Hearing Related Concerns Among Parkinson’s Patients and Their Care Partners

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HEARING RELATED CONCERNS AMONG PARKINSON’S PATIENTS AND THEIR CARE PARTNERS

by

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This manuscript has been read and accepted for the Graduate Faculty in Audiology in satisfaction of the capstone research requirement for the degree of Au.D.

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Abstract*

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by

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The goal of this study is to evaluate the relationship between self-reported subjective hearing loss and objective measures of hearing in older adults with Parkinson’s Disease (PD), as well as the relationship between self-reported hearing handicap of those with PD and the report of their care partners. Twenty-four individuals, comprised of older adults with PD and their primary care partners, underwent subjective and objective hearing screenings and completed measures of self-reported hearing handicap. Results revealed no significant relationship between the subjective and objective hearing screening results of those with PD, nor any significant relationship between the self-report of hearing handicap as reported by the individual with PD and the report of their care partner. Results support previous research, suggesting that those with PD fail to self-report hearing loss. Results of this study also suggest that the care partners of Parkinsonian adults may be unable to reliably identify the functional manifestations of hearing loss within their significant other. Results of this study therefore support a need for mandated audiological care within the Parkinsonian community in order to identify those affected by the co-morbid presentation of hearing loss and PD, and their care partners. Implications of this study encourage additional research into the relationship of PD and age-related hearing loss.

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Introduction

Parkinson’s Disease (PD) is one of the most prevalent neurodegenerative conditions in the world today. It is a progressive movement disorder which has a variety of motor and non-motor symptoms and co-morbidities, one of which may be hearing loss (Vitale et al., 2014). Over one million individuals in The United States have a diagnosis of PD. Of individuals affected, the majority are of advanced age (Promgsheim, Jette, Froklis & Steeves, 2014). Fewer than 4% of PD diagnoses occur before age 50 (The Parkinson’s Disease Foundation, 2015). A systematic review and meta-analysis of 47 studies performed by Promgsheim, Jette, Froklis and Steeves (2014) examining the prevalence and epidemiology of PD confirmed an increase in the prevalence of PD with increased age. The number of individuals with PD increases steadily with advancing age when stratified by every 10 years of age after age 40 (Promgsheim, Jette, Froklis & Steeves, 2014).

With life expectancy on the rise throughout the world, the prevalence of this chronic disease is projected to increase dramatically in the coming years. Dorsey et al. (2007) quantified the number of people projected to be diagnosed with PD, from the year 2005 through the year 2030. Projections were calculated utilizing two approaches. The first method involved calculation of the number of individuals with PD as per the country’s age-specific reported prevalence and the country’s expected population structure from 2005 to 2030. The second method evaluated door to door prevalence studies, identified the median prevalence in 2005, and then used population projections to define the expected median prevalence of PD for the year 2030. Using the first method, there was a projected increase in prevalence from 4.6 million in 2005 to 8.7 million in 2030. Results were similar for the second method with prevalence estimates in 2005 at 4.6 million with projected prevalence in 2030 reaching 9.3 million
worldwide. The expected increase in prevalence of this chronic condition among those of an advanced age carries important implications for audiologists, as older PD patients are at increased risk for developing hearing loss (Vitale et al., 2014; Lai et al., 2014).

Anatomical and Physiological Considerations in Parkinson’s Disease

PD is associated with a series of behaviors which are the result of neuron depletion in the Basal Ganglia, specifically the Substantia Nigra. Death of these cells causes a depletion of dopamine in the body which impairs movement tonicity, causing resting tremor, rigidity, postural imbalance and bradykinesia in those affected (Parkinson’s Disease Foundation, 2016). The four aforementioned motor symptoms are largely considered the primary motor symptoms of PD. Secondary motor symptoms including freezing of gait, a masked expression, micrographia and poor motor coordination are also well known symptoms of The Parkinsonian community. There are a variety of non-motor symptoms associated with Parkinson’s as well, though these have only begun to receive attention in recent years. Often, non-motor symptoms may present prior to motor symptoms. Loss of one’s sense of smell, depression, sleep disturbances and constipation are some of the established non-motor symptoms of PD (Parkinson’s Disease Foundation, 2016; Michael J. Fox Foundation for Parkinson’s Research, 2016). Chaudhuri, Yates, & Martinez-Martin (2005) identified six different categories of non-motor Parkinsonian symptoms, including sexual, gastrointestinal and autonomic symptoms. The “non-motor symptom complex” described by Chaudhuri, Yates & Martinez-Martin includes over 30 non-motor symptoms reported by individuals with Parkinson’s Disease, many of which go
unrecognized as Parkinsonian-related non-motor symptoms by patients and medical professionals.

*Hearing Loss and Dopamine: A physiological link*

Neurotransmitters relay impulses from one bodily system to another. A primary role of the neurotransmitter dopamine is to assist in the production of accurate, smooth fine motor movements (Triarhou LC, 2000-2013). Dopamine is sent between neurons of the Substantia Nigra and the Basal Ganglia to plan and execute motor movements. Dopamine is also found in the auditory system, at the level of the inner ear, through the lateral oliviocochlear bundle and the thalamus. In the inner ear, dopamine travels between the efferent terminals of the lateral oliviocochlear bundle and the dendrites of the afferent inner hair cells. Dopamine at the cochlear level affects the synapses between inner hair cells and the afferent dendrites of ganglion cells. In this way, dopamine affects what auditory information reaches the level of the cochlear nucleus (Pisani et al., 2015).

Within the inner ear, dopamine is released from efferent terminals when excess glutamate is present. Glutamate presents when inner hair cells are excited. In instances in which cells become over-excited, as is the case in ischemia and acoustic trauma, an excess of glutamate can build-up. The excess glutamate results in exotoxicity, or cell death. Dopamine, when released, decreases the amount of glutamate present, thus working to prevent cell death (Lendavi et al., 2011). When dopamine is not available for release, there is an increased likelihood of cell death in the inner ear. Higher along the pathway, dopamine has been found to modulate neural auditory activity. Dopaminergic terminals and receptors have been identified in the auditory brainstem,
inferior colliculus, thalamus and forebrain areas. Dopamine has been found to alter the firing rate, latency and jitter of sound-evoked neural firings in mice (Lendavi et al., 2011).

For those affected by PD, the depletion of dopamine causes the characteristic motoric symptoms of PD. After ingesting a synthetic form of dopamine, symptoms can be relieved or greatly reduced. Pisani et al. (2015) took advantage of synthetic dopamine treatments and measured otoacoustic emissions in Parkinsonian individuals before and after dopaminergic treatment. Eleven de-novo PD patients underwent audiometric evaluation and otoacoustic emission testing pre and post-treatment and the results obtained were compared to those of healthy sex-matched controls. Distortion product otoacoustic emissions were found to be more robust post-treatment when compared with their emissions pre-treatment. These findings support the claim that dopamine plays a role in the peripheral auditory system and indicates that the impact of the neurotransmitter can be assessed with clinical tools.

*Alpha Synuclein*

An additional physiological connection, as identified by Vitale et al. (2014), can potentially be found in the alpha synuclein protein. This protein is found in the efferent pathways of the auditory system and the protein is the primary component of Lewy bodies, a hallmark of Parkinson’s Disease dementia. This protein is typically found within the stria vascularis, the primary site of vascular presbycusis. While the role of this protein remains largely unknown, it has been hypothesized that the protein could play part in development of presbycusis (i.e. age related hearing loss).
Parkinson’s and Hearing Loss

In light of anatomic and physiological connections identified, researchers have begun to examine the prevalence of hearing loss in the Parkinsonian community. Yilmaz et al. (2008) evaluated the hearing status of twenty patients with Parkinson’s Disease and twenty-four unaffected individuals via pure tone audiometry and auditory brainstem response testing. All participants were evaluated by a neurologist and an otolaryngologist. Participants with Parkinson’s Disease were Stage 2 according to The Hoehn and Yahr scale. Participants with any condition which could affect ABR and/or pure tone audiometry results, including otological conditions, diabetes mellitus, vasculitis, polyneuropathy and multiple sclerosis, were excluded from the study. Pure tone audiometry revealed significantly poorer pure tone thresholds at 4000 Hz and 8000 Hz among those with Parkinson’s as compared to individuals without PD. Auditory brainstem response testing revealed longer absolute wave V latencies and longer wave I-V inter-peak latencies for those with Parkinson’s Disease. As there was no significant difference in the age composition of the two groups tested and they were matched on all other demographic variables, the results of the study suggest that those with Parkinson’s Disease experience a higher prevalence of high frequency hearing loss than their healthy peers.

A similar study was conducted in Italy by Vitale et al. (2014). 106 patients with a diagnosis of Parkinson’s Disease underwent a comprehensive audiological evaluation, including: case history interview, questionnaire aimed to assess perception of hearing handicap, otoscopic evaluation, immittance measures, pure tone audiometry and auditory brainstem response testing. Dementia was ruled out as defined by DSM-IV criteria and as per a passing score on the Mini Mental State Examination. Those with other comorbid conditions which are known to affect
hearing status, otological history and/or those with atypical manifestations of Parkinson’s Disease were excluded from the test group. Healthy age matched subjects underwent identical testing and served as the control.

Results revealed a higher prevalence of high frequency hearing loss in participants with PD than in those participants without PD. The prevalence of hearing loss identified in the group with PD was also higher than the normative values of hearing loss prevalence for age-matched peers without PD. Sixty-three percent of the individuals with Parkinson’s who had their hearing tested had a moderate sensorineural hearing loss. Those who were evaluated and had a hearing loss were more likely to be male, older in age and report a more advanced age of PD onset. A

significant correlation was found between severity of hearing loss and one’s Parkinson’s staging as per the Hoehn & Yahr Parkinson’s Disease Staging Scale. No significant correlation between audiometric values and demographic variables including total levodopa dose and disease duration were identified. Interestingly, none of the individuals with hearing loss self-identified as having a hearing handicap, though the method for determining perception was not made readily available by Vital et al. It is noted by Vitale et al that “an extensive otological case history and questionnaire to elicit evidence of hearing impairment” was employed. Details on the questionnaire were not provided; reliability and validity of the questionnaire remain unclear.

Most recently, Pisani et al (2015) measured the hearing thresholds of 11 Parkinsonian patients and 11 age-matched, healthy controls. All participants underwent otoscopy, acoustic immittance and pure tone audiometry twice, initially without dopaminergic treatment and then after the third dose of a four step dopaminergic titration of 100 mg. Results revealed poorer audiometric thresholds in the affected population, compared to age-matched, healthy participants. Statistically significant threshold differences were observed at 2000 Hz. No
significant changes in audiometric thresholds were found post-dopaminergic treatment. Despite the increased prevalence of hearing loss in the affected group, a comparison of raw scores obtained on a self-reported measure of hearing loss severity revealed similar scores between those with PD and those without, indicating no subjective perception of hearing disability among the participants with PD. The questionnaire utilized in this study was initially designed for a use in a different study, aimed at evaluating the level of hearing loss at which one perceives changes in their quality of life (Giordano et al., 2008). The sample that participated in the initial study was comprised of 180 male “industrial workers affected by hearing loss”. The use of this questionnaire in a study of Parkinsonian older adults may therefore have not been the most appropriate choice.

Lai et al. (2014) took a different approach in investigating the likelihood of hearing loss as an early, non-motor symptom of Parkinson’s Disease, as suggested by Vitale et al. (2014). These investigators sought to identify if those with hearing loss could potentially be more at risk for the development of PD. Lai et al. (2014) utilized a national universal health insurance database which encompasses 99% of the Taiwanese population for data collection purposes. Individuals affected by hearing loss and/or Parkinson’s Disease were identified by searching the database for the two conditions of interest as defined by The International Classification of Diseases, 9th revision.

The participants were identified by first searching for individuals whom had recently been diagnosed with hearing loss from 2000-2010. Those with a diagnosis of Parkinson’s which had been made prior to the diagnosis of hearing loss were excluded from the study. For each of the 4976 individuals with newly diagnosed hearing loss who were identified, four additional individuals without hearing loss, matched on the basis of sex and age range, were randomly
selected to be used as a control group. These individuals were then monitored until they either were diagnosed with PD, withdrew from the insurance program, or died. This continued until December 31, 2010.

By the end of 2010 the incidence of PD increased with increased age but at a significantly higher rate in the group of individuals with hearing loss than in the group of individuals with normal hearing. The highest incidence of Parkinson’s was observed in the group with hearing loss aged 75-84 years old. An obtained incidence rate ratio of 1.77 and a hazard ratio of 1.53 support the claim that hearing loss may be a potential non-motor symptom of Parkinson’s Disease. The hazard ratio increased with each year of age (1.06 per year). Interestingly, those identified as having hearing loss were more likely to be diagnosed with additional medical issues. While this study focused solely on the increased likelihood to acquire PD, it is worthwhile to note that those with hearing loss were more likely to acquire additional morbidities, on the whole.

Care Partner Burden

The burden of those caring for a spouse or significant other with Parkinson’s Disease carries significant implications for the caregiver. Informal caregivers provide physical and emotional support and their ability to successfully provide care to their loved one carries heavy economic implications in regards to the need for institutionalized care among the large aging population. Having an “informal caregiver”, such as a spouse, is correlated with positive outcomes in regards to patient quality of life (Schrag, Hovris, Morley, Quinn & Jahanshahi, 2006). These informal caregivers are at increased risk however to experience chronic stress and
illness, psychiatric morbidity and restricted socialization. The consistent stress and negative psychosocial impact that befalls an informal caregiver is known as caregiver burden. Therefore, to ensure Parkinsonian patients achieve their greatest quality of life, equal attention must be paid to the needs of their caregivers’ well-being in order for informal caregiving to remain a viable option (Schrag, Hovris, Morley, Quinn & Jahanshahi, 2006).

A survey of 123 caregivers to Parkinsonian adults was conducted in 2006 in London, England (Schrag, Hovris, Morley, Quinn & Jahanshahi, 2006). Results of the study indicated that of all symptoms associated with Parkinson’s, the non-motor symptoms, particularly those affecting one’s mental status, were most highly correlated with increased caregiver burden. Confusion and depression were among these highly effective non-motor symptoms. Poor patient-perception of quality of life was also correlated with a poor quality of life score for care partners.

D’Amelio et al. (2009) screened 40 pairs of individuals in which one had PD and the other served as their care partner and the study yielded similar results, indicating that a caregiver’s perception of burden was more highly correlated with the severity of their significant other’s non-motor symptoms, compared to that of their motor symptoms. While disease severity on the whole was linked to increased perception of burden, severity of the non-motor symptoms in particular was most associated with an increased perception of one’s caregiver burden. It is pertinent to note that individuals with PD have been reported to have an impaired ability to carry out activities of daily life, even more so than adults afflicted by stroke or dementia. Despite the impaired independence that may relate to physical limitations, impaired cognition and depression are reportedly more closely related to an increased severity of caregiver burden (Thommensessen et al., 2002).
For those individuals with hearing impairment, the spouse and/or caregiver is also known to be negatively impacted by their spouse’s limitations. Wallhagen, Strawbridge, Shema et al. (2006) surveyed 426 couples in which one individual had hearing impairment. Physical, psychological and social aspects of life were examined by the survey materials. Results indicated that a spouse with hearing loss is associated with “poorer physical, psychological and social well-being” for the caregiver of that individual, providing further evidence that the psychological status of the affected individual has a definite impact on the psychological well-being of their care partner. These findings corroborate the findings of Scarini, Worrall & Hickson (2008), who conducted in-depth interviews with ten older adults, all of whom had spouses with hearing impairment. They reported on the wide range of ways in which their spouse’s impairment negatively affected their day to day lives. Limitations on spousal independence and safety were particular sources of stress noted by these participants.

It is clear that the social and emotional status of the affected individual has a substantial impact on the caregiver, in the case of those with Parkinson’s disease as well as those with hearing loss. Non-motor, psychological and psychosocial abilities present as the most important factors influencing quality of life for both the affected individual and the care partner, who is vital for maintaining meaningful care. It is therefore of specific importance that spousal input be collected when looking to evaluate the impact of Parkinson’s disease and hearing loss as potential comorbidities.
Assessing the impact of hearing loss via self-reported measures

It has been well documented that audiometry alone fails to accurately predict the impact of hearing loss on one’s daily life and communication. Self-reported measures offer valuable insight into the patient’s perception of their hearing loss and its impact. The Hearing Handicap Inventory for the Elderly (HHIE) has become a well-used clinical utility since its conception in 1982 for assessing the emotional and social burdens of hearing loss, both before and after clinical intervention. The HHIE has excellent internal consistency and high test-retest variability (Newman, Weinstein, Jacobson & Hug, 1990). Single-item screeners can also be used to evaluate a patient’s percept of their hearing abilities. The Blue Mountains Hearing Study (Sindhusake et al., 2001) revealed that the use of a single question (“Do you feel you have a hearing loss?”) yielded responses with reasonable sensitivity and specificity to identify those with a true hearing impairment. The use of this single question in conjunction with the hearing handicap for the elderly screening version was able to provide “reasonable estimates” of hearing loss prevalence among a group of older adults within this study sample. The single question had a sensitivity/specificity of 71% and provided a prevalence estimate within 11.4% of the measured rate, as determined by pure tone audiometry. The single item screener was indicated to be more accurate in identifying a mild hearing impairment, while the HHIE was better for identifying moderate impairment. With one’s perception of loss being tied to one’s own well-being and to the well-being of their care partner, these self-reported measures will be employed by this study.
Objectives & Research Questions

The way in which the neurotransmitter dopamine functions in the auditory system has been noted to be similar to the way in which dopamine functions in the Basal Ganglia and Substantia Nigra. As dopamine is depleted in the system of an individual with Parkinson’s Disease, the shared utility of this neurotransmitter may therefore be of particular importance. It is evidenced by recent literature that hearing loss prevalence is higher in older adults with PD than it is among age-matched, unaffected peers (Vitale et al., 2014; Lai et al., 2014). Measures of hearing, including otoacoustic emissions and audiometric testing, have yielded data consistent with this finding. It has also been indicated that despite a quantitative difference in measured hearing levels, those with PD and hearing loss fail to report a perception of hearing handicap, which may contribute to the lack of attention hearing loss is currently garnering within the Parkinson’s community (Vitale et al., 2014; Pisani et al., 2015). As impairments of a socio-emotional nature have been shown to impact one’s informal caregiver with the most severity in the case of those with PD, proper acknowledgement of hearing loss is of the utmost importance given its established ability to impact socio-emotional well-being.

It is the goal of this study to shed additional light on the relationship between hearing loss and PD by examining the self-perception of the older Parkinsonian adult in regards to their hearing acuity and the impact of their hearing abilities on their social and emotional well-being. This study will also evaluate the perception of the informal care partners as to the affected individuals’ hearing abilities. In gathering perceptions from the affected individual as well as their care partner, important implications about potential care partner burden may be
uncovered. These results have the potential to provide further support for previously published findings which indicate hearing loss as an under-addressed, non-motor concern for those with PD. Rehabilitative implications for caregiver and person with PD could be substantial.

The following questions are addressed:

1. Is there a relationship between self-reported hearing status and outcome on hearing screening tests (pass/fail) within this population?

2. Is there a correlation between the self-reported hearing handicap of those with Parkinson’s Disease and the reports of care partners in regards to potential hearing handicap of the Parkinsonian adult?

3. Is there a significant difference between the severity of hearing handicap as reported by those with PD and as reported on their behalf by their informal care partners?
Methods

Subjects

Twenty-six adults between the ages of fifty-seven and eighty-nine participated in this study. Fourteen of the participants have PD and twelve of the participants self identified as a care partner for an adult with PD. Inclusion criteria for those with PD included a medical diagnosis of PD, English as a first language, minimum of fifty years of age and the participant needed to be in the “on” stage, having taken their medication appropriately. Inclusion criteria for the care partner participants were a minimum age of fifty years, English as a first language and no diagnosis of PD. Exclusion criteria included an inability to understand instructions and/or perform tasks required for participation, English as a second language and impacted cerumen (identified via otoscopy performed prior to hearing screenings). Two participants were excluded from the study as a complete set of data was not successfully collected from those participants during the time provided for data collection.

Parkinsonian participants ranged from age sixty-one to age eighty-nine. Disease duration among PD participants ranged from less than one year since diagnosis to over twenty-four years since diagnosis. Eleven of the fourteen PD participants reported additional medical diagnoses, three of these individuals reported two or more additional co-morbidities. Care partner participants ranged from fifty-seven to eighty-seven years of age. Half of the care partner participants reported diagnosed medical conditions including thyroid issues and hypertension. Nine of the twelve care partners identified themselves as the spouse of an individual with PD.
Participation in this study was voluntary and the subjects were able to refuse to participate at any time with no penalty. Participants were recruited via The Staten Island Chapter of The American Parkinson’s Disease Foundation (APDA). Permission to visit The APDA in May 2016 was granted by the Vice President of the Staten Island chapter (Appendix A). A flyer was provided by the investigator and mailed by The APDA to all active members to encourage members to attend the meeting (Appendix B). Subjects were reimbursed $10 for participating in this research.

Instrumentation

Objective hearing screenings were performed with two Welch-Allyn Audioscopes which were calibrated according to ANSI Standard S3.6-1969 (R1973): Standard for Audiometers, ensuring a standard 0 reference point, calibrated in compliance with OSHA recommendations.

A Heine Mini 3000 otoscope was utilized to evaluate potential cerumen blockages. Interview style data collection for the completion of the subjective questionnaires was performed with the use of a Williams Sound pocket talker 2.0 personal sound amplifier equipped with an internal microphone and dual stereo isolation and dual stereo headphone accessories and/or a Williams Sound PRM Pro 17 channel portable personal FM System. Subjective screening materials included: The Hearing Handicap Inventory for The Elderly Screening (HHIE-S) Version (Appendix C), a slightly modified version of The Spousal Hearing Handicap Inventory for The Elderly Screening Version (Appendix D), and a single item hearing screener, “Do you feel you have a hearing loss?; (Appendix E)” “Do you feel your care partner has a hearing loss?” (Appendix F). The Hearing Handicap Inventory for The Elderly Screening (HHIE-S) Version
(Appendix C) is a 10 question self-assessment screening tool, comprised of questions pertaining to emotional and social/situational aspects of life. The prompts ask the individual to respond with either “yes”, “no” or “sometimes”. A response of “yes” equates to four points, a response of “sometimes” is two points and a score of “no” is zero points. The internal consistency of the total scale, as well as the emotional and social/situational sub-scales of the HHIE-S, is high (.88-.95) as is the test-retest reliability of the tool (r>.90) (Newman & Weinstein, 1986). The Spousal Hearing Handicap Inventory for The Elderly Screening Version (HHIE-SP) is comprised of the same 10 prompts included on The Hearing Handicap Inventory for The Elderly Screening (HHIE-S) Version (Appendix C) only differing in that the word “you” is replaced by the words “your spouse”. When completed by spouses, the HHIE-SP has been shown to yield responses which correlate to those provided on the HHIE-S (Newman & Weinstein, 1986). For this study, the HHIE-SP was modified slightly, in that the word “spouse” was replaced by the word “care partner” in order to include other co-dependent relationships, in addition to married couples, in this study. The single item screener simply asks, “Do you feel you have a hearing loss?” (Appendix E) and asks for either a yes or no response from the participant. The single item screener for care partners asks, “Do you feel your care partner has a hearing loss?” and requires a yes or no response. Sindhusake et al. (2001) reported a 77-100% sensitivity and 55-88% specificity among adults aged 55-99 years old in identifying the presence of hearing loss on the basis of this single item screener. Ferritte et al (2010) found similar results, noting 77.4% sensitivity and 75.8% specificity of a single item screener in identifying hearing loss as confirmed by pure tone audiometry.
**Procedures**

Data collection was performed at The Staten Island APDA facility located at 135 Parkinson Avenue Staten Island, New York. Data were collected by the principal investigator, Samantha Morgan, and three doctoral research assistants: Jenna VanDiver, Hillary McManus and Meghan Joyce. All of the individuals who collected data are current doctoral students at The CUNY Graduate Center in pursuit of their Doctorate of Audiology (AuD) and have all CITI credentials mandated for participation in data collection with human subjects. A brief presentation about hearing loss and potential intervention options was shared with members of the Staten Island Chapter of the APDA. The requirements of study participation were explained following the lecture. Participants who wished to participate and met inclusion criteria were asked to read and sign the informed consent form (Appendix G). All participants underwent a hearing screening in the conference room of The APDA, a room separate from the main meeting room. Using the otoscope housed within the Audioscope and/or the Heine Mini 3000 otoscope, ear canals were checked for cerumen build-up. The only individuals present in the conference room were the two research assistants who were tasked with performing the screenings and the individuals being screened, in order to reduce noise within the screening environment. Hearing was screened at 25 dBHL at 1000, 2000, 4000 and 500 Hz bilaterally. The World Health Organization (WHO) defines “normal hearing” as hearing thresholds of 25 dB or better in both ears and as such, the screening stimuli were presented at 25 dBHL. To obtain a “pass” on the objective screening, participants indicated having heard all eight presented stimuli. If one or more of the presented stimuli was not heard, the results were judged as a “fail”. Results of the
screening were not shared with the participant until all self-reported measures had been completed in an effort to reduce potential bias in provided responses.

PD participants sat one on one with either the principle investigator or a research assistant and were asked the questions on the PD participant cover sheet (Appendix H), The HHIE-S (Appendix I) and the Single Item Screener (Appendix C) with the use of either a Williams Sound Pocket Talker 2.0 or a Williams Sound Personal FM System. Care partner participants were asked to complete the care partner cover sheet (Appendix I), The Spousal Hearing Handicap Inventory for The Elderly Screening (Appendix D) and The Care Partner Single Item Screener (Appendix F) independently. No identifying information was collected. Completed data packs were labeled sequentially so that #1 represented an individual with PD and #2 represented that individuals care partner.

When all three forms and the hearing screening had been completed, results of the hearing screening were shared with the participants individually. The principal investigator was the sole individual responsible for explaining the results of the hearing screening test and their potential implications. All those who failed the hearing screening, as defined by failing to hear any of the four presented stimuli in either ear, was provided with a list of local facilities for follow-up audiological care (Appendix J). All those who participated were asked to provide their name and home address on a separate sheet of paper (Appendix K) so that they could be mailed $10 compensation for their participation in June 2016, in conjunction with the guidelines of The Doctoral Student Grant, which funded participant compensation.
Data Analysis

All statistical analyses were completed using IBM SPSS. Measures of central tendency were used to evaluate differences between the two test groups. A chi-square test of independence was performed to determine if there was a relationship between the results of the hearing screening and the obtained self-reported measures for PD participants. A Spearman rank correlation was utilized to identify any potential correlations between the self-report provided by those with PD and the reported perception of their care partner in regards to the PD participant’s hearing handicap. The Mann-Whitney U was used to identify any significant differences in the report of severity of hearing handicap as reported by the individual with PD to the report of their care partner.
Results

Demographic Data

Twenty-six adults were included in this study, 14 with Parkinson’s Disease and 12 who self-identified as care partners for an older-adult with PD. One participant from each group was omitted from data analysis as incomplete data was not obtained from those individuals. Table 1 displays the mean and standard deviation for age and disease duration of participants with PD. As shown in Table 1, mean age of Parkinsonian participants was 69.69 years and as shown in Table 2, the mean age of care partner participants was 71.18 years. The mean age of all participants was comparable. Of the 13 individuals with PD included in this study, nine were male and four were female. Of the 11 care partners included, nine were female and one was male. Of the PD participants, 10 reported co-morbidities. The number of comorbid conditions ranged from one to as many as four, not including PD. Of care partner participants, five reported medical diagnoses of their own, ranging from one condition to as many as four conditions, none of which were PD. Ten of the 11 care partner participants identified themselves as a spouse; one identified as a friend. Two of the 11 PD participants reported Deep Brain Stimulation surgery. Two PD participants utilized hearing devices; none of the care partner participants utilized hearing devices. Results of the PD participants’ hearing screenings are displayed Table 3. Results are described by the frequency and percentage of ears which passed and failed at each frequency tested respectively. At three of the four frequencies screened (500 Hz, 1k Hz, 4k Hz) more than 50% of the ears evaluated failed to hear the presented stimuli. At 500 Hz, the majority
of ears tested (85%) failed to hear the presented 500 Hz stimuli. At 2k Hz, 58% of the evaluated ears successfully heard the presented 2k Hz tone.

Table 1: Mean and standard deviation of participant age and disease duration of PD participants

<table>
<thead>
<tr>
<th></th>
<th>PD Participant Age (In years)</th>
<th>Disease Duration (In years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>69.69</td>
<td>5.92</td>
</tr>
<tr>
<td>Standard Deviation</td>
<td>8.90</td>
<td>7.34</td>
</tr>
</tbody>
</table>

Table 2: Mean and standard deviation of care partner participant age

<table>
<thead>
<tr>
<th></th>
<th>Care Partner Participant Age (In years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>71.18</td>
</tr>
<tr>
<td>Standard Deviation</td>
<td>7.85</td>
</tr>
</tbody>
</table>
To analyze the relationship between PD participant report and care partner participant report, the results obtained for 20 participants were further analyzed. The 20 data sets analyzed are comprised of 10 PD-participant and care partner-participant couples. Data were analyzed in this way so that a direct comparison between PD and care partner report could be meaningfully analyzed.

**Table 3:** PD Participant’s hearing screening results by screening frequency in Hz

<table>
<thead>
<tr>
<th></th>
<th>500 Hz</th>
<th>1kHz</th>
<th>2kHz</th>
<th>4kHz</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pass</strong> (Number of ears)</td>
<td>4</td>
<td>11</td>
<td>15</td>
<td>12</td>
</tr>
<tr>
<td>(Percentage)</td>
<td>15%</td>
<td>42%</td>
<td>58%</td>
<td>46%</td>
</tr>
<tr>
<td><strong>Fail</strong> (Number of ears)</td>
<td>22</td>
<td>15</td>
<td>11</td>
<td>14</td>
</tr>
<tr>
<td>(Percentage)</td>
<td>85%</td>
<td>58%</td>
<td>42%</td>
<td>54%</td>
</tr>
</tbody>
</table>
Table 4: Mean scores and Standard Deviations of HHIE-S and HHIE-S Modified Spousal Version

<table>
<thead>
<tr>
<th></th>
<th>HHIE –S</th>
<th>HHIE-S Modified Spousal Version</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>8.2</td>
<td>5.6</td>
</tr>
<tr>
<td>Standard Deviation</td>
<td>11.56</td>
<td>9.32</td>
</tr>
</tbody>
</table>

Table 4 displays the average scores obtained on the HHIE-S (8.2) and the HHIE-S Modified Spousal Version (5.6). The mean and standard deviation of the scores obtained on each screener are similar, indicating a similar subjective report of perceived hearing handicap from the Parkinsonian participants and care partner participants.

Is there a relationship between self-reported hearing status and hearing screening test results (pass/fail) within this population?

Table 5: Results of objective hearing screening and subjective hearing screening among Parkinsonian participants

<table>
<thead>
<tr>
<th></th>
<th>Pass Result</th>
<th>Fail Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>Objective Hearing Screening</td>
<td>0%</td>
<td>100%</td>
</tr>
<tr>
<td>(25 dBHL Audioscope Screening)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single-Item Screener</td>
<td>60%</td>
<td>40%</td>
</tr>
<tr>
<td>(“Do you feel you have a hearing loss?”)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 5 displays the percentage of Parkinsonian participants who passed the objective hearing screening as well as the percentage of PD participants who passed the subjective screening. The percentage that failed each screener is included in Table 5. As shown in the table, 0% of PD participants passed the objective hearing screening at 25 dBHL, indicating that all PD participants failed to hear at least one of the eight presented tones. Comparatively, 60% passed the subjective single-item screener PD-participant version, indicating “no” in response to the prompt, “Do you feel you have a hearing loss?” 100% of PD participants failed the objective screening while 40% failed the subjective screening. This illustrates a clear discordance between the modalities used for hearing screening, with fewer participants self-reporting hearing loss than were identified via objective measures wherein the “fail” criterion was set at a level considered to be difficult for most older adults to hear (25 dBHL).

A chi-square test of independence was performed to examine the relationship between the results of the objective hearing screening (pass/fail) and the obtained subjective self-report of hearing loss for PD participants (yes/no response). The relationship between these two variables was insignificant when examining the result of Fisher’s exact test, as per the small cell size of variables included.

\[ X^1(n=20) = 1.00, \ p=.402. \]

This result indicates that there was no statistically significant relationship between objective screening results (pass/fail) and subjective screening results (yes/no).
Table 6: Comparison of PD Participant Failure Across Screening Tools

<table>
<thead>
<tr>
<th>Screening Tool</th>
<th>Failure Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Objective Hearing Screening (Audioscope screening at 25 dbHL)</td>
<td>100%</td>
</tr>
<tr>
<td>Subjective Hearing Screening (Single Item Screener PD Participant Version “Do you feel you have a hearing loss?”)</td>
<td>40%</td>
</tr>
<tr>
<td>HHIE-S</td>
<td>30%</td>
</tr>
</tbody>
</table>

Table 6 displays the percentage of PD participants who failed on each of the three hearing screening tools employed in this study. A “fail” on the HHIE-S was judged as a score of 10 or more, as a score of 10 or more indicates a perception of some degree of hearing handicap and warrants a referral, as per HHIE-S scoring (Appendix C). As shown above, 100% of PD participants failed the objective screening, 40% failed the single-item screener and 30% failed the HHIE-S. Hence, there was some correspondence between patient reported subjective screening outcomes which differed dramatically from objective outcomes obtained via the Audioscope™.
Is there a correlation between the self-reported hearing handicap of those with Parkinson’s Disease and their hearing handicap as reported by their care partners?

A Spearman rank correlation was run in order to determine if there was a correlation between the self-report provided by those with PD and the reported perception of their care partner in regards to the PD participant’s hearing handicap. Results indicate a non-significant, positive correlation between PD participant’s HHI Score and care partner participant’s HHI Score.

Correlation coefficient = (.222), p = (.538)

Is there a significant difference between the severity of hearing handicap as reported by those with PD and as reported on their behalf by their informal care partners?

The Mann-Whitney U test was used to compare the severity of hearing handicap as reported by the individual with PD to the severity of the hearing handicap as reported by the care partner. The mean rank of each group was extremely similar:

PD participant mean rank = 10.90; Care partner participant mean rank = 10.10

The difference between the obtained results on the HHI and HHI-SP was found to be insignificant.

(U= 46; p = .751).
This result indicates no significant difference between hearing handicap as reported by the Parkinsonian participant and as reported by the care partner.
Discussion

The goal of this study was to evaluate potential relationships between peripheral hearing acuity and self-reported hearing acuity, as well as the perception of hearing handicap, among older adults with PD and their care partners. Direct comparison was made between objective and subjective measures of hearing acuity, as well as measures of self-reported hearing handicap and hearing handicap as reported by one’s care partner.

In evaluating the relationship between the objective measure of hearing acuity (pass/fail result on a hearing screening) and the obtained subjective measure of hearing acuity (a yes/no response to the prompt, “Do you feel you have a hearing loss?”) a non-significant relationship was found. All PD participants failed the hearing screening and less than half indicated a perception of hearing loss via the single-item screener. No relationship was identified between the results of an objective hearing screening and the results of a subjective hearing screening.

The implications of this result, while not of statistical significance, are nevertheless of significant importance. Of the 10 PD participants included in full data analysis, all 10 failed the peripheral hearing screening. Eight of these participants failed bilaterally, two failed unilaterally. Only four of these participants indicated a subjective perception of hearing loss. These findings are therefore of significant importance, as they indicate that all PD participants were identified via objective measures as having some potential degree of peripheral hearing loss and yet less than half of the sample reported decreased hearing acuity. It must be taken into consideration however that the objective screening was performed at a level of 25 dBHL in an environment with ambient noise. These testing conditions may have led to an artificial increase in the objective hearing screening failure rate as the presented stimuli may have been too soft for the
target population. Additionally, one should consider the strong validity of the single item screening tools as identified in previous studies (Sindhusake et al., 2001; Ferritte et al., 2010). In view of the above considerations one must keep in mind the reason to screen the hearing of persons with PD. If the goal is to identify persons with objective hearing loss which may hinder patient centered communication and adherence to directives, then more objective testing is warranted. Objective testing, perhaps at the level of 40dBHL, would likely be more beneficial in reducing over referral rates. These results were collected using a lax “fail” criterion (not responding to one or more of eight sounds presented at 25 dbHL) and as such must be interpreted with caution.

Analysis of the HHIE-S and the modified HHI-SP indicated that there was no significant correlation, nor significant difference, between the subjective hearing handicap reported by PD participants and the report of their care partners. In examining the results further, there were seven instances in which the individual with PD reported a higher hearing handicap than did their care partner. There were only two instances in which the care partner reported a more significant hearing handicap than what was reported by the PD-affected participant. These findings raise concern, as it supports the notion that one’s care partner may be unable to identify the functional manifestations of hearing loss as exhibited by an older adult with PD. When comparing this finding with results from other research efforts aimed at exploring the relationship between patient report and spousal report, similar results are noted. A study performed by Newman & Weinstein in 1986 indicated that those with hearing loss reported their loss of acuity and the resultant hearing handicap they experienced to be more severe than did their spouses. Less than 25% of variance in spousal report was related to the self-report of those with hearing loss, as per The Index of Determination (Newman & Weinstein, 1986). In this way,
these results are similar to the results obtained in this study in regards to care partner report. Newman & Weinstein suggested that the variance in report may not reflect inaccuracies but instead reflect the spouse’s inability to truly understand the negative impact of hearing loss on their significant other’s well-being, particularly from an emotional standpoint. It is important to note however that the spouses utilized in the previous study entered into the study knowing that their spouse had a diagnosed hearing difficulty. The results obtained by Newman & Weinstein therefore speak to spousal perception but cannot be directly compared to the spousal input gathered by this study as most participants enrolled in the current study were unaware of any potential hearing difficulties.

Results of this study suggest corroboration with findings of prior research, as they may indicate that Parkinsonian adults with hearing loss fail to self-report decreased acuity and hearing handicap (Vitale et al., 2014; Pisani et al., 2015). These results are significant as research conducted with large sample sizes across the globe have indicated that there is a higher prevalence of hearing loss in those with PD than among their age-matched, healthy peers (Yylmaz et al., 2008; Vitale et al., 2014; Pisani et al., 2015; Lai et al., 2014). Furthermore, results of this study indicate that hearing loss may go unreported by the PD care partner. Upon examination of the results of the subjective hearing screener completed by care partners (“Do you think your care partner has a hearing loss?”) only four care partner’s indicated that they suspected their significant other with PD may also suffer from hearing loss. This finding is concerning, as all PD participants’ failed the objective hearing screening. This finding therefore suggests that care partners may be unable to identify the signs of hearing loss in their spouse/significant other co-morbidly affected by PD and hearing loss. The implications of these findings should be further examined, for if the affected individual nor their care partner, can be
readily relied upon to report a condition for which the Parkinsonian adult is at increased risk, an
effort must be made by the medical community to identify hearing loss objectively within the
Parkinsonian community.

Potential Impacts of Unidentified Hearing Loss

It is well known within the audiological community that hearing loss which goes
unidentified can have significant, negative downstream effects. While this study merely serves
to potentially identify those at-risk for hearing loss, knowledge of the effects of hearing loss may
prove beneficial to those who serve the Parkinsonian community.

A systematic review performed by Ciorba et al., (2012) revealed that only 39% of
subjects with hearing loss self-identified as having an “excellent” global quality of life,
compared with 68% of individuals without hearing loss. Research has indicated that decreased
independence, as well as decreased hearing acuity, may be linked to a poorer perception of one’s
quality of life. Gopinath et al. (2011) surveyed the ability of nearly 2000 adults age 60 and older
in completing activities of daily living (ADLs). Results indicated that of the 164 adults with self-
reported difficulty completing ADLs, a majority had hearing loss. The severity of hearing loss,
as measured by pure tone audiometry, was statistically significantly associated with an increased
limitation in ADL abilities. In 2012, Gopinath et al. then evaluated 811 older adults twice over a
five-year period and found that adults identified with any degree of hearing loss were at higher
risk for emotional distress than their normal hearing peers when tracked over time. These older
adults were also more likely to experience limited social engagement within a 5-year period.
These findings have since been corroborated by a study published in 2014 by Mick, Kawachi and
Lin, which revealed increased odds of social isolation in women with hearing loss aged 60-69 years old. Social isolation was measured by the The Social Isolation Score, an index with questions pertaining to social support and their hearing status was quantified by the pure tone average (500-4k Hz) of their better ear. Results indicated an increased odds ratio of 3.49 per 25 dBHL of hearing loss.

In addition to socio-emotional impacts, an additional area of concern for those with age-related hearing loss may be cognitive function. A study by Lin et al., (2011) revealed an increased hazard ratio for incident all-cause dementia for those with hearing loss. The ratio increased with increasing severity of hearing loss. It was suggested that the reduced quantity and quality of social interaction and sensory stimulation as a result of hearing loss may contribute to dementia. While an exact relationship between these hearing loss and cognitive function remains to be delineated, the comorbid presentation of these conditions can not be denied.

The well-established knowledge of the potential downstream consequences of hearing loss is of particular importance to the Parkinsonian adult as many of the threats to quality of life associated with hearing loss are concerns to those who experience PD in isolation. While this study does not provide significant evidence to support the co-morbid presentation of these conditions on its own, when considered in conjunction with previous data, additional attention to the potential co-morbid presentation of hearing loss and PD is certainly warranted. Limited independence and social interaction are inherent concerns of the Parkinsonian community, as is potential cognitive decline. The knowledge that these two conditions, PD and hearing loss, are of an increased likelihood to present concomitantly and that their associated sequela threaten such similar downstream consequences provides meaningful motivation for improved methods of identification and further exploration of their comorbid presentation.
**Implications**

Parkinsonian adults are faced with a wide variety of motor and non-motor symptoms that can dramatically hamper their quality of life. Hearing loss has been suggested as a potential non-motor symptom (Vitale et al, 2014). While hearing loss may in fact be one of the many non-motor symptoms of this neurodegenerative disease, the impactful consequences associated with hearing loss alone demand that this potential related symptom be addressed in Parkinsonian patients.

As a multitude of negative side effects are experienced by those with PD in isolation, as well as those with hearing loss in isolation, the potential compounding impact of their comorbid presentation must be further explored. The proven lack of self-report by those with PD, as well as the failure of the care partner to report hearing loss, as first identified by this study, provides a basis for the recommendation that the medical professionals responsible for PD management exercise concern about their patients’ hearing health. Additionally, as empirical data concerned with care partner burden indicates that aspects of disease which impair one’s socio-emotional well-being to have the most significant effect on care partner well being, hearing loss must be recognized in order to best address societal and economic concerns regarding care giver burden.

**Limitations and Suggestions for Future Research**

There are a number of recognized threats to the validity of this study which must be mitigated in order for future research to evoke more powerful results. The most significant threat to the validity of this study is the presentation level at which the objective screening was
performed. In using 25 dBHL as a screening level, it is likely that the number of failures obtained on the objective screening was artificially inflated by false positives. A more appropriate level of 40 dBHL should be utilized by future researchers in order to evoke more accurate objective hearing screening results as forty dBHL is considered the threshold for “disabling” hearing loss as per The World Health Organization. As a level of 25 dBHL was employed for the objective hearing screenings performed in this study, the objective screening results obtained must be interpreted with caution. A way to further strengthen objective hearing results obtained would be to utilize audiometric testing in a soundproof test suite. In performing a complete audiometric evaluation, exact thresholds at an increased range of frequencies could be obtained, providing more specific data as to peripheral hearing status. The information provided by audiometric measures would provide additional opportunities for analysis. Additionally, examination of hearing loss among care partners could potentially provide further insight into why care partners may make for unreliable reporters of hearing loss in their PD-affected peers. The use of a cognitive screener would also improve upon test result validity to ensure responses to prompts reflect proper comprehension of directives.

Repetition of this study with a larger sample size could prove beneficial as it would provide larger numbers for analysis and improve upon the generalizable validity. In addition to the small size of the sample utilized in this study, the group was fairly homogenous in that all participants were selected from a local chapter of The American Parkinson’s Disease Association. This sample was therefore from the same geographic location and as such, all participants are likely to be of similar socio-economic status. All sample participants are no longer a part of the work force, as these meetings are held during the early afternoon.
Additionally, all sample participants were Caucasian. A more diverse sample size would strengthen the internal validity of this study, if replicated.

**Conclusions**

Results of this study corroborate previous research efforts as they suggest a lack of self-reported hearing loss in the Parkinsonian community. Additionally, this research suggests that care partners may fail to be effective reporters of the hearing loss experienced by their Parkinsonian partners. In view of the known potential physiological link between hearing loss and PD, the documented increased prevalence of hearing loss in those with PD and the well-identified inherent risks related to these two conditions, there is a substantial basis of evidence to support the further exploration of the comorbid presentation of these conditions. The data, provided in part by this study, that those with PD and their care partners cannot be expected to self-report hearing loss, strongly suggests that evaluation of peripheral hearing status be a part of routine Parkinsonian care. Suggestions for future management include neurological referrals for audiological care.
February 25, 2016

Samantha Morgan
9 Stuyvesant Oval, 7H
New York, NY 10075

Re: Audiological Implications for the Parkinson’s Patient

Dear Samantha,

I am pleased to inform you that you can attend the May meeting of the Staten Island Chapter of the American Parkinson’s Disease Association Support Group (APDA) at which time we understand that you will deliver a brief presentation on hearing loss in the Parkinson’s population. Following the lecture, you are granted permission to invite members to participate in your study.

Thank you for helping to advance our member’s understanding of hearing loss among persons with Parkinson’s Disease.

Sincerely,

Robin Kornhaber, MSW
Vice President of Programs & Services
Hearing Loss & Parkinson’s Disease

Join us at next month’s meeting to learn about hearing loss and how it may affect those with Parkinson’s Disease.

Audiology doctoral student and student researcher Samantha Morgan of The Graduate Center, City Of New York, will be here to share her knowledge and answer questions about hearing loss and hearing technologies.

Samantha will be looking for volunteers to undergo a quick hearing screening and to complete two brief questionnaires for use in her research about those with Parkinson’s Disease and hearing loss. All volunteers will receive a FREE hearing screening!

CUNY University Integrated IRB
Protocol: 2016-0199
Approved: 03/07/2016
Expires: 03/06/2017
Appendix C

Instructions: Please respond to each of the following questions by saying "Yes" "No" or "Sometimes"

<table>
<thead>
<tr>
<th>Item</th>
<th>Hearing Handicap Inventory for the Elderly (HHIE-S)</th>
</tr>
</thead>
<tbody>
<tr>
<td>E1</td>
<td>Does a hearing problem cause you to feel embarrassed when you meet new people?</td>
</tr>
<tr>
<td>E2</td>
<td>Does a hearing problem cause you to feel frustrated when talking to members of your family?</td>
</tr>
<tr>
<td>S1</td>
<td>Do you have difficulty hearing when someone speaks in a whisper?</td>
</tr>
<tr>
<td>E3</td>
<td>Do you feel handicapped by a hearing problem?</td>
</tr>
<tr>
<td>S2</td>
<td>Does a hearing problem cause you difficulty when visiting friends, relatives, or neighbors?</td>
</tr>
<tr>
<td>S3</td>
<td>Does a hearing problem cause you difficulty when visiting friends, relatives, or neighbors?</td>
</tr>
<tr>
<td>E4</td>
<td>Does a hearing problem cause you to have arguments with family members?</td>
</tr>
<tr>
<td>S4</td>
<td>Does a hearing problem cause you difficulty when visiting friends, relatives, or neighbors?</td>
</tr>
<tr>
<td>E5</td>
<td>Do you feel that any difficulty with your hearing limits or hampers your personal or social life?</td>
</tr>
<tr>
<td>S5</td>
<td>Does a hearing problem cause you difficulty when in a restaurant with relatives or friends?</td>
</tr>
</tbody>
</table>

Total Points of Items with Letter Indications E1 through E5:

Total Points of Items with Letter Indications S1 through S5:

TOTAL RAW SCORE: _____________ (Sum of all points E+S)

INTERPRETING THE RAW SCORE:

0 to 8 = 13% probability of hearing impairment (no handicap/no referral)
10 to 24 = 50% probability of hearing impairment (mild-moderate handicap/refer)
26 to 40 = 84% probability of hearing impairment (severe handicap/refer)

Appendix D

Name: _________________________          Date: _________________________

Hearing Handicap Inventory-Spousal Revision (slightly revised)

Instructions: The purpose of this scale is to identify the problems you feel your spouse/significant other/care partner’s hearing loss may be causing. Answer YES, SOMETIMES, or NO for each question. Do not skip a question if you avoid a situation because of your hearing problem. If your spouse uses a hearing aid, please answer the way h/she hears with the aid.

<table>
<thead>
<tr>
<th>Scoring Value for Each Item</th>
<th>4</th>
<th>2</th>
<th>0</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>E-1</strong> Does a hearing problem cause your care partner to feel embarrassed when meeting new people?</td>
<td>Yes</td>
<td>Sometimes</td>
<td>No</td>
</tr>
<tr>
<td><strong>E-2</strong> Does your hearing problem cause your care partner to feel frustrated when talking to members of your family?</td>
<td>Yes</td>
<td>Sometimes</td>
<td>No</td>
</tr>
<tr>
<td><strong>S-1</strong> Does your care partner have difficulty hearing when someone/you speak in a whisper?</td>
<td>Yes</td>
<td>Sometimes</td>
<td>No</td>
</tr>
<tr>
<td><strong>E-3</strong> Does your care partner feel handicapped by a hearing problem?</td>
<td>Yes</td>
<td>Sometimes</td>
<td>No</td>
</tr>
<tr>
<td><strong>S-2</strong> Does a hearing problem cause your spouse/significant other/care partner difficulty when visiting friends, relatives, or neighbors?</td>
<td>Yes</td>
<td>Sometimes</td>
<td>No</td>
</tr>
<tr>
<td><strong>S-3</strong> Does a hearing problem cause your care partner to attend religious services less often than you would like?</td>
<td>Yes</td>
<td>Sometimes</td>
<td>No</td>
</tr>
<tr>
<td><strong>E-4</strong> Does a hearing problem cause your spouse/significant other/care partner to have arguments with you and/or family members?</td>
<td>Yes</td>
<td>Sometimes</td>
<td>No</td>
</tr>
</tbody>
</table>

CUNY
University Integrated IRB
Protocol: 2016-0199
Approved: 03/07/2016
Expires: 03/06/2017
Appendix E

Parkinsonian Participant Response Form

Do you feel you have a hearing loss?

______________________________________________
Appendix F

Care Partner Participant Response Form

Do you feel your care partner has a hearing loss?
CONSENT TO PARTICPATE IN A RESEARCH PROJECT

Project Title:  Hearing related concerns among Parkinson’s patients and their care partners.
Protocol number (2016-0199)

Principal Investigator:  Samantha Morgan
AuD Student - The CUNY Graduate Center
365 5th Avenue, New York, NY 10016
Phone:  646 431 6760  Email: smorgan@gradcenter.cuny.edu

Faculty Advisor:  Dr. Barbara Weinstein
Professor – The CUNY Graduate Center
365 5th Avenue, Room 7107, New York, NY, 10016
Phone: 212 817 7980

Site where study is to be conducted:
The American Parkinson’s Disease Association
135 Parkinson Avenue
Staten Island, NY 10305

Introduction/Purpose:  You are invited to participate in a research study. The study is conducted under the direction of Samantha Morgan, AuD student at The CUNY Graduate Center and her faculty advisor, Dr. Barbara Weinstein. The purpose of this research study is to gather information about how individuals with Parkinson’s Disease and their care partners feel that those with Parkinson’s Disease are able to hear. The results of this study may identify a potential hearing loss and/or a difficulty hearing in certain situations.

Procedures:  Approximately twenty individuals are expected to participate in this study. Each subject will have a trained research assistant look in their ears to check for excessive wax build up and will then perform a brief hearing screening. Those with excessive cerumen will be notified of the wax build-up and will be unable to participate in the study. Those without excess cerumen will proceed with the hearing screening and be able to fully participate in the study. Those with Parkinson’s Disease will then put on headphones and be asked 11 questions about how they think they hear. All questions can be answered with
Appendix G

either “yes,” “no” or “sometimes.” Care partners who participate will be provided with these 11 questions and asked to read the questions and document their answers independently. All questions can be answered either “yes,” “no” or “sometimes.”

Participation in this study is expected to take 15-20 minutes. All information will be collected at The American Parkinson’s Disease Association located at 135 Parkinson Avenue, Staten Island, NY, 10305.

Possible Discomforts and Risks: Your participation in this study may involve minimal discomfort, a breach of confidentiality or stress. To minimize these risks all procedures will be well explained and participants will be given time to ask any and all questions. If you are uncomfortable as a result of this study you should tell the research assistant and/or examiner immediately.

Benefits: A direct benefit of participation is the opportunity to have a brief hearing screening, the results of which will be provided to you. If this screening identifies a potential hearing loss, you will be provided with a list of locations in the area where one can pursue further hearing healthcare. Participating in the study may also increase general knowledge of the relationship between Parkinson’s Disease and hearing loss, including ways in which audiological care may benefit those with Parkinson’s Disease. Audiologist knowledge of the needs of Parkinsonian patients may also be improved.

Alternatives: If an individual is not comfortable participating in this study, they are not required to participate. Participation in this study is voluntary.

Voluntary Participation: Your participation in this study is voluntary, and you may decide not to participate without prejudice, penalty, or loss of benefits to which you are otherwise entitled. If you decide to leave the study, please contact the principal investigator Samantha Morgan to inform them of your decision.

Compensation:
All participants will receive $10 upon completion of all study procedures. Compensation will be mailed to you in June 2016.

Confidentiality: The data obtained from you will be collected via written documents. The collected data will be accessible to IRB Members and staff, the principal investigator and the faculty advisor. Authorities from the Office of Human Research Protections (OHRP) will be able to look at and copy your research records. The researcher will protect your confidentiality by not collecting any information which connects your results to your identity. The collected data will be stored in paper format and then scanned and uploaded.
Appendix G

onto the personal computer of the principal investigator. The paperwork will not contain any identifying information.

**Contact Questions/Persons:** If you have any questions about the research now or in the future, you should contact the Principal Investigator, Samantha Morgan, 646 431 6760, smorgan@gradcenter.cuny.edu. If you have questions about your rights as a research participant, or you have comments or concerns that you would like to discuss with someone other than the researchers, please call the CUNY Research Compliance Administrator at 646-664-8918. Alternately, you can write to: CUNY Office of the Vice Chancellor for Research Attn: Research Compliance Administrator 205 East 42nd Street New York, NY 10017”.

**Statement of Consent:**

“I have read the above description of this research and I understand it. I have been informed of the risks and benefits involved, and all my questions have been answered to my satisfaction. I attest to the fact that I am 18 years of age or older. Furthermore, I have been assured that any future questions that I may have will also be answered by the principal investigator of the research study. I voluntary agree to participate in this study. By signing this form I have not waived any of my legal rights to which I would otherwise be entitled. I will be given a copy of this statement.”

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Appendix H

Parkinsonian Participant Cover Sheet

Please provide the following information:

Gender: _____

Age at Diagnosis: __________

Current Age: ____________

Are you currently in the “on”-state? ________

Do you have any medical conditions in addition to Parkinson’s Disease?
   If yes, please list them below:

________________________________________
________________________________________
________________________________________
Appendix I

Care Partner Participant Cover Sheet

Please provide the following information:

Gender: _____

Current Age: ____________

Relationship to your care partner? __________

Do you have any medical conditions?

If yes, please list them below:

_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________
Appendix J

Referral Form

Based on the hearing screening results obtained on 5/10/16 at The American Parkinson’s Disease Association, you may have a hearing loss.

Below is a list of facilities which provide audiological care on Staten Island. Check with your insurance provider which hearing healthcare provider may work best for you.

Services provided by the following facilities may require payment. Please check with the provider before making an appointment.

Staten Island University Hospital
242 Mason Avenue
718-226-6070

Staten Island Audiological
1173 Forest Avenue
718 981 6020

Audiology Island
148 New Dorp Lane
718 980 0188
Participant List for Compensation

Please provide your name and address on the line below so that you may receive your $10 compensation as a thank you for participating in this research. Compensation will be sent out in June 2016.

Once compensation has been mailed, this form will be destroyed to protect confidentiality. Please note that there is no way to link the information you provide here to the results obtained on your screening measures.
References


