are doing a better including whole grains in their diets and limiting added sugar intake.<sup>50</sup> Mean added sugar component scores were similar to American older adult scores.<sup>50</sup> Dyads may need some education on how to incorporate protein and healthy fat into their diets as well as to minimize sodium intake.

Few studies have examined diet quality and patterns among PwPD but nutrition status has been extensively examined. Past research shows that PwPD have compromised nutrition status and are at nutrition risk<sup>3,13,24</sup>. Our findings were similar to key findings from Cassani et al<sup>25</sup>, who found no differences in summary scores assessing adherence to the Mediterranean diet

between PwPD and controls; results also showed both groups could be making dietary choices that better adhere with the Mediterranean diet.

Marczewska et al.<sup>26</sup> examined daily intake among PwPD and their spouses and found no difference in average daily energy intake, but did find differences in individual food groups such as vegetable protein and carbohydrates. Our study adds to this research by looking at overall dietary quality and adherence to the DGAs, rather than in terms of individual nutrients.

Obtaining self-reported nutrition concerns of PwPD and their caregivers adds to the body of patient-centered care research. Dyads expressed dietary concerns related to PD sequelae, such as mealtime related issues, change in appetite, and gastrointestinal issues. Findings from our study indicate participants want to increase nutrition literacy, have pre-existing perceptions around nutrition intake, and are using complimentary care services. These findings expand upon previous research which has found PwPD and caregivers want to be involved in the communication and decision making of their care.<sup>51</sup> Past research shows high levels of education and treatment of a movement disorder specialist were significantly related to PwPD using complementary health service.<sup>52</sup> The majority of dyads in our study had at least a college degree and most PwPD were receiving treatment from a movement disorders specialist. Young Shin et al.<sup>52</sup> found exercise and vitamin supplements were most commonly reported forms of complimentary healthcare. Many of our participants reported in their medical history questionnaire to be taking various supplements to manage health.

In addition to better understanding dietary quality and concerns among this population, our study expands upon previous research describing the day-to-day challenges of navigating PD and sheds light onto how this may impact not only diet quality but overall health-related QOL. The emerging theme from our study, *Managing Life*, supports previous literature published by Smith and Shaw,<sup>37</sup> which described the existential challenge shared by PwPD and their loved ones. Finally, exploring these self-reported nutrition concerns from this study may be able to help better understand the diet quality of participants in this study is warranted.

The lack of pattern consistency between HEI-2015 scores and the number of self-reported nutrition concerns related to PD sequelae may indicate our participants may be in varying stages of the Transtheoretical Model.<sup>53</sup> For instance, Dyad 16, the dyad with the highest HEI-2015 scores, also had the highest number of phrases coded within Self-Reported Nutrition Concerns Related to PD Sequelae (Table 4). This occurrence may indicate that this dyad was actively making dietary changes to minimize nutrition concerns and more cognizant of their dietary choices compared to other participants. The dyad with the second highest HEI-2015 scores, Dyad 4, had only two phrases coded within Self-Reported Nutrition Concerns Related to PD Sequelae. This suggests this dyad was actively managing their nutrition concerns. Most dyads had HEI-2015 scores ranging from 43-70 and 9-12 phrases coded around nutrition concerns. Findings suggest assessing dyads readiness to make dietary changes could be beneficial for helping to improve diet quality.<sup>53</sup>

Self-reported perceptions and actual dietary patterns may vary due to alterations in perception that PwPD experience as part of the disease. These findings, combined with poor diet quality, suggest this population can benefit from nutrition education to improve diet quality and nutrition knowledge.

Low adequacy and moderation HEI-2015 component scores may shed light on some of the self-reported nutrition concerns that came up during semi-structured dyadic interviews. The sub-theme Mealtime Related Issues coded in dyadic interviews may account for low dietary scores and influence dietary choices and help to explain overall low HEI-2015 total and component scores among dyads. Our participants were not meeting maximum adequacy in areas of fruits, vegetables, and whole grains, sources of fiber which may help to reduce self-reported complaints of constipation among our population. Future interventions should help PwPD obtain adequate fiber, manage dietary protein intake and reduce consumption of sodium and saturated fat. Low dairy intake among PwPD may be a concern. The literature shows that osteoporosis and osteopenia can impact up to 91% of women and 61% of men with PwPD.<sup>54</sup> Most of our participants were taking supplements, including supplements to support bone health, which could be why nutrition for bone health did not appear as a self-reported nutrition concern. Understanding nutrition concerns among dyads may be a way to address nutrients of concern unique to PD and in turn help improve diet quality scores. Similar HEI-2015 scores between caregivers and PwPD indicate that caregivers can also benefit from nutrition education, especially since the majority of the dyads were living together.

Findings from this study can also help to inform digital nutrition interventions, which are lacking in this population. Tailored nutrition counseling by a registered dietitian that includes both the PwPD and caregiver could be beneficial for this population. Nutrition counseling can help to increase nutrition knowledge and promote dietary behavior change.<sup>55,56</sup> Nutrition interventions should address the nutrition concerns discussed in semi-structured interviews among PwPD and caregivers as a way to help improve diet quality seek to help improve diet quality. Subsequently, including caregivers could optimize the health of the patient-caregiver dyad.<sup>27,28</sup> In addition to managing PD, both PwPD and caregivers were dealing with other health conditions that may need dietary attention and can help reduce caregiver strain. Couple-oriented interventions improve spousal coping strategies, promote disease related stress and anxiety management, increase self-efficacy, and help couples manage changes caused by PD.<sup>57</sup>

***Strengths and Limitations.*** This novel study had several strengths. Several measures were taken to ensure accuracy of the dietary intake information. To reduce recall bias, we used the multiple pass method, the gold standard for collecting dietary recall information.<sup>41</sup> Enrolling both PwPD and caregivers also helped increase accuracy of dietary information. For example, several male participants, both PwPD and caregivers, needed assistance from their spouse to report dietary intake during 24-hour recalls. To measure diet quality, HEI-2015 was used, which is a validated, comprehensive measure of dietary intake that is linked to adherence of 2015-2020 DGAs.<sup>42</sup> The mixed-

method study design collected both quantitative and qualitative data that provides an in-depth understanding of dyads' diet quality and nutrition concerns that may help explain diet quality. The use of semi-structured dyadic interviews promotes interaction between participants to provide detailed information regarding their nutrition concerns and PD management.<sup>58</sup> Finally, this study promotes the inclusion of PwPD and their caregiver as part of the healthcare team and the concept of patient-and caregiver-centered care for managing PD.

Despite study strengths, this study has several limitations. Findings from our study are not generalizable to all PwPD. Most of our participants were educated and all of them identified as Caucasian. Cognitive status was an inclusion criterion to enroll in this study and as a result most of our participants had low reliance on caregivers and were able to perform activities of daily living with minimal assistance. However, research supports including caregivers early at disease onset and encourages caregivers to partner with healthcare providers to help cope with disease progression.<sup>59</sup> A limitation of the HEI-2015 assessment measure is that it does not assess fluid intake. Many of our participants complained about a change in thirst, which could impact negatively impact hydration status. Cassani et al<sup>25</sup> found that PwPD drank significantly less fluid compared to healthy controls. Finally, requests for personal health information, including disease stage, were sent to physicians' office but we were unable to obtain this information for all 20 PwPD.

### ***Future Research.***

Concerns about low nutrition literacy in addition to poor diet quality among study participants may be explained by dyads' limited access to nutrition education. During semi-structured interviews, when asked "Where do you get information about foods and diets for people with PD?" most dyads described getting information from support groups or attending one or two education sessions. Only one PwPD reported working with a dietitian overtime to manage nutrition and PD. Future research should explore barriers PwPD and caregivers have for accessing nutrition professionals. Future work should also explore ways to improve access to nutrition professionals through expanding other healthcare professionals' knowledge of nutrition services as well as promote policy changes to expand insurance coverage for medical nutrition therapy among PwPD. This is important since several participants reported obtaining dietary recommendations that were not evidenced-based or from non-nutrition experts.

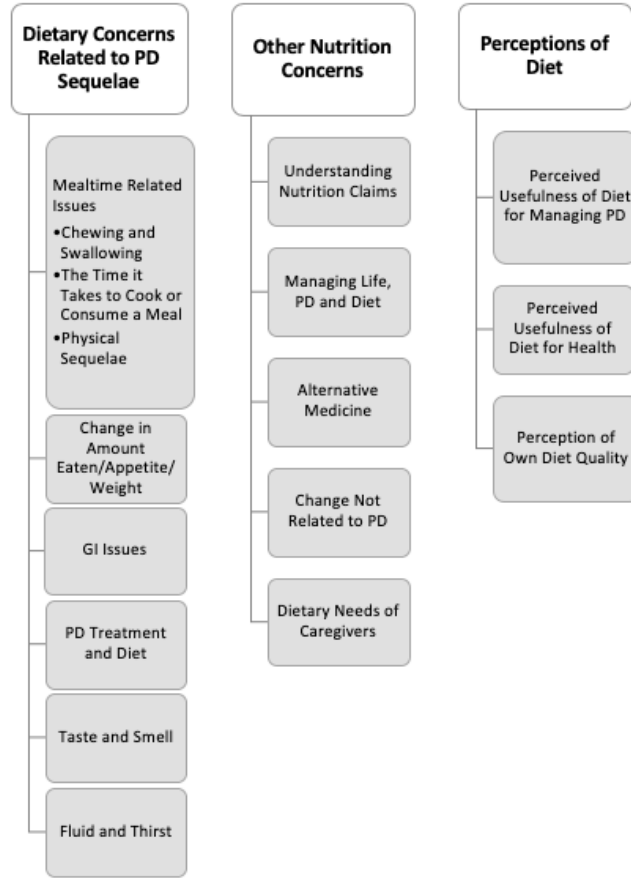
### **Conclusion**

This mixed-methods study focused on describing the diet quality and self-reported nutrition concerns of PwPD and their caregivers. Healthy Eating Index-2015 scores indicate PwPD and caregivers have low adherence to current dietary guidelines and present with dietary concerns related to PD. Poor diet quality and the self-reported nutrition concerns indicates dyads can benefit from nutrition education and support the inclusion of caregivers and nutrition professionals for managing nutrition and health.



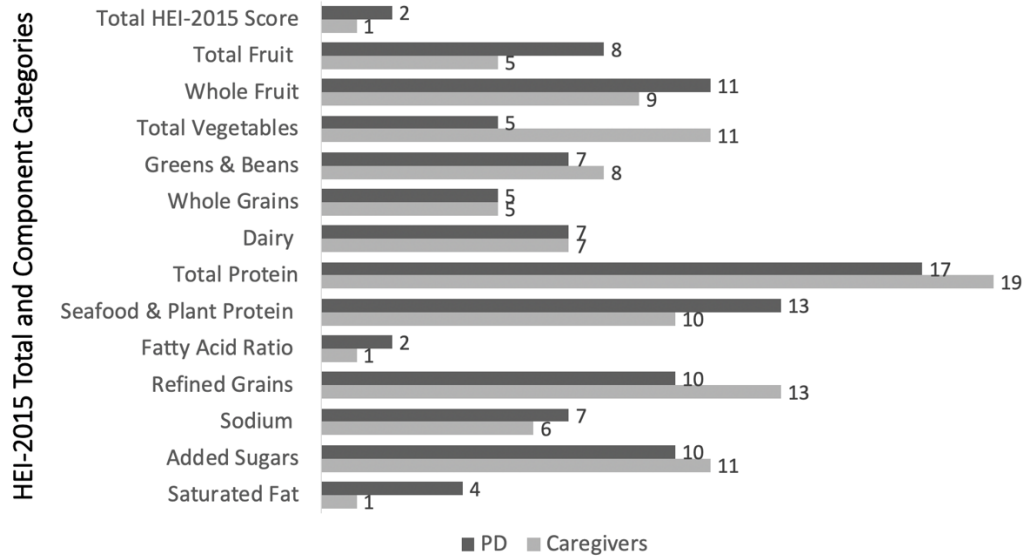
## Chapter 2 Tables and Figures

**Figure 1:** Flow Chart of Qualitative Data by Major Categories and Sub-Themes



*Figure 1 Abbreviations: PD=Parkinson's disease; GI=Gastrointestinal Issues*

**Figure 2: Frequency of PwPD and Caregivers with  $\geq 80\%$  Adequacy and Moderation Component Scores**



**Table 1:** Descriptive Characteristics of PwPD and Caregivers

Characteristics	PwPD	Caregivers	Range	<i>P</i>
Age (years)	69.7±9.2	66.4±13.0	39-89	0.4
Gender n(%) Male Female	13(65) 7(35)	4(20) 16(80)	NA	0.01
Education n(%) • HS Diploma/Some College • Technical Training/Trade School/Associates • ≥ College Degree or Greater	6(30) 3(15) 11(55)	1(5) 5(25) 14(70)	NA	0.11
Employment Status n(%) • Retired • Part Time • Full Time	15(75) 3(15) 2(10)	10(50) 2(10) 8(40)	NA	0.09
Years Since Diagnosis	7.6(5.4)	NA	0.33-18.0	NA
T-MoCA	19.8±1.5	20.4±1.1	18-22	0.2
Caregiver Relationship (%) • Spouse/Partner • Child • Friend	NA	17(85) 2(10) 1(5)	NA	NA

Independent samples t-tests and chi square analyses performed. A statistical significance was indicated at a p-value of <0.05. Abbreviations: T-MoCA=Telephone Montreal Cognitive Assessment.

**Table 2: Diet Assessment of PwPD and Caregivers**

<b>Diet Assessment Variables</b>	<b>PwPD (n=20)</b>	<b>Caregivers (n=20)</b>	<b>Range</b>
<b><i>Anthropometrics</i></b>			
Height (in)	66.1±3.3	65.1±3.8	57.5-70.7
Weight (kg)	77.3±19.9	77.4±16.4	35.6-116.6
BMI (kg/m <sup>2</sup> )	27.1±5.4	28.3±5.7	15.4-43.1
% Body Fat (n=33)*	29.1±8.8	34.2±7.8	13-49
Waist Circumference (in)	39.4±6.0	39.4±6.3	25.2-52.4
<b><i>Nutrient Intake</i></b>			
Kcalorie Intake	1887.4±728.1	1752.7±465.8	908.8-3344.4
% Calories from CHO	44.2±9.6	41.5±8.0	24.4-57.0
% Calories from Fat	36.7±6.7	37.7±7.2	24.7-50.3
%Calories from Protein	15.9±4.1	17.2±3.8	10.6-27.11
% Calories from Sat Fat	12.8±3.1	13.3±2.8	6.6-18.5

Analyses did not include dietary supplements; independent samples t-tests performed and a statistical significance was indicated at a p-value of <0.05. Mann-Whitney test for non-normally distributed data (g/kg protein; % calories from protein); %BF n=16 PwPD and 17 CG (implantable devices such as DBS and Pacemaker) Abbreviations: DRI=dietary reference intake; BMI=body mass index, Avg=average

**Table 3: HEI-2015 Scores of PwPD and Caregivers**

<b>HEI-2015 Scores</b>	<b>PwPD</b>	<b>Caregivers</b>	<b>Range</b>
<b>Total Score (0-100)</b>	58.3±12.4	58.1±10.6	37.7-83.4
<b><i>Adequacy Component:</i></b>			
Total Fruit (0-5)	2.9±1.9	2.5±1.7	0.0-5.0
Whole Fruit (0-5)	3.3±2.0	3.2±1.9	0.0-5.0
Total Vegetables (0-5)	2.6±1.9	3.4±1.6	0.1-5.0
Greens and Beans (0-5)	2.5±1.9	2.6±2.2	0.0-5.0
Whole Grains (0-10)	4.8±3.4	5.0±3.1	0.0-10.0
Dairy (0-10)	5.9±3.0	7.1±2.4	1.1-10.0
Total Protein (0-5)	4.6±0.7	4.7±0.6	2.8-5.0
Sea Food and Plant Protein (0-5)	3.6±1.9	2.9±2.2	0.0-5.0
Fatty Acid Ratio (0-10)	3.9±2.9	3.0±2.3	0.0-10.0
<b><i>Moderation Component:</i></b>			
Refined Grains (0-10)	7.0±3.1	8.0±2.6	0.0-10.0
Sodium (0-10)	5.5±3.7	4.8±3.8	0.0-10.0
Added Sugars (0-10)	7.6±2.5	7.4±2.6	1.2-10.0
Saturated Fat (0-10)	4.1±3.4	3.6±2.8	0.0-10.0

Group differences ran using independent samples t-tests and Mann-Whitney U tests, p-value of <0.05 indicated statistical significance. Abbreviations: HEI-2015=healthy eating index-2015

**Table 4:** Number of Times Nutrition Concerns Related to Parkinson’s Disease Sequelae Were Coded During Dyadic Interviews: A Side-By-Side Comparison with HEI Scores.

Dyads	Total Nutrition Concerns Related to PD-Sequelae	Total HEI-2015 Scores	
		PwPD (n=20)	Caregivers (n=20)
Dyad 1	9	65.7	43.7
Dyad 2	4	44.9	41.8
Dyad 3	1	63.1	62.8
Dyad 4	2	83.0	78.7
Dyad 5	9	45.1	51.8
Dyad 6	11	46.6	70.3
Dyad 7	10	48.6	43.7
Dyad 8	7	54.5	54.3
Dyad 9	7	54.3	54.5
Dyad 10	11	62.9	63.1
Dyad 11	11	63.1	62.9
Dyad 12	12	59.8	54.6
Dyad 13	11	59.3	56.6
Dyad 14	19	70.7	61.0
Dyad 15	13	46.1	57.2
Dyad 16	21	81.4	83.4
Dyad 17	10	47.0	57.5
Dyad 18	9	60.5	51.1
Dyad 19	5	71.0	59.3
Dyad 20	0	37.7	53.8
Total Phrases Coded	182		

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## CHAPTER THREE

Acceptance and Perception of Digital Health for Managing Nutrition in People with Parkinson's Disease and Their Caregivers and Their Digital Competence in the United States: A Mixed-Methods study

By

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**Abstract**

In order to deliver tailored nutrition education via digital mediums for people with Parkinson's disease (PwPD) and their information caregivers, this study examined the perception and acceptance of digital health for managing nutrition and health. Digital competence was also assessed. Using a mixed-methods design, qualitative data was collected through semi-structured, dyadic interviews and quantitative data through questionnaires from 20 dyads (20 PwPD and 20 caregivers). Data was collected in the Northeastern United States through home visits and phone interviews during the 2018-2019 academic year. Interview transcripts were deductively coded using the framework analysis method. Phrases related to Acceptance of digital were sub-coded into Accept, Neutral or Reject. Phrases related to perceptions of digital health were sub-coded into Perceived Usefulness, Perceived Ease of Use and Awareness of Digital Health. Quantitative data were analyzed using descriptives, independent samples t-tests and chi-square. To integrate this data, qualitative codes were transformed into variables and compared to

digital competence scores. A mean acceptance rate for digital health was calculated through examining the mean percent of phrases coded as Accept from interview transcripts. Twenty-five (62.5%) participants used the internet for at least 5 health-related purposes. The mean acceptance rate was 54.4%. Dyads rejected digital health devices if they did not see the added benefit. The majority of phrases coded revealed participants found digital health useful, but hard to use, and about half of the phrases coded suggest dyads needed education about existing digital health mediums. There was no difference in mean digital competence scores between PwPD and caregivers ( $28.6 \pm 12.6$ ). Findings reveal dyads were accepting of and use technology, but not to its fullest potential. This may be attributed to perceiving technology as hard to use. This finding combined with digital competence scores, reveal education is warranted prior to providing a digital health intervention to deliver nutrition services.

**Key words:** Parkinson's disease, digital health, caregivers, nutrition education, mixed methods

**What is known about this topic:**

- Increased disease burden with Parkinson's disease progression compromises the health of the caregiver and the person with Parkinson's
- The healthcare plan often overlooks nutrition and the caregiver in managing Parkinson's
- Digital health is an effective healthcare delivery mechanism, but little is known about how Parkinson's patients' and caregivers' perceptions of receiving nutrition and improving their own care

**What this paper adds:**

- Digital health and technology are convenient tools and provide Parkinson's patients and caregivers with new evidence-based knowledge on Parkinson's-related issues
- Parkinson's patients and caregivers are accepting of technology to manage nutrition, despite it being challenging.
- The digital competence scores indicate some training will be needed prior to implementing a digital health intervention



## Introduction

Parkinson's disease (PD) is an incurable, progressive neurodegenerative movement disorder that traditionally occurs in the second half of life (Fahn, 2003). Over 900,000 Americans are diagnosed with PD (Borlongan et al., 2013), and it costs the United States over \$14 billion per year (Kowal, Dall, Chakrabarti, Storm, & Jain, 2013). This cost is related to disease-related motor (e.g., postural instability, bradykinesia, muscle rigidity, resting tremors) and non-motor sequelae (e.g., cognitive decline, change in taste in smell, constipation). Sequelae resulting from PD, also compromise dietary intake and nutritional status (Barichella, Cereda, & Pezzoli, 2009), and warrant innovative nutrition care to help improve health outcomes (LoBuono et al., 2015). However, the unique nutrition services needed for PwPD are an under-recognized component of care (Vikdahl, Domellof, Forsgren, & Haglin, 2015). Additionally, PwPD can have limited access to all healthcare providers due to sequelae, age, and location, even with the presence of the caregiver (Dorsey et al., 2016). The increase in informal caregiver burden as the disease progresses is grossly under-estimated; the majority of informal caregivers spend up to 40 hours per week caring for a PwPD (Parkinson's Australia Inc., 2015). As a result, an improved healthcare model that addresses nutrition and includes the caregiver is needed to facilitate PD management.

Digital health describes technologies that enhance managing and tracking health status (Thomas & Bond, 2014), and include mediums such as videoconferencing, smart phones, internet applications, wearable devices, and online social networks. People with PD are promising candidates for digital

health because a visual assessment is needed as part of on-going care by a team but PwPD can have limited mobility, visuospatial impairment, and decreased access to transportation (Achey et al., 2014). Digital health increases access to health and nutrition services (Meyer et al., 2019; Siddique et al., 2019; Stillerova, Liddle, Gustafsson, Lamont & Silburn, 2016; Ventura Marra, Shotwell, Nelson, & Malone, 2017), enhances quality of care (Espay et al, 2016), allows healthcare providers to obtain visual, objective and continuous data (Stamford, Schmidt, & Friedl, 2015), decreases healthcare inefficiencies, offers more personalized services and social support (Attard & Coulson, 2012; Shah et al., 2015), reduces burden and medical costs for PwPD (Dorsey et al. 2013), and offers caregiver support (Shah et al., 2015). People with PD and caregivers are receptive to using technology, especially if there is an added value, such as improving disease management (Ozanne et al. 2018; Schulz et al., 2016). However, research has not directly examined the use of digital health for managing nutrition-related PD concerns

In 2019, the World Health Organization published recommendations for implementing digital health interventions (World Health Organization, 2019). They recommend tracking a client's health status and using videoconference to complement, rather than replace, in-person health services in a standardized protocol with infrastructure that promotes patient privacy. To facilitate the adoption of mobile health technologies for PD management, the Movement Disorder Society Task Force on Technology proposes to identify clinically relevant and patient-centered digital outcomes, utilize technological

mediums where the benefits exceed the burden for patients, and deliver a reliable intervention (Espay et al., 2019). The development of these digital nutrition services should include the views, needs and preferences of informal caregivers, as they are confronted with the evolving roles, increased responsibilities, and planning for the trajectory of PD (Ducharme et al., 2009; Espay et al., 2019).

This current study was part of a larger, cross-sectional study, which examined technology preferences and completed comprehensive nutrition assessments of PwPD and their informal caregivers (LoBuono et al., *In Preparation*). The purpose of this study was to examine PwPD's and their caregivers' perceptions and acceptance of digital health. This study also describes digital competence among PwPD and their caregivers.

## **Methods**

### **Study Design**

We used a mixed-methods, convergent design to compare and synthesize qualitative and quantitative data (Creswell and Plano Clark, 2018), and to fully capture dyads' perception and acceptance of digital health. How these self-reported experiences may inform digital competence were also examined. A mixed-methods design was selected to allow for a better understanding of the experiences that dyads have in relation to digital health and their needs and their preferences toward using technology for health- and

nutrition-related purposes (Espay et al., 2019; Creswell and Plano Clark, 2018).

Semi-structured, dyadic interviews and questionnaires were used to collect qualitative and quantitative data from PwPD (n=20) and their informal caregivers (n=20). The PwPD and their informal caregiver were interviewed together, but questionnaires related to digital competence and technology use were completed individually. Ethical approval for this study was provided by the University of Rhode Island's Institutional Review Board (HU1819-001).

### **Theoretical Framework**

The structure of this mixed-method study and interpretation of results were based on two theories. The technology acceptance model (TAM) provides a basis for understanding external factors that influence end users' perceptions, attitudes, and intentions to use technology (Davis, Bagozzi, & Warshaw, 1989). This study concentrated on the early stages of the development of digital health nutrition services, in which PwPD and caregivers provided personal opinions and preferences to inform the creation of a user-friendly, evidenced-based, digital nutrition service. The inclusion of informal caregivers is based on the emerging middle-range theory of transitions (Meleis, Sawyer, Im, Hilfinger, Messias, & Schumacher, 2000). A transition is the change from one state or condition to another, and includes life development stages, like progressing through a disease and becoming an informal caregiver. Collecting data from PwPD and caregivers provides a more complete perspective to better understand the transition dyads face as the role

of the caregiver evolves and the disease condition progresses, especially in relation to dietary management (Meleis et al., 2000).

### **Sampling, Recruitment and Eligibility**

Study recruitment and data collection went from October 2018 through April 2019. Emails, flyers and announcements at support groups for PwPD and community centers were used to recruit participants. Prior to the first study visit, dyads completed an informational phone call about the study and were screened for eligibility. Eligibility criteria were, both PwPD and their caregiver had to be community-dwelling, 18+ years old, and English-speaking, and both had to participate. All participants needed to score  $\geq 18$  on the Telephone Montreal Cognitive Assessment (T-MoCA), which is a cognitive screening tool (Castanho et al., 2014; Pendlebury et al., 2013). Transportation or prior technology use was not required to participate. Both PwPD and caregivers completed the informed consent process, and signed consent forms and each participant received a signed copy of the consent form.

Twenty-five dyads expressed interest. Five dyads did not continue with the study due to scheduling conflicts or low T-MoCA scores. Eighteen dyads were eligible, enrolled and interviewed. Two of these dyads included couples who were both living with PD and identified as each other's informal caregivers and were double counted as a PwPD and a caregiver. As a result, 20 dyads were included in analyses. Dyads were from Rhode Island, Massachusetts, New York, and Connecticut. We aimed to interview up to 20 dyads as previous research among PwPD and caregivers indicated this is where data

saturation was reached (Boersma et al., 2016; Zizzo, Bell, Lafontaine, & Racine, 2017). Saturation was reached in this study after the fourteenth interview.

### **Qualitative Data Collection and Analysis**

The 24-question moderator guide, informed by the previous literature and the research team was organized to capture three main domains: PD and Diet, Accessibility of Nutrition and Health Information, and Digital Health for PD. From these domains, participants' acceptance and perception were assessed. A copy of the moderator guide is provided in Appendix N. Prior to starting the study, interviews were piloted with two dyads and questions were modified based on participant feedback. Interviews were conducted in the participants' homes (facilitated by DL) and were audio-recorded using a digital recorder. The mean interview length was 39 minutes (range 21-64 minutes). Operational definitions of terms (technology, digital health, smart phones, smart watches, apps, videoconferencing) were provided during interviews. Photo prompts were used to help describe different technological devices and digital health tools and this was particularly important for understanding acceptance of devices.

Qualitative data was analyzed using deductive and inductive reasoning. Transcripts were deductively-coded using the framework analysis method (Gale, Health, Cameron, Rashid, & Redwood, 2013), which is a seven-stage, systematic procedure that has been used previously in healthcare research and is often used when answering specific research questions. Transcripts

were inductively-coded using Colaizzi's Strategy in Descriptive Phenomenology (Shosha, 2012) to identify emerging themes; this interpretative approach draws an understanding of participants' "lived experiences" of living with PD (Hycner, 1985).

The following steps were taken to analyze the data. Recordings were transcribed verbatim and DL checked transcripts for accuracy (stage 1). Transcripts were divided into three batches. DL and a trained research assistant (KS) analyzed one batch at a time. Separately, DL and KS coded for the following overarching a priori themes related to digital health: perception (perceived usefulness, perceived ease of use, awareness of digital health, image of technology) and acceptance (accept, neutral, reject). Themes related to perception and acceptance were identified a-priori adopting components of TAM (Davis, Bagozzi, & Warshaw, 1989). The model hypothesizes that perceived usefulness and perceived ease of use jointly determine acceptance, which can influence intention to use and actual behavioral use of technology (Davis, Bagozzi, & Warshaw, 1989).

Before coding individually, KS and DL read through an entire batch of transcripts and developed a list of initial impressions and themes and then coded a priori (stage 2). Both DL and KS coded one transcript from the batch independently and in duplicate (stage 3). The two researchers compared and reconciled coding, and there was a strong agreement between authors on the transcripts reviewed. During this discussion the two researchers developed a working analytical framework and agreed upon which codes to use on the

remaining transcripts (stage 4). The transcripts were uploaded to NVivo12 (QSR International Pty Ltd, AU) and coded separately by DL and KS. An inter-coder reliability was calculated and found acceptable (Bazeley and Jackson, 2013; Saladaña, 2016), with an agreement >80% achieved for each overarching theme. DL and KS met to discuss coding differences and came to consensus. The research committee and DL met to collapse and finalize themes (stage 5). Data was then charted into framework matrices using NVivo12 to display codes within each theme (stage 6). The number of phrases coded within themes were summed to calculate frequencies and percentages. Data was interpreted, and connections related to digital competence and technological preferences of PwPD and their caregivers were made (stage 7). Although a priori themes helped to inform this framework, a phenomenological and iterative approach throughout each stage of the analyses was also taken to identify emerging themes that may impact technology use among this population. Both DL and KS contributed to the framework development with the advisement of the dissertation committee.

### **Quantitative Data Collection and Analysis**

Both PwPD and caregivers completed demographics, medical history, dietary screening tool (Bailey et al., 2007), and digital competence (Measuring Digital Health Skills across the EU: EU Wide Indicators of Digital Competence, "European Commission, 2014) and technology use survey ("2015 Health Information National Trends Survey", Kontos, Blake, Chou, & Prestin, 2014; National Cancer Institute, 2015; Nelson et al., 2004). The specific questions used in each questionnaire are provided in Appendices P and Q.



Questionnaires examining technology use and digital health use, combined with qualitative data, informed dyads' acceptance of digital health. Questions related to where participants accessed health information and ease of obtaining health information was integrated with qualitative perception data.

To further describe the population, PwPD completed the 39-item Parkinson's Disease Questionnaire was administered (PDQ-39, Jenkinson, Fitzpatrick, Peto, Greenhall, & Hyman, 1997) to assess health-related quality of life, and caregivers completed the Multidimensional Caregiver Strain Index (MCSI) to assess caregiver burden (Stull, 1996). Height and weight were collected, and body mass index was calculated.

Quantitative data was analyzed using SPSSv26 (IBM Corp. Summers, NY). All data were normally distributed. Categorical variables are represented as frequencies and percentages, and continuous variables are reported as mean and standard deviations. Independent sample t-tests examined differences between PwPD and caregivers for continuous variables. A chi-square analysis explored differences for categorical variables. A p-value <0.05 indicates statistical significance.

### **Data Integration**

Acceptance of digital health was analyzed by assessing current technology use and purpose, as well as digital health usage from questionnaires and through themes coded from qualitative interviews. Phrases/sentences related to acceptance were categorized as Accept, Neutral, or Reject. To calculate acceptance rate among qualitative interviews, the number of phrases coded as Accept, Neutral, or Reject were counted and

totaled. The total number of phrases coded as Accept were divided by the total number of phrases coded across the three acceptance categories to calculate acceptance rates among each dyad. The percentages were averaged to calculate an Average Dyadic Acceptance Rate (n=20). Codes from the qualitative interviews were transformed into variables and reported as percent and frequencies. Side-by-side table displays of frequencies derived from perceptions and acceptance (qualitative data) and digital competence scores (quantitative data) were created and interpreted to better describe the population and readiness for a digital health intervention. A Pearson correlation was used to explore if there was an association between the percentage of phrases coded as Hard to Use and the Average Dyadic Acceptance Rate.

## **Results**

Participant demographics are highlighted in Table 1. All participants identified as Caucasian and one PwPD identified as Hispanic. The majority of caregivers (85%) were spouses/partners, while two caregivers were children of PwPD and one was a friend; 80% of dyads lived together.

### ***Acceptance of Digital Health***

All dyads had access to a laptop or desktop computer and internet connection at home. The majority of participants (n=17 PD and 19 CG) owned a smart phone and 60% (n=11 PD and 13 caregivers) owned a tablet. Five dyads reported owning an Alexa. One home owned an Amazon Firestick, another had a smart TV, and another reported using a DVR to record shows

regularly. Most participants (65%) did not own a smart watch (Apple Watch or FitBit), while 17.5% reported owning a smart watch but stopped using it and the remaining 17.5% were currently using a smart watch.

The reasons dyads used technology and the internet are provided in Tables 2a and 2b. Twenty-five (62.5%) participants used the internet for at least five or more health related purposes such as looking for health information for themselves or someone else, looking for information to manage PD, and discussing health concerns with friends/family. Five participants reported not using any technology or do not use the internet for health-related purposes.

There were 466 phrases/sentences coded from the interviews related to Acceptance of digital health and 52.1% of the phrases were coded as Accept. While 23.4% of phrases were coded as Neutral and 24.5% of phrases were coded as Reject. Phrases coded as Accept described the following: the various ways participants used technology in their everyday lives, how they used the internet to find information for managing PD, and/or participants' interest in trying a form of digital health to manage health. The majority of participants reported going to the internet first to look up health-related questions, especially for managing PD issues. Participants reported using digital health technologies such as patient portals, automated blood pressure cuffs, glucose meters, webinars, and apps to manage diet (e.g. Lose It and the Weight Watchers App) and track steps. Several participants reported setting alarms on their phone as reminders to take their medications

*PD02: “We’ve done the Weight Watchers app, which is very helpful...you can scan a product's label and it tells you how many points per serving”*

Those participants who had a high acceptance of technology reported how their enjoyment for using technology contributed to their desire to try digital health for managing nutrition and/or PD. For instance, when asked about what digital health products they would be interested in for managing food and eating, PD06 stated, *“I am the type, if it is digital, I try it.”* When asked what makes technology and digital health useful, CG05 explained,

*“I enjoy using it, if you enjoy something you will use it, you can get all that information from so many resources there, I like apps”*

Phrases and responses to questions were coded as Neutral when dyads expressed moderate interest for using digital health or specific digital health mediums. For instance, when asked if they would like to try a certain digital health medium and why, some participants were only interested in trying the product if it would benefit their provider. Other participants were interested in trying some products, such as dietary applications and wearable devices, but predicted they would likely lose interest in these mediums over time. For example, when asked if interested in using a Bite Counter, a watch that tracks motion to count bites and estimate calories consumed, PD05 stated:

*“If you could tell me that the results would be useful to you, then I would do it as a personal favor since you drove all the way down here!”*

When another dyad was asked if they would be interested in taking pictures of meals and snacks for a nutrition professional to review, a caregiver responded:

*CG17: "If nutrition was an issue there might be a reason to do it... if the doctor recommended it."*

Other participants said they felt they did not need certain digital health mediums at the moment but may want to take advantage of them in the future as PD progressed. For example, when asked if interested in using a wearable device to monitor gait changes, PD08 stated:

*"I'm not at the place where I need that yet, I'd imagine down the road, maybe."*

Finally, some participants discontinued their use of digital health mediums, such as wearable devices and dietary tracking apps. One participant stopped using FitBit (a wearable technology device that measures personal health data) due to physical limitations unrelated to PD, which decreased their ability to walk and no longer had many steps to track. This participant reflected,

*PD14: "Well when I first got my FitBit and I was kicking out 10,000 a day, and I kept getting all these messages about how good [I'm] doing..."*

Another participant stopped using his FitBit because it did not have enough technological features.

*PD12: "I just stopped using [FitBit] after a while ...it didn't have enough features, but I mean I did like that it kept track of how often I went up and down the stairs..."*

Phrases that were coded as Reject were typically due to certain digital health mediums or devices. However, some phrases coded were related to a rejection or skepticism of technology in general. For example, when asked if they were interested in using MyFitnessPal, an app to track dietary intake, one dyad stated:

*PD09: "I don't think I'm at the risk of eating too much or eating the wrong things."*

*CG09: "I'm just not interested in knowing that much detail"*

When asked how they would like to receive health information, several participants reported preferring hardcopies of literature rather than information provided digitally.

*PD07: "I like reading the information, so rather than email or electronic form, I like to see a paper with the information on it. That way I can reference it any time I want."*

### ***Perceptions of Digital Health***

There were 189 phrases/sentences coded across the 20 dyadic interviews related to perceptions of digital health. Phrases related to perceptions were categorized as Perceived Usefulness, Perceived Ease of Use, and Awareness of Digital Health. Frequencies of phrases/sentences coded are summarized in Table 3.

***Perceived Usefulness.*** When examining dyadic data related to perceived usefulness, 50% of dyadic interviews mentioned digital health or technology as Useful. Many of these participants noted that technological advancement could help them not only manage PD but maintain their independence.

*PD06: "I think I will be able to stay driving until the day I die because of autonomous cars. I have no problem with it. I think we are very lucky for the age we are that it is happening now."*

Other participants reported finding certain digital health technologies useful specifically for managing diet. For instance, when debating the usefulness of MyFitnessPal with her spouse, a caregiver stated:

*CG04: "We need to be more cognizant of the caloric intake because it affects how much you weigh, and if you lost 15 pounds, your core would be much more manageable."*

Many participants, 50% (n=10PwPD, n=10caregivers) felt that it would be helpful to work with a nutrition professional to manage eating for PD.

*PD16: "Well I think it's always good to have access to [a dietitian] that you can ask questions to, but I don't know how much they would be able to do for Parkinson's."*

Phrases were coded as Neutral for Perceived Usefulness when participants reported mixed feelings about the benefits of technology or if they were unsure if nutrition services could benefit PD. Supporting quotes from caregivers and PwPD are summarized below.

*CG17: "To me a computer is a tool... and I'm not going to sit in front of a screen, when I have other things to do."*

*PD10: I just type it in and whatever comes up I skim through, and some of it seems valuable and reliable, and some of it seems like a marketing scheme"*

Phrases that were coded as Useless when participants reported seeing little value or benefit from using technology. These participants may have also found nutrition interventions to be useless. For example:

*PD04: "Some of [technology] is very useful but the majority of it is junk."*

*CG20: "The information that came from [FitBit] was useless"*

In addition to questions around technology, during interviews dyads were also asked to rate how important they felt it was to follow an eating plan for PD. Forty-five percent of dyads agreed that it was important (n=10PwPD, n=8caregivers) to follow a healthy eating plan to manage PD, while 35% (n=6PwPD, n=8caregivers) reported: they were unsure, were neutral, or felt the question was not-applicable because they had not thought about the importance of healthy eating for PD.

***Perceived Ease of Use.*** When examining Perceived Ease of Use among participants, 70% of interviews contained phrases that were coded as Easy to Use, while 95% of interviews had phrases coded as Hard to Use. For those phrases/sentences coded as Easy to Use, participants often stated how technology helps them easily access health information. When asked if there was anything that prevents them from learning how to use a technological device or the internet, CG20 responded, “No, it makes life easier.” Participants described certain mediums as easier to use than others to access nutrition and health information. For instance, many found email and videoconferencing as an easy medium to receive nutrition information, and several felt that taking pictures of their meals to be reviewed by a dietitian would take little effortful and would be helpful.

*CG13: “I can certainly check an email easily. That’s probably the simplest, easiest way to get information”*

*PD11: “I think it's easier to make an appointment, you have more flexibility through a skype session.”*



Phrases/sentences were coded as Neutral Ease of Use when participants perceived digital health and technologies as neither difficult nor hard to use. Phrases/sentences were also coded as Neutral Ease of Use when participants that were actively using technological devices but reported some annoyances or inconvenience when using the device. However, if these inconveniences did not deter participants from using the device or technological medium, the related phrase or sentence was also coded as Neutral Ease of Use. For instance, one participant summarized her experience with ordering her meal-delivery subscription online:

*PD19: “[Sun Basket’s] a little bit time consuming, when [on the website], I feel I need time to go through it all, but I do it and it’s fine”*

Phrases/sentences related to accessing nutrition and health information were also often coded as Neutral Ease of Use. Many participants either had not thought to look for nutrition information specifically for PD or felt that finding nutrition information was easy, but interpreting this information was a challenge. For instance, when asked how easy or difficult is it to find information related to healthy eating, 55% (n=11PwPD, 11CG), said it was difficult or somewhat difficult. While 17.5% of participants responded neutral or felt the question was not applicable, with the rationale that they did not know nutrition was important or had not been looking for nutrition information prior to this study.

*CG01: “[It’s] easy to find, difficult to follow.”*

*CG13: “I would say we haven’t really looked for it yet.”*

Phrases/sentences were coded as Hard to Use when participants expressed difficulty with using technology. Most phrases coded as Hard to Use were stated by the PwPD.

*PD09: "It's [technology] become more complex I think, that bothers me too. I want it to be simpler like it used to be. it's just become more complex and I just don't I know how to do things now."*

*PD11: "... the cognitive limitations and challenges that come with Parkinson's, you know you can't always read something and immediately translate it into what it is you're supposed to be doing... so sometimes that's frustrating because if you don't understand it you aren't going to use it."*

Some participants specifically stated understanding nutrition information could be a challenge and may impact their experience utilizing digital health to manage nutrition,

*CG12: "...I feel that nutrition is a particularly difficult topic because [there's] so much conflicting information out there."*

**Awareness of Digital Health.** Phrases/sentences related to the theme Awareness of Digital Health were coded as Aware, Somewhat Aware and Not Aware. Phrases/sentences that showed dyads understood what digital health was, were coded as Aware. For instance, CG07 defined digital health as,

*"I guess it would be ... a broad term for categories that would have to do with your health and using technology to manage, look up information, to maintain your health, monitor your health."*

Phrases/sentences that revealed a limited understanding of digital health or provided an incomplete definition of digital health were coded as Neutral. For instance, PD04, defined digital health as, "I have no idea other than going online and getting some information, but I don't see that as being a useful tool." Phrases/sentences indicating participants did know what digital health

was were coded as Not Aware. For example, PD12 stated the term digital health “means not being married to your device continuously all day long.”

### **Digital Competence.**

There was no difference in total digital competence scores among PwPD and caregivers, the mean score translates to about a 63.6% competence level (Table 1). Responses to individual questions from the digital competence questionnaire are summarized in Table 4; the majority of participants (>80%) felt comfortable finding information, reading or downloading news, and seeking health information. All caregivers and all but two PwPD felt comfortable sending emails. Most participants also felt comfortable buying goods online and internet banking. Participants may need some assistance with using social media and uploading self-created content. About half of the participants may need assistance with completing a videocall.

### ***Data Integration***

The Average Dyadic Acceptance Rate calculated from dyadic interviews was 54.4%. A side-by-side display of individual digital competence scores among PwPD and caregivers, the mean acceptance rate, and percent of phrases coded as Hard to Use were compared (Table 5). Overall, it appears that dyads with higher digital competence scores had higher acceptance rates for technology. However, these acceptance rates could be influenced by the fact that in several dyads, one person was much more comfortable using technology than the other. For instance, within Dyad 01, the PwPD had a

much higher digital competence score compared to their caregiver (62.2% v. 17.8%), which may help explain an acceptance rate of 58% and 50% of phrases being coded as Hard to Use. Whereas within Dyad 05, both PwPD and the caregiver had high digital competence scores (91.1% and 97.8% respectively), and an acceptance rate of 80%. During this interview, 50% of phrases coded as hard to use. There was a negative, significant association between the number of phrases coded as Hard to Use and the Average Dyadic Acceptance Rate ( $r=-0.522$ ,  $p=0.018$ ).

## **Discussion**

This is the first study to analyze the perceptions and acceptance of digital health and digital competence among PwPD and their informal caregivers. It is also the first study aimed to obtain this data to help design a digital nutrition service for dyads. Findings from our study show, the majority of PwPD and their caregivers are currently using technology and have access to technological devices that can be equipped with digital health apps to facilitate delivery of nutrition services. Dyads find technology and digital health mediums useful, but hard to use. Digital competence scores and responses to individual questions provide insight to aspects of technology where PwPD and caregivers may need education and support. Digital health may be a viable medium to increase access to nutrition information related to managing PD, but the added benefits of these services must be clearly communicated to participants.

**Acceptance.** An average dyadic acceptance rate of 54.4% calculated from qualitative phrases coded reveals dyads were interested in specific aspects of technology for assisting with managing PD and nutrition, but also disinterested in technological mediums where they did not see the added benefit. For instance, many dyads were not interested in tracking food or steps or using wearable devices, as they were not interested in knowing that much detail about their health. However, many dyads expressed interest in videoconferencing with a dietitian, receiving nutrition email updates or taking photos of their food to be reviewed by a dietitian. Participants were using technology to email, search the internet, pay bills, and shop online. Over 55% of dyads used social media and participated in videoconference and watched videos, indicating these tools may be viable mediums to bring nutrition into the home. These findings show that a convenient, user-friendly digital health intervention that provides tailored nutrition information could be a way to improve access to care for this population.

Findings from our study build upon previous research examining the acceptance of technology and digital health among PwPD and their caregivers. Past research has found PwPD and caregivers are interested in using digital health for managing PD (Dorsey et al, 2016; Schulz et al, 2016). A recruitment webpage for a US-based randomized control trial utilizing virtual house calls for PwPD received 11,000 individual views worldwide (Dorsey et al, 2016). Ozanne et al (2017) found that PwPD saw the potential for wearable devices to improve treatment and felt this benefit outweighed the

inconvenience of having to wear a sensor. A study completed by Duroseau and colleagues (2016) examined acceptance among PwPD for using multiple electronic mediums to receive instructions and communicate with healthcare providers and found that older PwPD had a less favorable view of using technology to learn about their care plan and communicate with healthcare providers. Our studies expand upon previous research by specifically examining the acceptance of these technological mediums to receive nutrition information and interact with nutrition experts and includes the opinion of caregivers.

***Perceptions.*** Findings from qualitative analyses reveal that dyads perceive technology and digital health to be useful, but hard to use. Interviews revealed many of our participants, were also not aware of what the term digital health meant. These perceptions expand upon previous research examining views of PwPD around digital health. In a study completed by Duroseau et al (2016), nearly 65% of PwPD reported they were willing to use electronic methods and 48% believed using technology to communicate with providers would help to better understand their care (Duroseau et al, 2016). When stratifying participants by age, those 65 and over were less likely to believe using technology to communicate with a healthcare provider would enhance their understanding of care; this is attributed to the fact that older patients may not be as comfortable with using technology (Duroseau et al, 2016). This research, as well as our current study, indicates optimal communication

mediums among PwPD may vary based on patient demographics and that training older PwPD to use technology may be warranted.

**Digital Competence.** Findings support the need for educational training of digital health mediums among PwPD and their informal caregivers before implementing a digital health intervention. The reported reasons dyads were using technology matched their responses to the individual questions on the digital competence questionnaire. For instance, most participants are comfortable with corresponding via email, searching for health information and services, and shopping online. However, installing new devices and using social networks may be problematic for some participants. To help increase competence and perceived ease of use, future research could look to models such as Cyber Seniors®, an intergenerational program where college and high school students help older adults learn about technology (Rusnack & Cassady, 2014; Leedahl et al, 2018). Additionally, more information is needed about PwPD's and caregivers' knowledge of nutrition for managing PD and health literacy to ensure this population is accessing accurate and reliable nutrition information.

**Data Integration.** There was a negative, significant association between the number of phrases coded as Hard to Use and the Average Dyadic Acceptance Rate. This relationship combined with the lack of awareness of digital health among dyads and how nutrition can help manage PD, may help explain why dyads rejected certain digital health mediums. Finally, within dyads, digital competence scores varied, with one person within

the patient-caregiver dyad having a higher digital competence score than the other. This may account for the acceptance rate falling just above 50%. Future research should consider exploring ways to increase the acceptance rate among PwPD and caregivers, as well as educating dyads about how digital health can help enhance disease management. Research should also explore the facilitators and barriers for digital health adoption among dyads.

***Strengths and Limitations.*** Our study design promotes patient- and caregiver-centered care for managing PD and supports both as part of the healthcare team. Additionally, the utilization of mixed-methods study design provides an in-depth understanding of dyads' perception, acceptance and current level of digital competence. The use of semi-structured dyadic interviews is a strength, as dyadic interviews promote interaction between participants to help provide detailed information with regard to their experience on the topic of interest (Morgan, Eliot, Lowe, & Gorman, 2016). As a result, findings from this study can be incorporated in the TAM (Davis, Bagozzi, & Warshaw, 1989) and the emerging middle range theories of transition (Meleis et al, 2000).

While this study is novel it is not without limitations. The majority of participants were educated, Caucasian and had access to technology. Additionally, our participants were all from the northeast region of the United States. As a result, findings may not be generalizable to PwPD in other regions of the country or from marginalized populations. Additionally, since cognitive status was an inclusion criterion to enroll in our study, many of our



participants did not fully rely on caregivers and were able to perform many day-to-day activities on their own. However, including caregivers early at disease diagnosis and encouraging caregivers to partner with healthcare providers can help reduce stress and family conflict (Roth, Fredman, & Haley, 2015). Another limitation of this study is that the digital competence survey is not a validated tool, however items were adopted from the European Union Wide Indicators of Digital Competence, which is seen in the literature to create a digital competence framework (Görgényi Hegyes, Csapó, & Fekete Farkas, 2017). Future research should explore validating this instrument among both the general population and the PD community. Additionally, similar survey questions around technology acceptance have been used to survey PwPD in previous research (Duroseau et al, 2016). A final study limitation is that disease stage was only obtained from some of the PwPD. Requests were sent to physician offices for personal health information, but we were not able to obtain this information for all 20 PwPD.

***Implications.*** Results from this study can be used to help design and implement an acceptable digital health service to assist PwPD and caregivers manage nutrition. For this service to be accepted among dyads the benefits of utilizing technology and healthy eating must be clearly communicated to end-users. Training of the digital health service must be provided prior to implementing an intervention. Experts suggest when designing digital health interventions specifically for PwPD, developers should consider both PwPD and caregiver views, needs and preferences (Espay et al., 2019). Our findings

support recommendations presented by Duroseau and colleagues (2016), who suggest services be tailored to meet the technological preferences of PwPD and exploration of these preferences through qualitative research. These remote services can help increase access to nutrition information among PwPD and caregivers and have the potential to improve health-related quality of life, disease and caregiver burden.

**Conclusion.** This mixed-methods study focused on describing the acceptance and perceptions of digital health to manage nutrition for PwPD and their caregivers, as well as describe their level of digital competence. Results indicate mixed acceptance rates for technology and digital health mediums among dyads, possibly due to many participants perceiving digital health as useful, but hard to use. Digital competence scores suggest dyads participating in a digital health nutrition intervention will need some training prior to study participation. Findings from this study complement existing literature regarding digital health for managing PD and helps to better understand the opportunity to use digital health as an avenue to include nutrition and caregivers in the PD care plan. Future studies should explore digital health and technology as tools to provide evidenced-based nutrition and health knowledge to PwPD and caregivers. Prior to launching a digital health service to manage nutrition, dyads will need training and technical support.

## Chapter 3 Tables and Figures

**Table 1:** Participant Demographics

<b>Descriptive Variables</b>	<b>PwPD (n=20)</b>	<b>Caregivers (n=20)</b>	<b>Range</b>
Age (years)	69.7±9.2	66.4±13.0	39-89
Gender n(%) Male Female	13 (65) 7 (35)	4 (20) 16 (80)	NA
Education n(%) • HS Diploma/Some College • Technical Training/Trade School/Associates • ≥ College Degree or Greater	6 (30) 3 (15) 11 (55)	1 (5) 5 (25) 14 (70)	NA
Employment Status n(%) • Retired • Part Time • Full Time	15 (75) 3 (15) 2 (10)	10 (50) 2 (10) 8 (40)	NA
T-MoCA	19.8±1.5	20.4±1.1	18-22
Years Since Diagnosis	7.6±5.4	NA	0.33-18.0
Disease Burden (PDQ-39)	21.7±3.5	NA	3.12-50.01
Caregiver Burden (MCSI) <sup>†</sup>	NA	12.6±8.2	0-26
BMI (kg/m <sup>2</sup> )	27.09±5.4	28.3±5.7	15.4-43.1
DST Scores	56.95±9.3	59.5±10.7	37-81
Nutrition Risk n(%) • At Risk • Possible Risk • Not At Risk	10 (50) 10 (50) 0 (0)	11 (55) 8 (40) 1 (5)	NA
Digital Competence	27.5±12.8	29.7±12.6	0-45

Data reported as n(%) for categorical variables and mean±sd for continuous variables; <sup>†</sup>n=19; Abbreviations: HS=high school, T-MoCA=Telephone Montreal Cognitive Assessment, BMI=body mass index, DST=dietary screening tool.

**Table 2a:** Distribution of Technological Purposes Among PwPD and Caregivers Reported in Frequencies and Percentages

Variables n(%)	PwPD (n=20)	Caregivers (n=20)
Email	18 (90)	20 (100)
Social Media	10 (50)	12 (60)
Videos (Youtube)	13 (65)	14 (70)
Video Conference	11 (55)	8 (40)
Search Internet	17 (85)	17 (85)
E-banking/paying bills	14 (70)	17 (85)
E-Shopping	15 (75)	16 (80)

**Table 2b:** Description of Internet Use for managing Health Among PwPD and Caregivers Reported in Frequencies and Percentages

Variables n(%)	PwPD (n=20)	Caregivers (n=20)	<i>phi</i>
Look for health or medical information for yourself	15 (75)	18 (90)	0.197
Looked for health or medical information for someone else	11 (55)	17 (85)	0.327
Looked for information about managing Parkinson's disease	13 (65)	14 (70)	0.053
Participated in online forums or support groups for people with similar health or medical issue	1 (5)	4 (20)	0.227
Used a website to help you with your diet, weight or physical activity	7 (35)	8 (40)	0.052
Looked for a healthcare provider	7 (35)	5 (25)	-0.109
Downloaded health information to a mobile device, such as an MP3 player, cell phone, tablet computer, or electronic book device	8 (40)	4 (20)	-0.218
Shared health information on social media sites (Facebook, Twitter)	1 (5)	2 (10)	0.095
Exchanged support about health concerns with family and friends	12 (60)	12 (60)	0.00
Kept track of personal health information such as care received, test results, or upcoming medical appointments	11 (55)	12 (60)	0.051
Watched a health-related video on YouTube	10 (50)	6 (30)	-0.204

Values are reported as n(%). Chi Square Completed (looked for health info for someone else  $\phi=0.327$ ,  $p=0.008$ ) Effect size reported as *phi* (0.1 = small; 0.30=medium; 0.5=large).

**Table 3:** Themes for Acceptance and Perception of Digital Health Summarized by Number of Phrases Coded, Percent of Comments, and Number of Dyads Mentioning Acceptance or Perception within Each Category

	Number of Phrases Coded	Percent of Comments	Number of Dyads Mentioning Code/Theme Within Each Category
<b>Acceptance</b>	466	-	20
<i>Accept</i>	243	54.4%	20
<i>Neutral</i>	109	23.4%	20
<i>Reject</i>	114	24.5%	19
<b>Perceived Usefulness</b>	29	-	11
<i>Useful</i>	22	75.9%	10
<i>Neutral</i>	4	13.8%	4
<i>Useless</i>	3	10.3%	3
<b>Perceived Ease of Use</b>	104	-	20
<i>Easy to Use</i>	22	21.2%	14
<i>Neutral Ease of Use</i>	12	11.5%	10
<i>Hard to Use</i>	70	67.3%	19
<b>Awareness of Digital Health</b>	56	-	20
<i>Aware</i>	11	19.6%	8
<i>Neutral Awareness</i>	17	30.4%	13
<i>Not Aware</i>	28	50%	16

**Table 4:** Those Participants Who Responded Slightly or Strongly Agree to Individual Digital Competence Questions Among PwPD and Caregivers Reported by Frequency (Percentage)

Digital Competence Question n(%)	PwPD (n=20)	Caregivers (n=20)	Phi
Searching and finding information about goods and services	18(90)	18(90)	0.0
Reading or downloading news/newspapers/news magazines	16(80)	17(85)	0.07
Using copy/paste tools	13(65)	13(65)	0.0
Seeking health information	17(85)	17(85)	0.0
Sending/receiving emails	18(90)	20(100)	0.23
Using videocalls, such as skype	11(55)	10(50)	-0.05
Participating in social networks	11(55)	12(60)	0.05
Posting messages on social networks	9(45)	12(60)	0.15
Uploading self-created content to any website to be shared	7(35)	7(35)	0.0
Sharing talents and ideas with on social networks	6(30)	9(45)	0.16
Sharing interests and ideas with those you know	13(65)	16(80)	0.17
Connecting and installing new devices	12(60)	12(60)	0.0
Internet banking	13(65)	14(70)	0.05
Buying or ordering goods or services for private use (last 12 months) over the internet	16(80)	15(75)	-0.06
Making an appointment with a practitioner via a website	12(60)	14(70)	0.105

*Chi Square Analyses Completed to compare between group differences; phi co-efficient used to report effect-size: small=0.01, medium=0.30, larger=0.50*

**Table 5:** Data Integration: Side by Side Display of Digital Competence Scores (total scores(%)), Acceptance Rates Calculated From Semi-Structured Interviews

Dyads	PwPD Digital Competence	Caregiver Digital Competence	Acceptance Rate (%)	Hard to Use (% phrases coded)
Dyad 1	28 (62.2)	8 (17.8)	58.3	50.0
Dyad 2	33 (73.3)	26 (57.8)	90.0	25.0
Dyad 3	34 (75.6)	25 (55.6)	80	0.0
Dyad 4	18 (40)	31 (68.9)	31.6	60.0
Dyad 5	41 (91.1)	44 (97.8)	80.0	50.0
Dyad 6	41 (91.1)	33 (73.3)	78.9	25.0
Dyad 7	31 (68.9)	45 (100)	50.0	50.0
Dyad 8	4 (8.9)	25 (55.6)	31.8	100
Dyad 9	25 (55.6)	4 (8.9)	31.8	100
Dyad 10	39 (86.7)	40 (88.9)	69.4	87.5
Dyad 11	40 (88.9)	39 (86.7)	69.4	87.5
Dyad 12	45 (100)	41(91.1)	51.7	55.6
Dyad 13	16 (35.6)	29 (64.4)	25.0	50.0
Dyad 14	32 (71.1)	7 (15.6)	48.1	75.0
Dyad 15	21 (46.7)	31 (68.9)	39.3	80.0
Dyad 16	23 (51.1)	35 (77.8)	48.4	50.0
Dyad 17	16 (35.6)	14 (31.1)	31.8	75.0
Dyad 18	0 (0)	42 (93.3)	44.8	83.3
Dyad 19	19 (42.2)	39 (86.7)	57.1	100
Dyad 20	44 (97.8)	36 (80)	69.2	66.7

*Digital Competence scores are reported for both PwPD and Caregivers and are reported as total score(percentage). Acceptance Rate reported which was calculated by dividing phrases coded as Accept by total number of phrases coded related to Accept, Neutral and Reject for each interview. Percent of phrases coded as hard to use in each interview were calculated by dividing phrases coded as hard to use by total phrases coded related to Ease of Use.*

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## **APPENDIX A: Review of the Literature**

### **I. What is Parkinson's Disease**

Parkinson's disease (PD) is an incurable, progressive neurodegenerative movement disorder that traditionally occurs in the second half of life.<sup>1</sup> Over 900,000 Americans live with PD, approximately 60,000 new cases are diagnosed each year<sup>2,3</sup>, and the national economic burden of PD exceeds \$14.4 billion.<sup>4</sup> The life expectancy from PD onset of diagnosis to death is approximately 15 years.<sup>5,6</sup> The number of people with PD (PwPD) living in the US is expected to double by 2030 due to the growing number of people over 65 and an increase in life expectancy for PwPD. As a result, researchers and clinicians have recently started investigating symptoms and clinical features of PwPD 20 years out.<sup>7</sup>

The exact etiology of PD remains unknown but it is hypothesized to arise from an interaction between environmental and genetic factors resulting in degeneration of neurons.<sup>8</sup> Parkinson's disease results when there is a disruption of dopaminergic neurotransmission within the basal ganglia of the brain.<sup>9</sup> Dopamine are neurotransmitters that control motor function and movement control, as well as reward-motivated behavior.<sup>9</sup> As a result of PD, dopaminergic neurons in the substantia nigra are decreased. Within the residual dopaminergic neurons, Lewy bodies (deposits of alpha-synuclein) present.<sup>9</sup> The basal ganglia, located in the forebrain, controls voluntary movement, procedural and habitual learning, eye movement, cognition and emotion.<sup>10</sup> The substantia nigra, part of the basal ganglia circuitry, located in

the mid-brain, plays a role in movement and reward.<sup>10</sup> As PD progresses, problems extend beyond motor deficits and can impact nutrition, weight management, cognitive and physical functioning.

The diagnosis and therefore the prevalence and incidence of PD varies by age, geographic location, race, and gender.<sup>11</sup> Prevalence of PD increases with age, with the age of onset around 60 years old,<sup>8</sup> and impacting 2.6% of Americans who are 85-89 years of age.<sup>8</sup> Parkinson's disease infrequently occurs under the age of 40 years old and early onset increases the probability genetics may play role.<sup>12</sup> Rates of PD are highest in the Midwest and Northeast regions of the United States (US), with rates being up to 10 times higher than rates in the Western and Southern regions of the US.<sup>11</sup> There is a higher occurrence of PD among males, with a male to female ratio of 3:2.<sup>12,13</sup> Whether or not PD is more prevalent among whites versus non-whites needs further exploration.<sup>11</sup> Research regarding the prevalence of PD across race and ethnicity is consistent and inconclusive.<sup>11,14</sup>

Parkinson's disease can be characterized as idiopathic PD (primary parkinsonism) or non-idiopathic PD (secondary or atypical parkinsonism).<sup>9</sup> It is estimated that up to 85% are diagnosed with idiopathic PD<sup>15</sup> and respond well to dopaminergic medications. Those with non-idiopathic PD do not respond well to dopaminergic medications.<sup>9</sup> Idiopathic PD can be characterized into two main subtypes: tremor dominant (TD) and postural instability gait difficulty (PIGD).<sup>16</sup>

Currently there is no cure for PD. Levodopa, a medication that produces dopamine in the central nervous system, is the most common medication used to control motor sequelae.<sup>17,18</sup> Levodopa is cost-effective<sup>14</sup> and considered the most efficacious treatment because it improves motor function, quality of life (QOL), and reduces morbidity and mortality.<sup>15</sup> An “on” state is when motor symptoms subside when levodopa is taken, and an “off state” is where levodopa wears off before the next dose and PD motor symptoms are present. Off periods can result in functional disability and can be characterized by stiffness, slowness, tremor, as well as cognitive and mood changes.<sup>19</sup> The negatives of levodopa treatment are: 1) causes motor-symptoms which impact HRQOL and ability to perform activities of daily living (ADLs); and 2) over-time, patients build up a tolerance to levodopa and may require higher levodopa doses and eventually the medication loses effectiveness.<sup>20</sup>

About 6.5 million informal caregivers provide substantial help for medical and dietary management for older adults living with disability.<sup>21</sup> Informal caregivers are any unpaid family member or friend who provides the majority of care.<sup>22</sup> Almost 55% of caregivers for older adults assist with medication management<sup>23</sup>, and caregivers of PwPD likely play an integral role in managing food-drug interactions, given their role in managing dietary intake for PwPD.<sup>24</sup> With an increase in life expectancy for PwPD but no cure for PD, the socioeconomic and personal burdens for PwPD and their informal caregivers will also rise, which includes an exponential increase in excess



medical spending.<sup>4,12,25</sup> As the disease progresses, informal caregiver responsibility increases and caregivers will play a central role in utilizing digital health to access care for their loved one with PD.<sup>26</sup>

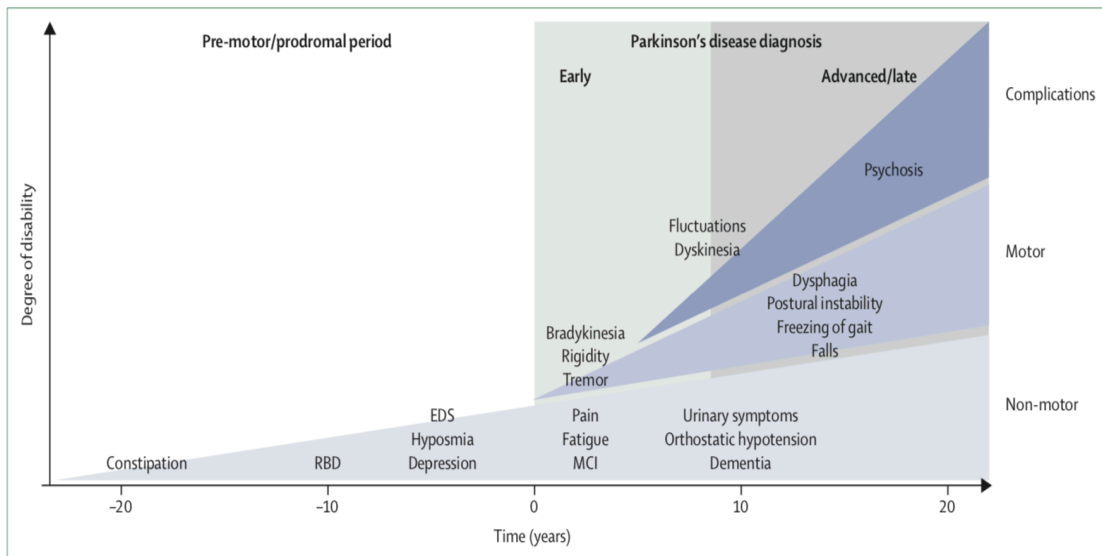
In general, caregivers spend 24+ hours per week caring for their loved one<sup>22</sup>, but caregivers of PwPD spend up to 40 hours per week performing care-related duties.<sup>27</sup> Compared to the general population, caregivers for PwPD are more likely to have depression, anxiety, decreased health status<sup>28</sup>, and/or poorer QOL<sup>29</sup>, which is partly attributed to observing the physical and cognitive decline of their loved one with PD<sup>29</sup>. Caregiver stress and burden can adversely affect caregiver's psychosocial and physical functioning, which may compromise the care provided and the health of the patient-caregiver dyad.<sup>28,30</sup> Specific to neurodegenerative diseases, caregivers are confronted with evolving roles and responsibilities, and need to plan for the trajectory of PD.<sup>31</sup> Couple-oriented interventions improve spousal coping strategies, minimize stress and anxiety, and increase self-efficacy to manage disease progression.<sup>32</sup>

## II. **Disease Progression**

Parkinson's disease-specific sequelae, conditions that result specifically from PD, impact motor and non-motor function. Disease sequelae can present 20 years prior to diagnosis (Figure 1).<sup>33</sup> Motor and non-motor sequelae can vary depending on the stage of PD. The Hoehn & Yahr (H&Y) scale is a five stage scale that examines PD severity based primarily on ratings of motor sequelae.<sup>34</sup> In stage 1 the patient exhibits unilateral symptoms, while in stage

2 the patient presents with bilateral symptoms. Those with stage 3 PD experience balance impairment but are still physically independent, while those in stage 4 exhibit severe disability but are able to stand or walk unassisted. Stage 5 is the most advanced stage and the person needs a wheelchair or is bedridden unless assisted.

**Figure 1:** “Clinical Symptoms and Time Course of Parkinson’s disease Progression”<sup>33</sup>



The Unified Parkinson Disease Rating Scale (UPDRS) is a tool to monitor disease trajectory and inform treatment plans for PwPD. The rating scale assesses motor and non-motor sequelae and consists of five sections: 1) Mentation, Behavior, and Mood, 2) Activities of Daily Living (ADL), 3) Motor Sections, 4) Modified Hoehn and Yahr Scale (H&Y), and 5) Schwab and England ADL scale. Higher UPDRS scores indicate more severe disability present, with the highest possible score being 199.<sup>35</sup>

Older age at diagnosis and disease duration are independently associated with a higher prevalence of motor and non-motor sequelae that can result in disability.<sup>7</sup> Due to its heterogenous and degenerative nature, research proposes to view PD as a complex syndrome, rather than a disease.<sup>36</sup> As a result, a comprehensive clinical assessment including biomarkers to assess motor and non-motor symptoms of PD is warranted to better treat and attenuate PD progression.<sup>37</sup> Tracking how disease sequelae impacts nutritional status overtime is also essential to provide adequate nutrition interventions.<sup>38</sup>

**a. Motor Sequelae**

Motor sequelae can be caused as a result of PD or emerge as a side effect of PD medication.<sup>35</sup> Levodopa-responsive motor sequelae include: dyskinesia (involuntary movement) and motor fluctuations including unpredictable and sudden “off” stage, where levodopa medication suddenly stops working throughout the day.<sup>35</sup> Non-levodopa-responsive motor symptoms include: tremors, hypomimia (poker face/lacking expression), rigidity, bradykinesia (slowness of movement) and hypokinesia (decreased movement), gait disturbances, freezing gait, balance issues, frequent falls, as well as dysphagia (difficulty swallowing) and speech difficulty. Decline in gait and balance as the disease progresses results in fall frequency.<sup>39,40</sup> Since so many symptoms do not respond to levodopa treatment, the most effective form of medication for managing PD, an interdisciplinary care team is needed to treat PwPD holistically to manage disease sequelae.<sup>41</sup>

### ***i. Physical Functioning***

Motor sequelae progress overtime and can compromise physical functioning.<sup>42,43</sup> Resting tremor is usually the first and most visible symptom of PD and it impacts one's legs, jaw, tongue and/or hands. Up to 90% of PwPD experience resting tremor, joint stiffness and/or muscle rigidity<sup>44</sup>. Resting tremor rarely cause disability among individuals since relief or diminution occurs during voluntary movement.<sup>44</sup> Bradykinesia is one of the most disabling characteristics of PD, impacting up to 90% of PwPD.<sup>45</sup> Bradykinesia is disabling as it cause freezing (i.e., sudden, short and transient inhibitions of movements) during other movements, such as walking, driving, talking, moving hands or writing.<sup>45</sup> Freezing gait is one of the main risk factors for falls among PwPD.<sup>46</sup> Nearly 68% of PwPD fall at least once per year<sup>47</sup>, compared to one third of community-dwelling adults over the age of 65.<sup>48,49</sup> Bradykinesia can progress into akinesia or the inability to initiate or continue movement.<sup>50</sup> Akinesia can present as freezing gait (i.e., trouble initiating gait and or turning while walking), speech problems, and incapacity to perform smooth and rapid alternating finger movements.<sup>50</sup>

Change in balance and gait lead to disability among PwPD, compromising ability to perform activities of daily living (ADLs), independence and QOL. Balance and gait issues typically become more compromised as the disease progresses but can also impact physical functioning in earlier stages of disease. Parkinson's disease gait is characterized by slower walking speed, smaller steps, larger stride length variability, and less arm swing

compared to healthy controls.<sup>51</sup> Slowing of gait and worsening of motor sequelae over a time and this is a concern among PwPD as it can reduce functional independence, which in turn can decrease quality of life.<sup>52</sup>

Research has also analyzed how physical functioning and ambulatory ability in PwPD changed overtime<sup>42,43</sup>. Cavanaugh et al<sup>42</sup> conducted a 2-year, prospective longitudinal study, assessing the ambulatory decline and evolving components of disability among 17 PwPD and found the dose and intensity of ambulatory activity significantly decreased. At the same time, the daily dose of levodopa increased overtime.<sup>42</sup> Findings from this study indicate natural ambulatory activity may be a strong indicator of physical decline, especially in early stages of disease<sup>51</sup>. Natural ambulatory activity is a subset of physical activity behaviors that entail stepping (walking, climbing stairs, mowing the lawn, jogging) and are used as a measurement strategy to assess physical activity, posture and movement.<sup>53</sup> Findings from this support the need for ambulatory activity monitoring to be included in the PD plan. Research is needed to examine how ambulatory activity changes beyond two years.

Another prospective, longitudinal study observed a significant decline in motor function and self-reported physical activity levels from year two to four in those living with early stage PD.<sup>43</sup> Higher levels of physical activity among PwPD were significantly associated with ability to perform ADLs, slower progression of motor symptoms and cognitive decline.<sup>43</sup> Physical disability and inability to perform ADLs can also decrease access to healthcare services that would better manage the disease.<sup>54</sup>

Finally, States et al.<sup>55</sup> examined change in physical functioning after one, three and five years of attending an exercise program for PwPD. Fifty-nine percent of participants completed one year of the exercise program, while 39% completed three years and 29% completed five years. Those participants that were categorized as consistent exercisers (PwPD who completed at least half of the exercise classes for at least one year) showed modest, but significant improvements in hand-grip strength, balance scores, and a six-minute walk test.<sup>55</sup> However, at years 3 and 5, no changes in these variables occurred, indicating consistent exercise may help PwPD maintain their functional status despite living with a neurodegenerative disease. Findings from this study support the need for an interprofessional team to successfully implement a supportive community-based exercise program to support participation of PwPD overtime.

Decline in mobility or ambulatory ability as PD progresses can not only increase risk for falls, but may also inhibit one's ability to carry out general (bathing, dressing, eating, toileting, getting in and out of bed, mobility both inside and outside of the home<sup>56</sup>) and instrumental ADLs (laundry, preparing meals, shopping, banking, managing money<sup>56</sup>).<sup>57</sup> As a result, PwPD may need assistance with buying, preparing, and consuming meals and snacks. Additionally, research has found a relationship between physical activity level and/or physical functioning with cognition and well-being measures such as QOL and depression among PwPD.<sup>58,59</sup> Such findings support the need for an interdisciplinary treatment approach for managing PD to promote health-

related QOL. However, more research is needed to understand how this relationship changes over the course of PD. Limited information also exists around the relationship between physical, cognitive, and swallowing functions, and their multi-faceted relationship with nutritional status in PwPD and how this interaction changes overtime.<sup>38</sup>

## ***ii. Swallow Function***

Similar to the decline in mobility, a decline in swallow function can hinder the ability to swallow medication<sup>60</sup>, decrease one's ability to consume nutrient rich foods and compromise nutritional status.<sup>61</sup> Dysphagia is a condition where one experiences difficulty swallowing food and can occur anywhere between the oral cavity to the stomach,<sup>62</sup> including difficulty initiating swallow and getting food stuck in the top or middle of the esophageus.<sup>62</sup> Oropharyngeal dysphagia, difficulty or inability to chew and mix food with saliva and move it to the back of the mouth with the tongue to the esophagus, is the most common form of dysphagia among PwPD.<sup>63</sup> Dysphagia among PwPD can be caused by impaired cognitive processing, which can result in difficulty initiating swallowing as a resulting of hypometabolism in the supplementary motor area and dysfunction of the anterior cingulate cortex, causing impaired cognitive processing.<sup>64</sup> It is estimated that up to 90% of PwPD will experience dysphagia throughout the course of their disease<sup>65</sup>, while prevalence of dysphagia only impacts 2-16% of the general population.<sup>66</sup> Symptoms of dysphagia include regurgitation, chest pain, aspiration, persistent coughs, sore throat, loss of appetite, hoarseness, hiccups, painful

swallowing, heartburn.<sup>62,67</sup> Regular swallow screenings are warranted among PwPD, rather than relying on self-reported concerns about swallowing among PwPD.<sup>68</sup>

In a cross-sectional study, Miller and colleagues<sup>68</sup> examined the frequency of impaired swallowing via a 150mL timed swallow test, how impaired swallowing relates to disease progression and frequency of self-reported swallowing issues among PwPD.<sup>68</sup> Results from this study found that 23% of participants could not completely drink the full 150mL glass of water provided during the swallow evaluation and there was a moderate association between swallow function performance and UPDRS II (ADLs) and III (motor function) scores.<sup>68</sup> Sixty-six percent of participants believed they did not have a swallowing problem but performed below average on the timed-swallow test.<sup>68</sup>

To help manage dysphagia and reduce risk of choking, swallow maneuvers and exercises, postural adjustments, and modified textures (puree, mechanical, soft foods) and fluid consistencies (thin liquid, nectar and spoon-thick) can be prescribed.<sup>69</sup> For PwPD prescribed a dysphagia diet, nutrition guidance is needed to help meet adequate nutrition and hydration needs.<sup>70</sup> Caregivers may also have a significant role in helping PwPD adhere to a dysphagia diet, especially as the disease progresses and cognitive decline emerges.<sup>71</sup> The risk of developing dysphagia coupled with nutrition risk present among PwPD warrants the need for ongoing nutrition and swallow screening and collaboration between speech therapists and registered



dietitians.<sup>41</sup>

Dysphagia can negatively impact dietary intake and increase nutrition risk. One study found that the majority of patients with dysphagia do not find mealtime enjoyable and 41% reported having anxiety or panic during meals.<sup>67</sup> Since dysphagia can disrupt mealtime, diet quality and nutrition risk is a concern among PwPD. Specifically, the amount consumed, and quality of the food consumed is compromised, which can impact body composition. Consequently, patients with dysphagia present with smaller calf and arm circumference, indicative of muscle wasting and under-nutrition.<sup>62</sup> Difficulty swallowing among PwPD has been well-studied<sup>67</sup>, but the exact interaction between nutritional status and swallow functioning and how this changes overtime among PwPD has not been examined.

Matushima et al.<sup>72</sup> conducted a cross-sectional study to assess the association between factors related to swallowing difficulty in 237 PwPD in Japan. This study also wanted to better understand behavior patterns behind the food types selected to cope with malnutrition and describe optimal characteristics of caregivers helping to manage swallowing difficulties their loved-one with PD is experiencing. Findings from this study indicate severity of swallowing difficulties was associated with increased age and more advanced disease. Only 11 participants reported using care foods for managing dysphagia, which included home delivery meals adhering to dysphagia diets or a la carte pre-prepared foods designed for those with dysphagia. The 11 participants consuming care foods were significantly older

and none of these participants presented with a lower BMI. Dietary modifications to manage dysphagia, were more likely to occur when PwPD lived with an informal caregivers, particularly children.<sup>72</sup> Findings indicate care foods may be effective in managing dysphagia and nutritional status but research assessing a larger sample of PwPD overtime is warranted.<sup>72</sup> The issue of care foods and its impact on health-related quality of life (HRQOL) among PwPD is also warranted, as PwPD experience non-motor sequelae, such as depression and apathy.

#### **b. Non-Motor Sequelae**

Non-motor sequelae are being recognized as neglected aspects of PD, and affect up to 88% of PwPD.<sup>73</sup> Non-motor sequelae include: change in mood (anxiety, depression, apathy), fatigue, pain, cognitive decline (dementia, memory, concentration attention), psychosis (hallucinations or delusions), excessive sweating, bladder urgency, dizziness, and/or orthostatic hypotension.<sup>7,74</sup> Many non-motor sequelae among PwPD can impact dietary intake and nutritional status, and include: dysphagia, change in taste and smell, gastrointestinal issues (gastroparesis, constipation, acid reflux).<sup>61,75</sup> Dysphagia, while characterized as a motor symptom when assessing PD severity via the UPDRS is considered a mixed motor and non-motor symptom.<sup>74</sup>

A cross-sectional study examining presence of non-motor symptoms among 89 PwPD self-reported a mean of 11 non-motor symptoms.<sup>76</sup> Non-motor sequelae tend to vary with fluctuations in motor sequelae associated

with on/off states<sup>74</sup>, and are key causes of loss of independence and caregiver strain.<sup>77</sup> In a prospective study, Duncan and colleagues<sup>78</sup> evaluated impact of non-motor symptoms on HRQOL among newly diagnosed PwPD and found depression, anxiety, poor concentration, memory issues, insomnia and incomplete bowel emptying had the greatest impact on HRQOL.<sup>78</sup> Subsequently, screening and managing these non-motor symptoms should be prioritized early at diagnosis.<sup>78</sup>

*i. Parkinson's Disease, Mood, and Mental Health*

Up to 50% of PwPD have anxiety, depression, and/or sleep disturbances.<sup>79,80</sup> Apathy, depressed mood, and anhedonia (inability to feel pleasure) are characteristics for clinical diagnosis of depression and are related to the low levels of norepinephrine (hormone), dopamine and serotonin (neurotransmitters) among PwPD and associated with more severe motor sequelae.<sup>81</sup>

Storch et al.<sup>74</sup> examined the frequency and severity of nonmotor fluctuations among 100 PwPD, as well as the association of nonmotor and motor sequelae and found presence of fatigue, anxiety, depression, and pain is associated with poorer HRQOL independent if non-motor symptoms were present in the on or off state.<sup>74</sup> Non-motor symptoms were more severe in the off state than the on state.<sup>74</sup> Fatigue was the most frequently reported non-motor symptom, impacting 88% of PwPD.<sup>74</sup> The second most common non-motor symptom reported was issues with concentrations/attention, reported by 67% of PwPD, while dysphagia was least commonly reported (29%).<sup>74</sup>

However, lack of energy may impact the ability to prepare and consume food, while decline in concentration can impact the way nutrition education is presented.

Medication to treat psychiatric conditions can also impact well-being and physical functioning among PwPD. Benzodiazepines, prescribed to treat anxiety, can impact cognition, alertness, and gait, and increase fall and fracture risk.<sup>82</sup> However, selective serotonin reuptake inhibitors and norepinephrine reuptake inhibitors used to treat depressive symptoms among PwPD can improve depressive symptoms and freezing of gait but have little impact on feelings of apathy.<sup>83</sup> Unfortunately, gastrointestinal events may be more common in PwPD managing depressive symptoms with SSRIs (nausea, diarrhea, abdominal stomach, vomiting) which can further impact dietary intake and quality.<sup>83</sup>

In addition to non-motor sequelae, PwPD and their informal caregivers also experience stigma as a result of living with a progressive disease, which can further impact well-being. Maffoni et al.<sup>84</sup> conducted a literature review of qualitative studies examining stigma among PwPD and caregivers and found stigmas included: disgrace, shame, embarrassment, feeling awkward, horrible, terrible or dishonorable. Findings revealed that stigma presents as a complex, multi-faceted construct that is linked not only with the physical decline PwPD experience but also the undesirable self-image and loss of self-efficacy and independence that emerges from the progressive disease<sup>84</sup>; many PwPD felt shame because of physical dependence on caregivers to do even simple

tasks.<sup>84</sup> Stigma was also linked to relational and communication problems, where many PwPD attribute voice and articulation sequelae a contributor to stigma. It is important to recognize PwPD and their caregivers journey of living with PD to recognize their inner psychological needs to optimize care provided.<sup>84</sup>

**ii. Cognition, Mild Cognitive Impairment and Dementia in PD**

Cognitive dysfunction can occur early in diagnosis<sup>85,86</sup>, and eventually up to 40% of PwPD present with dementia.<sup>79</sup> Cognitive symptoms are strongly associated with increased economic burden and nursing home placement, as well as morbidity, disability, and compromised QOL for PwPD and their informal caregivers, increasing caregiver burden.<sup>87-89</sup> Common cognitive issues that emerge among PwPD include impairments in executive function, working memory and attention.<sup>90</sup> Kudlicka et al<sup>86</sup> examined executive function impairment in those living with mild to moderate PD and found PwPD to more frequently have issues with attention control assessments than those assessing abstract thinking performance. Research indicates PwPD with mild cognitive impairment (MCI) are more likely to have issues with performing cognitive set-shifting tasks involved in decision making.<sup>91</sup> Among PwPD with mild cognitive impairment there is an increased presence of disability and physical impairment, which can impact QOL.<sup>25</sup> Cognitive deficits among PwPD are predictive of the development of dementia and as a result longitudinal assessment and management of cognition in this population is warrant.<sup>90,92</sup>

Arie and colleagues<sup>92</sup> conducted a five-year, prospective study of 57

participants saw a significant decline in cognitive scores in both those with TD and PIGD. However, findings from this study suggest, PIGD participants exhibited a larger magnitude of cognitive decline, particularly in the area of executive function and motor-cognitive skills. Despite these differences, this study found no difference in HRQOL or disease burden between PIGD and TD.<sup>92</sup> However, future research needs to examine the longitudinal change of nutritional status presents as changes in cognition occur.

In a mixed-methods study, Raein et al.<sup>88</sup> interviewed dyads comprised of PwPD and their informal caregivers to determine subjective cognitive complaints. Findings from 22 dyads participating in focusing group identified subjective cognitive complaints across the following domains: memory, language and communication, attention and processing speed, executive functioning and episodic confusion/fluctuations in thinking ability.<sup>88</sup> Dyads described subjective complaints that are not often objectively assessed when measuring cognitive status, such as fluctuations in cognitive abilities, lapses in prospective memory, and issues with recalling names, an issue distinct from an issues with general word-finding.<sup>88</sup> Those PwPD without dementia reported more subjective cognitive complaints compared to observed cognitive complaints reported by their informal caregiver.<sup>88</sup> The top treatment priority among PwPD was related to language (recall, word finding, difficulty following instructions), while for informal caregivers the top treatment priority for PwPD were related to executive function (improving decision making abilities and a reduced desire to start tasks).<sup>88</sup> Findings suggest practitioners should

consider the unique aspects of cognitive decline in PwPD by examining both subjective and objective cognitive functions. Understanding cognitive deficits and self-reported cognitive concerns can help better design, develop and deliver effective nutrition education.

### ***iii. Sensory and Perception Changes***

People with PD experience sensory changes and reduced insight, which can impact decision making, cognition, physical functioning, swallowing ability and food intake. Such changes include increased saliva production, drooling, change in the ability to taste and smell, altered time and vision perceptions, deficits in perception of loudness, failure to identify emotion and prosody, and inability to change or shift sets quickly.<sup>93-96</sup> More than 50% of PwPD report issues with drooling<sup>97</sup> and approximately a quarter of PwPD experience issues with frequent drooling<sup>97</sup>; people with PD are five times more likely to experience issues with drooling than healthy controls. Drooling frequency is associated with disease severity.<sup>97</sup> Speech language pathologists are critical for the care team in helping PwPD manage drooling. Changes in tactile function, thermal, nociceptive (perception of pain), and proprioceptive (perception of self-movement and body position) sensations also occur among PwPD.<sup>96</sup>

These sensory changes among PwD are either pure disorders of conscious perception or disorders of sensorimotor integration (“the use of sensory information to guide movement”).<sup>96</sup> Disorders of conscious perception can cause elevations in the sensory threshold, while disorders of

sensorimotor integration occurs when there is an alteration in the interaction between sensory input and motor output.<sup>96</sup> Despite normal cognitive functioning, PwPD have a decreased sensitivity to visual sensory and cognitive stimuli, which implies alterations to the visual cortical and subcortical areas, along with possible impacts on the retina.<sup>98</sup> It is also speculated that dopaminergic treatments worsen sensory impairments (e.g. postural instability), by disrupting the primary somatosensory cortex, found in the postcentral gyrus of the brain.<sup>99</sup> As a result, how PwPD perceive situations, their own health status and dietary intake, as well as process nutrition and health education may be impacted. Multiple modalities and repetition to educate PwPD may be warranted.<sup>100</sup>

Cognitive-linguistic changes can impact QOL and day-to-day functioning of PwPD. While nearly 75% of PwPD experience a speech disorder at some stage in the disease, PwPD have an impaired perception of their own speech loudness as well as impaired perception of verbal emotions when interacting with others.<sup>94</sup> It is proposed that altered perception of own speech loudness is due to the inconsistency between perceived level of effort and produced vocal loudness.<sup>101</sup> Meanwhile, inability to detect verbal emotion may be due to compromised working memory, executive function, and acoustic processing.<sup>94,102</sup> As a result, on-going monitoring cognitive status among PwPD is vital. This information is also important for health professionals providing ancillary services and education to PwPD to design and implement effective services.



In addition to lack of insight about perceived loudness and interpretation of emotional parody, PwPD also can have challenges with shifting tasks and perception of time.<sup>93,95</sup> When examining the change in muscle responses when provided a cue to complete two different tasks, PwPD needed to perform the original task several additional times before switching to the new task.<sup>95</sup> Those PwPD taking levodopa did not see improvements in their ability to change tasks quickly.<sup>95</sup> Findings of this study should be taken into account when designing nutrition education and assessment programs for PwPD. Temporal information processing is another sensorimotor integration process altered among PwPD and may explain some PD symptoms, such as poor time perception.<sup>84</sup> Research has found PwPD tend to underestimate time, and it is proposed dopamine deficit may cause a delay in the body's internal clock. Distortion of time is a concern among PwPD as time perception is fundamental for the relationship between humans and their environment. As a result, how PwPD perceive their surroundings and experiences may be altered. How alterations of perceptions among PwPD impact nutrition assessment, dietary recalls and nutrition education has not been explored. Changes in perception also warrant the inclusion of caregivers to provide insight on the diets of their loved one living with PD.

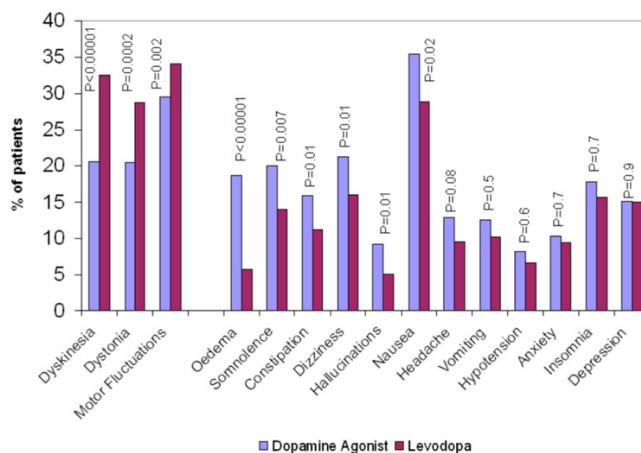
### III. PD Management

#### a. Treatment Options for Managing PD

##### *i. Pharmacologic Anti-Parkinson Treatment*

**Dopamine Agonists.** Dopamine agonists, while less effective and potent than levodopa, are usually used as the initial medication for PD.<sup>9</sup> Compared to levodopa, they are associated with a lower risk of motor fluctuations and dyskinesia for the first five years of treatment.<sup>9,103</sup> Dopamine agonists bind to dopamine receptors to mimic the neurotransmitter dopamine.<sup>104</sup> However, overtime levodopa is usually used in conjunction with dopamine agonists to control advancing symptoms.<sup>9</sup> Those on dopamine agonists are more likely to experience non-motor side effects compared to those on levodopa (Figure 2).<sup>105</sup> Nutritional side effects of dopamine agonists include weight gain and compulsive behaviors, such as excessive spending and eating, which can impact health-related QOL among PwPD.<sup>9,61</sup>

**Figure 2:** Incidence of adverse effects in Parkinson’s disease for trials of Dopamine Agonists (with and without levodopa) versus Levodopa Alone<sup>105</sup>

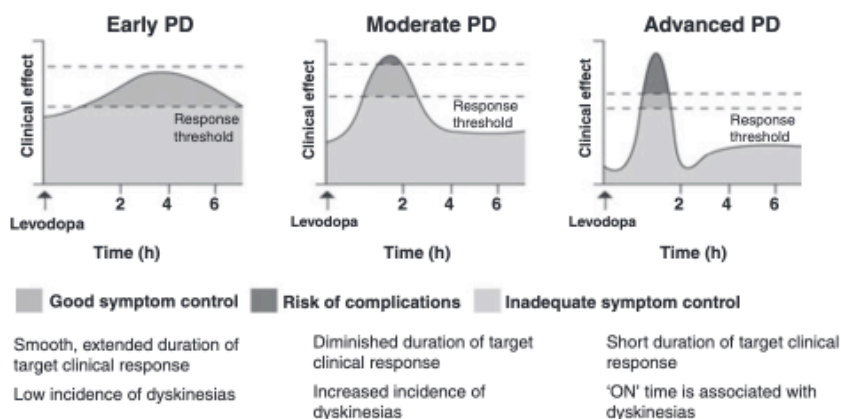


**Levodopa Containing Medications.** Levodopa is the most effective medication for treating PD motor sequelae, because it improves function, QOL and reduces morbidity and mortality among PwPD.<sup>18</sup> The medication is

converted to dopamine in the brain and is administered to increase striatal dopamine levels.<sup>18</sup> Its tolerability and efficacy was improved by combining levodopa with dopa-decarboxylase inhibitor (carbidopa-levodopa).<sup>18</sup> While levodopa is the gold standard for managing PD motor sequelae, overtime PwPD can build a tolerance to levodopa and the medication can become ineffective. The response time where levodopa is effective and motor sequelae is minimized is known as the “on” time. The “off” time is the period before the next levodopa dose is consumed and motor sequelae are present. **Figure 3** highlights the change in levodopa response over the progression of PD.<sup>18,106</sup> Those with early stage PD seem to have a prolonged response to levodopa containing medication with longer “on” times and shorter “off” periods. As the disease progresses, the short half-life of levodopa and increase tolerance, medication duration of action and motor benefit wears off quicker before the next dose is scheduled. In advanced PD, adverse effects of levodopa, such as dyskinesias during the “on” time emerge and levodopa becomes ineffective. As a result, PwPD have to take levodopa more frequently and often at higher doses.<sup>18</sup> To optimize the effectiveness of levodopa, levodopa containing medications are not usually prescribed in the early stages of PD and introduced later as motor sequelae become more pronounced. Levodopa also competes with absorption with neutral amino acids found in animal protein, and if consumed with high protein meals the medication is less effective. People with PD taking levodopa-containing medication are encouraged to wait 30-minutes to an hour between consuming a high protein meal and taking their

levodopa containing medication.<sup>61</sup> As a result, working with a Registered Dietitian (RD) to manage medication and nutrient timing is essential to prolong the effectiveness of levodopa-containing medication.<sup>41</sup>

**Figure 3:** Change in Levodopa Response Over the Course of PD<sup>18,106</sup>



**Other Pharmacologic Treatments for PD.** Anticholinergic agents and MAO-B Inhibitors can also be prescribed to treat PD but are less common due to their adverse effects or ineffectiveness. Side effects of anticholinergic agents include confusion, impaired memory, constipation, blurred vision, urinary retention, dry mouth and glaucoma.<sup>9</sup> MAO-B Inhibitors, while produce less side effects, are ineffective when used alone to manage PD. Side effects of MAO-B Inhibitors include insomnia, nausea, anorexia, hallucination, and potential interaction with medications such as selective serotonin reuptake inhibitors and meperidine. Many PwPD receive a combination of medications to manage PD which may have side-effects that impact, dietary intake, medication-interactions and health-related quality of life. These side-effects can impact adherence to medication and working closely with a neurologist, pharmacist and RD can help optimize medication effectiveness.

***Pharmacologic Adherence.*** People with PD taking anti-parkinson medication often need to take a steady level of medications throughout the day. As PD advances medication management becomes more complex and PwPD may have to take anti-parkinson medication every 2-3 hours. However, with advanced disease, motor and cognitive deterioration may make adhering to such complex medication treatment too difficult for PwPD on their own, resulting in greater amount of time, effort and family support needed to manage medications regimens.<sup>107,108</sup> In the US it is estimated that 27.3-67% of PwPD have poor adherence to anti-parkinson medication management.<sup>108-</sup>

111

In an exploratory, qualitative study, Shin et al<sup>108</sup> interviewed 16 PwPD and five informal caregivers to better understand challenges to anti-parkinson medication adherence and strategies used by PwPD and caregivers to overcome these challenges. Challenges among participants included medication responses, cost of medication, or forgetting to take medications.<sup>108</sup> Those who described medication response as a reason for missing doses was because they did not notice any difference or effects after taking their anti-parkinson medication.<sup>108</sup> Several participants also noted that the cost of medication was a burden, despite coverage from their insurance company. Participants also had a concern about protein and levodopa interaction, describing uncertainty about the time they were supposed to wait to consume a high protein meal after taking medication and difficulty scheduling daily routines around meal times.<sup>108</sup> Finally, a few participants reported not taking

their medication at the prescribed time because they forgot.<sup>108</sup> Strategies used by PwPD and caregivers to facilitate medication adherence included seeking knowledge about the medication, seeking advice from family and friends, using pillboxes to keep track of medications or using alarms and smartphones to set reminders to take their medication.<sup>108</sup> Findings from this study can help inform medication adherence interventions among PwPD to minimize food-drug interactions and optimize medication effectiveness. In addition to using smart phones for medication adherence, digital health technologies, such as cloud technologies are being used internationally to promote medication safety and adherence in aged societies.<sup>112</sup> Such findings advocate or exploration of how cloud technologies and digital health may support medication safety and adherence among PwPD.<sup>112</sup>

## ***ii. Deep Brain Stimulation***

Deep brain stimulation (DBS) is an established and effective treatment strategy for those living with advanced PD.<sup>113</sup> This surgical procedure involve implanting a device that delivers small electric shocks to areas of the brain. In PwPD the target areas of the brain include the subthalamamic nucleus (STN) or the globus pallidus pars interna (GPi).<sup>113</sup> Deep brain stimulation can effectively help manage motor fluctuations and dyskinesias. Findings found the motor benefits from DBS were sustained over 36 months and longer longitudinal evaluation is warranted.<sup>113</sup> When targeting STN specifically, there is a significant reduction oral medication required among PwPD.<sup>113</sup> However, DBS targeting the STN does seem to improve depressive symptoms to the

significant extent as stimulation to the Gpi.<sup>113</sup> Research suggests veterans with PD who received DBS compared to those who received usual care have longer survival rates.<sup>114</sup> Stroupe and colleagues<sup>115</sup> compared the healthcare utilization and costs of veterans with PD who received DBS compared to those who did not over five-years and found average healthcare costs for veterans who received DBS were \$77,131 higher (\$162,489 vs \$85,358). However, when excluding costs for DBS procedures and complications, there was no significant difference in average total healthcare costs between veterans that received DBS and those who did not.<sup>115</sup> When assessing the economic value of DBS, a cost benefit analyses should be taken into consideration, including the survival benefits of DBS.<sup>114,115</sup> In addition to medication and surgical treatment for managing PD, ancillary services can help curtail disease progression.

#### **b. Ancillary Services for Managing PD**

Rehabilitative and complimentary medicine programs are being promoted to compliment pharmacological and DBS treatment.<sup>41</sup> This includes physical therapy and speech therapy, occupational and exercise regiments.<sup>41</sup> Lee Silverman Voice Therapy Big (LSVT BIG Therapy) consists of five tasks focusing on large trunk and extremity functional movements,<sup>116</sup> and requires PwPD to attend four sessions per week for four weeks.<sup>117</sup> The therapy improves physical functioning among PwPD and helps manage PD related feelings of fatigue and depression.<sup>118</sup> Exercise programs help prevent falls, optimize body composition, and improve physical functioning and ability to

perform ADL.<sup>119</sup> Exercise programs that can benefit physical functioning and overall health of PwPD include: treadmill<sup>120</sup> and resistance training<sup>121</sup>, Tai Chi<sup>122</sup>, dancing<sup>123</sup>, biking<sup>124</sup> and boxing.<sup>125</sup>

Visits with a speech language pathologist (SLP) are also a vital part of the PD treatment plan, as the SLP can evaluate, diagnose and treat swallowing and cognitive-linguistic issues that develop among PwPD.<sup>126</sup> The SLP is also vital in prescribing appropriate modified textured and fluid consistencies to help reduce risk of choking and aspiration pneumonia. An SLP can also provide swallowing exercises to strengthen muscles related to swallowing and improve QOL.<sup>127</sup> The SLP can also treat speech and voice disorders that emerge from PD, which include mono-pitch, reduced loudness, slowed and slurred speech or inaccurate articulation.<sup>128</sup> Lee Silver Voice Treatment LOUD (LSVT LOUD) is an effective form of speech therapy for managing speech disorder related to PD.<sup>128</sup> The treatment requires PwPD to attend one-on-one sessions four days a week for four weeks.<sup>128</sup> The one-hour sessions have been found to increase vocal loudness and functional communication among PwPD. Both LSVT Loud and BIG require tone ups and to keep up with the exercises in between the 4-week sessions.<sup>129</sup> For PwPD to have added benefits of such programs, high frequency and repetition is needed and this can be time consuming for PwPD and their informal caregivers and prevent PwPD from accessing an interdisciplinary treatment plan.



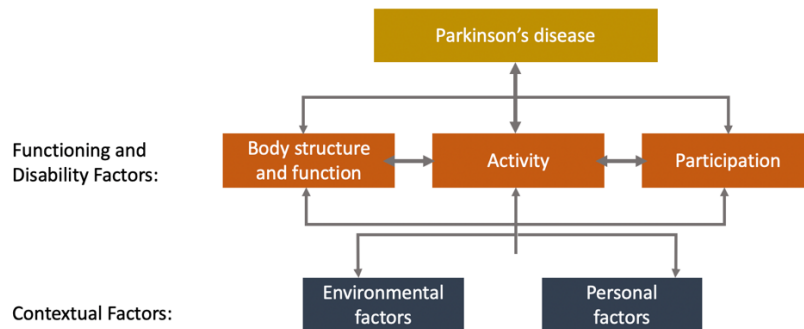
### **c. The International Classification of Functioning, Disability and Health**

The International classification of Functioning, Disability and Health (ICF) is a framework approved by the World Health Organization to describe and classify functioning and disability among adults and children living with health-related conditions.<sup>130</sup> The ICF can be used with the International Classification of Disease and Related Health Problems (ICD) to provide a comprehensive picture of a person's health. Health is defined by the World Health Organization as "the complete physical, mental and social functioning of a person and not merely the absence of disease."<sup>130</sup> With this proposed definition, ICF is an essential component.<sup>130</sup> The framework can be used in interprofessional practice, to promote person-centered care and to establish a common language across disciplines, including for those working with PwPD.<sup>130,131</sup>

The ICF framework is broken down into two major components: 1. Functioning and Disability and 2. Contextual Factors. Figure 4 has been adopted to capture the major components when working with PD.<sup>130</sup> Functioning and disability factors include: body functions and structures, activity and participation.<sup>130</sup> Body functions and structure describe the actual physical and psychological status of the person. While activity and participation describes their ability to function and participate in desired activities. Functional status includes mobility, communication, interpersonal relationships, ability to safely feed oneself, self-care, and knowledge

acquisition and application.<sup>130</sup> Contextual factors include environmental factors and personal factors. Environmental factors are those factors that can influence one's health that are not within the person's control (family, government policies, cultural beliefs and work). Personal factors (race, gender, age, education level and coping styles) may influence how a person manages their disability and activities they participate in.<sup>130</sup> The domains within each factor are highlighted in **Figure 5**.

**Figure 4:** World Health Organization's 2001 ICF Model Adopted for PwPD<sup>130</sup>

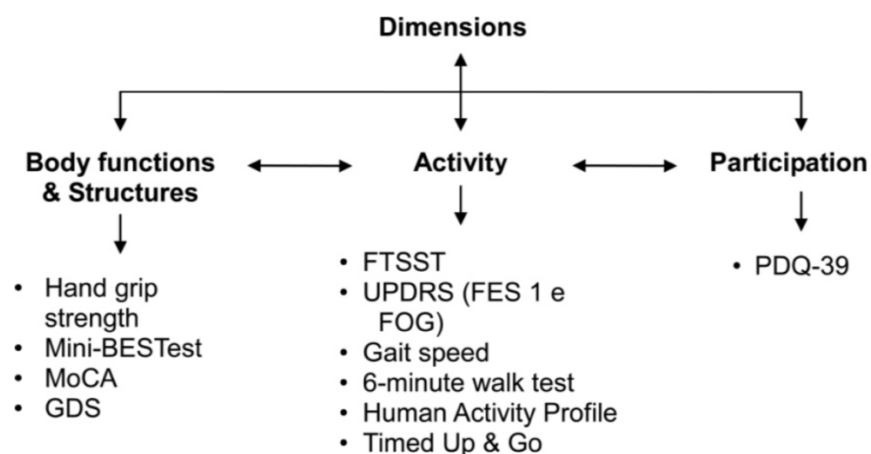


**Figure 5:** World Health Organization's 2001 ICF Major Components and Domains<sup>130</sup>

<p><b>Body Function:</b>            Mental functions            Sensory functions and pain            Voice and speech functions            Functions of the cardiovascular, haematological, immunological and respiratory systems            Functions of the digestive, metabolic, endocrine systems            Genitourinary and reproductive functions            Neuromusculoskeletal and movement-related functions            Functions of the skin and related structures</p>	<p><b>Activities and Participation:</b>            Learning and applying knowledge            General tasks and demands            Communication            Mobility            Self care            Domestic life            Interpersonal interactions and relationships            Major life areas            Community, social and civic life</p>
<p><b>Body Structure:</b>            Structure of the nervous system            The eye, ear and related structures            Structures involved in voice and speech            Structure of the cardiovascular, immunological and respiratory Systems            Structures related to the digestive, metabolic and endocrine systems            Structure related to genitourinary and reproductive systems            Structures related to movement            Skin and related structures</p>	<p><b>Environmental Factors:</b>            Products and technology            Natural environment and human-made changes to environment            Support and relationships            Attitudes            Services, systems and policies</p>

Vojciechowski and colleagues<sup>131</sup> completed a literature review to describe and quantify the development use of IFC and portray the different components of IFC that have been used in PD. Only four studies have examined the relationship between IFC and PD. Questionnaires and assessments administered among PwPD and their relationship between ICF domains are summarized in **Figure 6**.<sup>131</sup> Findings from this review concluded more research is needed to better examine the association between the ICF and PD.<sup>131</sup> Additionally, ICF and its relationship to PD outcomes following a health intervention is also warranted.<sup>131</sup> Adoption of the ICF for PD and understanding the relationship between ICF and PwPD outcomes, can help better track changes among PwPD and provide a universal language between the healthcare team, and promotes PwPD and their caregivers at the center of the careteam.<sup>130</sup>

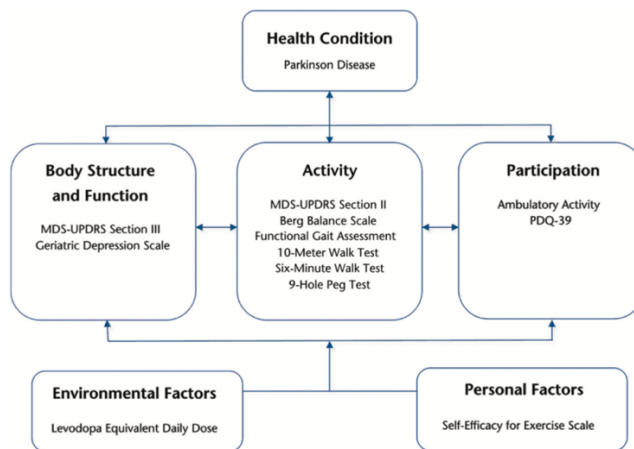
**Figure 6:** Questionnaires and Function Tests Related to the ICF Domains and PD<sup>131</sup>



*Abbreviations: Mini-BESTest=balance, evaluation systems test; MoCA=Montreal cognitive assessment; GDS=geriatric depression scale; FTSST=five times sit to stand test; FES 1 e FOG=falls efficacy scale, freezing of gait; PDQ-39=PD questionnaire-39*

Components of the ICF model cover aspects of health-related QOL and allows for interaction between domains as a result ICF can serve as a predictor for health-related QOL and health status.<sup>58</sup> The model is encouraged to be used by physical therapists among PwPD to guide daily functioning and identify specific needs.<sup>58</sup> How ICF can be used across other help professionals, such as RDs, for the treatment plan of PwPD and impact health-related QOL needs further explanation. In a prospective, two-year study, Cavanaugh et al examined clinical measures associated with ambulatory activity decline among PwPD. The clinical measures assessed fit into the major domains of the ICF model (**Figure 7**). Findings from this study showed the potential to use ICF model to track long-term ambulatory function among PwPD. Utilization of this model assessing and tracking PD progression over longer periods of time is warranted.

**Figure 7:** Study measures for PwPD according to ICF model domains

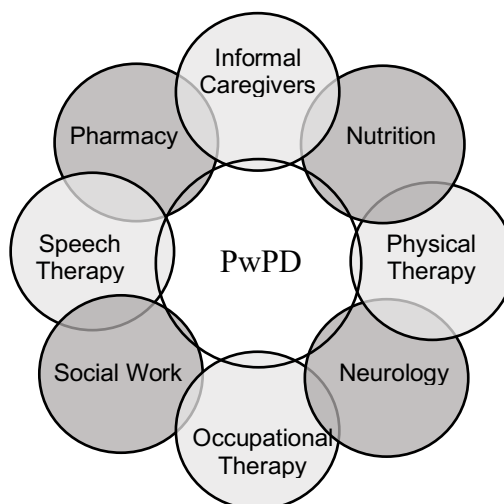


**Figure.** Study measures categorized according to *International Classification of Functioning, Disability and Health* model domains. MDS-UPDRS=Movement Disorder Society–Unified Parkinson’s Disease Rating Scale, PDQ-39=39-item Parkinson’s Disease Questionnaire.

#### d. Care Model for Managing PD

Worsening of disease sequelae overtime, combined with declining nutritional status negatively impact QOL<sup>132</sup>, which can further compromise ability to perform ADL, making PwPD more reliant on caregiver.<sup>133,134</sup> Due to this increase reliance, caregivers are essential to healthcare and can partner with healthcare providers to more effectively implement treatment and promote adherence of PD treatment.<sup>70,135</sup> Including caregivers in interventions can address some of the nutritional concerns PwPD face, allowing caregivers to help maintain the health of PwPD and their own health.<sup>41,70</sup> Interdisciplinary care is recommended for managing PD, but nutritional care and inclusion of informal caregivers is often overlooked; **Figure 8** has been modified to include informal caregivers and nutrition services in interdisciplinary PwPD care.<sup>136</sup>

**Figure 8:** Modified Interdisciplinary Service Model for PwPD<sup>136</sup>



In a mixed-methods study, Kessler and colleagues<sup>137</sup> surveyed 57 PwPD and 30 caregivers and interviewed 13 PwPD, six caregivers, and six healthcare providers to develop an integrated care program for managing PD. The development of these program advocates for a collaborative approach, integrating PD and caregivers as an active part of managing PD. The collaboration calls for self-management, support and communication with and between healthcare providers. To create this tertiary PD clinic, co-design was utilized, which included viewpoints of key stakeholders, including PwPD and caregivers. Promoting self-management of care provides PD dyads with the skills and confidence needed to manage a chronic health condition on a day to day basis. People with PD and caregivers wanted more support with goal-setting to promote self-management, follow up with healthcare providers and access to services to better manage PD. Both PwPD and caregivers expressed satisfaction when they were able to make decisions collaboratively with their health care providers. Findings from this study should be considered when designing healthcare services for PD dyads to promote access to comprehensive care.

#### **e. Resource Availability**

Since many PwPD have limited access to healthcare due to disease sequelae, age and location<sup>138,139</sup>, an improved model to address healthcare access and need is critical.<sup>138,139</sup> People with PD experience cognitive and physical decline that can impact mobility and driving ability, which in turn can reduce access to medical care.<sup>54</sup> While more research is needed to determine

if there is a higher occurrence of PD among rural vs urban populations, research has found a link between occupational exposures and increased incidence of PD. These occupations that appear to have an increased occurrence of PD include agriculture, working with pesticides, and heavy metals.<sup>140</sup> Those PwPD living in rural areas are especially at increased risk for inadequate access to treatment.

According to the current interdisciplinary care model, PwPD should see a neurologist 2-4 times a year<sup>141</sup>, and physical therapists and speech language pathologists up to 4 times a week for certain treatments.<sup>54,142</sup> This can be burdensome for PwPD and their caregivers, due to limited access to transportation and compromised physical mobility.<sup>50</sup> Up to 40% of Medicare beneficiaries with PD do not seek care from a neurologist within the first four years after diagnosis.<sup>138</sup> Additionally, while physical and speech therapies exist to help manage PD sequelae, there are no recommendations for routine appointments with allied health professionals, including speech-language pathologists, physical and occupational therapists, exercise physiologists and/or registered dietitians (RDs).<sup>41</sup> Monitoring how PwPD change across the domains of nutrition, cognitive-linguistic and physical functioning can help better understand health needs of PwPD.<sup>38</sup> Inclusion of allied health professionals can help attenuate burden of disease sequelae, improve QOL and may lower healthcare costs.<sup>143</sup>

Due to limited mobility, visuospatial impairment, decreased access to transportation options, need for visual assessment and on-going care, PwPD

are excellent candidates for digital health.<sup>26,139</sup> However, nutritional services via digital health are not utilized in this population and the individualized nutrition care needed by PwPD is also an under-recognized component of care.<sup>144</sup> Monitoring the nutritional status of PwPD and caregivers can help better understand nutritional needs and provide effective digital health nutrition services. Tracking how PwPD change overtime can also help monitor and track treatment efficacy provided across disciplines and further promote interprofessional practice to manage PD.

#### I. Theoretical Framework: Technology Acceptance Model

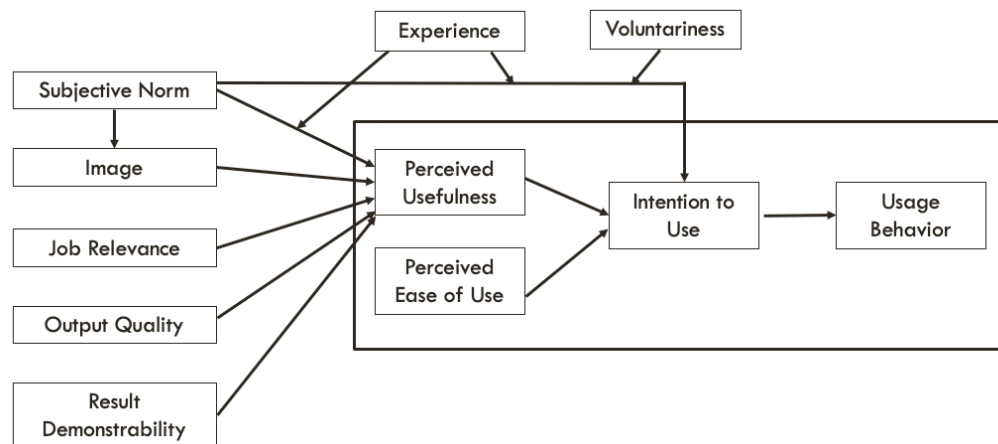
Obtaining PwPD preferences and opinions regarding features of technology to manage health can help to inform the creation of a user-friendly, evidenced-based digital health service.<sup>145</sup> Formative analysis has been used to effectively employ digital health technologies for older adults<sup>146,147</sup>, and in the development of dyadic interventions for PwPD.<sup>148</sup> Understanding PD dyads preferences for technology to manage and track nutrition health can be incorporated into the technology acceptance model (TAM).<sup>149</sup>

The TAM was created to explain computer usage behavior across a broad range of user populations and end-user technologies.<sup>149</sup> The model seeks to provide a basis for understanding external factors that influence internal beliefs, attitudes and intentions to use technology (**Figure 9**).<sup>149</sup> External factors can directly impact perceived usefulness and perceived ease of use related to various computing technologies. The model hypothesizes that perceived usefulness and perceived ease of use jointly determine acceptance,



which can influence intention to use and actual behavior use of technology.<sup>149</sup> The TAM has also been modified to specifically examine technology acceptance among older adults, known as the Senior Technology Acceptance Model (STAM). The external factors STAM examines specifically relate to aging populations that may impact technology use and attitudes toward technology.<sup>150</sup> These external factors include: self-efficacy to learn technology, anxiety toward technology, facilitating conditions, self-reported health conditions, cognitive ability, social relationships, attitude to life and satisfaction and physical functioning.<sup>150</sup> External factors that impact PD dyads to use technology are important to understand to ensure usability and utilization of digital health for managing PD.<sup>150</sup> As a result, including PwPD and caregivers in the formative stages of research can facilitate the creation of user-friendly digital health nutrition services.<sup>145</sup>

**Figure 9: Technology Acceptance Model<sup>149</sup>**



## II. Digital Health

### A. Overview of Digital Health

Improvement in the current healthcare model for PwPD is needed to effectively meet patient needs.<sup>54,138</sup> Digital health describes technologies that better manage and track health.<sup>151</sup> Additionally, as technology adoption increases, eight in ten (113 million internet users) seek health information online.<sup>152</sup> Specifically, 64% of adults living with one or more chronic diseases seek health information from online sources.<sup>153</sup> Most US adults (77%) report owning a smart phone device.<sup>154</sup> Recent efforts have been made to develop and use digital health to assess, monitor, and provide therapeutic treatments for PwPD.<sup>26,155</sup> Such efforts can increase access to care and promote efficiencies in providing care.<sup>156</sup>

More than 40% of PwPD are over the age of 65, and most PwPD living in rural areas will not see a neurologist after diagnosis.<sup>138</sup> Forty-percent of Medicare beneficiaries with PD do not seek care from a neurologist within the first four years after diagnosis.<sup>138</sup> In addition to visits with neurologists 2-4 times per year<sup>141</sup>, multidisciplinary care models, including visits with physical therapists and speech language pathologists, are encouraged and effective.<sup>157,158</sup> Some of these treatments require sessions four times per week<sup>142</sup> which can be a challenge for those with limited access to transportation and compromised physical mobility, thus becoming burdensome for PwPD and caregivers.<sup>54</sup> Disease stage is associated with driving safety, where stage 3 is significantly associated with a decline in driving ability.<sup>159</sup> Due

to immobility, limited means of transportation, and ongoing multidisciplinary care, PwPD are excellent candidates for digital health.<sup>139</sup>

Digital health serves as a gateway to efficacious and convenient health information and treatment.<sup>156</sup> Digital health increases access to health services, decreases healthcare inefficiencies, offers more personalized services, and reduces burden and medical costs for those living with neurological disorders, including PD.<sup>156</sup> Technological advancements such as cloud computing, sensors/wearable devices, mobile and video communications<sup>160,161</sup>, and social networks<sup>151</sup> increase access and quality of care for PwPD.<sup>26</sup>

In addition to usability and increasing access to care, digital health adoption can help minimize healthcare costs. In 2012, the Veterans Health Administration served 150,000+ telehealth beneficiaries, and estimated an annual savings of \$6,500 per user; a billion dollar savings system-wide.<sup>162</sup> People with PD that have utilized digital health services have saved on miles traveled and commute time to healthcare providers.<sup>156</sup> Specifically, PwPD saved 100 miles of travel and three hours of time compared to in person visits.<sup>156</sup> Patients and clients are interested in utilizing digital health, and high patient satisfaction is reported by those PwPD who have utilized digital health.<sup>156,163</sup>

#### **A. PwPD Viewpoints on Digital Health**

Interests and opinions of digital health among PwPD and their caregivers have been assessed. A recruitment webpage for a US-based

randomized control trial utilizing virtual house calls for PwPD received 11,000 individual views worldwide.<sup>164</sup> Caregivers are also receptive and willing to pay for technologies that monitor and support care recipients.<sup>165</sup> Specifically, 20% of informal caregivers were willing to pay for kitchen (e.g., technologies that assist with meal preparation and washing dishes) and self-care activities (e.g., technology to help the care recipient getting in and out of bed, dressing, eating, bathing, or toileting).<sup>165</sup> Of those caregivers willing to pay for such technologies, these caregivers reported willingness to pay 50 dollars per month for monitoring technologies and 70 dollars per month for technologies that both monitor and provide assistance to the care recipient.<sup>165</sup> Findings indicate that a combination of private pay and government subsidy may promote development and adoption of these technologies among informal caregivers.<sup>165</sup> Experts suggest when designing digital health interventions specifically for PwPD, designers and developers should consider caregiver views, needs and preferences.<sup>166</sup>

A large cohort study measured the proportion of PwPD interested in telehealth (i.e., interactive videoconferencing with a healthcare provider) and identified predictors of patient interest to use telehealth. Among PwPD who currently use telehealth services, 85% chose to continue utilizing the service.<sup>167</sup> The five patients who discontinued telehealth were treated with deep brain stimulation (DBS), who required trained professional to be present during the visit due to the lack of training/experience of the nurse/technician with telehealth to manage DBS equipment and monitoring DBS programming.

Approximately 65% of participants who continued to use telehealth reported they wanted a combination of in person and remote services.<sup>167</sup> Of those PwPD who had never used telehealth before, 53% were interested in using the services, believing utilization of the service could result in significant cost savings.<sup>167</sup> Others interested in telehealth were in the early stages of PD and believed physical examinations by a physician were not necessary at every appointment, so telehealth could serve as check-ins with their physician.<sup>167</sup>

In contrast to these findings summarized above, a cross-sectional survey assessing PwPD views on using different electronic mediums for communicating and exchanging information with healthcare providers, found PwPD may have a less favorable views around technology for communicating with health providers.<sup>168</sup> Nearly 65% of PwPD reported they would be willing to use electronic methods and 48% indicated that using technology to communicate with providers would help PwPD better understand their care. People with PD were asked which forms of technology would help with care. Of the modalities suggested, ~15% supported electronic forms at check-in for medical visits and 40% stated they would like a summary of care/home instructions emailed to them. Of the participants surveyed, ~35% noted they would like the ability to communicate with healthcare providers through email and 33% indicated they would like video education about services offered to PwPD.<sup>168</sup> When stratifying participants by age, those over 65 and over were less likely to believe using technology to communicate with a health provider would enhance their understanding of care. Those 75 years of age and older

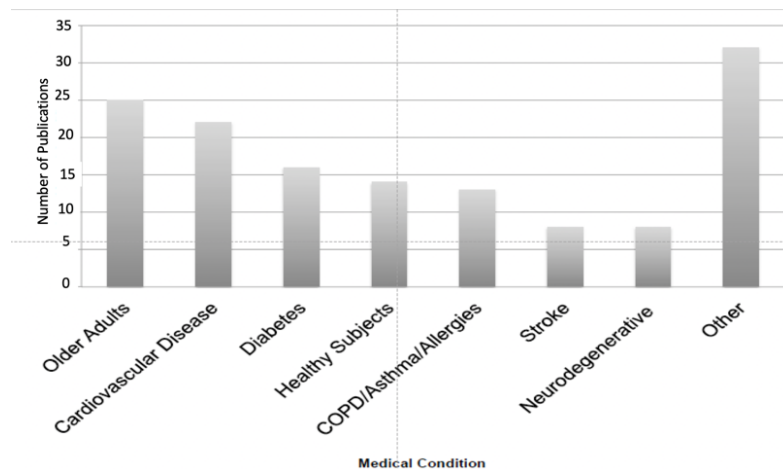
had a lower odds of being willing to use electronic methods and believing that technology would result in better understanding of medical needs or their healthcare providers better understanding their medical needs.<sup>168</sup> Findings from this study indicate optimal communication mediums among PwPD may vary on patient demographics and that training older PwPD to use technology may be warranted. Qualitative interviews are needed to better understand technology choices and preferences of PwPD. Additionally, research that has implemented digital technology among PwPD shows implementation can be advantageous to PwPD and their informal caregivers, including reduced burden and time saved, which further promotes digital health as an efficacious medium for delivering healthcare services.<sup>169</sup>

### **B. Efficacy of Digital Health for Managing Parkinson's**

Digital health, such as telemedicine, has been used successfully in a variety of populations that have evaluated usability (**Figure 10**).<sup>170</sup> A review of 138 studies was conducted, eight included end-users with neurodegenerative diseases, including PD.<sup>170</sup> People with PD have used telehealth for visits with specialty physicians and multidisciplinary care providers, such as physical therapy, speech therapy and mental healthcare.<sup>142,156</sup> Digital health mediums used for managing PD include wearable devices<sup>171</sup>, telehealth<sup>142,163</sup>, and online communities.<sup>172</sup> Telehealth, or interactive videoconferencing, provide healthcare providers visual cues of patients, which makes the visit more objective<sup>139,173</sup>. Wearable devices collect continuous data to provide a more realistic portrayal of PwPD's daily behaviors and clinical outcomes overtime

unlike subjective data or cross-sectional assessments.<sup>171,174</sup> Telehealth can also provide social support and reduce burden and cost for PwPD and caregivers.<sup>175,176</sup> For example, speech therapy for PwPD via telehealth saved each caregiver 48 actual hours involved in a speech therapy visit, 92 hours of work time (time taken off from work), and over \$1000.<sup>169</sup> In addition to economic benefits and reduced participation burden, telehealth increases access to health information, provides effective quality of care, and influences individuals to make healthy lifestyle choices.<sup>177,178</sup> Telehealth is believed to motivate patients to increase access to care, achieve greater control over disease management, and serves as an effective medium for healthcare management in older adults.<sup>179-181</sup>

**Figure 10: Medical conditions and telemedicine<sup>170</sup>**



Online communities are another form of digital health may empower PwPD to be more active participants in their own care.<sup>172</sup> Online health communities are a form of communication technology that allow patients to interact with their team of healthcare providers, other patients with the same diagnosis, and

caregivers. These communities also allow patients to track their health information and become involved in research.<sup>182</sup>

### **1. Telehealth**

There have been successful telehealth interventions in PwPD across various disciplines. Dorsey et al.<sup>156</sup> conducted a 7-month, trial in which PwPD were randomly assigned to receive specialty care from a neurologist in-person or home via telehealth and found telehealth to be as effective as in person-care. Study findings indicate feasibility of telehealth for specialty visits, with a 93% completion rate of visits.<sup>156</sup> Constantinescu et al.<sup>142</sup> conducted an intervention where PwPD were randomized to receive voice treatment therapy via videoconference or in person and found that both groups saw an increase in acoustic measures and reported high patient satisfaction. Findings from this study confirmed the efficacy, validity and reliability of videoconference for voice treatment.<sup>142</sup> Additionally, there was no difference between quality of life scores and motor scores between groups.<sup>156</sup> Another randomized trial found telerehabilitation could effectively assess ADLs and hand function compared to an in-person assessment.<sup>183</sup> Whether a comprehensive nutrition assessment can also be conducted via telemedicine has yet to be explored.

Two studies support using telemedicine as part of patient care but not in place of in-person care. Sekimoto et al.<sup>184</sup> conducted a randomized crossover pilot study of telemedicine via iPads using Facetime. During the telemedicine visit, clinicians performed perform a structured interview, medication review and motor examination in between in-person visits.



Findings from this study indicate telemedicine service could be used in conjunction with in-person visits, as no difference in quality of life was reported between groups and PwPD in the telemedicine group reported high satisfaction. Finally, Wilkinson et al.<sup>163</sup> examined if telehealth delivered in the home and at a satellite clinic compared to those receiving usual-care and found no difference in patient satisfaction or clinical outcomes between groups. Those in the telehealth group saw a significant decrease in travel time, but compared to the usual-care groups the satellite arm had significantly lower proportion of “no-shows”/cancellations.<sup>163</sup> Findings reiterate telehealth can enhance usual care health services and can benefit patients who face barriers to receive in-person care regularly.<sup>185</sup>

## ***2. Devices, Wearables, & Sensors***

Over the last decade, advancements in sensors and wearable technologies have been made, allowing these innovative mediums to gain popularity to complete and compliment evaluations of PwPD.<sup>186</sup> Devices such as Kinesia™ and Parkinson’s KinetiGraph (PKG™) can help detect bradykinesia, record resting and postural tremors, and differentiate patterns of bradykinesia and dyskinesia in the “on” and “off states.”<sup>186</sup> Other wearables, such as accelerometers, gyroscopes (device used for measuring or maintaining orientation and angular velocity), and magnetometers (a non-invasive device that monitors heat function), can be integrated in garments or accessories.<sup>187</sup> These accessories can also be used in conjunction with web-based applications.

People with PD report added value of wearable devices. Ozanne et al.<sup>187</sup> conducted focus groups among PwPD and found that participants saw the potential for wearable sensors to improve treatment, and believed the benefits outweighed the inconvenience of wearing sensors. When examining facilitators and barriers to utilizing sensors, participants indicated that user-friendly and a simple design interface would promote usability, as well as receiving interactive information from providers.<sup>187</sup> However, participants were concerned about unclear information, inconclusive recordings and had concerns about protecting personal health information and integrity. In order to encourage use of sensors, findings indicate PwPD need to feel well-informed and find added value when using sensors.<sup>187</sup> Wearables also need to be easy to use, have an attractive design and be efficacious for improving disease management.<sup>187</sup> Findings further support the use of digital health to help manage track Parkinson's disease.

Devices, such as smart phones or iPads are becoming popular mediums to deliver health services to PwPD. mHealth, or "the use of mobile and wireless devices to improve health outcomes, healthcare services and research," has been effectively used in PD management. One study found peer coaching through mHealth can promote physical activity among PwPD and is safe, feasible and acceptable among participants.<sup>188</sup> Both peer coaches and PwPD were satisfied or very satisfied with the program and all PwPD participating saw an increase average steps per day.<sup>188</sup> These findings are significant because delivering support by telephone may be a viable way

to increase physical activity and promote other healthy lifestyle patterns among PwPD. In a pilot study, Arrora and colleagues<sup>189</sup> demonstrated the ability of consumer-grade smart phones to accurately differentiate PwPD from age-matched controls through effectively measuring symptoms. Findings from this study reveal the potential for mHealth to evaluate disease severity.<sup>189</sup>

The integration of wearable technology with smart devices can enable remote monitoring of PwPD and provide clinicians, caregivers and patients with real-time feedback.<sup>26</sup> Patel et al.<sup>190</sup> found that combining wearable sensors with a web-based application for home monitoring PwPD can provide reliable quantitative information that can inform clinical decisions. The system these researchers developed includes 8 accelerometers on the upper and lower limbs which is relayed to a mobile device or computer. The system promotes patient-clinician interaction through video-conferencing or real time access to the sensor data.<sup>190</sup> The proposed system can successfully gather data from PwPD to inform symptom severity and motor fluctuations in between medication doses. Findings from this work indicate that this home monitoring system has the potential to simplify the process of monitoring medication effectiveness.<sup>190</sup>

### **3. *Online Health Communities***

Online support groups via forums, blogs and social media are becoming popular sources for health information.<sup>191</sup> Over 50% of American adults living with a chronic disease have looked online for health information.<sup>192</sup> It is estimated that 90 million (84%) Americans have participated in online

communities and that 43% of internet users are involved in online groups to help manage career, medical conditions or parenting.<sup>152</sup> Approximately, 12% internet using adults with one or more chronic health conditions (e.g., cancer, fibromyalgia, non-specified chronic pain conditions, diabetes, Addison’s disease, bipolar disorder, celiac disease, trigeminal neuralgia, Parkinson’s disease, systemic lupus erythematosus (SLE), rheumatoid arthritis, Sjögren’s syndrome, schizophrenia, cystic fibrosis, and cerebral palsy) maintain a blog and 28% read blogs about their condition written by others (**Figure 11**).<sup>192</sup> A 2019 report examining social media use among Americans revealed 68% of Americans between 50-64 years of age, and 46% 65+ report using Facebook.<sup>193</sup>


**Figure 11:** Internet Activities Among Those With and Without Chronic Conditions<sup>192</sup>

Internet activities			
What internet users reporting 2+, 1+, and no chronic conditions do online			
	No conditions	1+ conditions	2+ conditions
Send or read email	90%	90%	91%
Bank online	58*	46	45
Look for info on Wikipedia	51*	38	31
Get financial information	40*	32	28
Use social network site~	39*	25	19
Read someone else's blog	34*	28	26
Use Twitter or another service~	12*	7	7
Buy or sell stocks, mutual funds, or bonds online	12*	9	5
Create or work on your own blog	11	12	11
Participate in an online discussion	7	8	8

\* indicates a significant difference between those without chronic conditions and those with chronic conditions.

~Twitter and social network site use have grown since this survey was fielded.

Source: Pew Internet & American Life Project Survey, November-December 2008. N=1650. Interviews conducted in English or Spanish. Margin of error is ±8%.



Online discussion forums are one of the most popular ways people interact with each other online. In a discussion forum, one person writes a message/post that can be answered by other members, which forms a conversation thread.<sup>194</sup> Attard et al.<sup>191</sup> examined positive and negative aspects of online PD supports groups through analyzing forum posts from four different support groups; membership within each group ranging from 1000 to 100,000. Benefits of peer communication appeared to be: exchange of knowledge between participants, formation of friendships and the development of support systems to cope with living with PD. The results revealed that participation in forums allowed patients to share experiences and knowledge, form friendships and help each other cope with the challenges of living with PD.<sup>191</sup>

While less frequently reported, there were some drawbacks to participating in online, peer-to-peer communication through forum posts.<sup>191</sup> First, there are a lack of replies or lag time in between replies,<sup>191</sup> which can hinder the experience. Findings revealed that tremors and cognitive impairments can hinder engagement in forum posting among PwPD. For instance, tremors would hinder one's their ability to answer posts when desired.<sup>191</sup> Another barrier of online forum posting is that many PwPD did not want share personal information, as a result personal connections could not be formed between participants. For some participants, online support was not enough, and they felt lonely in their offline environment. Finally, misunderstanding and disagreements occurred on the forums due to lack of non-verbal cues. Findings from this study indicate online communities can

offer PwPD emotional support and foster knowledge but should be used alongside traditional forms of support.<sup>191</sup> Additionally, health professionals should partake in these online support groups through monitoring or facilitating posts to ensure the accuracy of information exchanged.<sup>191</sup> Health professionals may also help guide PwPD using such online communities to reputable websites and publications.<sup>191</sup> Roles of healthcare professionals in online communities is becoming especially important with the rise of online blogs.

Illness blogs are a type of online blog, where patients freely describe their experience managing their condition overtime.<sup>195</sup> Readers have an opportunity to respond to blog posts, and as readers become more involved in the blog, a community is created.<sup>195</sup> Shapira and colleagues<sup>195</sup> completed a thematic analysis of 78 illness blog authors with PD to explore medical illness concerns blog authors had and found these authors typically discussed diagnosis and symptoms, treatment, coping mechanisms and providing information to their readers about PD. Treatments discussed included: medication, exercise, supplements, nutrition, complimentary therapies and surgeries. Only three authors blogged about nutritional modifications for PD, which included experimenting with diets to optimize medication management, trying vegan diets, fasting, and lowering sugar and protein intake.<sup>195</sup> The reason that so few PwPD discussed diet in blog posts could be because nutrition is often excluded from the PD care plan.<sup>41</sup> However, findings from this study reveal analyzing illness blogs may be a viable way understand the

health concerns and medical and nutrition issues raised by PwPD online and in a non-medical setting.<sup>195</sup>

Personal online health communities have also been developed to promote online communication between PwPD and their healthcare providers.<sup>172</sup> Visser et al.<sup>172</sup> conducted semi-structured interviews and observed the use of online health communities among PwPD for over a year. Patients could communicate with their provider through diary entries or virtual meetings/postings. Providers did not receive notifications when the PwPD posted a diary entry but did with the virtual meeting post. Participants could also update a stored list of health problems and upload health documents.

Three major themes that emerged from these analyses were: “number of postings,” “coming across as a complainer,” and “hesitating about legitimacy of knowledge.” In regard to “the number of postings,” many PwPD expressed concerns about burdening their healthcare providers with too many questions and limited their number of postings to only concerns that needed immediate attention from their provider. However, PwPD found the diary section of the online health community to be less disruptive to healthcare providers and shared more information in their section of the community.<sup>172</sup> The PwPD also felt obligated to report and update symptoms, but did not want to come across as a complainer, so refrained from expressing emotions or feelings regarding PD sequelae.<sup>172</sup> The use of online communities can change the power-dynamics between the provider and PwPD, especially when the provider can no longer visually assess the PwPD and must depend on self-reported

symptoms from the PwPD.<sup>172</sup> Many PwPD believed the provider still possessed the greatest amount expertise about their condition, despite the change in delivery of care.<sup>172</sup> As a result, PwPD presented their knowledge and interpretation of their symptoms as an opinion and were hesitant to make claims about their condition.

Findings from this study reveal even though online communities are innovative mediums to deliver healthcare services they have not met the expectation of creating more pro-active patients or changing the power processes between provider and patient and pre-existing norms regarding patient-provider dynamics persist. Future health communities need to focus on creating a two-way exchange between provider and patient, where healthcare providers share additional resources for managing PD to help PwPD gain more knowledge about the disease. More research also needs to assess digital health to manage the nutritional status and diet intake for PwPD or their caregivers. This is because PwPD are likely at nutrition risk and as nutrition concerns increase as PD progresses, caregiver responsibility to manage diet increases, but nutrition is often excluded from the treatment plan of managing PD.<sup>41</sup>

#### **A. Efficacy of Digital Health for Managing Nutrition**

Research has not directly examined the use of digital health for managing nutrition and PD, but success with digital health for PD, as well as digital health's ability to help manage nutrition in other populations<sup>196,197</sup>, compels expanded use of digital health nutrition services for PwPD. Digital



health services can increase fruit and vegetable consumption<sup>196,197</sup>, decrease fat intake<sup>198</sup>, self-efficacy to make healthy dietary choices<sup>197</sup>, and promote sustainable dietary changes.<sup>198</sup> Tailored digital nutrition interventions addressing participants' environment and learning preferences improved diet quality more than providing generic nutrition information through online modules (n=1349).<sup>199</sup>

Mobile devices can help track dietary intake.<sup>200,201</sup> Using mobile applications (e.g., Lose It! and MyFitnessPal) to track food intake can provide instant feedback about all calories and nutrients consumed. Dietary self-monitoring however takes time and effort and technological advances such as Remote Food Photography Method are being developed to improve the ease of self-tracking dietary intake.<sup>200</sup> Through the Remote Food Photography Method users submit photos pre and after consuming food to researchers and researchers perform semiautomatic computer analysis to determine the nutritional value of those foods.<sup>200</sup> Neriah and Gelibeter<sup>201</sup> conducted a retrospective cohort study to determine the effectiveness of using photography to track food intake via a smartphone weight loss application. Compared to the traditional weight loss app group the group with the photography feature lost significantly more weight and tracked their food for a longer duration. Weight loss in the photography group was mediated by the duration of app use and number of logged days in the program.

Telenutrition is another solution for PwPD and can help to increase access to nutrition information in rural areas.<sup>202</sup> Telenutrition is the remote

delivery of medical nutrition therapy (MNT) by a registered dietitian using interactive electronic information and telecommunication technology (e.g. videoconferencing).<sup>202</sup> A randomized controlled trial assessing the feasibility of telenutrition weight loss intervention in middle-aged and older men with cardiovascular risk factors, found telenutrition services demonstrated patient satisfaction as well as good adherence and retention rates.<sup>203</sup> During this 12-week intervention, men were randomized to either the intervention group or enhanced usual care group. The intervention group received three medical nutrition therapy sessions from a registered dietitian at week one, five, and nine to nine nutrition coaching sessions at weeks 2-4, 6-8 and 10-12.<sup>203</sup> The MNT sessions included individualized nutrition assessment, education and counseling sessions. The coaching sessions were patient-led discussions around topics such as, self-monitoring weekly weight, goal setting, and overcoming barriers to dietary adherence. The enhanced usual care group did not receive nutrition coaching in between their in-person sessions at weeks one, six and 12.<sup>203</sup>

Both groups lost a significant amount of weight and there was no difference in the amount of weight loss in between groups. Both groups saw an improvement in total fruit ( $p=0.05$ ), whole grains ( $p=0.004$ ), and fatty acid ratio scores ( $p=0.002$ ). Participants lowered refined grain ( $p=0.04$ ), sodium ( $p=0.01$ ), added sugars ( $p=0.01$ ) and saturated fat scores ( $p=0.002$ ) healthy eating index (HEI) component scores. However, the intervention groups saw a greater improvement in total fruit ( $p=0.04$ ), whole fruit ( $p=0.04$ ), and green

beans ( $p=0.013$ ). Findings from this study show promise for PwPD, as there is a higher occurrence of PD among men than women.<sup>12,13</sup> More information is also needed to determine how digital health nutrition interventions may impact caregivers and reduce caregiver burden, as caregivers are involved in managing dietary intake for PwPD.<sup>24</sup>

### **B. Efficacy of Digital Health for Informal Caregivers**

Technology, including digital health can support caregivers and promote better coping.<sup>204</sup> More than 30 million US adults provide home caregiving and approximately 80% of these caregivers seek health information online.<sup>205,206</sup> Caregivers believe that technology can help provide more efficient, effective and safer care and reduce stress when delivering care.<sup>204</sup> Nearly 75% of caregivers stated they would be willing to pay for access to a website for a complex care matter and 85% believe insurance should pay for access to such websites.<sup>207</sup> While digital health has been used to manage chronic disease more information is needed to understand the impact of telehealth interventions can have on informal caregivers and how digital health can offer support and address informal caregivers' health needs.<sup>204</sup>

Chi and Demiris<sup>204</sup> conducted a systematic review assessing of 65 studies that included informal caregivers and utilized digital health technologies to provide education, consultations, psychosocial therapy, social support, data collection and monitoring systems, or deliver clinical services. The most common medium used by studies reviewed was videoconferencing. In 95% of the articles reviewed, caregivers reported improvements in

outcomes, such as psychological health, satisfaction and comfort with digital health, caregiving knowledge and skill, and social support.<sup>204</sup> Nearly a quarter of the studies reviewed, were conducted among caregivers living in remote or rural areas and brought significant improvements in caregivers' QOL and psychological well-being. Findings from this review conclude telehealth can provide acceptable care and save travel costs for caregivers of patients who need long-term care and monitoring, such as PwPD.<sup>204</sup>

Several studies have specifically examined digital health interventions delivered for caregivers of PwPD.<sup>176,208</sup> These studies specifically looked at virtual support groups and their impact on coping with caregiving responsibilities, disease burden and QOL.<sup>176,208</sup> In a study conducted by Marziali et al.<sup>208</sup>, caregivers of persons with Alzheimer's, Stroke or PD met weekly for 10 weeks via videoconference in small groups lead by a support group leader. At the end of 10 weeks and six-month follow up, 90% of participants reported a positive experience and found the group helped with coping with the stresses of caregiving. Findings revealed virtual support groups were comparable to in-person groups. In a small pilot study, caregiver tele-support groups was a feasible option and showed promise to potentially improve depression scores and decrease caregiver burden.<sup>176</sup> Whether nutrition assessment and nutrition interventions can also be delivered to caregivers of PwPD warrants exploration.

## **II. Nutrition Assessment**

Poor nutritional status is an imbalance of energy and/or nutrient intake, resulting in suboptimal body weight and composition, function, and/or clinical outcomes, which can eventually lead to malnutrition in the forms of over- and under-nutrition.<sup>209,210</sup> Assessing the nutritional status of PwPD includes the traditional examination of dietary intake, anthropometrics, and biochemical and clinical measures,<sup>209,210</sup> as well as a focus on possible food-drug interactions, duration of medications and history of depression and anxiety.<sup>70</sup> A cross-sectional study, examining nutritional intake of PwPD for nutritional and protein risk, found that nearly 63% of PwPD would be categorized as with malnutrition or at risk for malnutrition, ~53% exhibited weight loss in the last three months but presented with elevated waist circumference.<sup>211</sup>

#### **A. Dietary Intake and Diet Quality**

Disease sequelae, physiological factors and treatments for PD can compromise dietary intake and quality.<sup>61</sup> Disease stage and side-effects from medication or surgery can impact dietary choices by impacting appetite and the ability to consume food.<sup>212</sup> Other factors that related to PD that can impact dietary choices include: nausea, delayed gastric motility, dehydration, constipation, change in taste and smell, and dysphagia.<sup>61</sup> Complaints relate to change in taste and smell are among the most frequently reported from PwPD. One study found 26% of PwPD complained of taste/smell issues, compared to only 7% of controls.<sup>213</sup> How change in taste and smell impact nutritional status and diet quality has not been directly explore. Cognitive

decline and depression, common among PwPD, can also compromise food intake by impacting mealtime and appetite<sup>214</sup>

Dysphagia can also impact mealtime and the amount consumed as it results in change in dietary choices and avoidance of certain foods, which can impact weight status. Those with dysphagia are more likely to experience unintentional weight loss, especially PwPD avoiding solid foods due to swallowing issues.<sup>214</sup> A longitudinal prospective study, examining dietary intake, weight, and swallow function among, found that PwPD with weight loss were more likely to avoid solid foods due to swallowing difficulties compared to controls.<sup>214</sup> Those PwPD who experienced weight loss also consumed less vegetables, fresh fruit, meat on sandwiches and drinks without energy at the first evaluation.<sup>214</sup> However, whether this weight loss was associated with swallowing difficulties was not explored. Avoidance of solid food and fluid can result in nutritional imbalances and hydration. Variability in weight and nutritional status is a concern because it can impact diet quality as well as physical functioning, which can lead to muscle wasting and difficulties in performing ADL.<sup>215</sup>

Though low dietary quality scores are associated with chronic disease such as cardiovascular disease<sup>216</sup>, few studies have examined diet quality and intake in PwPD. LoBuono et al.<sup>38</sup> found low dietary quality scores among a small cohort of PwPD. Cassani and colleagues<sup>217</sup>, further examined dietary intake among PwPD and healthy controls, specifically regarding the adherence to a Mediterranean diet, and found PwPD ate more fruit, cooked

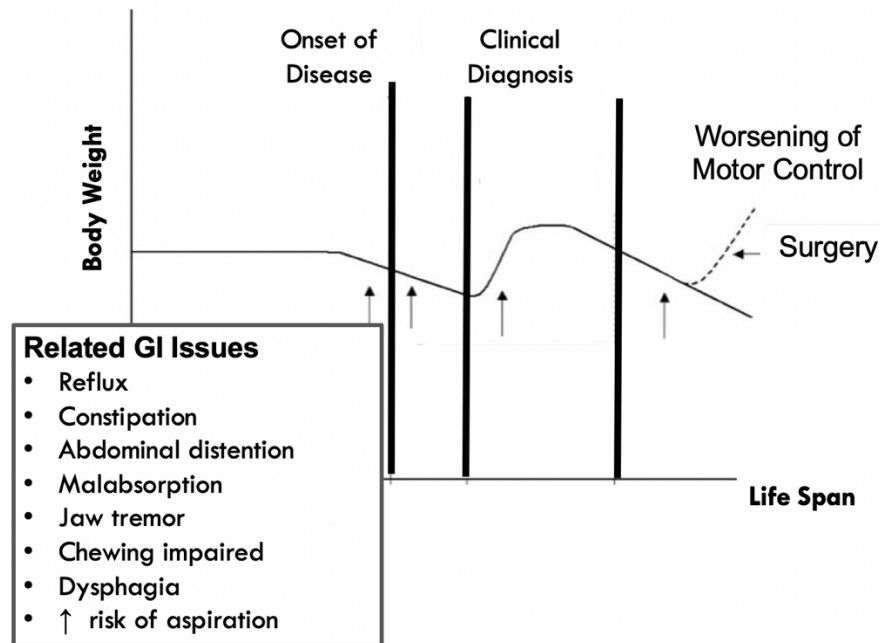
vegetables, cereals and baked items, as well as more sweets and dressings.<sup>217</sup> Those with PD also consumed less fish and alcohol and drank significantly less water, coffee or milk,<sup>217</sup> and as a result, consumed significantly less fluid overall.<sup>217</sup> Overall PwPD had higher intake of calories, iron, zinc, folate, and vitamins A, and C, however PwPD also had significantly lower BMIs compared to controls ( $26.2 \pm 4.9$  vs.  $28.5 \pm 6.4$  kg/m<sup>2</sup>,  $p < 0.001$ ).<sup>217</sup> Dysphagia was self-reported among 12% which resulted in a significant decrease in fluid intake and preference for more vicious foods, but did not impact adherence to the Mediterranean Diet. There are two major areas of significance with these findings. First, the difference in dietary intake between PwPD and control warrants a similar exploration between PwPD and their informal caregivers. Also, a prospective, longitudinal examination of how dietary intake and quality relate to disease progression.<sup>217</sup>

Protein intake among PwPD is also a concern for those taking levodopa. Dietary protein and levodopa compete for absorption and transport across the gut, blood-brain barrier, and peripheral nervous system.<sup>218</sup> It is advised to wait 30 to 60 minutes between taking levodopa and eating a high protein meal.<sup>211</sup> Participants taking levodopa exceeded daily protein recommendations, consuming  $1.4 \pm 0.6$  per day, rather than the 0.8 grams/kg/day.<sup>211</sup> Seventy-five percent of PwPD ingested levodopa with food.<sup>211</sup> Findings highlight the need for nutrition education on protein timing and medication.

## B. Impact on Weight and Body Composition

Weight and nutritional status in PwPD varies during disease progression (Figure 12)<sup>61</sup> and can adversely affect body composition, cognitive and physical functioning<sup>144,214,219</sup>, QOL and health outcomes.<sup>220</sup> A decade before diagnosis, an average 5.2 pound weight loss is reported, despite increased energy intake.<sup>221</sup> Much of this weight loss is attributed to the increase in energy expenditure caused by untreated motor symptoms.<sup>221</sup> Once treatment is initiated symptoms are minimized, and weight gain is observed<sup>61,222,223</sup>

**Figure 12:** Nutritional Status Over the Course of PD<sup>61</sup>



Weight status changes throughout the course of PD (Figure 12), at the beginning of treatment for PD excess weight is a problem, but as the disease progresses, underweight and nutrition results.<sup>61</sup> Weight gain among PwPD



can result in overnutrition<sup>224</sup> caused by excessive oral intake and/or inadequate activity.<sup>225</sup> One study found a majority of PwPD and their spouses are overweight or obese<sup>226</sup>, indicating the need for early nutrition intervention for PwPD and caregivers to reduce chronic disease risk.<sup>227</sup> Side effects from some PD medications, such as dopamine agonists, can increase impulsivity, lead to overeating and result in weight gain.<sup>227</sup> Additionally, treatments can reduce dyskinesia, which can decrease energy expended and result in weight gain.<sup>61</sup> Furthermore, anxiety and depression are common in PwPD and prescribed medications can cause weight gain.<sup>228,229</sup> Following the implantation of deep brain stimulation (DBS), a mean weight gain of 3.1 to 9.3 kg within three months has been reported, and typically curtails about a year after implantation.<sup>227,230</sup> Weight gain among PwPD first receiving DBS is attributed to reduced energy expenditure since dyskinesias are reduced after DBS.<sup>168</sup> Being overweight increases risk of developing sarcopenic-obesity, higher body fat and decreased muscle strength that can exacerbate a deterioration in physical function.<sup>215</sup>

Due to disease-related decline in mobility, it is speculated the age-related loss of skeletal muscle mass and muscle strength<sup>231</sup> are prevalent in PwPD and impact the ability to perform ADLs, increase fall and fracture risk, and compromise QOL.<sup>232</sup> People with PD often weigh less than healthy controls, but have similar amounts of abdominal fat<sup>20</sup> and a higher proportion of visceral to subcutaneous fat<sup>233</sup>, excess visceral fat is linked with increased risk for chronic disease.<sup>233</sup> For PwPD, presence of central obesity is a risk factor for

cognitive impairment<sup>234</sup>, and changes in body fat distribution may be attributed to changes in macronutrient distribution.<sup>234</sup> Conversely, other research indicates PwPD have a higher fat-free mass and possibly a more favorable body composition compared to healthy controls.<sup>235,236</sup> Inconsistent findings related to diet and body composition warrants a deeper understanding of chronic disease in PwPD, such as cardiometabolic.<sup>237</sup>

A study assessing weight stability of PwPD over one year found a significant amount of muscle converted to fat.<sup>224</sup> However there was no association between nutritional variables (BMI, weight, Seniors in the Community: Risk Evaluation for Eating and Nutrition version II questionnaire, mid-upper arm circumference, hand grip strength, triceps skin-fold) of interest and motor and non-motor features of PD. Findings from this study warrant longer observational studies to track nutrition outcome variables overtime to better understand the relationship between nutrition outcome variables and motor and non-motor sequelae. Findings from this study also indicate malnutrition should be screened regularly among PwPD to help identify those at risk of muscle loss and decrease mobility, and that nutrition professionals should be included in the care plan of PD.

As PD progresses, levodopa tolerance develops, sequelae worsen, and weight loss and under-nutrition are common.<sup>61</sup> Undernutrition results from inadequate intake to meet energy expenditure.<sup>225</sup> Up to 25.5% of PwPD are malnourished and up to 26.5% are at risk for malnutrition.<sup>70,220,238</sup> After PD diagnosis, PwPD weight can fluctuate up or down and very few maintain their

body weight. One study found, despite increased energy intake, the average weight loss in PwPD (n=174) was 7.7 pounds 8 years following diagnosis.<sup>239</sup> Significant weight loss is experienced among both men and women.<sup>240</sup> Unintentional weight loss can be caused by a variety of factors.<sup>70</sup> Mobility limitations make it challenging to buy, prepare, and cook food,<sup>61</sup> and PwPD may exhibit dysphagia and gastrointestinal problems, which can diminish appetite.<sup>212</sup> Higher levodopa dosages are associated with a lower BMI,<sup>229</sup> which is associated with compromised motor and non-motor function.<sup>219</sup> Weight loss among PwPD is negatively associated with cognition, suggesting an association between cognition and nutritional status.<sup>214</sup> Weight loss is also exhibited among PwPD experiencing dementia or visual hallucinations.<sup>241</sup> Whether PwPD experience Despite under- or over-nutrition, malnutrition in PwPD is under-treated.<sup>144,242</sup> The variability in weight status, cognition, and physical functioning warrants innovative nutrition care to improve health outcomes.<sup>38</sup> Caregivers should be part of/included when making care/treatment plans for PwPD whose responsibilities increase as PD advances<sup>25</sup>, in turn compromising the health of the caregivers.<sup>29</sup> Fluctuations in nutrition and weight status compromises body composition and can impact cognitive and physical functioning.<sup>144,214,219</sup> A decrease in fat-free mass and an increase in fat mass is a natural part of aging and can accelerate decline in physical function<sup>215</sup>, however the added effect PD has on age-related muscle loss is unclear.<sup>144,235</sup> How this fat free mass increase impacts cardiometabolic status among PwPD also needs greater exploration.

### C. Cardiometabolic Risk in PD

Inconsistent research exists regarding cardiometabolic risk among PwPD. In a small cross sectional study, six of seven participants had at least one sub-optimal cardiometabolic lab value and two PwPD were on statin-lowering drugs.<sup>38</sup> Chahine et al<sup>243</sup> examined vascular risk factors (diabetes, hypertension, obesity) among early PD and found an association between the presence of vascular risk and concentration of white matter hyperintensities (WMH). Greater presence of WMH was predictive of decline in verbal memory two years later.<sup>243</sup> Cardiometabolic and vascular risk factors are associated with cognitive decline.<sup>244</sup> Research needs to exam how vascular risk factors can impact cognition beyond two years needs to be assessed.

Previous research suggests a cardiometabolic protective effect of PD and theorizes that optimal HDL-C levels among PwPD may explain this theory.<sup>237</sup> In a larger cross-sectional study (n=150), despite excess visceral fat or poor nutritional status, longer PD duration was associated with optimal high-density lipoprotein (HDL) cholesterol levels, indicating possible cardiometabolic protective properties of PD.<sup>237</sup> Cereda et al<sup>236</sup> also investigated the cardiometabolic status among PD and found compared to healthy controls, PwPD exhibited a lower percentage of body fat and more-optimal glucose levels and lipid profiles. However, there was no difference in waist circumference between PwPD and healthy controls.<sup>236</sup> Wei et al<sup>245</sup> performed a retrospective study comparing serum lipid and lipoprotein levels among PwPD (n=110), controls (n=130), persons with intracerebral

hemorrhage (n=140) and with an acute cerebral infarction (n=140); findings revealed PwPD had reduced serum levels of triglycerides, apolipoprotein B and very low density lipoprotein (VLDL) cholesterol.<sup>245</sup> Further research is needed to explore the relationship between nutrition and the changes of lipids and lipoproteins among PwPD.<sup>245</sup> Additionally, how this protective cardiometabolic profile may impact health outcomes overtimes warrants further investigation.<sup>236</sup>

#### **D. Nutrition Recommendations**

Protein, water, fiber, vitamin D, and omega-3 fatty acids are nutrients of concern for PwPD due to sequelae and medications.<sup>61</sup> Over-time, patients with higher dietary protein intake may require higher levodopa doses and eventually the medication loses effectiveness.<sup>20</sup> Common gastrointestinal sequelae include delayed gastric emptying and constipation and warrant the need to manage daily water and fiber intake.<sup>246</sup> Reported low vitamin D status in PwPD can impact bone health and increase risk of fracture with disease-related physical decline.<sup>247</sup> Since PwPD are at increased risk for falls, helping this population to optimize bone health to prevent fracture is essential.<sup>41</sup> In addition to neuroprotective effects<sup>52</sup>, omega-3 fatty acid can improve depressive symptoms in PwPD.<sup>248</sup>

Formal, comprehensive dietary guidelines for PwPD have not been established.<sup>249</sup> This is partly due to the heterogeneity of PD and the need for individualized recommendations. There are multiple dietary recommendations for PwPD that focus on weight management, protein intake, and constipation<sup>20</sup>

and can be confusing for PwPD and their caregivers. Diets adequate in fiber and probiotics are proposed for early phase PD to improve gastrointestinal issues, increase absorption of levodopa<sup>250</sup> and promote optimal cognitive function.<sup>61,222</sup> Plant-based, vegetarian, or Mediterranean diets are proposed for early-phase PD prior to the introduction of levodopa containing medications because they are adequate in fiber and pre- and probiotics. These specific diets can improve gastrointestinal issues, increase absorption of levodopa<sup>20,61,251</sup> and promote optimal cognitive function.<sup>61,222</sup>

National organizations for PD provide dietary suggestions which include: 25-35 grams of fiber per day,<sup>252</sup> up to 70 fluid ounces of water<sup>252</sup>, and encourage consumption of nuts, tuna, salmon and dark green leafy vegetables to promote cognitive health.<sup>253</sup> These organizations also advise to monitor vitamin D status.<sup>253</sup> Supplementing with vitamin E and omega-3 may also be beneficial. A trial found co-supplementing with 400 IU of Vitamin and 1000 mg/day of omega-3 fatty acid from flax seed oil significantly improved overall PD clinical outcome scores, total antioxidant capacity, insulin metabolism, glutathione concentrations, and high-sensitivity C-reactive protein levels.<sup>254</sup>

Guidelines for managing dietary protein intake with levodopa also exist and must be based on the frequency and timing of taking levodopa. As a result, there is confusion among PwPD and their caregiver on how to optimize medication timing and dietary protein intake.<sup>108</sup> Recommendations include: 1) a low protein diet; 2) a protein redistribution diet; 3) allowing thirty minutes to two hours before or after eating to take levodopa medication.<sup>251,255</sup> A low

protein diet restricts protein intake to <0.8g/kg of ideal weight/day.<sup>256</sup> A protein redistribution diet recommends consuming the recommended dietary allowance (RDA) of 0.8g/kg of protein/day to ensure adequate protein intake, but requires the majority of dietary protein to be consumed at dinner to reduce daytime motor symptoms and minimize interaction between medication and protein.<sup>251</sup> Cereda et al<sup>251</sup> completed a systematic review examining the effectiveness of the low protein and protein redistribution diets, and found evidence supports the safety and efficacy of a protein redistribution diet.

Among PwPD there seems to be low adherence to protein the redistribution diet and low protein diets due to low palatability and acceptability as well as logistic difficulties for adopting the diet.<sup>223</sup> As a result, waiting an 30 minutes to two hours for meals is encouraged by most PD organizations.<sup>223</sup> More research is needed to understand long-term effects of the protein redistribution diet on nutritional status and to help participants find them more appealing and less burdensome.<sup>223</sup> Increasing access to nutrition information through innovative mediums such as digital health will allow PwPD and caregivers to work with dietitians, pharmacists and physicians to manage medication side-effects and interactions.

### **E. Nutrition and Quality of Life**

Nutritional status is an important component of QOL and should be incorporated in the care PwPD<sup>257</sup>, but is often an under-recognized component of care for PwPD.<sup>144</sup> Under-nourished PwPD receiving general nutrition intervention or personalized dietary recommendations saw a significant

improvement in emotional overall well-being.<sup>20</sup> Many PwPD and their caregivers experience decline in psychosocial health, and support groups and group education can alleviate these feelings through promoting interactions with other PwPD and caregivers.<sup>75,258,259</sup> Health promotion programs designed for PwPD increase overall wellbeing but also foster feelings of enjoyment and sense of social self.<sup>260</sup> Access to transportation due to disease sequelae can be a barrier and increases caregiver burden.<sup>261</sup> The observed variability in weight status, cognition, and physical functioning may warrant innovative nutrition care<sup>38</sup>, and should also include informal caregivers whose responsibilities increase as PD advances.<sup>25</sup>

### III. Emerging Middle Range Theory of Transitions

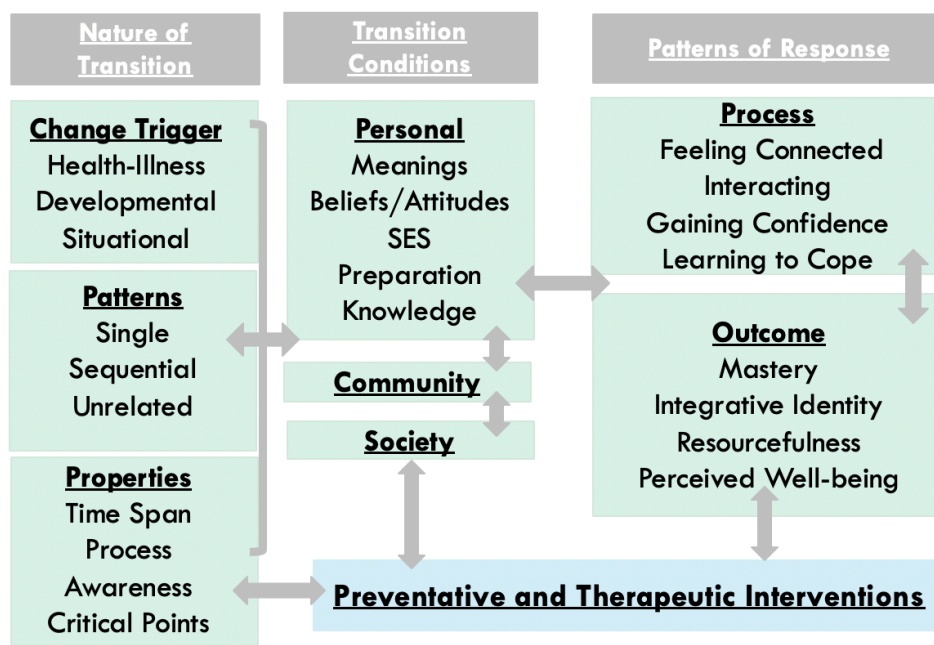
Including caregivers in formative research targets elements of the emerging middle-range theory of transitions (**Figure 13**).<sup>262</sup> A transition represents change from one state or condition to another, and includes life development stages, such becoming an informal caregiver. The theory promotes the exploration and understanding health and illness transition experiences, through understanding facilitators and barriers to a successful transition, and assessing the outcomes of successful transitions.<sup>148,262</sup>

Successful outcomes examined include: increase knowledge and skills that promote self-efficacy, coping, and satisfactory relationships with family, friends and formal services.<sup>262</sup> The theory posits itself on helping informal caregivers to acquire new skills and knowledge to cope with situations related to caregiving, and creating feelings of informal support for caregivers, which play



a central role in successful role transition.<sup>262</sup> The theory has been incorporated previously to guide the development of dyadic interventions for PD<sup>148</sup> and Alzheimer' disease.<sup>263</sup>

**Figure 13:** Schematic of the Emerging Middle Range Theory of Transitions<sup>262</sup>



Research and services are beginning to identify the need for informal caregivers to help manage long-term conditions such as PD.<sup>137,264,265</sup> Development of more comprehensive approaches to help PwPD and their caregivers adapt to changes they experience as a consequence of a long-term condition are warranted.<sup>265,266</sup> Caregivers of PwPD are often faced with restricted work and social activities, increased worry and uncertainty about the future, loss of income, and feelings of guilt, frustration and/or grief.<sup>267,268</sup> Consequently, PD caregivers are at risk for compromised psychosocial outcomes, which include poor QOL, emotional and financial strain, sleep disturbances, social isolation and increased risk of chronic illness.<sup>28,267</sup> Non-

motor sequelae among PwPD (e.g., depression, cognitive impairment) and depression among caregivers are predictive of caregiver burden.<sup>267</sup> While social support may be a protective feature in minimizing caregiver burden.<sup>267</sup> Whether caregiver burden is associated with poorer nutrition status for caregivers or their loved one with PwPD has yet to be explored.

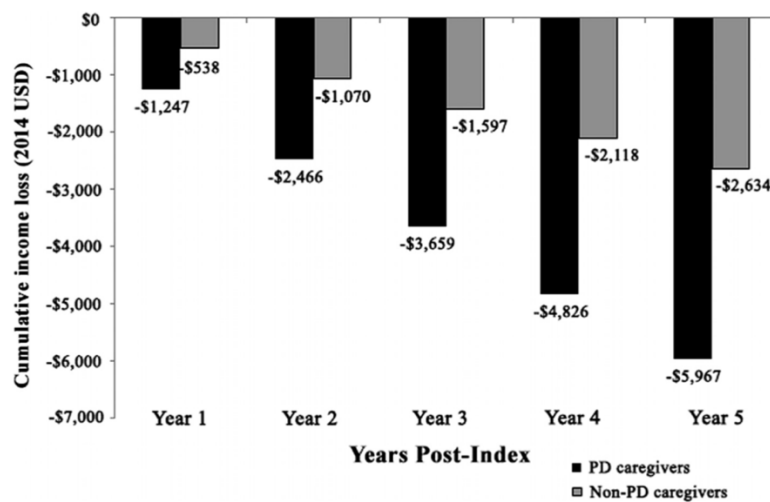
As a result, future programs and services for PwPD should incorporate the preferences and needs of informal caregivers as their responsibility tends to increase as the disease progresses.<sup>266</sup> Comprehensive, interdisciplinary services can help both PwPD and caregivers better cope and adjust with living with PD and improve QOL.<sup>265</sup> Including PwPD and caregivers will be especially beneficial in digital health interventions and nutrition services as caregivers will likely have an active role in managing both of these as PD progresses and reliance on caregivers increase. Qualitative dyadic research among PwPD and caregivers, show concerns about keeping both parts of the dyad healthy.<sup>148</sup> As a result, how the inclusion of caregivers can help promote healthy dietary patterns among PD Caregivers warrants exploration.

#### IV. Inclusion of Caregivers

Up to 6.5 million family caregivers provide substantial help, including coordination of care, medication management, and personal care for older adults living with disability.<sup>21</sup> One quarter of informal caregivers provide nearly 45 hours of care per week for their loved with PD,<sup>22</sup> and over a quarter spend more than 75 hours per week providing care.<sup>269</sup> Additionally, caregivers commonly support PwPD at visits with clinicians, but are only engaged by

physicians 40-70% of the time.<sup>270</sup> Compared to matched control caregivers, caregivers of PwPD exhibit higher direct and indirect costs consistently over five-years.<sup>271</sup> When examining income progression over five-years, caregivers of PwPD also exhibited a higher cumulative income loss (**Figure 14**).<sup>271</sup>

**Figure 14:** Cumulative Income Loss for PD caregivers versus matched controls<sup>271</sup>



In addition to economic disadvantage, PD caregivers also experience stress and burden for caring with their loved one with PD.<sup>29</sup> Male PD caregivers have decreased access to informal caregiving resources, despite reporting less strain than female caregivers.<sup>272</sup> Women with PD receiving care from a male informal caregiver are more likely to use, formal, paid caregivers.<sup>272</sup> Caregiving is a fundamental and valuable part of PD treatment but limited research has been conducted on caregiving patterns and needs for caring for a loved one with PD.<sup>272</sup> In particular, dietary concerns, nutritional status, and how technology can enhance dietary management caregiving has not been explored. To help include caregivers in the healthcare team,

innovative mediums are necessary to increase access to caregiving and reduce disparities among PwPD.<sup>272</sup>

Caregivers experience primary stressors and secondary role strains as a result of providing care for their loved one.<sup>56</sup> Primary stressors include both subjective and objective difficulties directly related to providing care.<sup>273</sup> Examples of objective primary stressors include care tasks and the degree of impairment of the care recipient.<sup>273</sup> Subjective primary stressors are the caregivers' emotional and psychological response to objective stressors.<sup>273</sup> Primary stressors can negatively impact caregivers' physical and mental health.<sup>274</sup> Secondary role strains are when hardships experienced in roles and activities that originate from primary stressors proliferate to other life areas.<sup>273</sup> An example of secondary role strain is decreased participation in non-care activities or reluctance to partake in activities due to the time, energy and resources required to providing care.<sup>275</sup> Older caregivers and those providing help with ADLs and healthcare management (e.g. scheduling appointments) are more likely to decrease participation in non-care activities.<sup>56</sup>

Caregiver activity restriction is also associated with poor health outcomes for the caregiver, such as reduced sleep quality and high blood pressure.<sup>276,277</sup> Compared with matched controls caregivers, PD caregivers had higher rates of comorbidities, such as headache, gastroesophageal reflux disease, hypertension, and irritable bowel syndrome.<sup>271</sup> Many of these diseases require dietary modifications to minimize and manage symptoms and suggest nutritional education may be beneficial. Further research is needed to assess

the nutritional status and nutrition needs of PD caregivers. Additionally, given the later-onset of PD, most caregivers are older adults and have their own medical conditions.<sup>259</sup>

Informal caregivers for PwPD are at increased risk for poorer QOL, which is partly attributed to observing disease-related physical and cognitive decline in their loved ones.<sup>29</sup> Informal caregivers are typically responsible for performing the majority of ADL, including buying and preparing food, and transportation.<sup>22</sup> Caregiving stress can also resonate adverse consequences on the patient-caregiver dyad, compromising the care provided, as well as negatively impacting relations with the larger-family system.<sup>56</sup>

Studies have examined the lived experience of living with PD, needs and preferences of PD-Caregiver Dyads related to managing Parkinson's disease.<sup>278</sup> Smith and Shaw<sup>279</sup> examined the lived experience of both the PwPD and their caregiver within a family unit and found partners share the impact of PD, were learning to live in a new way to adopt to disease progression and felt a sense of belonging from support groups. Additional research can help identify services required to facilitate the process of learning to live with PD,<sup>279</sup> such research should include how nutritional management can help facilitate this process. How dyads experience related to food and access nutrition information has yet to be explore.

Habermann & Shin<sup>278</sup> conducted a descriptive qualitative study among caregiver and PwPD to explore how dyads discuss needs, concerns and preferences for advanced PD. Findings indicated dyads wanted improved

communication with healthcare providers and had concerns with choking, falls, voice production, financial strain and the future of disease progression.<sup>278</sup>

Increasing access to nutrition services can help address some of these concerns; nutrition professionals can provide education on optimizing dietary intake when modifying textures and calculating nutrition support needs to accommodate swallowing issues, as well as optimize dietary intake to promote a healthy body composition to prevent fall risk.

Educating caregivers early at disease diagnosis and encouraging caregivers to partner with healthcare providers can reduce stress and family conflict.<sup>135</sup> Couple-oriented interventions improve spousal coping strategies, promote disease related stress and anxiety management, increase self-efficacy (one's belief in his/her capability to perform, organize, or execute a task or succeed in a situation<sup>280</sup>), and help couples manage changes caused by PD.<sup>32</sup> Innovative mediums, such as digital health via video, web-based, telephone-based and remote-monitoring can have a significant improvement on caregiver outcomes.<sup>204</sup> The use of technology can enhance caregiving experience and facilitate shared decision making, where patients and caregivers are actively involved in the care process and participate in the decision making processes.<sup>204</sup>

## V. *Conclusion*

Due to limited mobility, transportation access, need for visual assessment and ongoing interdisciplinary care, PwPD are excellent candidates for digital health<sup>26,139</sup>, which may help increase opportunities for nutrition services.

Understanding how the nutritional status of PwPD change overtime can help health care professionals better understand the nutritional needs of PwPD and provide effective nutrition services via digital health. Therefore, the purpose of this mixed-methods project is to: 1.) Understand how the nutritional status of PwPD changes overtime; 2.) examine the perceptions, acceptance, facilitators, and barriers for adopting digital health to improve the nutritional health of PwPD and their informal caregivers; 3.) understand the nutritional status and digital competence of PwPD and their informal caregivers.

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## APPENDIX B

### EXTENDED METHODOLOGY

#### Overview

The completed studies are part two major studies / projects at the University of Rhode Island. Project 1 is part of a 5-year longitudinal study examining the change in nutrition, physical function, cognition and swallowing among those living with neurological disorders and neurotypical participants. Project 2 is a formative, mixed-methods analysis, assessing people with Parkinson's disease (PwPD) and their informal caregivers. The specific aims for this dissertation, the chapters of the dissertation they are addressed in and the corresponding study project are summarized in Table 1. Enclosed is the methodology for both projects and their aspects that address the specific aims.

**Table 1:** Specific Aims, Corresponding Chapter and Project Number

Overarching and Specific Aims	Chapter #	Project #
Aim 1: To assess the nutrition risk of PwPD overtime. <ul style="list-style-type: none"><li>Track the nutritional status of PwPD overtime</li><li>Examine how disease sequelae may influence nutritional status.</li></ul>	1	1
Aim 2: Evaluate the nutritional status in PwPD and their caregivers <ul style="list-style-type: none"><li>Evaluate the diet quality among PwPD and their informal caregivers;</li><li>Describe the self-reported nutrition concerns among PwPD and their informal caregivers;</li><li>Explore if the nutrition concerns match the dietary quality of PwPD and informal caregivers.</li></ul>	2	2
Aim 3: Examine PwPD's and their caregivers' perceptions and acceptance of digital health	3	2
Aim 4: Describe digital competence among PwPD and their caregivers.	3	2



## **Project 1 Design and Methodology (Aim 1, Chapter 1)**

This is an ancillary study of a five-year observational, longitudinal study assessing the nutritional, cardio-metabolic, cognitive and physical function status of PwPD, acquired brain injury (ABI) and neurotypical participants (Longitudinal Study of Communication, Nutrition and Physical Activity, IRB HU1314-006). Participants come to URI's Speech and Hearing Clinic located at the Kingston Campus and are assessed every six months for five years. Participants are enrolled in the study on a rolling basis. Potential participants aged 18-85 years are recruited via brochures and word-of-mouth; one-year post-PD or -ABI diagnosis. The time commitment for participants is three hours per evaluation for a total of 30 hours for the five years. Written data were stored in a locked file cabinet in the Department of Communicative Disorders. Prior to their first assessments, participants went through the informed consent process (Appendix C).

For Chapter 1, those PwPD who completed an assessment their baseline year, year 2 and year 4 were included in this study. These participants completed their assessments from Fall 2013 through Spring 2019. Table 2 summarizes the research timeline for chapter 1. Table 3 summarizes the measures performed at each assessment visit.

**Table 2:** Specific Aim 1 Study Timeline

Activities	Fa 2013 – Sp 2017	Fa 2017	Sp 2018	Fa 2018	Sp 2019	Fa 2019	Sp 2020
IRB	X	X					
Recruit	X						
Assessment Visits	X	X	X	X	X		
Data Entry	X	X	X	X	X		
Data Analysis					X	X	
Manuscript Preparation						X	X

**Table 3:** Assessment Protocols by Domain

Assessment Domain	Assessment Tool
Nutrition	The Dietary Screening Tool (DST)* <sup>1</sup>
Cardiometabolic	Lipid profiles and blood pressure*
Anthropometric	Height, weight, body mass index (BMI), percent body fat*
Physical Functioning	Short Physical performance Battery (SPPB) <sup>2</sup>
Swallowing	Swallowing Quality of Life Survey (SWAL-QOL) <sup>3</sup> ; Timed Swallow Test <sup>4</sup>
Cognition	Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) <sup>5</sup>
Medical History	Past Medical History Questionnaire
*Assessments used to for Aim1	

## Data Collection

### *Nutritional Assessment Measures*

Within the nutrition assessment, the dietary screening tool was used to assess nutrition risk, and biochemical, clinical, and anthropometric data were obtained. Participants completed the dietary screening tool (DST, Appendix D), a 25-item questionnaire validated and used to identify dietary patterns and nutritional risk in older adults.<sup>1,6</sup> A total of 105 points can be achieved. Scores can be categorized as: at risk (<60), possible risk (60-75), and not at nutrition risk (>75). The eight component scores from the DST were also examined, which include: whole fruit and juice (15 points), vegetables (15 points), whole grains (15 points), lean protein (10 points), processed meats (10 points), dairy

(10 points), added fats, sugars and sweets (25 points), and supplements (5 points). We determined participants who achieved  $\geq 80\%$  for each DST component score.

*Biochemical and Clinical Data (Appendix E).* Serum total cholesterol, low-density lipoprotein cholesterol, high-density lipoprotein cholesterol, triacylglycerol, and glucose will be obtained using a finger stick (Cholestech<sup>®</sup> LDX system, Hayward, CA) after a 12-hour fast. Blood pressure will be measured using automatic blood pressure machine (Omron Healthcare Inc., Bannockburin, IL).

*Anthropometrics.* Height was measured using a stadiometer (Seca, Birmingham, UK) to the nearest 0.5 cm in duplicate and then averaged. Measures were repeated if obtained height was not within 0.2 cm of each other. Weight was obtained using a calibrated electronic scale (Healthometer 752KL, Jarden Consumer Solutions, Boca Raton, FL) to the closest 0.1 kg. Weight measurements were taken in duplicate and averaged. The average height and weight value were used to calculate body mass index (BMI, kg of body weight/height in meters<sup>2</sup>). A BMI between 28 and 23 was considered within an optimal range, aligning with older adults.<sup>7</sup>

### ***Other measures***

The measures described below were collected at each assessment visit and analyzed to help better understand and explore factors that may influence nutritional status among PwPD.

*Physical Functioning.* The SPPB (Appendix F) assessed participants' global physical functioning and includes gait speed, standing balance tests, and five repeated chair stands.<sup>2</sup> Scores <10 indicated mobility disability.<sup>2</sup>

*Cognitive Evaluation.* To measure attention, language, memory, constructional and visual-spatial abilities, the RBANS (Appendix G) will be used.<sup>5</sup> The test includes 12 subtests that can be completed in 30 minutes. A score <80 indicates cognitive impairment may be present.

*Swallowing Evaluation.* The SWAL-QOL (Appendix H) is a 44-item survey that takes 10 minutes to complete. Participants rate factors about 10 quality of life concepts related to swallowing.<sup>3</sup> A timed swallow test (ml/s) is administered to assess strength, coordination, range of movement, and timing of movement of swallowing muscles in those with neurological disorders (Appendix I).<sup>4</sup> The number of swallows and the time it takes to swallow the water are counted.

*Medical History.* A medical history questionnaire (Appendix J) is used to identify health-related conditions and takes ten minutes to complete.

**Statistical Analysis.** Data was analyzed in SPSSv26. Categorical variables were represented as numbers and percentages and continuous variables were reported as mean±standard deviations. Data was assessed for normality and non-normally distributed data was transformed for analyses but original mean±standard deviations were reported. To assess changes in nutritional risk via DST scores, a repeated measures analysis of covariance was completed with time since diagnosis as a covariate. A Bonferroni

adjustment was made for multiple comparisons. Analyses were 2-tailed and a  $p < 0.05$  will indicate statistical significance. Paired sample t-tests were also conducted among outcome variables from baseline to year 2, year 2 to year 4 and baseline to year 4 were also conducted. Analyses were 2-tailed and a  $p < 0.05$  will indicate statistical significance. Participants were then individually analyzed for suboptimal scores across each outcome variable and the frequency of sub-optimal scores were reported.

## **Project 2 (Chapters 2 & 3, Aims 2-4)**

### ***Project 2 Overview***

Chapters 2 and 3 were from a descriptive, cross-sectional study collected qualitative and quantitative data from PwPD ( $n=20$ ) and their informal caregivers ( $n=20$ ) via dyadic semi-structured interviews ( $n=20$ ), questionnaires, and anthropometric assessment. The project was approved by the Institutional Review Board (HU1819-001, Telenutrition and Parkinson's disease). The purpose of project 2 was to examine the perception and acceptance of digital health technologies in PwPD and their caregivers, as well as understand facilitators and barriers for digital health adoption for the nutrition care process. This study also evaluated the nutritional status and digital competence in PwPD and caregivers. A concurrent mixed-method design<sup>8</sup> was used to assess the nutritional status and nutrition concerns of PwPD and their informal caregivers. This mixed-methods design was chosen to gain a more complete understanding of nutritional needs of PwPD and caregivers through comparing and synthesizing both quantitative and

qualitative data.<sup>8</sup> Data was collected over four assessments completed between November 2018 and April 2019. A summary of activities that occurred in each session is provided in Table 4. Sessions 1, 3, and 4 were conducted by phone, while Session 2 was conducted in the participants' home. The study timeline is summarized in Table 5.

**Table 4: Aims 2-4 Proposed Study Timeline**

Activities	Fall 2017	Su 2018	Fall 2018	Spr 2019	Fall 2019	Spr 2020
Proposal Defense	X					
IRB		X				
Recruit and Consent		X	X			
Assessment Visits		X	X	X	X	
Data Entry		X	X	X	X	
Data Analysis				X	X	
Manuscript Preparation					X	X
Defend Dissertation						X

**Table 5: Description and Timeline of Evaluations for Project 2**

Session	Location	Activities	Time
Session 1	Phone call	Informational Phone Call; Cognitive Screening	30 minutes
Session 2	In-person	Informed Consent; Questionnaires; Anthropometrics, Timed Swallow Test; Semi-Structured Interviews	125 minutes
Session 3	Phone call	1 <sup>st</sup> 24-hour Dietary Recall	60 minutes
Session 4	Phone call	2 <sup>nd</sup> 24-hour Dietary Recall	60 minutes
		<b>Total Participant Time</b>	<b>275 minutes</b>

Assessment 1 was an informational phone call during which participants were screened for eligibility and informed about the study protocol. At the beginning of Assessment 2, the study protocol was reviewed and both PwPD and their informal caregiver completed the informed consent process.

Assessment 2 was an in-person home visit, which consisted of a timed-swallow screening, questionnaires, and a semi-structured, dyadic interview. Assessments 3 and 4 were phone calls during which participants completed two 24-hour recalls.

***Theoretical Framework.*** This mixed-methods study targeted elements of the emerging middle-range theory of transitions.<sup>9</sup> A transition represents change from one state or condition to another, and includes life development stages, such becoming an informal caregiver. Research shows helping informal caregivers acquire new skills to cope with situations related to caregiving, and creating feelings of informal support for caregivers, plays a central role in successful role transition.<sup>9</sup> Acquisition of subjective and objective data from PwPD and caregivers was collected to help better understand the transition dyads face as the patient-caregiver relationship changes, and the role of the caregiver evolves<sup>9</sup>, especially in relation to dietary management. The approach has been used to provide tailored health interventions for those with neurodegenerative diseases and their caregivers.<sup>10,11</sup>

This study concentrated on the early stages of digital health nutrition services, in which PwPD and caregivers provided personal opinions and preferences to inform the creation of an user-friendly, evidenced-based, digital health service.<sup>12</sup> Formative analysis has been used to effectively employ digital health technologies for older adults<sup>13,14</sup>, and in the development of dyadic interventions for PwPD.<sup>10</sup> Findings from the proposed study can be incorporated into the technology acceptance model (TAM).<sup>15</sup>

**Inclusion Criteria.** Both the PwPD and their informal caregiver were required to participate and needed to be community-dwelling, English speaking, and  $\geq 18$  years old. Participants also needed to score  $\geq 18$  on the Telephone Montreal Cognitive Assessment (T-MoCA), a cognitive screening tool, that was administered during Assessment 1.<sup>16,17</sup> A list of inclusion criteria for both PwPD and caregivers are summarized in Table 6.

**Table 6: Inclusion Criteria for Project 2 (Specific Aims 2-4)**

<b>PwPD</b>	<b>Informal Caregiver</b>
18+ years old	18+ years old
English Speaking	English Speaking
Cognitive Function $< 18$ on t-MoCA	Cognitive Function $< 18$ on t-MoCA
Has identified an informal caregiver	Performs majority of care

**Recruitment and Data Saturation.** Recruitment occurred following study approval by URI’s Institutional Review Board (HU1819-001). Emails, flyers (Appendix K), announcements at support groups, word of mouth and current statewide collaborations and contacts were used to recruit participants. Participants were recruited from support groups throughout New England, New York and New Jersey via announcements and flyers at community centers, via healthcare providers, the American Parkinson’s Disease Association website, and through popular press coverage from the University.

Twenty-five dyads expressed interest. Five dyads did not continue with the study due to scheduling conflicts or low T-MoCA scores. Eighteen dyads were eligible, enrolled and interviewed. Two of these dyads included couples who were both living with PD and identified as each other’s informal caregivers and were double counted as a PwPD and a caregiver. As a result, 20 dyads



were included in analyses. Dyads were from Rhode Island, Massachusetts, New York, and Connecticut. We aimed to interview up to 20 dyads as previous research among PwPD and caregivers indicates this is where data saturation is reached.<sup>18,19</sup> Saturation was reached after the fourteenth interview.

***Incentive Structure.*** Dyads who complete all 4 sessions will receive tailored dietary recommendations based on individual assessments, and a chance to win a wearable device to monitor health. Emerging themes and general findings from interviews related will be provided

***Informed Consent Process.*** Potential participants will receive an informational phone call (session 1) to review the study purpose and requirements. Consent was provided or declined from the PwPD and their informal caregiver at the beginning of the in-person evaluations (session 2). Both the caregiver and the PwPD were consented. Interested and eligible dyads were enrolled in the study. (Appendix L & M). Enrolled dyads will complete a demographic and medical history questionnaire, then the semi-structured interview. During the informed consent, there was a request authorization for disclosure of protected health information from primary care physicians or neurologists for PwPD, which included: PD stage, date of diagnosis, current medications and treatment. Permission to request personal health information from PwPD's neurologist was also obtained (Appendix X), in order to obtain information regarding disease staging.

## **Collection and Analyses of Qualitative and Quantitative Data**

### ***Qualitative Assessment and Analysis.***

*Semi-structured Dyadic Interviews.* A 24-question moderator guide, informed by the previous literature and the research team was organized to capture three main domains: PD and Diet, Accessibility of Nutrition and Health Information, and Digital Health for PD. From these domains, participants' acceptance and perception were assessed. A copy of the moderator guide is provided in Appendix L. The moderator guide included three key sections of the moderator's script: 1.) PD and Diet, 2.) Accessibility of Nutrition and Health Information, 3.) Digital Health for PD. Prior to starting the study, interviews were piloted with two dyads and questions were modified based on participant feedback. Interviews were conducted in the participants' homes (facilitated by DL) and were audio-recorded using a digital recorder. The mean interview duration was 39 minutes (range 21-64 minutes). During interviews, participants were provided operational definitions of terms (technology, digital health, smart phones, smart watches, apps, videoconferencing). Photo prompts were used to help describe different technological devices and digital health tools and this was particularly important for understanding acceptance of devices.

### ***Qualitative analyses related to digital health specific aims (Aim 3):***

Qualitative data was analyzed using deductive and inductive reasoning. Transcripts were deductively-coded using the framework analysis method<sup>20</sup>, a seven-stage, systematic approach used in healthcare research. Transcripts

were inductively-coded using Colaizzi's Strategy in Descriptive Phenomenology<sup>21</sup>; this interpretative approach draws an understanding of participants' "lived experiences".<sup>22</sup>

The following steps were taken to analyze the data related to perception and acceptance of digital health, facilitators and barriers and identified features for a digital health service. Recordings were transcribed verbatim and DL checked transcripts for accuracy (stage 1). Transcripts were divided into three batches. DL and a trained research assistant (KS) analyzed one batch at a time. Separately, DL and KS coded for the following a priori themes related to digital health: perception (perceived usefulness, perceived ease of use, awareness of digital health, image of technology) and acceptance (accept, neutral, reject). These a-prior themes adopts components of the technology acceptance model (TAM).<sup>15</sup>

Before coding individually, KS and DL read through an entire batch of transcripts, met to discuss initial impressions, developed a list of initial themes and then coded a-priori (stage 2). Both DL and KS coded one transcript from the batch independently and in duplicate (stage 3). The two researchers compared and reconciled coding, and there was a strong agreement between authors on the transcripts reviewed. During this discussion the two researchers developed a working analytical framework and agreed upon which codes to use on the remaining transcripts (stage 4). The transcripts were uploaded to NVivo12 (QSR International Pty Ltd, AU) and coded separately by DL and KS. An inter-coder reliability was calculated and found acceptable<sup>23</sup>,

with an agreement >80% achieved for each overarching theme across each batch. DL and KS met to reconcile coding differences. The research committee and DL met to collapse and finalize themes (stage 5). Data was then charted into framework matrices using NVivo12 to display codes within each theme (stage 6). Data was interpreted, and connections related to digital competence and technological preferences of PwPD and their caregivers were made (stage 7). Although a priori themes helped to inform this framework, a phenomenological and iterative approach throughout each stage of the analyses was also taken to identify emerging themes that may impact technology use among this population. Both DL and KS contributed to the framework development with the advisement of the dissertation committee.

***Qualitative Analyses Related to Nutrition (Aim 2):***

The two coders (DL and KS) took a similar approach to analyze the interviews for nutrition concerns. Before coding individually, KS and DL read through all of the transcripts and developed a list of initial impressions and themes, which fell under three categories: Dietary Concerns Related to PD Sequelae, Other Nutrition Concerns and Perceptions of Diet. Both DL and KS coded one transcript from each batch independently and met to compare and reconcile coding. At this point DL and KS created a working analytical framework and agreed upon codes to use for analyzing the remaining transcripts. The transcripts were uploaded to NVivo12 (QSR International Pty Ltd, AU) and coded separately by DL and KS. An inter-coder reliability was calculated, with an agreement >80% achieved.<sup>23</sup>

DL and KS compared codes between each batch and reconciled differences between codes, until a consensus was reached. Codes were then finalized. To ensure information related to dietary intake was not overlooked in other sections of the transcripts, DL went through all of the transcripts and coded the remaining sections. KS reviewed these codes to verify coding structure, added additional codes when needed and DL and KS discussed differences in coding and collapsed themes. The larger research team and DL met to further collapse and finalize themes.

### ***Quantitative Data Collection and Analyses.***

The following assessments will be completed and analyzed for **both** PwPD and their informal caregiver, unless otherwise noted.

### ***Dietary Data. Nutrition Risk and Diet Quality.***

Within the nutrition assessment, the dietary screening tool was used to assess nutrition risk, and biochemical, clinical, and anthropometric data were obtained. Participants completed the dietary screening tool (DST, Appendix D), a 25-item questionnaire validated and used to identify dietary patterns and nutritional risk in older adults.<sup>1,6</sup>

Both PwPD and caregivers completed two 24-hour recalls via telephone (sessions 3 and 4). These recalls included one weekend and week day, and were conducted using the gold-standard, multiple-pass interview method (Appendix O).<sup>24</sup> Participants received a food amounts booklet to estimate and report accurate portion sizes. Twenty-four-hour recalls were entered into Nutrition Data System for Research Software 2017 (NDSR, University of

Minnesota, Minneapolis, MN) and analyzed for total energy, food group and nutrient intake. The NDSR data was assessed for diet quality using the Healthy Eating Index (HEI)-2015 scoring metric.<sup>25</sup> Total scores can range from 1-100; the higher the score, the better the diet quality. Mean scores from the two days were used. Outputs from NDSR were used to calculate HEI-2015 component scores (whole grains, whole fruits, total fruits, vegetable, greens and beans, dairy, total proteins, seafood, plant protein and seafood, refined grains, sodium, added sugars, and saturated fat) derived using USDA SAS codes.<sup>26</sup> Component scores help to provide insight into types of food consumed and nutrients of interest for future interventions.

***Anthropometrics.*** Height was measured using a stadiometer (Seca, Birmingham, UK) to the nearest 0.5 cm in duplicate and then averaged. Measures were repeated if obtained height was not within 0.2 cm of each other. Weight was obtained using a calibrated electronic scale (Tanita HD351, Japan) to the closest 0.1 kg. Weight measurements were taken in duplicate and averaged. The average height and weight value were used to calculate body mass index (BMI, kg of body weight/height in meters<sup>2</sup>). A BMI between 28 and 23 was considered within an optimal range, aligning with older adults.<sup>7</sup>

The bioelectrical impedance analysis (InBody, Korea) device<sup>27</sup>, assessed body composition<sup>28,29</sup>, and has been used with PwPD.<sup>30</sup> The analysis takes five minutes to complete. Body composition was not be obtained for participants with implantable medical devices. Guidelines proposed by the American Council on Exercise were used to assess percent

body fat<sup>31</sup>, with values of <32% for women and <25% for men considered acceptable.<sup>31</sup> Standardized protocol was used to measure waist circumference with Gulick anthropometric tape (Fabrication Enterprises Inc. White Plains, NY).<sup>32</sup> Waist circumference was measured in the horizontal plane at the superior border of the iliac crest. Measurements were taken in duplicate and averaged.

***Digital Competence and Technology Use.*** In addition to digital health data gathered during semi-structured interviews, questions related to technology competence, technology use and digital health use will be gathered through two questionnaires. Questions will be adopted from “Measuring Digital Health Skills across the EU: EU Wide Indicators of Digital Competence,” (Appendix P)<sup>33</sup> which assessed use and level of comfort using various aspects of technology via 15 questions/statements.<sup>33</sup> For each statement, participants responded strongly disagree, slightly disagree, slightly agree or strongly agree. We also collected data regarding device use, frequently and purposes of device use.

Digital health was assessed using questions from the “2015 Health Information National Trends Survey”, Section B (Appendix Q), which contains 11 yes/no questions, as well as questions describing technology use and how health information is accessed.<sup>34-36</sup> Questions from this questionnaire also asked participants where they go first to search for health information, rate the amount of effort it took to find the information and the describe the confidence in finding quality health information. Questions also asked PwPD and

caregivers to rate the level of trust they had for obtaining nutrition and health information from an array of sources, including doctors, other health professions, family and friends, organizations and online blogs.

***Other Measures.*** Assessment tools measured cognition, anthropometrics, disease related QOL, caregiver burden, swallowing function, medical history, and demographics. These variables were used to help describe participants.

***Cognitive Status.*** Cognitive status was assessed using the T-MoCA (Appendix R).<sup>16,17</sup> The test takes about 10 minutes to complete and is validated in community-dwelling adults with mild cognitive impairment.<sup>17</sup> It includes eight subtests assessing digit span, attention, calculation, repetition, verbal fluency, abstraction, recall and orientation.<sup>16</sup> Participant who have less than 12 years or less of formal education will receive one point toward their total score. Scores <18 out of a possible 22 points indicate mild cognitive impairment.

***Swallowing Function.*** A timed swallow test (ml/s) was administered to assess swallowing muscles in those with neurological disorders.<sup>4</sup> Specifically, it assesses: strength, coordination, range of movement and timing of movement of swallowing muscles (Appendix I). The Eating Assessment Tool (EAT-10)<sup>37</sup>, a validated 10-item questionnaire, screened for self-reported swallowing difficulties (Appendix S). Scores on the EAT-10 range from 0-40; higher scores indicate a swallowing problem.

***Disease Related Quality of Life.*** The 39-item Parkinson's Disease Questionnaire (PDQ-39) is a disease-specific tool that assessed the health-



related quality of life of PwPD (Appendix T).<sup>38,39</sup> The questionnaire contains eight sub-scales (mobility, emotional well-being, stigma, social support, cognitions, communication and bodily discomfort), which were used to calculate global health-related quality of life. Each item scores from 0 (never) to 4 (always), with the highest possible score of 156, and higher scores indicate worse quality of life.<sup>38,39</sup> Results are reported using an index percentage (0%=no disability and 100%=maximum disability).

*Caregiver Burden.* The Multidimensional Caregiver Strain Index (MCSI) assessed caregiver burden.<sup>40</sup> This 18-item tool collected subjective information from informal caregivers across six domains: physical strain, social constraints, financial strain, time constraints, interpersonal strain, and elder demanding/manipulative. Response to individual questions are reported on a 0 (never) to 4 (a great deal) scale. Scores range from 0-64 points and are reported as an index percentage<sup>130</sup>; higher scores indicate higher caregiver strain<sup>130</sup>. The scale has been previously used successfully in the PD population<sup>131</sup>.

*Medical History and Demographics.* To identify health-related conditions and past medical history, a non-validated medical history questionnaire was used. Topics covered included: questions related to neurological, endocrine and cardiovascular and gastrointestinal health. Demographics (age, gender, race/ethnicity, employment status) were collected. Health information and demographic information was obtained from both PwPD and their caregivers (Appendix V and W).

**Quantitative Statistical Analyses.** Quantitative data was analyzed using SPSS v26 (IBM Corp, Summers, NY). Descriptive statistics are reported as mean±standard deviation for continuous variables and percentages and frequencies for categorical variables. Data was examined for outliers, and outliers were found among the following HEI-2015 variables: HEI-2015 Total Scores, Protein, and Refined Grains component scores. Independent t-tests explored differences between PwPD and caregivers for all normally distributed continuous variables. A Mann-Whitney U test examined group differences between non-normally distributed continuous variables. A chi-square analysis explored differences for categorical variables. A p-value of <0.05 indicated statistical significance. Finally, the percent and frequency of PwPD and caregivers who met >80% of adequacy and moderation HEI-2015 components scores were calculated.

***Data Integration.***

*Manuscript 2:* The research team reviewed both data sets and considered the themes coded from the qualitative research in conjunction with the findings from the statistical analyses of the HEI-2015 scores. Qualitative data was mapped into framework matrices and reported as frequencies using NVivo12 to quantify codes within the over-arching category of Dietary Concerns Related to PD Sequelae. This frequency data stemmed from the qualitative themes and a side-by-side comparison of themes were compared with individual HEI-2015 Scores for each participant. Data was interpreted for

consistent patterns between HEI-2015 scores and frequency of self-reported Dietary Concerns Related to PD sequelae from PwPD and their caregivers were made.

*Manuscript 3:* Acceptance of digital health was analyzed by assessing current technology use and purpose from questionnaires and through themes coded from qualitative interviews. Phrases/sentences from qualitative interviews related to acceptance were categorized as Accept, Neutral or Reject. To calculate average acceptance rate among qualitative interviews, the number of phrases coded as Accept, Neutral or Reject were counted and totaled. The total number of phrases coded as Accept were divided by the total number of phrases coded across the three acceptance categories to calculate acceptance rates among each dyad. The percentages were averaged to calculate an average acceptance rate (n=20). Codes from the qualitative interviews were transformed into variables and reported as percent and frequencies. Side-by-side table displays of frequencies derived from perceptions and acceptance (qualitative data) and digital competence scores (quantitative data) were created and interpreted to better describe the population and readiness for a digital health intervention. A Pearson correlation was used to explore if there was an association between the percentage of phrases coded as hard to use and the mean average acceptance rates.

***Resources Required and Utilized:***

Partial funding for Project 1 came from the URI Spark Grant and Enhancement for Graduate Research Award. There was no funding for Project 2. Data collection for Project 1 took place in Independence Square in the URI Speech and Hearing Clinic. Data for Project 2 was collected through phone calls and home visits. Department equipment included: stadiometer, bio-electric impedance scale, electronic scale, cholestech analyzers, portable automatic blood pressure machines, and measuring tape. Data was analyzed using software found on the lab computers in the Lipid Metabolism Lab, including Nvivo 12, SPSS, SAS and NDSR.

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## **APPENDIX C: Longitudinal Study Consent Form (Study 1)**

### **Longitudinal Study of Communication, Nutrition and Physical Activity**

Leslie A. Mahler, PhD, Principal Investigator

Ingrid Lofgren, PhD, co-Investigator

Matthew Delmonico, PhD, co-Investigator

CONSENT FORM FOR RESEARCH: Participant

Version 5: May 24, 2016

The University of Rhode Island  
Department of Communicative Disorders  
25 W Independence Square, Suite I  
Kingston, RI 02881

#### **Purpose of the Consent:**

You have been invited to take part in a research project described below. The purpose of the consent form you are about to read is to provide you with details about the research study and to inform you of your rights if you agree to participate in the study. Your participation is completely up to you. The researcher will explain the project to you in detail. You should feel free to ask questions. If you have more questions later you can call, Dr. Leslie Mahler, the person mainly responsible for this study, at 401-874-2490. You may also contact Dr. Ingrid Lofgren at 401-874-5706 or Dr. Matthew Delmonico at 401-874-5440, who are co-Investigators on the study. You must be at least 18 years old and speak English to be in this research project.

#### **Description of the project:**

This is a research project designed to look at communication, nutrition, and physical activity characteristics of adults who have a stroke, traumatic brain injury or Parkinson disease and healthy adults with no known neurological disorder or head injury to be a control group. All evaluations will be conducted at one of two University of Rhode Island locations; in Independence Square on the Kingston Campus at 25 West Independence Way, Kingston or in Independence Square at 500 Prospect Street in Pawtucket.

You are being asked to be in this study because we want to determine the long-term impact of neurological disorders on communication, nutrition, and physical activity. We are looking for 200 people who have a stroke, traumatic brain injury or Parkinson disease to participate in this project. Participation in this study is entirely your choice.

If you decide to take part in this study, you should understand that the evaluations are investigational and you may not experience any benefit from participation. Participation may also involve additional risks as listed in the Potential Risks and Discomforts section. The consent form will help make sure you understand the tasks

included in the study before you decide whether you want to take part in the study. You may also quit the study at any time.

**What will be done:**

If you agree to take part in this study, you will be asked to complete up to 11 evaluations over five years. Evaluations will take place every six months. The evaluations will include a variety of tasks such as reading sentences and describing a picture, an assessment of how your muscles move, a cognitive screening, an interview, a clinical swallowing evaluation, and questionnaires regarding swallowing, diet and physical activity. The total time for each evaluation will be approximately 3½ hours. All evaluations will be conducted in a quiet private room at one of the University of Rhode Island Speech and Hearing Clinic locations (Kingston or Pawtucket).

With your permission, we will request health information from your physician about the following specific items only:

- Date of diagnosis
- Current medications
- Imaging information about where the brain damage is located (if appropriate)
- Stage of Parkinson disease (if applicable)

You will sign a separate form to indicate whether you give your permission to release this health information for the study. This information will not be requested for healthy adults enrolled in the study

**Potential risks and discomforts:**

There are minimal foreseeable risks associated with these evaluations. There have been no reported adverse affects from clinical evaluation of speech and swallowing. There may be some unknown or unanticipated risks, but every precaution will be taken to ensure your personal safety. Even though experienced personnel will obtain the blood samples from a finger prick, there is a chance of discomfort and minor bruising from the finger stick. For physical function testing there is a risk of muscle soreness or other muscle injury as well as skeletal injury but we will minimize these risks by using standard safety practices.

## Purpose and benefits of the study:

The purpose of this study is to describe communication, nutrition, and physical activity behaviors over time to see how they change and affect quality of life. The information obtained is important because it will help us to understand how to provide services to meet the needs of people with neurological diagnoses. This is an investigational study and there is no guaranteed benefit to your communication or nutrition or physical function as a result of participation in this research study. You will receive personal health information such as your height and weight, physical function determined by a physical assessment, your blood lipids such as cholesterol

and triglycerides. In addition, you will receive information about your thinking skills and language skills and dietary choices.

**Drugs, devices or instruments to be used:**

Drugs will not be used in this study. The equipment for the evaluations include: microphone, sound level meter, tongue blade, a digital tuner, tape recorder, and video cameras. All equipment used to collect cognitive-linguistic and physical function data is considered non-invasive. A lancet and capillary tube will be used to obtain the blood sample from a finger prick and the sample will be analyzed on a small portable machine that is on a table.

**Cost to participant:**

There is no cost to you for participation in the evaluations. Parking is available for free.

**Confidentiality:**

Your part in this study is confidential. Your individual privacy will be maintained in all published and written data resulting from this study. No names of participants will be published or included in written data resulting from this study. Results of this study may be used for purposes of research, educational lectures, and/or professional presentations. When you are entered into the study you will be assigned a code that does not include any identifying information. For example, the first participant will be coded as Long01. The code number will be used on all response forms and in the analysis of the data.

Dr. Mahler and her research team will have sole access to all contact information and evaluation results containing your name. This information will be kept in a locked filing cabinet in a locked office. However, the U.S. Department of Health and Human Services, and the University of Rhode Island Institutional Review Board have the right to inspect all of your records relating to this research for the purpose of verifying data. Because of the need to release information to these parties, absolute confidentiality cannot be guaranteed. Following completion of this project, contact information will be destroyed for those participants who wish, for any reason, not to be contacted in the future. All other information will be archived and kept in a locked filing cabinet with the study results at the University of Rhode Island. All research data will be retained for a minimum of three years following completion of the study and then will be destroyed. Research data will be located in a locked filing cabinet in the principal investigator's locked office.

Cognitive-linguistic evaluations will be audio and video recorded to allow for data analyses. At times these recordings can be useful for teaching students or professionals about the disorders of people with a neurological diagnosis such as yours. Please indicate by signing below whether you give your permission to use your samples for lectures and presentations. Audio and/or videotapes may be used for teaching for up to 3 years after completion of the study. If you agree, you will never be identified by name in the presentations or lectures. Your decision to give

permission to use audio and/or video samples in lectures has no impact on your participation in the study.

\_\_\_\_\_ Yes, I give permission to use audio samples in lectures and presentations.

\_\_\_\_\_ Yes, I give permission to use video samples in lectures and presentations.

\_\_\_\_\_ No, I do not want audio samples used except for research analysis.

\_\_\_\_\_ No, I do not want video samples used except for research analysis.

**In case there is any injury to you during the study:**

If this study causes you any injury, you should immediately contact Dr. Leslie Mahler at (401) 874-2490 or contact the University of Rhode Island Speech and Hearing Clinic at (401) 874-5969. You may also call the office of the Vice President for Research Integrity, 70 Lower College Road, University of Rhode Island, Kingston, RI at (401) 874-4328. If you are injured during an evaluation or during treatment every effort will be made to get you medical attention but you will be responsible for paying for the medical treatment needed.

**Decision to quit at any time:**

The decision to take part in this study is up to you. You do not have to participate. If you decide to take part in the study, you may quit and stop participating in this study at any time. You have the right to refuse to answer any question(s) or participate in any procedure for any reason. Deciding not to participate will have no effect on your potential to receive services from a speech-language pathologist. If you wish to quit, simply inform Leslie Mahler at 874-2490 of your decision. If you wish to pursue an alternative treatment instead of completing the study you will be provided with information on how to obtain those services.

**Rights and complaints:**

If you are not satisfied with the way this study is performed, you may discuss your complaints with Dr. Leslie Mahler ([lmahler@uri.edu](mailto:lmahler@uri.edu); 401-874-2490), Dr. Ingrid Lofgren ([ingridlofgren@uri.edu](mailto:ingridlofgren@uri.edu), 401-874-5706), or Dr. Matthew Delmonico ([delmonico@uri.edu](mailto:delmonico@uri.edu); 401-874-5440), or you may contact the office of the Vice President for Research for concerns or any questions about your rights as a research subject at: 70 Lower College Road, University of Rhode Island, Kingston, RI at (401) 874-4328 and speak to them anonymously if you choose.

**Authorization:**

Your authorization means that you have read this paper and know the purpose of the study and the possible risks and benefits. It also means you know that being in this study is voluntary and you choose to be in this study. You can also withdraw at any time. Your questions have been answered. Your signature on this form means that you understand the information and you agree to participate in this study.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Signature of Researcher

\_\_\_\_\_  
Participant Typed/printed Name

\_\_\_\_\_  
Researcher Typed/printed name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Guardian

\_\_\_\_\_  
Signature of Researcher

\_\_\_\_\_  
Guardian Typed/printed Name

\_\_\_\_\_  
Researcher Typed/printed name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Date

***Please sign both consent forms, keeping one for yourself.***

## APPENDIX D: Dietary Screening Tool

### 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 cereals?**

- 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 IS NOT 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)

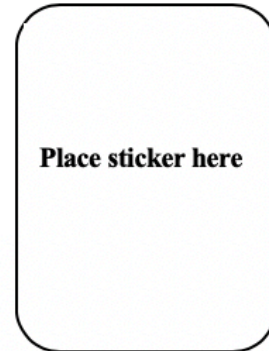
## APPENDIX E: Biochemical and Clinical Data

### Blood Lipids, Glucose, Blood Pressure Results

Name \_\_\_\_\_

Participant ID \_\_\_\_\_

Your Results:



**Blood Pressure:**

- Desirable: <120/80 mmHg
- Borderline high:  $\geq$  130/85 mmHg
- High:  $\geq$ 140/90 mmHg

**Total Cholesterol:**

- Desirable: < 200 mg/dL
- Borderline: 200-239 mg/dL
- High:  $\geq$  240 mg/dL

**HDL Cholesterol:**

- Low: < 40mg/dL
- High:  $\geq$  60 mg/dL

**LDL Cholesterol:**

- Optimal: <100 mg/dL
- Near optimal/above optimal: 100-129 mg/dL
- Borderline high: 130-159 mg/dL
- High: 160-189 mg/dL
- Very high:  $\geq$  190 mg/dL

**Triglycerides:**

- Normal: < 150mg/dL
- Borderline high: 150-199 mg/dL
- High: 200-499 mg/dL
- Very high:  $\geq$  500mg/dL

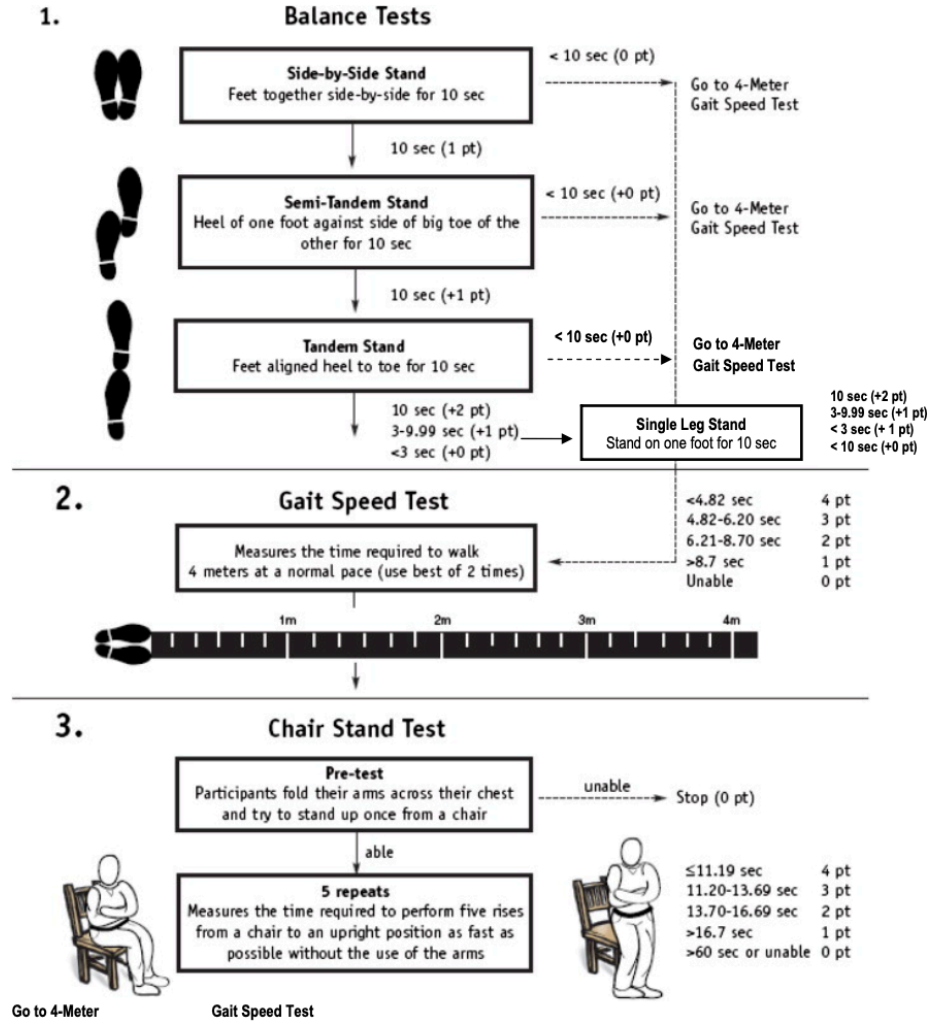
**Glucose:**

- Normal fasting glucose: < 100mg/dL
- Impaired fasting glucose: 100-126 mg/dL
- High fasting glucose:  $\geq$  126 mg/dL

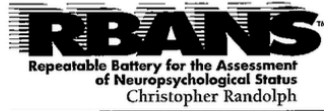
<b>BP 1</b>	
<b>BP 2</b>	
<b>BP 3 (if necessary)</b>	
<b>BP 4 (if necessary)</b>	

*National Cholesterol Education Program Adult Treatment Panel III Guidelines, American Diabetes Association*

# APPENDIX F: Short Physical Performance Battery



# APPENDIX G: Repeatable Battery of the Neuropsychological Status



## Record Form B

Name \_\_\_\_\_ Age \_\_\_\_\_ Sex \_\_\_\_\_ Education Level \_\_\_\_\_

Examiner \_\_\_\_\_ Date of Testing \_\_\_\_\_ Ethnicity \_\_\_\_\_

Observations: \_\_\_\_\_

	Immediate Memory	Visuospatial/Construc-tional	Language	Attention	Delayed Memory	Total Scale
Index Score						
Confidence Interval %						
Percentile						
Index Score						Total Scale Index Score
160						160
155						155
150						150
145						145
140						140
135						135
130						130
125						125
120						120
115						115
110						110
105						105
100						100
95						95
90						90
85						85
80						80
75						75
70						70
65						65
60						60
55						55
50						50
45						45
40						40
					Percentile Rank	
					>99.9	
					>99.9	
					>99.9	
					99.9	
					99.6	
					99	
					98	
					95	
					91	
					84	
					75	
					63	
					50	
					37	
					25	
					16	
					9	
					5	
					2	
					1	
					0.4	
					0.1	
					<0.1	
					<0.1	
					<0.1	



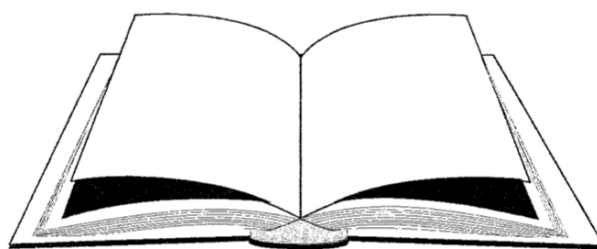
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27 28 29 30 31 32 33 34 35 36 C D E

Product Number 0154166049

## **The SWAL-QOL SURVEY**



**Understanding  
Quality of Life  
in Swallowing Disorders**

## Instructions for Completing the SWAL-QOL Survey

This questionnaire is designed to find out how your swallowing problem has been affecting your day-to-day quality of life.

Please take the time to carefully read and answer each question. Some questions may look like others, but each one is different.

***Here's an example of how the questions in the survey will look.***

	Always	Frequently	Sometimes	Rarely	Never
How often do you...			<input type="radio"/>		

**Thank you for your help in taking part in this survey!**

**IMPORTANT NOTE:** We understand that you may have a number of physical problems. Sometimes it is hard to separate these from swallowing difficulties, but we hope that you can do your best to concentrate **only** on your **swallowing problem**. Thank you for your efforts in completing this questionnaire.

1. Below are some general statements that people with **swallowing problems** might mention. In the last month, **how true** have the following statements been for you.

*(circle one number on each line)*

	<b>Very much true</b>	<b>Quite a bit true</b>	<b>Somewhat true</b>	<b>A little true</b>	<b>Not at all true</b>
Dealing with my swallowing problem is very difficult.	1	2	3	4	5
My swallowing problem is a major distraction in my life.	1	2	3	4	5

2. Below are aspects of day-to-day eating that people with **swallowing problems** sometimes talk about. In the last month, **how true** have the following statements been for you?

*(circle one number on each line)*

	<b>Very much true</b>	<b>Quite a bit true</b>	<b>Somewhat true</b>	<b>A little true</b>	<b>Not at all true</b>
Most days, I don't care if I eat or not.	1	2	3	4	5
It takes me longer to eat than other people.	1	2	3	4	5
I'm rarely hungry anymore.	1	2	3	4	5
It takes me forever to eat a meal.	1	2	3	4	5
I don't enjoy eating anymore.	1	2	3	4	5



3. Below are some physical problems that people with **swallowing problems** sometimes experience. In the last month, **how often** you have experienced each problem as a result of your swallowing problem?

(circle one number on each line)

	<b>Almost always</b>	<b>Often</b>	<b>Sometimes</b>	<b>Hardly ever</b>	<b>Never</b>
Coughing	1	2	3	4	5
Choking when you eat food	1	2	3	4	5
Choking when you take liquids	1	2	3	4	5
Having thick saliva or phlegm	1	2	3	4	5
Gagging	1	2	3	4	5
Drooling	1	2	3	4	5
Problems chewing	1	2	3	4	5
Having excess saliva or phlegm	1	2	3	4	5
Having to clear your throat	1	2	3	4	5
Food sticking in your throat	1	2	3	4	5
Food sticking in your mouth	1	2	3	4	5
Food or liquid dribbling out of your mouth	1	2	3	4	5
Food or liquid coming out your nose	1	2	3	4	5
Coughing food or liquid out of your mouth when it gets stuck	1	2	3	4	5

4. Next, please answer a few questions about how your **swallowing problem** has affected your diet and eating in the last month.

(circle one number on each line)

	<b>Strongly agree</b>	<b>Agree</b>	<b>Uncertain</b>	<b>Disagree</b>	<b>Strongly disagree</b>
Figuring out what I can and can't eat is a problem for me.	1	2	3	4	5
It is difficult to find foods that I both like and can eat.	1	2	3	4	5

## Appendix I: Time Swallow Test

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

Participant Code: \_\_\_\_\_

### Timed Test of Swallowing Capacity for Neurological Patients

#### Pre-Test:

- Give the participant a tablespoon (approximately 10 ml) to drink. If they swallow without overt signs of coughing or choking proceed with the test.

#### Timed Swallow Test:

- Give the participant 150 ml of cold tap water to drink from a standard glass.
- The instructions are to drink the water as quickly as possible when I tell you to begin.
- Once the examiner says go, time how long it takes to finish all the water and how many swallows were completed.
- If there is residual water in the cup then measure how much to determine the amount of water that was swallowed.
- Calculation:
  - Results =

Avg Volume =  
(total ml/# of swallows)

Avg Speed =  
(total ml/seconds)

- Interpretation
  - Swallowing speed < 10 ml/second is a sensitive indicator of swallowing problems in neurological patients (Nathadwarawala, Nicklin, & Wiles (1992). A timed test of swallowing capacity for neurological patients. *Journal of Neurology, Neurosurgery, and Psychiatry*, 55, 822-825.)

Clinician: \_\_\_\_\_

**APPENDIX J: Past Medical History**

**INTERVIEW**

**Longitudinal Study of Communication, Nutrition and Physical Activity**

Leslie Mahler, PhD, CCC-SLP, Principal Investigator

Ingrid Lofgren, PhD, co-Investigator

Matthew Delmonico, PhD, 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 any 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?

---

---

---

---

**APPENDIX K: Recruitment Materials**

# People with Parkinson’s disease and their Caregivers Needed for Research Study



The University of Rhode Island’s Lipid Lab invites people with Parkinson’s disease and their caregivers to participate in a 4-part research study (~4.5 hours total) to collect information related to diet, access to health information and technology use. Dr. Ingrid Lofgren is the principal investigator of this URI research study, which has been approved by the URI Institutional Review Board.

**Inclusion Criteria:**

- 18+ years of age
- Community dwelling
- English speaking
- Telephone access
- Participation of person with Parkinson’s and their informal caregiver
- Informal caregiver is an unpaid friend/family member that provides majority of care
- No prior technology use or transportation access is required



Dara LoBuono 401-874-2785 lipidlab@etal.uri.edu	Dara LoBuono 401-874-2785 lipidlab@etal.uri.edu	Dara LoBuono 401-874-2785 lipidlab@etal.uri.edu	Dara LoBuono 401-874-2785 lipidlab@etal.uri.edu	Dara LoBuono 401-874-2785 lipidlab@etal.uri.edu	Dara LoBuono 401-874-2785 lipidlab@etal.uri.edu	Dara LoBuono 401-874-2785 lipidlab@etal.uri.edu
---	---	---	---	---	---	---

Dear \_\_\_\_\_

The University of Rhode Island's Lipid Lab is looking for people with Parkinson's disease and their caregivers (18 years+) to participate in a research study to collect information related to diet, access to health information and technology use. The total time commitment for the study is approximately 4.5 hours and is completed over 4 time points.

Dr. Ingrid Lofgren, Department of Nutrition and Food Sciences, is the principal investigator for this study. We are asking you to display our recruitment flyer in your office, meeting area and/or lobby to help us recruit participants for this study. The flyer is attached to this email. If you know of any participants who are interested, please direct them to our recruitment flyer with our contact information.

Thank you for your time and support. If you have any questions regarding the study please feel free to contact us.

Sincerely,  
Dara LoBuono MS RD LDN  
PhD Student  
Department of Nutrition and Food Sciences  
University of Rhode Island  
401-874-2785  
dara\_lobuono@my.uri.edu

## APPENDIX L: Parkinson's and Telenutrition Consent Form for Person with Parkinson's Disease

THE  
UNIVERSITY  
OF RHODE ISLAND

COLLEGE OF  
HEALTH SCIENCES

DEPARTMENT OF NUTRITION AND FOOD SCIENCES

125 Fogarty Hall, Kingston, RI 02881 USA p: 401.874.2253 f: 401.874.5974 web.uri.edu/nfs



Tailoring Digital Health to Improve the Nutrition and Health of People with Parkinson's Disease  
Consent form for Person with Parkinson's Disease  
Version 1: June 15, 2018

**Principal Investigator**, Ingrid E. Lofgren 401-874-5706 ingridlofgren@uri.edu  
**Co-Investigator**, Leslie A. Mahler, PhD 401-874-2490 lmahler@uri.edu

### Key Information

- The purpose of this research project is to learn more about people with Parkinson's disease and their informal caregivers' perceptions of technology to manage health and food intake. Additionally, we want to better understand your food intake and current level of technology use.
- If you choose to participate you will be asked to complete 4 assessments total. Which include, an informational phone call, an in-person evaluation and 2-phone calls to collect 24-hour dietary recall information. The anticipated total study time is 4 hours and 20 minutes.
- There are minimal risks for participating in this study.
- Both you and your caregiver will receive personal health information, such as tailored dietary guidelines and body composition.
- You and your caregiver will be provided a copy of this consent form.
- Taking part in this research project is voluntary. You don't have to participate and you can stop it any time.

### Invitation

You have been invited to take part in a research project described below. The purpose of the consent form is to provide you with details about the research study and to inform you of your rights if you agree to participate in the study. Your participation is voluntary. The researcher will explain the project to you in detail. You should feel free to ask questions. If you have more questions later you can call, Dr. Ingrid Lofgren, the study's Principal Investigator, at 401-874-5706.

### Why you are being asked to be in this research study?

To participate in this study, you must be at least 18 years old and speak English. You must also have a diagnosis of Parkinson's disease and an identified informal caregiver who will enroll in the study with you. Participation of both you and your caregiver is required.

With your permission, we will request the following health information from your physician:

- Date of diagnosis
- Current medications and treatments

The University of Rhode Island is an equal opportunity employer committed to community, equity, and diversity and to the principles of affirmative action.



IRB NUMBER: HU1819-001  
IRB APPROVAL DATE: July 21, 2018  
IRB EXPIRATION DATE: July 21, 2019

- Stage of Parkinson disease

You will sign a separate form to indicate whether you give your permission to release this health information for the study.

**What is the reason for doing this research study?**

The purpose of this research project is to learn more about your perceptions of technology using technology to manage health. Additionally, we want to better understand your food intake and current level of technology use.

**What will be done during this research study?**

This study will be completed in four sessions, which will all occur within one month. The first session was the informational phone call you completed and cognitive screening. The Second Session will take place in person, either at one of the University of Rhode Island Speech and Hearing Clinic locations (Kingston or Pawtucket) or you will be offered the option of a home visit. The other 2 sessions will be completed by phone. The sessions are described below in detail and total participation time will be about 4 hours and 20 minutes. If there are any questions you do not wish to answer just let me know and we can skip it. You may also stop the interview/assessments at anytime. Our conversation and your responses will remain completely confidential.

**Session 1 (Informational Phone Call, ~15 minutes)**

- This is the phone call you recently completed to learn about the study and screen for eligibility.
- The Telephone Montreal Cognitive Assessment (T-MoCA) was used to screen for eligibility. If you chose to enroll in the study, your T-MoCA results will be used for research purposes for this study only. If you do not choose to enroll in the study, T-MoCA information will be destroyed.

**Session 2 (~125 minutes)**

- This session will be completed in person today.
- You and your caregiver will complete a semi-structured interview designed by study staff. The interview will last about an hour and questions will revolve around Parkinson's and diet, access to health information and technology use. This interview will occur in a private space and will be audio recorded with your permission.
- During this time you will complete questionnaires related to dietary intake, swallowing, disease-burden, technology use, past medical history and demographics.
- A timed swallow test will be administered by a trained professional from Communicative Disorders.
- You will also have your height, weight, percent body fat and waist circumference measured.

**Session 3 (~60 minutes total, ~30 minutes for person with Parkinson's disease)**

- This session will be completed by phone. The study staff administering the phone call will be in a private room and have the phone on speaker. The call will be recorded with your permission.
- Both you and your caregiver will each complete a 24-hour dietary recall, which take each of you about 30 minutes to complete. A 24-hour dietary recall is a way to characterize your nutritional intake and consists of 5-steps to collect all the foods and beverages you consume in the past 24-hours. You will receive a Foods Amounts Booklet during Session 2



IRB NUMBER: HU1819-001  
 IRB APPROVAL DATE: July 21, 2018  
 IRB EXPIRATION DATE: July 21, 2019

to help you estimate portion sizes for this part of the study. Along with dietary intake, we will also ask you questions about medication timing and supplement use.

Session 4 (~60 minutes total, ~30 minutes per person with Parkinson's disease)

- This session will be completed by phone. The study staff administering the phone call will be in a private room and have the phone on speaker. The call will be recorded with your permission.
- This will be the second dietary 24-hour recall that you complete and will take about 30 minutes.

**What are the possible risks and benefits of being in this research study?**

There are minimal risks for participating in this study. There may be some unknown or unanticipated risks, but every precaution will be taken to ensure your personal safety. You are being asked to participate in this study because we want to determine the best medium of digital health to help manage diet and increase access to nutrition and diet information. Understanding your preferences and your caregiver's preferences, will allow us to develop a tailored, user-friendly digital health nutrition intervention. Obtaining this information will also help use innovative mediums to increase access to nutrition information for managing Parkinson's disease. Both you and your caregiver will receive personal health information, such as tailored dietary guidelines and body composition. You will also receive information related to your thinking and language skills.

**How will information about you be protected?**

Reasonable steps will be taken to protect your privacy and the confidentiality of your study data. All information will be kept in 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 response from questionnaires, interview, dietary data, medical history and demographics. The code number will be used on all response forms and in the analysis of the data. Results of this study may be used for purposes of research, educational lectures, and/or professional present. In publications you will be identified as "participant number." Dr. Lofgren and her research team will have sole access to all contact and personal information containing your name. This information will be kept in a locked filing cabinet in a locked laboratory. All electronic data will be stored through a secure server and will only be seen by the research team. All research data will be retained for a minimum of three years following completion of the study and then will be destroyed. Research data will be located in a locked filing cabinet in the principal investigator's laboratory.

The only persons who will have access to your research records are the study personnel, the Institutional Review Board (IRB), and any other person, agency, or sponsor as required by law. The information from this study may be published in scientific journals or presented at scientific meetings but the data will be reported as group or summarized data and your identity will be kept strictly confidential.

**Voluntary Participation**

Research studies include only people who agree to take part in the study. You can tell us you do not want to take part in the study. If you decide to take part in this study, you should understand that the evaluations are investigational and you may not experience any benefit from participation. The consent form will help make sure you understand the tasks included in the



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study before you decide whether you want to take part in the study. You may also quit the study at any time. 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.

**Costs and Compensation to Participants**

You will not receive any compensation for your time in this study. If you chose to have your assessment at the University of Rhode Island, free parking will be provided.

**What should you do if you have a problem during this research study?**

Your welfare is the major concern of every member of the research team. If you have a problem as a direct result of being in this study, you should immediately contact one of the people listed at the beginning of this consent form.

**What will happen if you decide not to be in this research study or decide to stop participating once you start?**

You can decide not to be in this research study, or you can stop being in this research study ("withdraw") at any time before, during, or after the research begins for any reason. Deciding not to be in this research study or deciding to withdraw will not affect your relationship with the investigator or with the University of Rhode Island (list others as applicable).

**What are your rights as a research subject? (rights and complaints):**

You may ask any questions concerning this research and have those questions answered before agreeing to participate in or during the study. If you have any additional questions about this study, please feel free to contact Dr. Ingrid Lofgren at 401-874-5706. If you are not satisfied with the way this study is performed, you may discuss your complaints with Dr. Ingrid Lofgren ([ingridlofgren@uri.edu](mailto:ingridlofgren@uri.edu), 401-874-5706), or Dr. Leslie Mahler ([lmahler@uri.edu](mailto:lmahler@uri.edu); 401-874-2490). You may also contact the Institutional Review Board at 401-874-4328/[researchintegrity@etal.uri.edu](mailto:researchintegrity@etal.uri.edu) or the Vice President for Research and Economic Development for concerns or any questions about your rights as a research subject at: 70 Lower College Road, University of Rhode Island, Kingston, RI at (401) 874-4328 and speak to them anonymously if you choose.

**Documentation of Informed Consent**

You are voluntarily making a decision whether or not to be in this research study. Signing this form means that (1) you have read and understood this consent form, (2) you have had the consent form explained to you, (3) you have had your questions answered and (4) you have decided to be in the research study. You will be given a copy of this consent form to keep.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Signature of Researcher

\_\_\_\_\_  
Participant Typed/printed Name

\_\_\_\_\_  
Researcher Typed/printed name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Date

Please keep a copy of the signed consent form for your records.



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**AUDIO/VIDEO ADDENDUM TO THE CONSENT FORM FOR RESEARCH**

By signing this consent form, I confirm that I give my permission for *audio* recording(s) of me, to be used for the purposes listed above, and to be retained *for three years after study completion*. You may still participate in this study if you are not willing to be recorded.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Signature of Researcher

\_\_\_\_\_  
Participant Typed/printed Name

\_\_\_\_\_  
Researcher Typed/printed name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Date

**ADDENDUM FOR HIPAA INFORMATION (PERSONAL HEALTH INFORMATION) ACCESS**

You have rights regarding the privacy of your medical information collected before and during this research. This medical information, called "protected health information" (PHI), typically may include, depending upon the nature of this research, demographic information (like your address and birth date), the results of physical exams, blood tests, x-rays and other diagnostic and medical procedures, as well as your medical history.

By signing this consent form, you are allowing the research team to have access to your PHI. The research team includes the investigators listed on this consent form and other personnel involved in this specific study at [add additional personnel/institutions as applicable].

Your PHI will be used only for the purpose(s) described in the section "What is the reason for doing this research study?"

Your PHI will be shared, as necessary, with the Institutional Review Board (IRB) and with any person or agency required by law. You are also allowing the research team to share your PHI with other people or groups listed below all of these persons or groups listed below are obligated to protect your PHI.

The protected health information that may be used and disclosed includes:

- Date of Parkinson's Diagnosis
- Medication dosing and timing for Parkinson's
- Treatments for Parkinson's disease, such as Deep Brain Stimulation
- Stage of Parkinson's as measured by Hoehn & Yahr and Unified Parkinson's Disease

Rating Scale

You may cancel your authorization for further collection of PHI for use in this research at any time by contacting the principal investigator in writing. However, the PHI which is not included in the



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research data obtained to date may still be used. If you cancel this authorization, you will no longer be able to participate in this research.

You are authorizing us to use and disclose your PHI for as long as the research study is being conducted.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Signature of Researcher

\_\_\_\_\_  
Participant Typed/printed Name

\_\_\_\_\_  
Researcher Typed/printed name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Date



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# APPENDIX M: Parkinson's and Telenutrition Consent Form for Caregiver

THE  
UNIVERSITY  
OF RHODE ISLAND  
  
COLLEGE OF  
HEALTH SCIENCES



DEPARTMENT OF NUTRITION AND FOOD SCIENCES  
125 Fogarty Hall, Kingston, RI 02881 USA p: 401.874.2253 f: 401.874.5974 web.uri.edu/nfs

Tailoring Digital Health to Improve the Nutrition and Health of People with Parkinson's Disease  
Consent form for Caregivers  
Version 1: June 15, 2018

**Principal Investigator**, Ingrid E. Lofgren 401-874-5706 ingridlofgren@uri.edu  
**Co-Investigator**, Leslie A. Mahler, PhD 401-874-2490 lmahler@uri.edu

### Key Information

- The purpose of this research project is to learn more about people with Parkinson's disease and their informal caregivers' perceptions of technology to manage health and food intake. Additionally, we want to better understand your food intake and current level of technology use.
- If you choose to participate you will be asked to complete 4 assessments total. Which include, an informational phone call, an in-person evaluation and 2-phone calls to collect 24-hour dietary recall information. The anticipated total study time is 4 hours and 20 minutes.
- There are minimal risks for participating in this study.
- Both you and your loved one with Parkinson's disease will receive personal health information, such as tailored dietary guidelines and body composition.
- You and your loved one will be provided a copy of this consent form.
- Taking part in this research project is voluntary. You don't have to participate, and you can stop it any time.

### Invitation

You have been invited to take part in a research project described below. The purpose of the consent form is to provide you with details about the research study and to inform you of your rights if you agree to participate in the study. Your participation is voluntary. The researcher will explain the project to you in detail. You should feel free to ask questions. If you have more questions later you can call, Dr. Ingrid Lofgren, the study's Principal Investigator, at 401-874-5706.

### Why you are being asked to be in this research study?

To participate in this study, you must be at least 18 years old and speak English. You must be an informal caregiver for someone with Parkinson's disease. Your loved one with Parkinson's disease must also enroll in the study in order for you to participate. An informal caregiver is defined as: an unpaid family member or friend who provides the majority of care for their loved one with Parkinson's disease.

The University of Rhode Island is an equal opportunity employer committed to community, equity, and diversity and to the principles of affirmative action.



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**What is the reason for doing this research study?**

The purpose of this research project is to learn more about your perceptions of technology using technology to manage health. Additionally, we want to better understand your food intake and current level of technology use.

**What will be done during this research study?**

This study will be completed in four sessions, which will all occur within one month. The first session was the informational phone call you completed and cognitive screening. The Second Session will take place in person, either at one of the University of Rhode Island Speech and Hearing Clinic locations (Kingston or Pawtucket) or you will be offered the option of a home visit. The other 2 sessions will be completed by phone. The sessions are described below in detail and total participation time will be about 4 hours and 20 minutes. If there are any questions you do not wish to answer just let me know and we can skip it. You may also stop the interview/assessments at anytime. Our conversation and your responses will remain completely confidential.

**Session 1 (Informational Phone Call, ~15 minutes)**

- This is the phone call you recently completed to learn about the study and screen for eligibility.
- The Telephone Montreal Cognitive Assessment (T-MoCA) was used to screen for eligibility. If you chose to enroll in the study, your T-MoCA results will be used for research purposes for this study only. If you do not chose to enroll in the study, T-MoCA information will be destroyed.

**Session 2 (~125 minutes)**

- This session will be completed in person today.
- You and your loved one with Parkinson's disease will complete a semi-structured interview designed by study staff. The interview will last about an hour and questions will revolve around Parkinson's and diet, access to health information and technology use. This interview will occur in a private space and will be audio recorded with your permission.
- During this time, you will complete questionnaires related to dietary intake, swallowing, disease-burden, technology use, past medical history and demographics.
- A timed swallow test will be administered by a trained professional from Communicative Disorders.
- You will also have your height, weight, percent body fat and waist circumference measured.

**Session 3 (~60 minutes total, ~30 minutes for person with Parkinson's disease)**

- This session will be completed by phone. The study staff administering the phone call will be in a private room and have the phone on speaker. The call will be recorded with your permission.
- Both you and loved one with Parkinson's disease will each complete a 24-hour dietary recall, which take each of you about 30 minutes to complete. A 24-hour dietary recall is a way to characterize your nutritional intake and consists of 5-steps to collect all the foods and beverages you consume in the past 24-hours. You will receive a Foods Amounts Booklet during Session 2 to help you estimate portion sizes for this part of the study. Along with dietary intake, we will also ask you questions about medication timing and supplement use.

Session 4 (~60 minutes total, ~30 minutes per person)

- This session will be completed by phone. The study staff administering the phone call will be in a private room and have the phone on speaker. The call will be recorded with your permission.
- This will be the second dietary 24-hour recall that you complete and will take about 30 minutes.
- You may also participate in your loved one with Parkinson's disease's 24-hour dietary recall.

**What are the possible risks and benefits of being in this research study?**

There are minimal risks for participating in this study. There may be some unknown or unanticipated risks, but every precaution will be taken to ensure your personal safety. You are being asked to participate in this study because we want to determine the best medium of digital health to help manage diet and increase access to nutrition and diet information. Understanding your preferences, will allow us to develop a tailored, user-friendly digital health nutrition intervention. Obtaining this information will also help use innovative mediums to increase access to nutrition information for managing Parkinson's disease. Both you and your loved one with Parkinson's disease will receive personal health information, such as tailored dietary guidelines and body composition. You will also receive information related to your thinking and language skills.

**How will information about you be protected?**

Reasonable steps will be taken to protect your privacy and the confidentiality of your study data. All information will be kept in 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 response from questionnaires, interview, dietary data, medical history and demographics. The code number will be used on all response forms and in the analysis of the data. Results of this study may be used for purposes of research, educational lectures, and/or professional present. In publications you will be identified as "participant number." Dr. Lofgren and her research team will have sole access to all contact and personal information containing your name. This information will be kept in a locked filing cabinet in a locked laboratory. All electronic data will be stored through a secure server and will only be seen by the research team. All research data will be retained for a minimum of three years following completion of the study and then will be destroyed. Research data will be located in a locked filing cabinet in the principal investigator's laboratory.

The only persons who will have access to your research records are the study personnel, the Institutional Review Board (IRB), and any other person, agency, or sponsor as required by law. The information from this study may be published in scientific journals or presented at scientific meetings but the data will be reported as group or summarized data and your identity will be kept strictly confidential.

**Voluntary Participation**

Research studies include only people who agree to take part in the study. You can tell us you do not want to take part in the study. If you decide to take part in this study, you should understand that the evaluations are investigational, and you may not experience any benefit from participation. The consent form will help make sure you understand the tasks included in the study before you decide whether you want to take part in the study. You may also quit the study

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SCHOOL OF BUSINESS  
AND ECONOMIC  
DEVELOPMENT

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at any time. 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.

**Costs and Compensation to Participants**

You will not receive any compensation for your time in this study. If you chose to have your assessment at the University of Rhode Island, free parking will be provided.

**What should you do if you have a problem during this research study?**

Your welfare is the major concern of every member of the research team. If you have a problem as a direct result of being in this study, you should immediately contact one of the people listed at the beginning of this consent form.

**What will happen if you decide not to be in this research study or decide to stop participating once you start?**

You can decide not to be in this research study, or you can stop being in this research study ('withdraw') at any time before, during, or after the research begins for any reason. Deciding not to be in this research study or deciding to withdraw will not affect your relationship with the investigator or with the University of Rhode Island (list others as applicable).

**What are your rights as a research subject? (rights and complaints):**

You may ask any questions concerning this research and have those questions answered before agreeing to participate in or during the study. If you have any additional questions about this study, please feel free to contact Dr. Ingrid Lofgren at 401-874-5706. If you are not satisfied with the way this study is performed, you may discuss your complaints with Dr. Ingrid Lofgren ([ingridlofgren@uri.edu](mailto:ingridlofgren@uri.edu), 401-874-5706), or Dr. Leslie Mahler ([lmahler@uri.edu](mailto:lmahler@uri.edu); 401-874-2490). You may also contact the Institutional Review Board at 401-874-4328/[researchintegrity@etal.uri.edu](mailto:researchintegrity@etal.uri.edu) or the Vice President for Research and Economic Development for concerns or any questions about your rights as a research subject at: 70 Lower College Road, University of Rhode Island, Kingston, RI at (401) 874-4328 and speak to them anonymously if you choose.

**Documentation of Informed Consent**

You are voluntarily making a decision whether or not to be in this research study. Signing this form means that (1) you have read and understood this consent form, (2) you have had the consent form explained to you, (3) you have had your questions answered and (4) you have decided to be in the research study. You will be given a copy of this consent form to keep.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Signature of Researcher

\_\_\_\_\_  
Participant Typed/printed Name

\_\_\_\_\_  
Researcher Typed/printed name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Date

Please keep a copy of the signed consent form for your records.



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**AUDIO/VIDEO ADDENDUM TO THE CONSENT FORM FOR RESEARCH**

By signing this consent form, I confirm that I give my permission for *audio* recording(s) of me, to be used for the purposes listed above, and to be retained *for three years after study completion*. You may still participate in this study if you are not willing to be recorded.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Signature of Researcher

\_\_\_\_\_  
Participant Typed/printed Name

\_\_\_\_\_  
Researcher Typed/printed name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Date



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## APPENDIX N: Moderator Guide for Semi-Structured Dyadic Interviews

### Moderator Guide and Script

*Script: Hello my name is Dara LoBuono. I am a PhD student at the University of Rhode Island in the Department of Nutrition and Food Sciences. Today we will discuss how you get health information, how you would like to get health information and what would help you get this information more easily. Remember, there are no right or wrong answers, so please answer questions as best as you can. As a reminder, I will be recording our discussion and taking notes for research purposes. Before we begin, do you have any questions?*

*Transition: Great! Let's get started. The first few questions will be about Parkinson's disease and what you eat.*

### **PD and Diet**

1. Do you make different food choices as a result of having PD? Please explain.
  - a. *Probes: Sugar intake? Fluid Intake? Types of food you eat?*
  - b. *Prompt: In what ways is eating more difficult for you as a result of Parkinson's disease?*

*Follow up: How does Parkinson's disease impact the amount you eat?*

- c. *Probes: Changes due to: Taste and smell? Constipation? Appetite? Time it takes to cook a meal or limited time to cook meals?*
2. What food choices or diet modifications help you manage the symptoms of your Parkinson's disease? Why or why not?
  - a. *Probes: Changing textures to minimize difficulty chewing and swallowing? Eating certain foods to manage constipation?*

*Transition: Now we will discuss your ability to get nutrition and health information and ways that may help you increase access to these services.*

### **Accessibility of Nutrition and Health Information**

3. How does having Parkinson's disease influence your ability to get health information? (Are you able to find the health information you need for managing Parkinson's?)
4. How do you access health information for managing Parkinson's disease?
5. Where do you get information about foods and diets for people with Parkinson's disease?
  - a. **Follow up:** Please describe what information was provided.



6. What information related to eating do you want to learn more about? Please explain.
  
7. How would you like to receive information about food and eating?
  - a. *Probes:* At visits with a healthcare provider, pamphlets, the internet, support groups
  
  - b. **Follow up:** How often?

*Transition: Thank you for that information. Now we are going to explore information related technology\* for managing Parkinson's disease. For the purposes of this interview, technology will be defined as: tools that support independent living, social interaction and assist in managing and providing care. Examples include computers and internet. When responding to these questions, please think about forms of technology that either of you may use or be interested in using.*

**Digital Health for PD:**

8. What forms of technology do you currently use and for what purpose?
  - a. *Probes:* computers, tablets, internet, e-mail, smart phones\*, smart-watches\*  
 \*Smart phones – a cell phone that also includes internet access, camera, email access, and storage. (Example: iPhone, Pixel, Android)  
 \* Smart watches – a wristwatch that can also perform tasks similar to a smart phone or computer. (Example: Apple Watch)

9. What does the term digital health\* mean to you?

*Transition: So, for the purpose of this study, digital health is a broad term used to describe technologies that better manage and track health.*

10. What digital health products do you currently use?
  - a. *Probes:* Apps\* for medication management, devices to monitor gait/speech/blood pressure, videoconferencing\*  
 \*Apps – also known as mobile or computer applications are programs designed to perform a function, task or activity that can benefit the user  
 \*Videoconferencing – is a technology that allows two or more people to communicate from different locations through video and audio signals. Like talking on the phone, but you can see the person (Example: Facetime, Skype)

11. What (additional) digital health products would you be willing to try and why?
  - a. *Probes:* Apps, devices to monitor gait/speech,\* wearables\*,

videoconferencing, websites

- i. *Wearable device to Monitor Gait/Speech* → sensors (ankle bracelet or sock) that measure your stride length and time. Information collected can determine if you are shuffling or taking short steps and can provide information about disease progression.
- ii. *wearables* such as fit bits and apple watches are devices that can track steps taken, heart rate, calories burned and sleep quality. There is also one that helps manage tremors and writing.

12. What digital health products would you be willing to try to help manage **food and eating** for Parkinson's disease and why?

13. The following scenarios are possible ways digital health can be used to make information Tell me if you would be interested in learning more about utilizing the following example of digital health and explain why.

- a. Using videoconferencing to have nutrition counseling sessions from home.
- b. Wearing a watch at meals and snacks that counts your bites\*.  
*Bite Counter* - a watch that tracks wrist motion to count bites and estimate calories while you eat. It provides real-time feedback on amount consumed.
- c. Taking pictures of meals and snacks for a nutrition professional to review.
- d. A website that allows you to post questions to nutrition professionals and other people living with Parkinson's disease and their caregivers about nutrition.
- e. Using phone applications and websites to track the food you eat. (example: MyFitness Pal, Lose it,

14. What makes technology and digital health useful for you?

15. What makes it difficult for you to use digital health (more)?

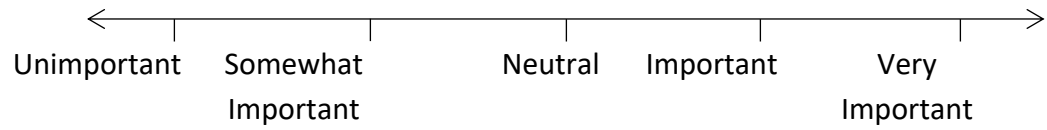
16. What else should I know about how digital health could help you with your eating to optimize your management of Parkinson disease?

*Transition: Thank you for answering all of my questions. We have a few more questions related to the information we discussed today. I will read you the question/statement and the possible responses. Please select one choice that most closely aligns with your response.*

#### **Quantitative Questions.**

17. How important is knowledge about your disease to you?

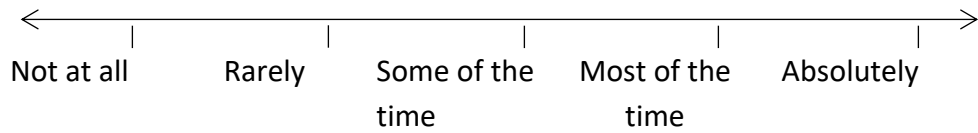
1. Unimportant 2. Somewhat Important 3. Neutral 4. Important 5. Very important.



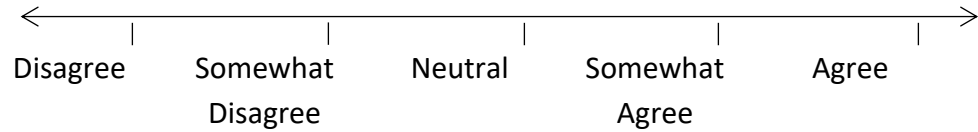
18. Which of these is your main source of knowledge about your disease? (Please Pick one).

1. Healthcare
2. Patients organizations
3. Found myself online
4. Other patients
5. Family, relatives, and friends
6. Other sources.

19. Have you been able to find the knowledge you need about your disease?



20. How strongly do you agree or disagree that it is important to follow an eating plan for managing PD?



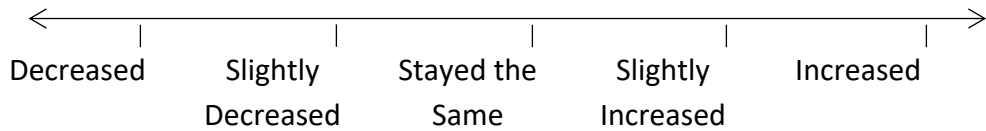
21. How easy or difficult is it to find information related to healthy eating for Parkinson's?

- Very Difficult
- Difficult
- Somewhat Difficult
- Easy
- Very Easy

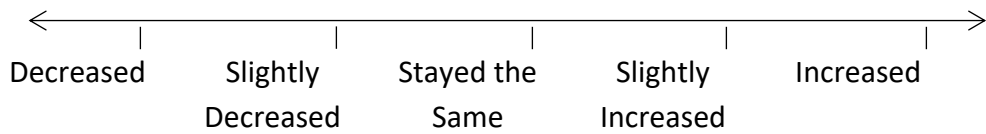
22. How helpful would it be to work with a nutrition professional to manage eating for Parkinson's disease?

- Very Unhelpful
- Unhelpful
- Somewhat unhelpful
- Neither unhelpful or helpful
- Somewhat Helpful
- Helpful
- Very Helpful

23. Since being diagnosed with Parkinson's disease my appetite has:



24. Since being diagnosed with Parkinson's disease the overall amount you eat each day has:



*Script: This concludes the interview. Thank you for all your valuable information and participation in this study.*

## APPENDIX O: Supporting Documents for 24-Hour Dietary Recall Data Collected

### 24-Hour Recall Questions Spring 2018

All enrolled participants will complete two 24-hour recalls. During Sessions 3 and 4 (via telephone), PwPD and caregivers will complete two 24-hour dietary recalls; detailed information about food and beverages intake from midnight to midnight the previous day. Each 24-hour recall will last about 30 minutes per participant.

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 24-hour. 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?

### **Session 3: Phone Call Script**

“Good Morning/Afternoon/Evening \_\_\_\_\_,

Today we will be discussing your dietary intake as part of the URI Parkinson’s disease research

study. This is the third of four sessions. Both you and your loved one will each be completing a 24-hour recall today.

We will go over all of the foods and beverages that you consumed yesterday, from midnight to midnight. This phone call should last approximately 60 minutes or about 30 minutes per recall.”

- Study staff will proceed to administer the 24-hour dietary recalls, one with the PwPD and one with the caregiver. Each recall is anticipated to be about 30 minutes.

“Thank you for your participation in this third assessment, I will be calling in the near future to complete your fourth and final session, another 24-hour dietary recall session by phone. “

### **Session 4: Phone Call Script**

“Good Morning/Afternoon/Evening \_\_\_\_\_,

Today we will be discussing your dietary intake as part of the URI Parkinson’s disease research

study. This is the fourth and final session. Both you and your loved one will each be completing a 24-hour recall today.

We will go over all of the foods and beverages that you consumed yesterday, from midnight to midnight. This phone call should last approximately 60 minutes or about 30 minutes per recall.”

- Study staff will proceed to administer the 24-hour dietary recalls, one with the PwPD and one with the caregiver. Each recall is anticipated to be about 30 minutes.

“Thank you for your participation in this final session. Both you and your loved one will be receiving individual dietary analyses and recommendations in the mail in the next few weeks “

## APPENDIX P: EU Indicators of Digital Competence

Tailoring Digital Health to Improve the Nutrition and Health of People with Parkinson's Disease

Participant ID# \_\_\_\_\_

Date \_\_\_\_\_

Questions Adopted from the European Union Wide Indicators of Digital Competence

The following questions relate to your technology use

**1. ACTIVITIES: For the activities listed below, please select the answers that best reflects how often you take part in that activity:**

	Never	Rarely (less than once a month)	Sometimes (at least once a month)	Often (at least once a week)
Doing unpaid community service or volunteer work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Doing paid community work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Taking courses or participating in discussion groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Going to a movie, restaurant or sporting event	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participating in social and community groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Talking on the phone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Visiting friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Attending group exercise activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Corresponding with friends and family on the internet (Facebook, FaceTime, Skype)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**2. How frequently do you use the following technological devices?**

	Daily	Weekly	Monthly	Never
Desktop Computer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Laptop Computer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tablet (e.g., iPad, Kindle)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Smartphone (e.g., iPhone, Android)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**3. For what purpose(s) do you use technological devices? (Please select all that apply)**

- |   |   |
|---|---|
| <input type="checkbox"/> Email  | <input type="checkbox"/> Search the Internet              |
| <input type="checkbox"/> Social Media (Facebook, Twitter)                       | <input type="checkbox"/> Online Banking or Paying Bills   |
| <input type="checkbox"/> Watch Videos (YouTube)                                 | <input type="checkbox"/> Shopping                         |
| <input type="checkbox"/> Video Conferencing (Skype, FaceTime or Google Hangout) | <input type="checkbox"/> Other (please specify):<br>_____ |



**4. How much do you agree with the statements, I feel competent:**

	Strongly Disagree	Slightly Disagree	Slightly Agree	Strongly Agree
Searching and finding information about goods and services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reading or downloading online news/newspapers/news magazines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using copy/paste tools	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Seeking health information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sending/receiving emails	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using videocalls, such as Skype	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participating in social networks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Posting messages on social networks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Uploading self-created content to any website to be shared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sharing talents or interests on social networks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sharing my interests and ideas with those you know	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Connecting and installing new devices	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Internet banking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Buying or ordering goods or services for private use (last 12 months) over the internet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Making an appointment with a practitioner via a website	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## APENDIX Q: 2015: Health Information National Trends Survey (HINTS)

Tailoring Digital Health to Improve the Nutrition and Health of People with Parkinson's Disease

Participant ID# \_\_\_\_\_

Date \_\_\_\_\_

Questions Adopted from Health Information National Trends Survey

*The following questions are related to how you look for overall health information, eating and food, and/or Parkinson's disease.*

1. Have you ever looked for information about health or medical topics from any source?

Yes  No

2. The most recent time you looked for information about health or medical topics, where did you go first? **Mark only one.**

<input type="checkbox"/> Books	<input type="checkbox"/> Internet
<input type="checkbox"/> Brochures, pamphlets, etc.	<input type="checkbox"/> Library
<input type="checkbox"/> Public Health organization	<input type="checkbox"/> Magazines
<input type="checkbox"/> Family	<input type="checkbox"/> Newspapers
<input type="checkbox"/> Friend/Coworker	<input type="checkbox"/> Telephone information number
<input type="checkbox"/> Doctor or health care provider	<input type="checkbox"/> Complementary, alternative, or unconventional practitioner

3. Based on the results of your most recent search for information about health or medical topics, how much do you agree or disagree with each of the following statements?

	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree
a. It took a lot of effort to get the information needed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. You felt frustrated during a search for information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. You were concerned about the quality of the information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. The information you found was hard to understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. Overall, how confident are you that you could get health information if you needed it? Circle one of the following choices:

(1)	(2)	(3)	(4)	(5)
Completely confident	Very confident	Somewhat confident	A little confident	Not at all confident

□

5. In general, how much would you trust information about health or medical topics from each of the following?

	Not at all	A little	Some	A lot
a. A doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. A healthcare provider	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Family or friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Government health agencies (e.g. the Food and Drug Administration (FDA), National Institute of Health (NIH), or Centers for Disease Control (CDC))	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Health organizations or groups (e.g. American Parkinson's Disease Association (APDA))	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Charitable organizations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Religious organizations and leaders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Online forums and blogs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. On a typical weekday, about how many hours do you...

	Hours
a. Watch television	
b. Listen to the radio	
c. Use the internet for personal reasons	

7. During a typical weekend, about how many hours do you...

	Hours
a. Watch television	
b. Listen to the radio	
c. Use the internet for personal reasons	

8. In the past seven days, how many days did you read a newspaper?

days

9. What information did you look for the most recent time you looked for information about Parkinson's disease?

\_\_\_\_\_

10. What information did you look for the most recent time you looked for information about food and diet?

\_\_\_\_\_

11. In general, how much would you trust information about Parkinson's from each of the following?

	Not at all	A little	Some	A lot
a. A doctor/pharmacist/health care provider	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Family or friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Government health agencies (e.g. FDA, NIH, CDC)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Health organizations or groups (e.g. APDA)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Charitable organizations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Religious organizations and leaders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Pharmaceutical companies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Online forums and blogs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12. In general, how much would you trust information about food and nutrition from each of the following?

	Not at all	A little	Some	A lot
a. A doctor/pharmacist/health care provider	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Family or friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Government health agencies (e.g. FDA, NIH, CDC)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Health organizations/groups (APDA, Academy of Nutrition and Dietetics (AND))	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Religious organizations and leaders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Pharmaceutical companies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Online forums and health blogs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Dietary programs (e.g. Weight Watchers, Paleo)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The following questions related to using the internet to access health information.

13. A. Do you ever go online to access the Internet/World Wide Web, or to send and receive e-mail?

Yes       No

B. How often do you access the internet through each of the following?

	Daily	Sometimes	Never	N/A
a. Computer at home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Computer at work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Public computer (library/ community center)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Mobile device (cellphone/smartphone)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Tablet (iPad, Amazon Fire, other)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Other (please specify): _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



14. A. Some people notice information about health on the Internet, even when they are not trying to find out about a health concern they have or someone in their family has. Have you read such health information on the Internet in the past 12 months?

Yes                       No

B. About how often have you read this sort of information in the past 12 months.

Once a month or more

Less than once a month

15. Sometimes people use the **Internet** specifically for health-related reasons.

In the **past 12 months**, have you used the Internet for any of the following reasons?

	Yes	No
a. Looked for health or medical information for yourself	<input type="checkbox"/>	<input type="checkbox"/>
b. Looked for health or medical information for someone else	<input type="checkbox"/>	<input type="checkbox"/>
c. Looked for information about managing Parkinson's disease	<input type="checkbox"/>	<input type="checkbox"/>
d. Participated in an online forum or support group for people with similar health or medical issue	<input type="checkbox"/>	<input type="checkbox"/>
e. Used a website to help you with your diet, weight, or physical activity	<input type="checkbox"/>	<input type="checkbox"/>
f. Looked for a health care provider	<input type="checkbox"/>	<input type="checkbox"/>
g. Downloaded health information to a mobile device, such as an MP3 player, cell phone, tablet computer, or electronic book device	<input type="checkbox"/>	<input type="checkbox"/>
h. Shared health information on social media sites (Facebook, Twitter)	<input type="checkbox"/>	<input type="checkbox"/>
i. Exchanged support about health concerns with family and friends	<input type="checkbox"/>	<input type="checkbox"/>
j. Kept track of personal health information such as care received, test results, or upcoming medical appointments	<input type="checkbox"/>	<input type="checkbox"/>
k. Watched a health-related video on YouTube	<input type="checkbox"/>	<input type="checkbox"/>

## APPENDIX R: Telephone Montreal Cognitive Assessment

### MONTREAL COGNITIVE ASSESSMENT / MoCA-BLIND

Version 7.1 Original Version

Name:  
Education:  
Sex:  
Date of birth:  
Date:

MEMORY		FACE	VELVET	CHURCH	DAISY	RED	POINTS	
Read list of words, subject must repeat them. Do 2 trials even if 1st trial is successful. Do a recall after 5 minutes.	1st trial						No points	
	2nd trial							
<b>ATTENTION</b>								
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 point if $\geq 2$ 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	
<b>LANGUAGE</b>								
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 $\geq$ 11 words)							___ / 1	
<b>ABSTRACTION</b>								
Similarity between e.g. banana - orange = fruit [ ] train - bicycle [ ] watch - ruler							___ / 2	
<b>DELAYED RECALL</b>		Has to recall words	FACE	VELVET	CHURCH	DAISY	RED	Points for UNCUEDE recall only
		<b>With no cue</b>	[ ]	[ ]	[ ]	[ ]	[ ]	
<b>Optional</b>		Category cue						
		Multiple choice cue						___ / 5
<b>ORIENTATION</b>								
[ ] Date [ ] Month [ ] Year [ ] Day [ ] Place [ ] City							___ / 6	
© Z. Nasreddine MD		www.mocatest.org		Normal $\geq$ 18 / 22		TOTAL		___ / 22
Administered by: _____						Add 1 point if $\leq$ 12 yr edu		

# APPENDIX S: EAT-10 Questionnaire

**EAT-10:**  
A Swallowing Screening Tool



LAST NAME AGE	DATE	FIRST NAME	SEX
------------------	------	------------	-----

**OBJECTIVE:**

EAT-10 helps to measure swallowing difficulties.  
It may be important for you to talk with your physician about treatment options for symptoms.

**A. INSTRUCTIONS:**

Answer each question by writing the number of points in the boxes.  
To what extent do you experience the following problems?

**1 My swallowing problem has caused me to lose weight.**

0 = no problem  
1  
2  
3  
4 = severe problem

**6 Swallowing is painful.**

0 = no problem  
1  
2  
3  
4 = severe problem

**2 My swallowing problem interferes with my ability to go out for meals.**

0 = no problem  
1  
2  
3  
4 = severe problem

**7 The pleasure of eating is affected by my swallowing.**

0 = no problem  
1  
2  
3  
4 = severe problem

**3 Swallowing liquids takes extra effort.**

0 = no problem  
1  
2  
3  
4 = severe problem

**8 When I swallow food sticks in my throat.**

0 = no problem  
1  
2  
3  
4 = severe problem

**4 Swallowing solids takes extra effort.**

0 = no problem  
1  
2  
3  
4 = severe problem

**9 I cough when I eat.**

0 = no problem  
1  
2  
3  
4 = severe problem

**5 Swallowing pills takes extra effort.**

0 = no problem  
1  
2  
3  
4 = severe problem

**10 Swallowing is stressful.**

0 = no problem  
1  
2  
3  
4 = severe problem

**B. SCORING:**

Add up the number of points and write your total score in the boxes.  
**Total Score** (max. 40 points)




**C. WHAT TO DO NEXT:**

If the EAT-10 score is 3 or higher, you may have problems swallowing efficiently and safely. We recommend discussing the EAT-10 results with a physician.

**Reference:** The validity and reliability of EAT-10 has been determined. Belafsky PC, Mouadeb DA, Rees CJ, Pryor JC, Postma GN, Allen J, Leonard RJ. Validity and Reliability of the Eating Assessment Tool (EAT-10). Annals of Otolaryngology & Laryngology 2008;117(12):919-924.

[www.nestlenutrition-institute.org](http://www.nestlenutrition-institute.org)

## APPENDIX T: PDQ-39



# PDQ-39 QUESTIONNAIRE

**Please complete the following**

*Please tick one box for each question*

***Due to having Parkinson's disease, how often during the last month have you....***

		Never	Occasionally	Sometimes	Often	Always or cannot do at all
1	Had difficulty doing the leisure activities which you would like to do?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	Had difficulty looking after your home, e.g. DIY, housework, cooking?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	Had difficulty carrying bags of shopping?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	Had problems walking half a mile?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	Had problems walking 100 yards?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	Had problems getting around the house as easily as you would like?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	Had difficulty getting around in public?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8	Needed someone else to accompany you when you went out?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	Felt frightened or worried about falling over in public?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10	Been confined to the house more than you would like?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11	Had difficulty washing yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12	Had difficulty dressing yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13	Had problems doing up your shoe laces?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Please check that you have ticked **one** box for each question before going on to the next page*



**Due to having Parkinson's disease,  
how often during the last month  
have you....**

**Please tick one box for each question**

		Never	Occasionally	Sometimes	Often	Always or cannot do at all
14	Had problems writing clearly?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15	Had difficulty cutting up your food?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16	Had difficulty holding a drink without spilling it?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17	Felt depressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18	Felt isolated and lonely?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19	Felt weepy or tearful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20	Felt angry or bitter?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21	Felt anxious?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22	Felt worried about your future?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23	Felt you had to conceal your Parkinson's from people?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24	Avoided situations which involve eating or drinking in public?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25	Felt embarrassed in public due to having Parkinson's disease?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26	Felt worried by other people's reaction to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27	Had problems with your close personal relationships?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28	Lacked support in the ways you need from your spouse or partner?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<i>If you do not have a spouse or partner tick here</i>		<input type="checkbox"/>			
29	Lacked support in the ways you need from your family or close friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Please check that you have ticked **one** box for each question before going on to the next page*

***Due to having Parkinson's disease, how often during the last month have you....***

***Please tick one box for each question***

		Never	Occasionally	Sometimes	Often	Always
30	Unexpectedly fallen asleep during the day?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31	Had problems with your concentration, e.g. when reading or watching TV?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32	Felt your memory was bad?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33	Had distressing dreams or hallucinations?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34	Had difficulty with your speech?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35	Felt unable to communicate with people properly?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36	Felt ignored by people?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37	Had painful muscle cramps or spasms?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38	Had aches and pains in your joints or body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39	Felt unpleasantly hot or cold?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Please check that you have ticked **one box for each question** before going on to the next page*

***Thank you for completing the PDQ 39 questionnaire***

## APPENDIX U: MCSI Questionnaire



Parkinson's Toolkit

### The Multidimensional Caregiver Strain Index

Instructions: Circle the number which most closely reflects in general your feelings about caring for your partner, relative, or friend.

	Never	A little	Moderate	A Lot	A great Deal
1. I feel I have less energy now that I am caring for my spouse or family member.	0	1	2	3	4
2. I fee; physically strained because of caring for my spouse or family member.	0	1	2	3	4
3. I feel that my physical health has suffered because of caring for my spouse or family member.	0	1	2	3	4
4. I feel that my social life has suffered because of caring for my spouse or family member.	0	1	2	3	4
5. I have had to give upon vacations or trips because of caring for my spouse or family member.	0	1	2	3	4
6. I am able to go out when I want.	0	1	2	3	4
7. I have had to make adjustments in my work or personal schedule.	0	1	2	3	4
8. Caring for/ providing help for my spouse or family member is a financial strain.	0	1	2	3	4
9. I resent the extra cost of caring for my spouse or family member.	0	1	2	3	4
10. I have enough time to do the things I need to do (Such as chores and helping).	0	1	2	3	4
11. I have a lot of time to myself.	0	1	2	3	4
12. I feel resentful toward my spouse or family member.	0	1	2	3	4
13. I feel angry toward my spouse or family member.	0	1	2	3	4
14. I feel pleased about my relationship with my spouse or family member.	0	1	2	3	4
15. My relationship with my spouse or family member is strained.	0	1	2	3	4
16. I am glad that I can provide care for my spouse or family member.	0	1	2	3	4

---

17. I feel my spouse or family member tries to manipulate me.	0	1	2	3	4
18. I feel that my spouse or family member is overly demanding	0	1	2	3	4

Scoring: Reverse code questions 6,10,11,14, and 16 for a total score.

Adapted from: Stull D. (1996) – The Multidimensional Caregiver strain Index (MCSI): Its Measurement and Structure. *Journal of Clinical Geropsychology*, Vol. 2, (3), 175-196.

# APPENDIX V: Past Medical History Questionnaire – Person with Parkinson’s Disease

## Tailoring Digital Health to Improve the Nutrition and Health of People with Parkinson’s Disease

Ingrid Lofgren, PhD, Principal Investigator  
Leslie Mahler, PhD, CCC-SLP, Co-Investigator

Version 1: 4.4.2018  
Interview for Person with Parkinson’s disease

Name: \_\_\_\_\_ Initials: \_\_\_ \_\_\_ ID#: \_\_\_\_\_

Name of Interviewer: \_\_\_\_\_ Date: \_\_\_\_\_

Participant Address: \_\_\_\_\_

Phone Number: \_\_\_\_\_

Email: \_\_\_\_\_

Emergency contact name & 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.

### Overview

Date of Birth: \_\_\_\_\_ Age: \_\_\_\_\_ Gender: \_\_\_\_\_

### Parkinson’s disease:

What is your neurological diagnosis? \_\_\_\_\_

When were you diagnosed (month/year)? \_\_\_\_\_

What were your symptoms at that time? \_\_\_\_\_

What are your symptoms now? \_\_\_\_\_

What treatments have you had for Parkinson’s disease? \_\_\_\_\_

Do you currently take any medications to manage your Parkinson’s disease? \_\_\_\_\_

If so, which ones? \_\_\_\_\_ For how long? \_\_\_\_\_

How many times/day? \_\_\_\_\_

**Gastrointestinal and Diet:**

- What is your diet like? \_\_\_\_\_
- Do you have any food allergies? \_\_\_\_\_
- Do you have any known gastrointestinal conditions (reflux, celiac disease, irritable bowel syndrome, diverticular disease, etc.) \_\_\_\_\_

- If yes, when were you diagnosed? \_\_\_\_\_
  - How do you manage this condition? (medication, diet, etc.) \_\_\_\_\_
- 

- Do you experience any other symptoms that may impact dietary intake (bloating, constipation, loose stools, distended stomach, nausea, vomiting, diarrhea, gas)

- If yes, for how long and how frequently?
- How do you manage this?

- Do you take any dietary or herbal supplements? If so, which ones and for what reason?

- Have you experienced any weight change in the last year?

- If so, how recently?
- Intentional or Unintentional?
- What is your usual body weight?

**Speech & Swallowing:**

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?

\_\_\_\_\_

**Musculoskeletal system:**

Has your doctor ever told you that you have: (check 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

**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 and which? \_\_\_\_\_
- 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 as evidenced by previous blood lipid tests?  
\_\_\_\_\_
  - If yes, were you given any medications and if so, which one(s)? \_\_\_\_\_

**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      (circle one)  
Date of onset \_\_\_\_\_  
Are/were you on any medication, or is it diet/exercise controlled? \_\_\_\_\_  
\_\_\_\_\_

**Neurological system:**

- Do you have any neurological conditions or a history of a neurological condition?

- 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?
- 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? \_\_\_\_\_
- 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 any of the following? (check 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?
- Do you have problems with walking? If yes,
  - Do you fall frequently and how often? \_\_\_\_\_
  - Is your walking problem related to pain, weakness or loss of balance? \_\_\_\_\_

Have you ever had an operation on skull or brain? \_\_\_\_\_ If so, when? \_\_\_\_\_

Have you ever had meningitis or "brain fever"? \_\_\_\_\_



**Previous Treatments:**

Have you had previous speech/swallow treatment, occupational therapy or physical therapy? \_\_\_\_\_

If yes, please describe (when, what): \_\_\_\_\_  
\_\_\_\_\_

Was it beneficial and what changes did you notice? \_\_\_\_\_  
\_\_\_\_\_

**Other Lifestyle Factors:**

Have you experienced any changes in your mood? If so, please describe.  
\_\_\_\_\_

Do you participate in physical activity/exercise? If so what type and of how often? (hours&days/week)  
\_\_\_\_\_

Do you currently smoke cigarettes? \_\_\_\_\_

If you have a history of smoking cigarettes, when did you quit? \_\_\_\_\_

Do you have any other health problems or conditions that would affect your health?

Are there any other medications or supplements you take that we did not discuss in this interview?  
\_\_\_\_\_

---

How would you describe your health? (circle one)



**Employment:**

Are you currently employed? \_\_\_\_\_ Type of employment and hours per week \_\_\_\_\_

**Education:** Which best describes your education?

- \_\_\_ Less than a HS Diploma
- \_\_\_ GED/HS Diploma
- \_\_\_ Some College
- \_\_\_ Associates Degree
- \_\_\_ Bachelor's Degree
- \_\_\_ Post-Baccalaureate Degree
- \_\_\_ Technical/Trade School

-Continue on Next Page-

**Race/Ethnicity:**

Are you Hispanic or Latino? \_\_\_\_\_

What race/ethnicity do you identify with? (Chose one)

White/Caucasian \_\_\_\_\_ African American \_\_\_\_\_ Asian \_\_\_\_\_ American Indian/Alaskan

Native \_\_\_\_\_ Native Hawaiian/Pacific Islander \_\_\_\_\_ Middle Eastern \_\_\_\_\_

I prefer not to answer \_\_\_\_\_ Other \_\_\_\_\_

***The follow set of questions relate to relationships in your life.***

**FRIENDSHIPS:** When answering the items below, consider all friends including those who live in your neighborhood.

	None	One	Two	3-4	5-8	9+
How many of your friends do you see or hear from at least once a month?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How many friends do you feel at ease with that you can talk about private matters?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How many friends do you feel close to such that you could call on them for help?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**FAMILY:** When answering the items below, consider all of the people to whom you are related by birth, marriage, adoption, etc. (include spouse/partner)

	None	One	Two	3-4	5-8	9+
How many of relatives do you see or hear from at least once a month?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How many relatives do you feel at ease with that you can talk about private matters?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How many relatives do you feel close to such that you could call on them for help?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**RELATIONSHIPS:** Please respond to the following questions below. *How much do you agree or disagree with the following?*

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I am content with my friendships and relationships.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have enough people I feel comfortable asking for help at any time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My relationships are as satisfying as I would want them to be.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

###-END-###

# APPENDIX W: Past Medical History Questionnaire for Caregiver

Tailoring Digital Health to Improve the Nutrition and Health of People with Parkinson's Disease  
Ingrid Lofgren, PhD, Principal Investigator  
Leslie Mahler, PhD, CCC-SLP, Principal Investigator

Version 1: 5.4.2018  
**Interview for Caregiver of Person with PD**

Participant Name: \_\_\_\_\_ Initials: \_\_\_ \_\_\_ ID#: \_\_\_\_\_

Name of Interviewer: \_\_\_\_\_ Date: \_\_\_\_\_

Participant Address: \_\_\_\_\_

Phone Number: \_\_\_\_\_

Email: \_\_\_\_\_

Emergency contact name & 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.

**Overview:**

Date of Birth: \_\_\_\_\_ Age: \_\_\_\_\_ Gender: \_\_\_\_\_

**Gastrointestinal and Diet:**

- What is your diet like? \_\_\_\_\_
- Do you have any food allergies/intolerances? \_\_\_\_\_
- Do you have any known gastrointestinal conditions (reflux, celiac disease, irritable bowel syndrome, diverticular disease, etc.) \_\_\_\_\_

○ If yes, when were you diagnosed? \_\_\_\_\_

○ How do you manage this condition? (medication, diet, etc.) \_\_\_\_\_

- 
- Do you experience any other symptoms that may impact dietary intake (bloating, constipation, loose stools, distended stomach, nausea, vomiting, diarrhea, gas)? \_\_\_\_\_
    - If yes, for how long and how frequently?
    - How do you manage this?

- Do you take any dietary or herbal supplements? If so, which ones and for what reason?
  
- Have you experienced any weight change in the last year?
  - If so, how recently?
  - Intentional or Unintentional?
  - What is your usual body weight?

**Speech & Swallowing**

Are you experiencing any symptoms of a swallowing disorder?

---

If yes, what is the problem with your swallowing? \_\_\_\_\_

**Musculoskeletal system:**

Has your doctor ever told you that you have: (check 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:

**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 and which? \_\_\_\_\_
- 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 as evidenced by previous blood lipid tests?
   
\_\_\_\_\_
  - If yes, were you given any medications and if so, which one(s)? \_\_\_\_\_

**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/exercise controlled? \_\_\_\_\_
   
\_\_\_\_\_

**Neurological system:**

- Do you have any neurological conditions or a history of a neurological condition?
  
- 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?
- 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? \_\_\_\_\_
- 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 any of the following? (check 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 and how often? \_\_\_\_\_
  - Is your walking problem related to pain, weakness or loss of balance?

Have you ever had an operation on skull or brain? \_\_\_\_\_ If so, when? \_\_\_\_\_

Have you ever had meningitis or "brain fever"? \_\_\_\_\_

**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? \_\_\_\_\_

\_\_\_\_\_

**Other Lifestyle Factors**

Have you experienced any changes in your mood? If so, please describe.

\_\_\_\_\_

Do you participate in physical activity/exercise? If so what type and of how often? (hours&days/week)

\_\_\_\_\_

Do you currently smoke cigarettes? \_\_\_\_\_

If you have a history of smoking cigarettes, when did you quit? \_\_\_\_\_

Do you have any other health problems or conditions that would affect your health?

\_\_\_\_\_

Are there any other medications or supplements you take that we did not discuss in this interview?

\_\_\_\_\_

How would you describe your health? (circle one)



**Education:** Which best describes your education?

- \_\_\_ Less than a HS Diploma
- \_\_\_ GED/HS Diploma
- \_\_\_ Some College
- \_\_\_ Associates Degree
- \_\_\_ Bachelor's Degree
- \_\_\_ Post-Baccalaureate Degree
- \_\_\_ Technical/Trade School

**Employment:**

Are you currently employed? \_\_\_\_\_

Type of employment and hours per week \_\_\_\_\_

**Race/Ethnicity:**

Are you Hispanic or Latino? \_\_\_\_\_

What race/ethnicity do you identify with? (Chose one)

White/Caucasian \_\_\_\_\_ African American \_\_\_\_\_ Asian \_\_\_\_\_ American Indian/Alaskan

Native \_\_\_\_\_ Native Hawaiian/Pacific Islander \_\_\_\_\_ Middle Eastern \_\_\_\_\_

I prefer not to answer \_\_\_\_\_ Other \_\_\_\_\_

-Continue on Next Page-

*The follow set of questions relate to relationships in your life.*

**FRIENDSHIPS:** When answering the items below, consider all friends including those who live in your neighborhood.

	None	One	Two	3-4	5-8	9+
How many of your friends do you see or hear from at least once a month?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How many friends do you feel at ease with that you can talk about private matters?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How many friends do you feel close to such that you could call on them for help?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**FAMILY:** When answering the items below, consider all of the people to whom you are related by birth, marriage, adoption, etc. (include spouse/partner)

	None	One	Two	3-4	5-8	9+
How many of relatives do you see or hear from at least once a month?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How many relatives do you feel at ease with that you can talk about private matters?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How many relatives do you feel close to such that you could call on them for help?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**RELATIONSHIPS:** Please respond to the following questions below. *How much do you agree or disagree with the following?*

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I am content with my friendships and relationships.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have enough people I feel comfortable asking for help at any time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My relationships are as satisfying as I would want them to be.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

###-END-###



## APPENDIX X: Request for Personal Health Information

THE  
UNIVERSITY  
OF RHODE ISLAND

COLLEGE OF  
HEALTH SCIENCES

THINK BIG  WE DO™

DEPARTMENT OF NUTRITION AND FOOD SCIENCES

125 Fogarty Hall, Kingston, RI 02881 USA p: 401.874.2253 f: 401.874.5974 web.uri.edu/nfs



### AUTHORIZATION FOR USE OR DISCLOSURE OF PROTECTED HEALTH INFORMATION FOR RESEARCH: For Person with Parkinson's Disease

The University of Rhode Island  
Department of Nutrition and Food Sciences  
Fogarty Hall  
41 Lower College Rd  
Kingston RI, 02881  
Tailoring Digital Health to Improve the Nutrition and Health of People with Parkinson's Disease

The privacy law, Health Insurance Portability & Accountability Act (HIPAA) protects individually identifiable health information. The privacy law requires that an investigator explain in detail what information will be obtained during a study and how that information will be used, and with whom it will be shared.

You have been asked to participate in the above named study. The protected health information that may be used and disclosed includes:

- Date of Parkinson's Diagnosis
- Medication dosing and timing for Parkinson's
- Treatments for Parkinson's disease, such as Deep Brain Stimulation
- Stage of Parkinson's as measured by Hoehn Yahr and Unified Parkinson's Disease Rating Scale

The investigators may use and disclose your protected health information until the end of the study (*August 2020*) . They will use and/or share this information with:

The University of Rhode Island Institutional Review Board

The University of Rhode Island is an equal opportunity employer committed to community, equity, and diversity and to the principles of affirmative action.

Government Agencies when required by law

You do not have to sign this authorization. If you do sign, you may end your participation by notifying the investigator (*name and telephone # of investigator*). Withdrawal of authorization will not affect treatment, payment or enrollment in any health plans or affect your eligibility for benefits. When you withdraw authorization investigators may only use and disclose the protected health information already collected for this research study. Withdrawal of authorization also means that you may not be allowed to participate in the study.

The investigator will respect the confidentiality of the health information, however, should the health information be disclosed by the investigator, to someone outside of this study, it may no longer be protected by the HIPAA regulation.

Signing your name at the bottom of this form means that you have read or listened to what it says and you understand it. Signing this form also means that you agree to authorize the use and disclosure of personal health information. You will be given a copy of this form after you have signed it.

\_\_\_\_\_  
Signature of participant

\_\_\_\_\_  
Signature of Researcher

\_\_\_\_\_  
Typed/printed Name

\_\_\_\_\_  
Typed/printed Name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Date