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Evaluating the impact of low health literacy and language barriers in underserved populations with Parkinson’s disease

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EVALUATING THE IMPACT OF LOW HEALTH LITERACY AND LANGUAGE BARRIERS IN UNDERSERVED POPULATIONS WITH PARKINSON'S DISEASE

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EVALUATING THE IMPACT OF LOW HEALTH LITERACY AND LANGUAGE BARRIERS IN UNDERSERVED POPULATIONS WITH PARKINSON'S DISEASE

AARON LEE

ABSTRACT

Parkinson's Disease (PD) is a neurodegenerative disorder affecting multiple domains in patients. Previous studies have illustrated the impact of healthcare disparities in patients with PD, illustrating worsened health outcomes between Black and White patient groups in all steps of the healthcare system such as diagnosis. Furthermore, the current literature has also illustrated the impact of low literacy levels on health-related outcomes in PD patients. While its role specifically in PD patients needs further understanding, language barriers have also affected patients and their interactions with the healthcare system, and its role in PD patients should be considered.

In this research study, we aim to address the gaps in the existing literature through a mixed-methods design, using both qualitative and quantitative methods to address patients of Black/African-American, Hispanic/Latinx ethnicities or patients who speak Haitian Creole and Spanish regarding their experiences with diagnosis and treatment of PD.. We also aim to assess providers and their attitudes towards barriers they feel their patients from these populations may face, and to ultimately use the data of this study to develop educational videos for PD patients of these backgrounds. Ultimately, the findings of this research study may be influential not only for PD patients from these backgrounds

by potentially improving their healthcare experience, but also other researchers continuing to investigate these disparities in PD and medicine overall.

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LIST OF ABBREVIATIONS

BMC…….....Boston Medical Center

PD……..Parkinson's Disease

CHAPTER ONE: INTRODUCTION

Parkinson's Disease affects patients in multiple domains

Parkinson's Disease (PD) is a chronic, neurodegenerative disease that, when compared to other neurodegenerative disorders, is second in prevalence only to Alzheimer's disease (De Lau and Breteler 2006). In industrialized countries, PD is prevalent in about 1% of individuals who are over 60 years of age (De Lau and Breteler 2006). The disorder is associated with the loss of dopaminergic neurons within the substantia nigra pars compacta (SNpc) (Kalia and Lang 2015). While this loss of dopamine is connected to motor dysfunction, the disorder causes a wide variety of symptoms in patients, including both motor and non-motor symptoms (Kalia and Lang 2015; Sveinbjornsdottir 2016). Motor symptoms that are caused by the disorder include tremor, bradykinesia, and muscular rigidity (Hughes et al. 1992). Additional motor symptoms include disturbances in gait such as freezing, postural instability, and festination (short steps that speed up as the patient walks making them unable to stop themselves) (Virmani et al. 2015). On the other hand, some examples of non-motor symptoms that are caused by the disorder include sleep disturbances and cognitive dysfunction (Sveinbjornsdottir 2016). The existing literature has also suggested the existence of two subtypes within the disease: tremor-dominant Parkinson's and non-tremor-dominant Parkinson's disease, along with an additional subgroup of patients with a mixed phenotype. Tremor-dominant Parkinson's disease differs in course, with a rate of progression slower than that of the other groups (Parkinson Study Group 1990).,

Neuropsychiatric symptoms such as visual hallucinations, delusions, and mood changes occur in a large

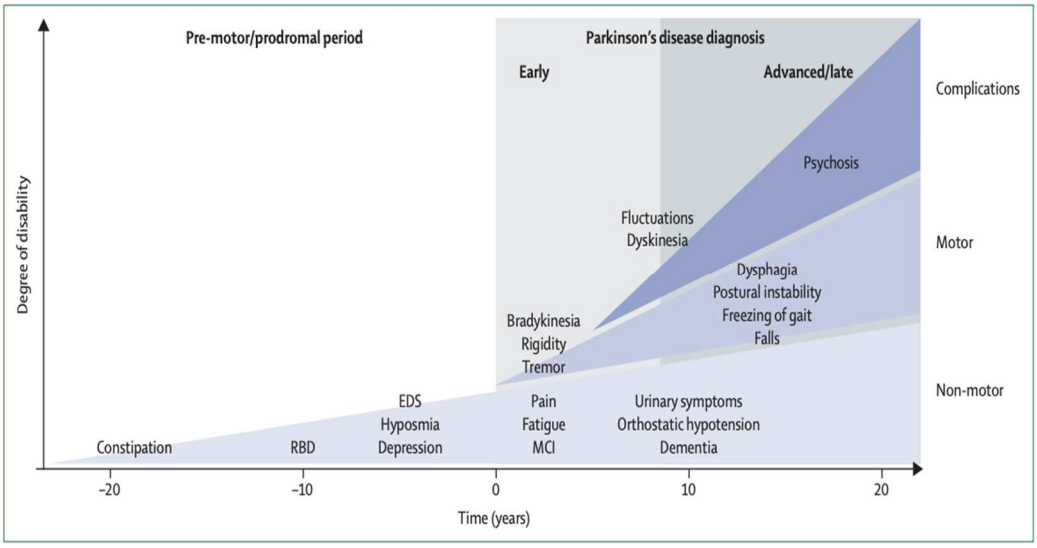


Figure 1: The time course of the symptoms associated with Parkinson's disease. Figure taken from Kalia and Lang 2015. The diagram displays the time course associated with progression of Parkinson's disease in patients.

percentage of patients (Onofrj et al. 2007). Other non-motor features include olfactory and autonomic dysfunction (Kalia and Lang 2015). Diagnosis is made when motor symptoms occur clinically; however, some non-motor symptoms may appear in a preceding period known as the premotor or prodromal phase (Figure 1) (Kalia and Lang 2015). While the specific, exact etiology has not been determined for the disease, much of the existing literature has considered the impact of both environmental and genetic influences (Figure 2).

Neuropathologically, a variety of changes within the brain are associated with PD, with the disease connected to both the presence of Lewy bodies and the loss of dopamine neurons (Braak et al 2003). Previous research has suggested the basal ganglia as a region

where this dopaminergic loss occurs (Kalia and Lang 2015). Researchers have previously proposed that the changes in Lewy pathology may be divided into stages that correspond to progression of the disease (Figure 2) (Kalia and Lang 2015; Braak et al., 2003). In the

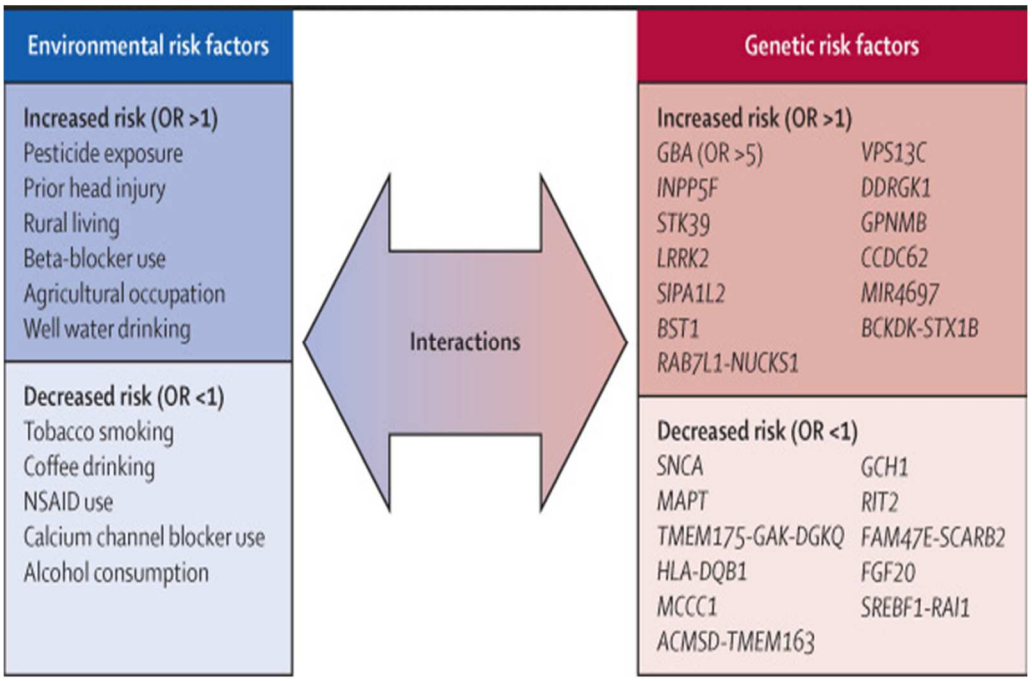


Figure 2: The genetic and environmental interactions that are associated with Parkinson's disease. Figure taken from Kalia and Lang, 2015. As depicted in the diagram, a variety of both genetic and environmental influences are associated.

Braak staging model of PD, the dorsal motor nucleus of the vagal nerve, which connects the enteric and central nervous systems, is the initial area in which PD begins before advancing towards the cerebral cortex (Figure 3; Braak et al., 2004). As the stages progress, the symptoms and severity of the disease increase (Braak et al., 2004). For instance, as the pathology reaches the substantia nigra pars compacta in Stage 3, the staging model suggests that an individual would begin exhibiting motor symptoms, due

to dopamine deficiency in this region (Figure 3; Kalia and Lang 2015). Other studies

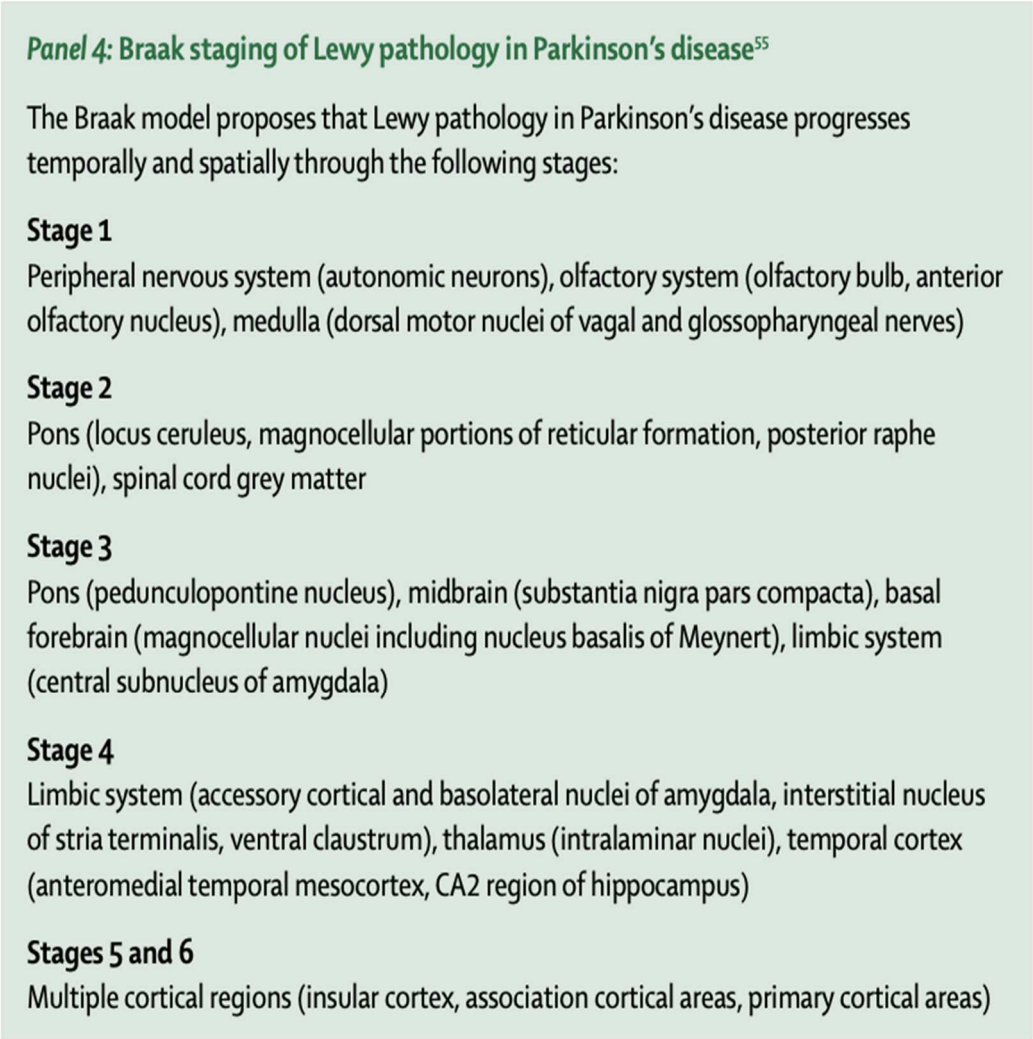


Figure 3: The stages involved in the Braak model for Parkinson's disease. Figure taken from Kalia and Lang, 2015 and developed from Braak et al., 2003. As depicted in the diagram, the Braak staging model uses the above stages to match disease progression.

have also suggested neuroinflammation to be a neuropathological change in PD (Tansey and Goldberg 2010).

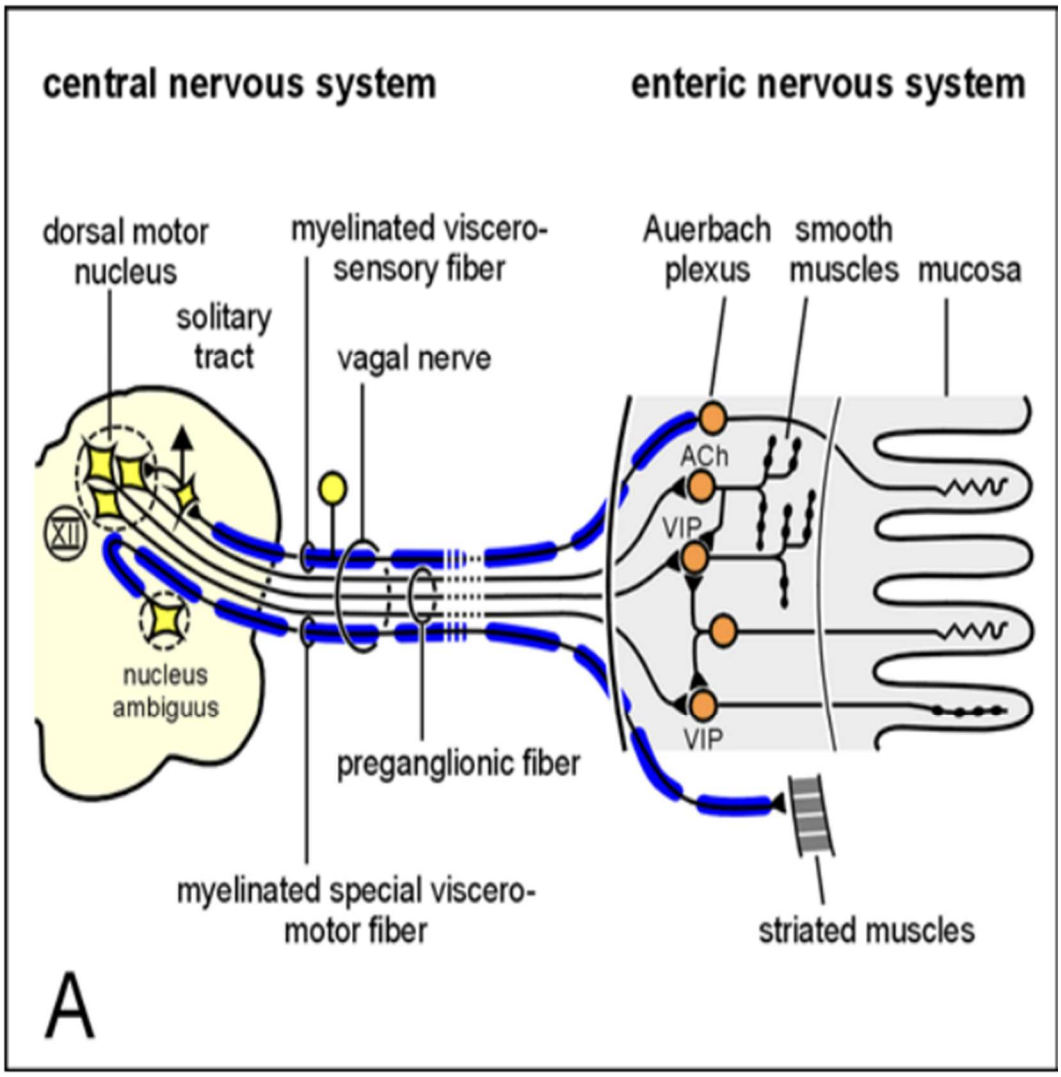


Figure 4: The vagal nerve connection between the enteric and central nervous systems. Figure taken from Braak et al., 2004. As depicted in the diagram, the two nervous systems are connected through the vagal nerve.

Due to the lack of a cure for the disorder, a wide variety of treatment approaches for patients with PD have largely focused on countering the symptoms caused by the disorder, such as drug-based interventions that act on dopamine concentrations or receptors (Kalia and Lang, 2015). Furthermore, patients take additional medication to

treat non-motor symptoms caused by the disorder; for instance, selective serotonin reuptake inhibitors are often taken to treat depression (Kalia and Lang, 2015). Other methods used to treat symptoms in PD also include surgical methods such as deep brain stimulation, with areas such as the subthalamic nucleus or globus pallidus internus effective targets for patients with moderate-to-severe disease (Kalia et al., 2013). Ultimately, as indicated in the literature discussed above, PD is a complex neurodegenerative disorders that affects patients in multiple domains.

Healthcare disparities in Parkinson's disease

Past research studies have explored the impact of healthcare disparities amongst patients with PD. Disparities exist as early in the disease course as diagnosis, with white patients being diagnosed with PD twice as much as those of African-American descent (Dahodwala et al. 2009). African-American patients with PD were also found to be more likely to under-report symptoms when self-reporting on the Unified Parkinson's Disease Rating Scale (UPDRS) part 2 (Dahodwala et al. 2011). In the study, when comparing patient disability scores on the UPDRS 2 at the same level of motor impairment, the self-reported disability scores of African-American patients were less than those of white patients (Dahodwala et al. 2011). In this sample, African-American patients, in comparison to white patients, were also found to be more likely to be diagnosed at a later stage of PD (Dahodwala et al. 2011). Researchers have previously explored and identified racial disparities in treatment of PD, with African-American patients being four times less likely when compared to white patients to receive dopaminergic medication

and advanced surgical treatment (Dahodwala et al. 2009; Chan et al. 2014). In addition, previous research has also suggested differences in likelihood of seeing a neurologist, with African-American patients 30% less likely compared to white patients and Hispanic patients 40% less likely (Saadi et al. 2017). There was an increased likelihood for hospitalizations and visits to the emergency department for Black patients as well (Saadi et al. 2017).

Some studies have attempted to explore these disparities through frameworks such as the Health Belief Model (Figure 5), which connects the interactions involved between health-related beliefs and actions of individuals and various factors that may influence them (Glanz et al., 2008). For instance, two critical concepts explored in the model are an individual's "self-efficacy", referring to the individual's belief in his or her ability to carry out a health-related action, and "perceived barriers", or negative effects and characteristics associated with carrying out a health-related action (Figure 6 (Pan et al., 2014; Glanz et al., 2008). Other concepts explored in the model also include "perceived benefits", which refers to an individual's belief that carrying out a certain behavior may help address a threat, and "cues to action", which describes the different methods that may help prepare an individual to carry out a course of action (Pan et al., 2014; Glantz et al., 2008). When using this framework, Pan et al. 2014 found that when asked about the reasoning behind not seeking medical care, African-American individuals attributed their lower likelihood to factors such as a lack of trust in physicians (Pan et al. 2014). Participant discussions in focus groups within the study suggested mistrust in physicians' diagnoses and judgments (Pan et al. 2014). On the other hand,

white participants mentioned a lack of knowledge regarding PD symptoms, while

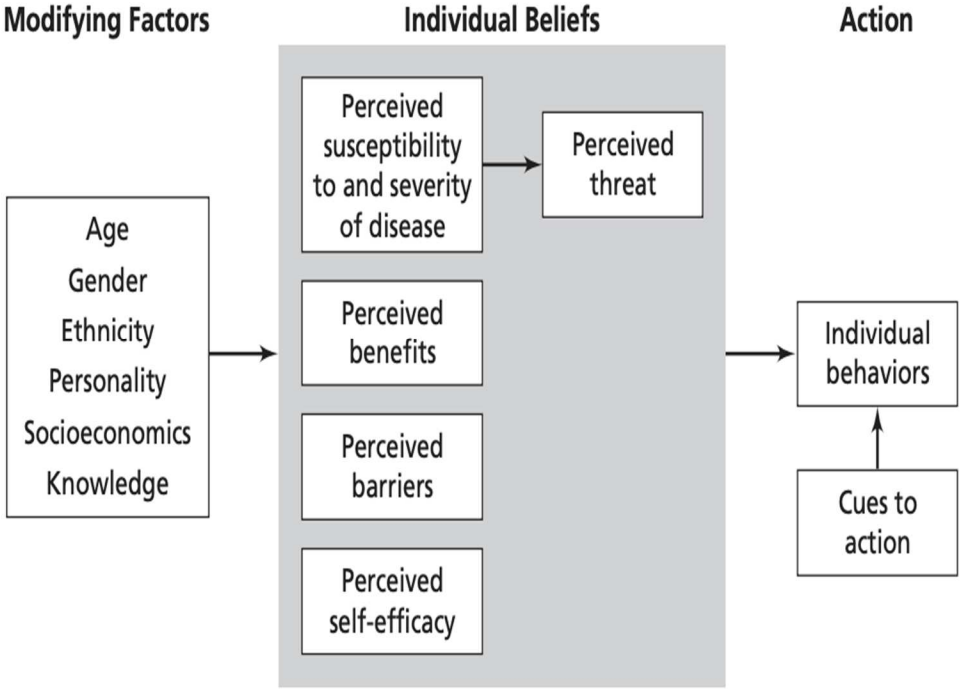


Figure 5: The Health Belief Model. Figure taken from Glanz et al., 2008. The Health Belief Model uses six concepts to explore the factors affecting health-related beliefs and actions.

Chinese-American participants discussed not knowing where to go to receive treatment, along with language barriers (Pan et al., 2014). Also, in this same study, African-American patients were more likely to attribute characteristics of PD to normal aging, and when assessed on their knowledge of PD, a majority of community members had low knowledge of PD (Pan et al. 2014). While applying the framework of the Health Belief Model to their study, the researchers in this study were able to identify several different barriers among participants, whether it be language barriers among Chinese-American participants or mistrust of physicians in African-American participants (Pan et al. 2014). However, the researchers do point out limitations in using this model, such as the Health Belief Model not accounting for the impact of environmental factors, such as social

TABLE 3.1. Key Concepts and Definitions of the Health Belief Model.

Concept	Definition	Application
Perceived susceptibility	Belief about the chances of experiencing a risk or getting a condition or disease	Define population(s) at risk, risk levels Personalize risk based on a person's characteristics or behavior Make perceived susceptibility more consistent with individual's actual risk
Perceived severity	Belief about how serious a condition and its sequelae are	Specify consequences of risks and conditions
Perceived benefits	Belief in efficacy of the advised action to reduce risk or seriousness of impact	Define action to take: how, where, when; clarify the positive effects to be expected
Perceived barriers	Belief about the tangible and psychological costs of the advised action	Identify and reduce perceived barriers through reassurance, correction of misinformation, incentives, assistance
Cues to action	Strategies to activate "readiness"	Provide how-to information, promote awareness, use appropriate reminder systems
Self-efficacy	Confidence in one's ability to take action	Provide training and guidance in performing recommended action Use progressive goal setting Give verbal reinforcement Demonstrate desired behaviors Reduce anxiety

Figure 6: The main concepts of the Health Belief Model. Figure taken from Glanz et al., 2008. The framework of the Health Belief Model is primarily centered around these six concepts regarding health-related behaviors and actions.

factors (Pan et al. 2014). Consequently, further work may be needed to better understand the mechanisms behind these health disparities.

When it comes to rehabilitation options, African-American patients have also been shown to participate in physical therapy less often than white patients although the treatment is less invasive and has been shown to improve symptoms and maintain function. For instance, Fullard et al. 2017 demonstrated how African-American and Hispanic patients utilized physical therapy services less when compared to white patients (Fullard et al. 2017). In another study comparing PD patients at a public hospital and PD patients at a Parkinson's Foundation Center of Excellence, patients in the public hospital were less likely to have insurance or begin treatment methods such as physical therapy (Nwabuobi et al. 2021). These studies suggest the importance of considering the immediate impact of these health disparities on patients and their management of PD.

Other studies in medicine and healthcare have illustrated the impact of delays in care on patient outcomes. For instance, delay of treatment in patients with early-onset bipolar disorder was associated with poorer outcomes such as increased severity of depression in adulthood (Post et al., 2010). Significant associations between treatment delay and increased severity of clinical presentation were found in tuberculosis patients (Virenfeldt et al., 2014). Studies have also suggested the benefit of beginning treatment earlier in Alzheimer's disease (AD), another chronic, incurable, neurodegenerative disease; previous research has suggested the benefits of beginning treatment with the pharmacological agent donepezil earlier to reduce the progression of the cognitive decline associated with the disease (Gauthier 2005). Overall, the glaring healthcare

disparities for Parkinson's patients and their impact on patient outcomes must be considered when evaluating a patient. The involvement of factors such as knowledge about PD, barriers such as low health literacy and its impact on patients and their interactions with the healthcare system are all primed for interventional initiatives to reduce barriers and thereby improve patient outcomes.

Significance of understanding health literacy differences in medicine

Health literacy has previously been defined by the US Institute of Medicine as "the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions" (Institute of Medicine 2004). Baker 2006 presents a conceptual model to outline health literacy (Baker 2006). The model integrates two primary domains: "individual capacity" and "health literacy" (Baker 2006). Within each of those domains, Baker additionally suggests sub-domains; for individual capacity, Baker focuses on "reading fluency", "prior knowledge", and "conceptual knowledge of health and healthcare" (Baker 2006). For health literacy, Baker suggests that the domain involves interactions between both an individual's literary abilities and the varying situations that the individual encounters in healthcare (Baker 2006). In addition, Baker proposes through his model that "health literacy" is just one of other factors, such as social factors or access to healthcare, that may impact an individual's self-efficacy and health outcomes (Baker 2006).

In addition to Baker's model, Paasche-Orlow and Wolf present a model outlining causal relationships between health literacy and health outcomes (Paasche-Orlow and Wolf 2007). In this model, the researchers list and discuss several different factors

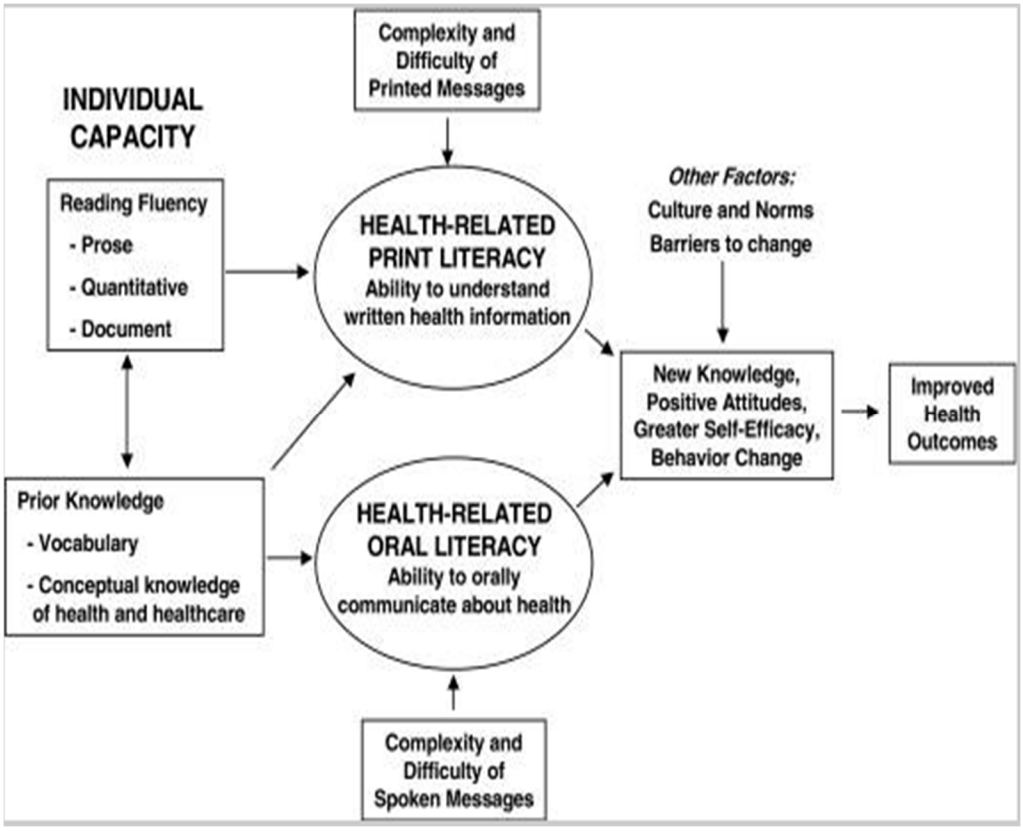


Figure 7: A conceptual model of domains involved in health literacy. Figure taken from Baker 2006. As indicated in the figure, Baker proposes that multiple domains interact with one another in the construct of health literacy.

involving both the patient and the healthcare system (Paasche-Orlow and Wolf 2007). At the patient level, low levels of health literacy may affect access to healthcare as these patients may not be as informed of the relevant signs of a disorder that should cause concern, and therefore may affect when they make the decision to pursue healthcare (Paasche-Orlow and Wolf 2007). Baker has also previously noted that patients with low levels of health literacy in patients may also feel shame (Baker et al. 1996). Patients with low levels of health literacy may also have difficulty physically navigating the healthcare

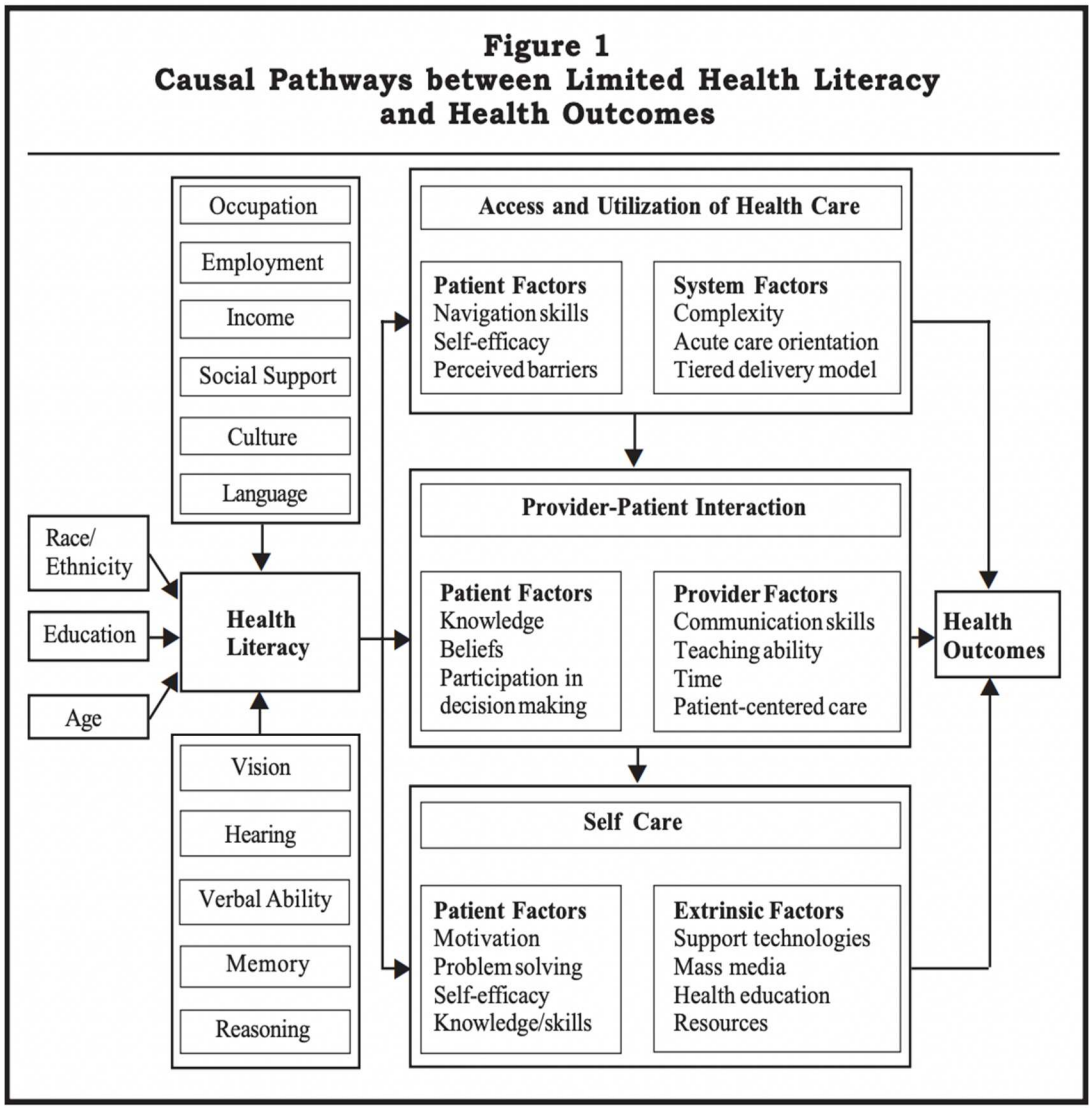


Figure 8: A conceptual model of the associations between health literacy and health outcomes. Figure taken from Paasche-Orlow & Wolf 2007. The researchers depict several factors involved in the association between health literacy and various health outcomes.

system; for instance, patients may have difficulty locating where to go in a healthcare facility (Paasche-Orlow and Wolf 2007). The researchers also discuss factors at the level of the provider, such as providers overestimating literacy levels of their patients (Bass et

al 2002). Ultimately, Paasche-Orlow and Wolf demonstrate the interactions of a variety of factors that make up the construct of health literacy.

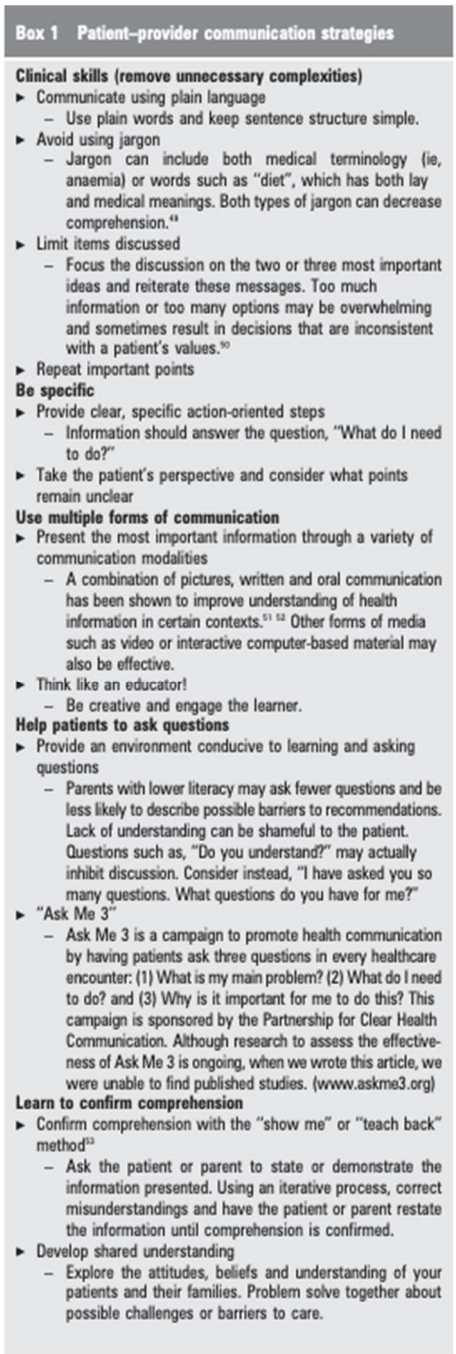
Limited health literacy has also previously been linked to factors such as poverty and limited education (Kutner et al., 2006). Additional factors that were associated with the risk of having lower levels of health literacy included having less education and being uninsured (Christy et al., 2017). Furthermore, in medically underserved patients, individuals who could not be employed due to factors such as disability or who self-identified as an ethnic minority were at a greater risk of having lower levels of health literacy, in comparison to employed individuals and those who identified as non-Hispanic Whites, respectively(Christy et al., 2017).

In evaluating healthcare disparities and their impact on patients and their health outcomes, several studies have also pointed towards health literacy as a critical factor, with lower levels associated with worsened health outcomes (Berkman et al., 2011). In a previous review of the current literature, low health literacy has been associated with outcomes such as increased hospitalizations in patients with conditions such as asthma and congestive heart failure (Berkman et al., 2011). A review article by DeWalt et al. has also associated low literacy levels with negative health outcomes through assessing factors such as medication adherence (DeWalt et al., 2004). For instance, low literacy levels were associated with a greater likelihood of worsened medication adherence in HIV clinic patients (Kalichman et al., 1999). In addition, for medically underserved patients with type 2 diabetes, lower health literacy scores were significantly associated

with an increased amount of unintentional nonadherence to medications, with a majority of these patients being low-income and African-American (Fan et al., 2016).

Health literacy and the risks for low health literacy are important given the influence it has on the physician-patient relationship. In a study assessing medically underserved patients, researchers found that adequate health literacy was significantly associated with a greater likelihood of the patient preferring to be involved in decision-making, as opposed to patients with lower levels of health literacy (Seo et al., 2016). Other patients also reported increased levels of self-efficacy to speak with physicians when having more information about their disease (Peek et al., 2009). These consequences are critical to consider as shared decision-making (SDM) has been associated with improved patient outcomes, such as improved control of blood sugar in diabetic patients (Greenfield et al., 1988).

With the current literature illustrating these differences in health literacy among patients, there remains a clear need for improvement in communication strategies between patients, providers, and the healthcare system. The current literature has recommended strategies at the level of the clinician to improve patient-provider communication (Figure 9). Some strategies suggested, for instance, include actively involving patients in shared decision-making and having providers perform a "literacy walk through", which involves clinicians evaluating the literary skills that would be required by patients in navigating a visit (Hironaka and Paasche-Orlow 2007; Hixon 2004). Other strategies include not using medical jargon when interacting with patients



Box 1 Patient–provider communication strategies

Clinical skills (remove unnecessary complexities)

- Communicate using plain language
  - Use plain words and keep sentence structure simple.
- Avoid using jargon
  - Jargon can include both medical terminology (ie, anaemia) or words such as "diet", which has both lay and medical meanings. Both types of jargon can decrease comprehension.[49]
- Limit items discussed
  - Focus the discussion on the two or three most important ideas and reiterate these messages. Too much information or too many options may be overwhelming and sometimes result in decisions that are inconsistent with a patient's values.[50]
- Repeat important points

Be specific

- Provide clear, specific action-oriented steps
  - Information should answer the question, "What do I need to do?"
- Take the patient's perspective and consider what points remain unclear

Use multiple forms of communication

- Present the most important information through a variety of communication modalities
  - A combination of pictures, written and oral communication has been shown to improve understanding of health information in certain contexts.[51 52] Other forms of media such as video or interactive computer-based material may also be effective.
- Think like an educator!
  - Be creative and engage the learner.

Help patients to ask questions

- Provide an environment conducive to learning and asking questions
  - Parents with lower literacy may ask fewer questions and be less likely to describe possible barriers to recommendations. Lack of understanding can be shameful to the patient. Questions such as, "Do you understand?" may actually inhibit discussion. Consider instead, "I have asked you so many questions. What questions do you have for me?"
- "Ask Me 3"
  - Ask Me 3 is a campaign to promote health communication by having patients ask three questions in every healthcare encounter: (1) What is my main problem? (2) What do I need to do? and (3) Why is it important for me to do this? This campaign is sponsored by the Partnership for Clear Health Communication. Although research to assess the effectiveness of Ask Me 3 is ongoing, when we wrote this article, we were unable to find published studies. (www.askme3.org)

Learn to confirm comprehension

- Confirm comprehension with the "show me" or "teach back" method[52]
  - Ask the patient or parent to state or demonstrate the information presented. Using an iterative process, correct misunderstandings and have the patient or parent restate the information until comprehension is confirmed.
- Develop shared understanding
  - Explore the attitudes, beliefs and understanding of your patients and their families. Problem solve together about possible challenges or barriers to care.

Figure 9: Several different strategies recommended to improve communication between the patient and the provider. Figure taken from Hironaka & Paasche-Orlow 2007. The researchers outline various strategies to improve patient-provider communication.

(Oates and Paasche-Orlow 2009). Visual aids have been suggested in previous research to improve features such as information processing. (Tversky 2011). All in all, health literacy and its potential impact on patient interactions with healthcare providers cannot be ignored when evaluating patient outcomes.

Evaluating how health literacy affects patients with Parkinson's disease

When assessing neurology outpatients, researchers have also found support for the duration of a neurologic disease to have a strong predicting effect of low health literacy (Fleisher et al., 2014). The researchers suggest that physicians may be more inclined to spend less time with and provide shorter explanations to chronic patients after assuming a greater familiarity with disease management in these patients, compared to that of newly diagnosed patients (Fleisher et al., 2014). In neurology outpatients, health literacy was also associated with other factors, such as demographic and social factors. For instance, low health literacy has previously been associated with patients who self-identify as African-American or those who report a lower education level (Fleisher et al. 2014). Outcomes in PD patients have also been related to health literacy. For instance, previous research has suggested an association between PD patients with low health literacy and outcomes such as greater caregiver burden and hospitalization (Fleisher et al., 2016). Previous studies have also illustrated common misconceptions regarding PD-related knowledge in patients (Salinas et al., 2020). The impact of how much disease-related knowledge a patient holds may be key to consider, as previous studies have shown a strong association between self-reports of increased levels of disease-related

knowledge and a greater likelihood of satisfaction with neurologist interactions (Riggare et al., 2019). Given the chronic nature of PD and the wide variety of treatment approaches involved in combating the disease, health literacy and disease knowledge have been considered a critical factor to understanding disparities in PD (Fleisher et al., 2016).

Another factor related to health literacy for PD patients and critical to consider is medication knowledge, or the information involving various aspects of a medication, such as its purpose or the method in which it should be taken. (Zipprich et al. 2021). For patients at a primary care clinic, lower levels of health literacy were associated with worsened medication knowledge (Mosher et al., 2012). Similar findings have been shown in PD and have been related to poor medication adherence (Mendorf et al., 2020). Medication knowledge may be a critical factor to consider for PD patients and their health outcomes, as PD is a disease where multiple medications may be needed for a patient (Grosset et al. 2005). Previous research has found factors such as age and the number of medications taken on a daily basis to be associated with low levels of medication knowledge for patients with PD (Zipprich et al. 2021). Researchers in this study assessed medication knowledge by using a Likert scale to ask participants how familiar they believed they were with various aspects about their medications, such as the dosages, timing, and names (Zipprich et al., 2021). In addition, these low levels of medication knowledge were also associated with lower scores in areas such as social functioning, a dimension of health-related quality of life (Zipprich et al. 2021). Despite the existing literature on health literacy and medication nonadherence for PD patients,

little is known about how factors such as limited health literacy influence outcomes such as the time it takes patients to begin treatments involved in management of the disease including physical therapy and exercise, and further research is needed to examine these factors and how they impact patients.

The impact of language barriers on patient care

Just as with low health literacy levels in patients, the impact of language barriers and its effects on communication between patients and the healthcare system must be considered when evaluating patient outcomes. Communication itself is a process that is critical to the sharing of information between healthcare members, patients, and patients' families, through both oral methods such as conversations and writing (Schvye 2007). Low health literacy levels, cultural differences and limited English proficiency all contribute to form a "triple threat" in impeding communication in healthcare (Schvye 2007). Effective communication involves discourse that all parties are able to comprehend, and a lack of comprehension potentially leads to a compromise of the quality of healthcare delivered to patients (Schvye 2007). A lack of effective communication furthermore may have serious consequences; in previous studies, adverse events for patients with limited English proficiency, compared to those of patients who spoke English, had a greater likelihood to be associated with errors in communication. (Divi et al., 2007). An adverse event is defined here as "unintended harm to the patient by an act of commision or omission rather than by the underlying disease or condition of the patient" (Erickson et al., 2003). In addition, language barriers negatively affect the

quality of healthcare services received by a patient, and implementation of interpreter services may increase the cost and length of treatment visits (Al Shamsi et al. 2020). Furthermore, in a qualitative study assessing nurses in England, language barriers were defined as the main impediments to patient care for patients with limited English proficiency (Ali and Watson 2017). Limitations in the use of interpreter services were also addressed, such as poor availability of an interpreter (Ali and Watson 2017). When alternative suggestions were discussed by nurses, such as having a healthcare provider who was able to speak a patient's language, these options were not always feasible (Ali and Watson 2017).

The impact of language barriers is also further illustrated in patients with other disorders or areas of medicine. For instance, in a qualitative study focusing on asthma patients, a common barrier that was mentioned by participants was poor communication, and participants generally agreed that having information in their primary language may have been more helpful (Poureslami et al., 2011). Emergency department patients who identified as non-English speakers were at a significant lower likelihood of reporting satisfaction with the care that they received (Carrasquillo et al., 1999). Previous research has also demonstrated patients with limited English proficiency had a lower likelihood of understanding aspects of hospital discharging and follow-up appointments, such as appointment type and medication category (Karliner et al., 2012). Just as with its impact on patients with other disorders, language barriers may play a critical role in affecting patients with PD by impacting their ability to manage the disease, but its role has not clearly been outlined in the existing literature, and further research is needed.

Specific Aims

The current literature has illustrated the impact of factors such as low health literacy and language barriers in medicine and healthcare. Low levels of health literacy have been previously associated with worsened health outcomes such as an increased hospitalization for PD patients. Furthermore, while its role in PD patients requires further research, language barriers have also previously been associated with outcomes such as lowered satisfaction with healthcare services by patients. However, there is a lack of research in the literature with regards to how these factors relate to the disparities seen in PD patients from underserved populations, particularly with regards to factors involved in the management of PD like medication adherence and exercise after diagnosis. This research study will therefore set out to explore these themes through a mixed methods design, using both qualitative and quantitative methods to collect and analyze patient experiences and ultimately understand and address these gaps in the existing literature.

This research study has three specific objectives: First, this study aims to assess the diagnosis experience of PD patients who identify as Black/African-American, Hispanic/Latinx or speak Haitian-Creole or Spanish; Second, this research study aims to assess providers beliefs regarding the barriers that patients from these populations may face while being treated for PD; Finally, this research study aims to ultimately use the findings to develop and produce educational videos on PD diagnosis and treatment. These educational videos will also be subject to thematic analysis and feedback through the use of community focus groups. Prior studies have suggested an interest by a majority of healthcare providers in implementing visual aids for patients to discuss PD-related

issues (Udow et al., 2017) and therefore we hope that this approach will provide one intervention that can be utilized to overcome health literacy and language barriers.

CHAPTER TWO: METHODS

Study Design

For this study, a mixed-methods approach will be used with both qualitative and quantitative methods implemented to assess patients and clinicians. Benefits of using mixed-methods approaches in research include potentially having increased validity through allowing for triangulation of data (Doyle et al., 2009). The use of both qualitative and quantitative methods in this study allows for triangulation of data, which refers to the process of using more than one approach in the research process (Heale and Forbes 2013). In the context of mixed methods, triangulation allows for data convergence where conclusions are drawn from areas where quantitative and qualitative responses agree (Heale and Forbes 2013). In this research study, the qualitative analysis method of thematic analysis will be applied to the data collected. Thematic analysis has previously been defined as "a method for identifying, analyzing and reporting patterns (themes) within data" (Figure 10; Braun and Clarke 2006). This qualitative process of analyzing data involves repeated analysis to discover recurring patterns within the data (Braun and Clarke 2006). The use of thematic analysis has many advantages, such as its accessibility even to researchers who are not highly experienced with qualitative research (Braun and Clarke 2006). Furthermore, in this research study, the qualitative research process will be applied towards all recorded narrative responses received in the study. On the other hand, in this study quantitative methods will also be applied through a retrospective chart review of patient data.

Table 2 A 15-point checklist of criteria for good thematic analysis

Process	No.	Criteria
Transcription	1	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'.
Coding	2	Each data item has been given equal attention in the coding process.
	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive.
	4	All relevant extracts for all each theme have been collated.
	5	Themes have been checked against each other and back to the original data set.
	6	Themes are internally coherent, consistent, and distinctive.
Analysis	7	Data have been analysed – interpreted, made sense of – rather than just paraphrased or described.
	8	Analysis and data match each other – the extracts illustrate the analytic claims.
	9	Analysis tells a convincing and well-organized story about the data and topic.
	10	A good balance between analytic narrative and illustrative extracts is provided.
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.
Written report	12	The assumptions about, and specific approach to, thematic analysis are clearly explicated.
	13	There is a good fit between what you claim you do, and what you show you have done – ie, described method and reported analysis are consistent.
	14	The language and concepts used in the report are consistent with the epistemological position of the analysis.
	15	The researcher is positioned as *active* in the research process; themes do not just 'emerge'.

Figure 10: The steps involved in thematic analysis. Figure taken from Braun and Clarke 2006. Multiple steps are involved in the process of thematic analysis.

Study Population and Recruitment

Study patient recruitment will be primarily done through targeting the patient population at the Parkinson's Disease and Movement Disorder clinic at Boston Medical Center (BMC), an academic medical center that is affiliated with the Boston University School of Medicine and the largest safety net hospital in the New England area. According to the the Boston Medical Center website at www.bmc.org, a majority of the patient population that BMC serves is patients from underserved populations, with 59% falling into this category due to being a racial/ethnic minority, non-primary English speaker,

homelessness, or elderly to name a few; in addition, 32% of patients are either of immigrant status or do not have English as their primary language. This diverse patient

Table 1: Statistics of an initial list of patients compiled for potential recruitment in this research study based on the demographics of the BMC Parkinson's Disease and Movement Disorders Clinic.

Total	Male	Female	Black/African-American	Hispanic/Latino	Preferred language of English	Preferred language of Haitian Creole	Preferred language of Spanish
N = 366	N = 203 (55.5%)	N = 163 (44.5%)	N = 140 (38.3%)	N = 51 (13.9%)	N = 188 (51.4%)	N = 49 (13.4%)	N = 80 (21.9%)

population of BMC is ideal for this type of diversity research as we aim to better understand the above-mentioned disparities in patients from different cultural or ethnic groups. During the recruitment phase of the study, potential subjects will be contacted with letters, via methods such as phone and email, or their desired preference of communication based on their medical record. Patients will be continued to be recruited as needed until thematic saturation is determined. Thematic saturation refers to the point at which no new themes are generated from the data analyzed in a study (Green and Thurogood 2004). We ideally estimate each group of patients to ultimately include about 10 to 15 participants, for a total study sample that may ultimately reach up to 40 participants. At the time of submission of this study thesis, the study team is currently planning to initiate the initial stages of patient recruitment and begin sending recruitment

letters and messages. A list of participants to be reached out to were pulled from a list of patients who were treated at the Parkinson's

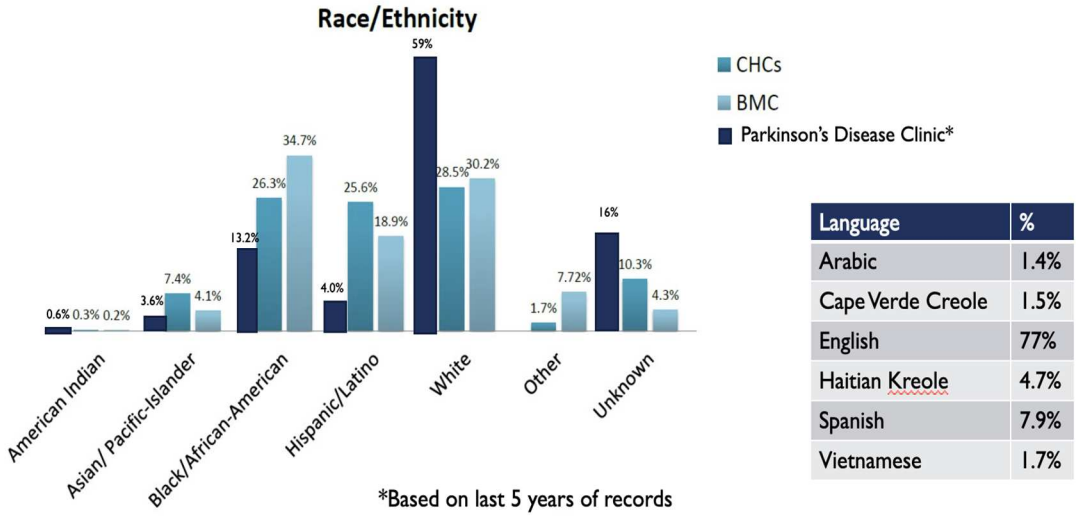


Figure 11: A diagram of race/ethnicity statistics of BMC-affiliated patients within the last 5 years. Figure taken from Doyle, 2013, slide 9. The indicated figure depicts the variation in patients at BMC in the last 5 years.

Disease and Movement Disorder clinic at BMC within the last five years; a total of 1088 patients were pulled from the medical records system Epic and compiled into an initial database. From within these patients, a list of 366 patients was further identified for potential study recruitment. Among these 366 patients, 203 identified as male, and the remaining 163 as female. 140 patients identified their race as Black or African-American, while 51 patients identified themselves as of Hispanic or Latino race. Interestingly, there were 18 patients who had unknown race listed, and 2 patients had more than one race listed in the medical record. This number may be suggestive of difficulty by participants with mixed races or ethnicities to indicate an option from the choices provided to them. Furthermore, 188 patients indicated their preferred language as English. Of the remaining

patients, 49 patients indicated Haitian Creole and 80 patients indicated Spanish as their primary language.

Participant Screening

Patients will be screened for inclusion in the study through administration of the Rowland Universal Dementia Assessment Scale (RUDAS): A Multicultural Cognitive Assessment Scale, along with an additional quiz assessing understanding of research. While previous research studies have used the Folstein Mini-Mental State Examination (MMSE), the RUDAS has previously been found to be less affected by factors such as language and education level (Naqvi et al., 2015). Consequently, the RUDAS may more accurately identify those patients from diverse populations with cognitive impairment. The RUDAS consists of six items that test several different cognitive domains such as judgment and memory recall (Figure 12; Navqi et al., 2015). Participants who complete the RUDAS with a score of 22 or greater will qualify to participate in the study. For those patients who score below a 22, letters indicating patient RUDAS scores, along with a copy of the RUDAS, will be sent to their primary care providers so that they can further screen and treat the patient if indicated.

In addition to the implementation of the RUDAS, patients will be administered a true/false quiz to ensure that they understand that they are participating in research. Participants who complete this quiz with a score of 100% through 3 attempts or less will qualify to participate in the study. Furthermore, both of these screening assessments will be administered with the help of an translator for Spanish or Haitian Creole for participants as needed.

Table 1: The Rowland Universal Dementia Assessment Scale

Cognitive domain	Question*	Points
Registration	Given 4 grocery items to register (and recall later)	0
Visuospatial orientation	Left/right orientation with body parts	5
Praxis	Alternating hand movements with fist and palm	2
Visuoconstructional drawing	Copying image of a cube	3
Judgment	Safety precautions when crossing a street	4
Memory recall	Recalling 4 grocery items from above	8
Language	Animal naming in 1 minute	8
	Total score	/30

*Questions have been abridged. The full test and details are available at https://fightdementia.org.au/sites/default/files/20110311_2011RUDASAdminScoringGuide.pdf.

Figure 12: The domains assessed in the Rowland Universal Dementia Assessment Scale. Figure taken from Navqi et al., 2015. As indicated in the above figure, the instrument assesses six cognitive domains.

Qualitative Methods

As mentioned above, potential study participants will continue to be recruited and assessed through these methods until thematic saturation is reached for this study. These participants will be asked for their consent for participation, and if consent is given, they

will be interviewed regarding their experience with Parkinson's disease diagnosis and treatment. To begin these interviews, we will ask participants to describe general experiences regarding their health and PD. For instance, questions may include open-ended questions regarding participants' own opinions on their health, and questions asking participants to describe and discuss how PD has affected their lives. Additional questions will ask participants about their experiences with their diagnosis of PD, along with their understanding of the disease. For instance, participants will be asked to describe the time of their diagnosis, along with their feelings about it. Participants will also be asked to describe their own understanding of the disease and any information about PD they may have received outside of visits to their physicians. Other questions will ask about areas such as participants' social networks. Questions asked in this area include asking participants to describe the individuals they consider most important to them in their personal lives, along with questions about the extent of support that they receive from their caregiver and neurologist. Additional questions on the interview will ask about the physician-patient relationship; for instance, the participant will be asked to describe whether they visit their neurologist on a regular basis, and what types of topics are discussed with their neurologist. They will also be probed for discussion of treatment recommendations and compliance as well. In addition to these topics on the interview guide, other areas may be discussed with participants if introduced by the participant. Furthermore, as the research study progresses and more patient interviews occur, the interview guide may be adjusted to reflect common themes occurring in these interviews.

All interviews will be audio recorded. After completion of interviews, recordings of these interviews will be transcribed and these original recordings will be deleted.

The process of qualitative analysis in this research study also includes two phases: memoing and coding. For the process of memoing, while collecting data, study team members will make various notes on the data collection process and do so again after completion of the data collection process. These notes may be subdivided into three types: observational, methodological, and theoretical notes. This process of note-taking will allow the research study team to begin to analyze the data and search for common themes that may begin to appear repeatedly within the data. For example, certain questions may illicit similar body language or hesitations that can help with interpretation of the responses the participants provide.

After each interview is transcribed, the transcript will be read repeatedly by the research study team and be subject to a process of open coding. In this process, the transcript will be analyzed for common areas of discussion between participants that may be "coded". Coding refers to the process of categorizing and marking various aspects and characteristics of the data collected in the study. Upon completion of the first five patient interviews, the study research team will draft the first codebook of the study that can be used to code future interviews. The coding process will also account for the adaptive nature of the qualitative process and any changing or new codes that may be identified with later patient interviews. After the open coding phase, a process of axial coding will then occur, which refers to the process of the research study team linking and connecting

the initial codes and categories identified in the study. Finally, the research study team members will re-code the same transcripts upon the development of a coding scheme.

Retrospective Chart Review

In addition to survey responses provided by patients, after obtaining consent from patients, additional data about patients will be collected through a retrospective chart review. Data such as demographics (race, ethnicity, primary language) will be collected through this chart review. In addition, information regarding any changes in medication since diagnosis of PD for each patient, along with the length of time in between diagnosis of PD and initiation of any medication or exercise, will be collected through this chart review. To supplement this data, we will also ask patients to fill out a demographic questionnaire regarding topics such as current employment status or current income level and highest level of education completed. The information gathered from this retrospective chart review and survey will then be used alongside patient responses from interviews for triangulation of data.

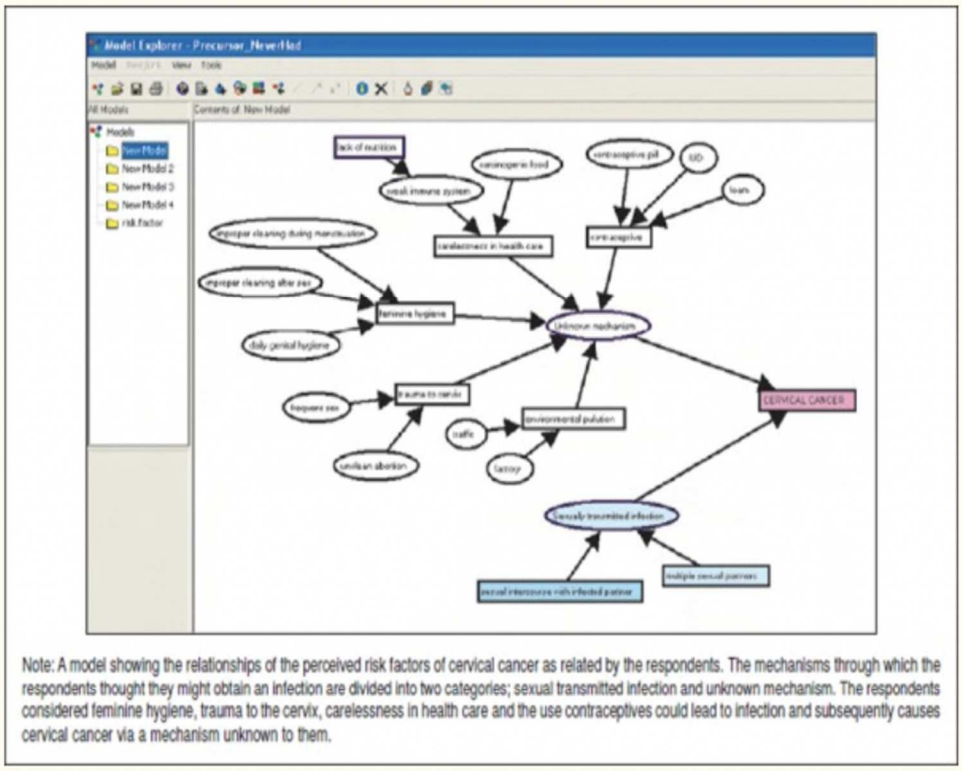
Assessing Healthcare Providers

In addition to surveying patient participants in the study, movement disorder specialists in Massachusetts will be given surveys to assess their opinions on the topics and concepts in PD that are important for a patient who may be recently diagnosed with PD. They will also be asked their opinions of the barriers that their under-represented patients experience. For instance, questions on the survey include questions such as

asking providers their opinions on what barriers may potentially exist for underrepresented patients in medication compliance, or what barriers may exist for underrepresented patients in starting treatment. These surveys will be sent through the data management platform Research Electronic Data Capture (REDCap), an online database through which surveys and collected data may be managed and stored. (Harris et al., 2009). Questions on the survey will consist of both open-ended and multiple choice questions. Providers will also be asked to estimate the demographics of their practice; for instance, questions will ask providers to estimate the percentage of their patients who identify as Black or African-American, or the percentage of their patients who primarily speak Spanish. As with the patient interviews in the study, provider responses will also be subject to the above qualitative analysis methods, including similar phases of coding and thematic analysis.

Data Analysis

To manage the qualitative data, the software program NVivo will be used. Developed by QSR International, NVivo is a computer-assisted qualitative data analysis software (CAQDAS) program that also assists with the management and organization of qualitative data (Wong 2008). Through NVivo, researchers may also model the data to reflect interacting themes and connections within the data (Figure 13; Wong 2008). The



Note: A model showing the relationships of the perceived risk factors of cervical cancer as related by the respondents. The mechanisms through which the respondents thought they might obtain an infection are divided into two categories; sexual transmitted infection and unknown mechanism. The respondents considered feminine hygiene, trauma to the cervix, carelessness in health care and the use contraceptives could lead to infection and subsequently causes cervical cancer via a mechanism unknown to them.

Figure 7.

Model explorer showing the perceived risk factors of cervical cancer

Figure 13: An example of modeling in NVivo. Figure taken from Wong 2008. As indicated in the diagram, NVivo allows for modeling of concepts and ideas and their interconnections.

use of NVivo provides several benefits and advantages to research studies, such as saving researchers time that can be directed towards other efforts of the qualitative research process, such as finding themes in the data (AlYahmady and Alabri 2013). Following the data mapping and analysis that will be conducted in NVivo, we predict that the data will

suggest associations between several different themes and factors. On the other hand, for the quantitative data collected from the chart review in this study, statistical analysis will be conducted through a separate software program such as the Statistical Product and Service Solutions program (SPSS), through which procedures such as multivariate analyses may be conducted. Statistical values such as odds ratios could be calculated to evaluate the strength of associations between factors.

Development of educational videos

As indicated above, there remains a need for improved communication between patients and the healthcare system, and this issue may be further reinforced with the findings of this current research study. The study team plans to use the data collected and analyzed from patient responses to ultimately develop videos aimed to improve patient education and awareness on PD. With the assistance of other parties such as interpreters and the BMC media department, videos will be recorded in three different languages: English, Spanish, and Haitian Creole. Furthermore, each of these videos will be developed with respect to the target population in terms of utilizing patients from each community and include cultural references where appropriate. Each video will be no longer than ten minutes and each will focusd on various topics of PD, such as general information on PD or medication management. Upon completion of initial development, these videos will then be assessed in focus groups consisting of community members representative of the patient populations evaluated in this study. Focus groups will be recorded and memoed as described above. A similar process of qualitative analysis be

employed. Doing so will provide the study team with any feedback and allow for continued editing and modification of the videos, to maximize the potential benefit these videos may provide for their respective target patient populations.

Proposed timeline of the study and current study status

This study will take place over a timeline of approximately 12 to 18 months (Figure 14). This includes submission to the Institutional Review Board (IRB), recruitment, data collection and analysis phases, and also accounts for future video and manuscript development. Also, the proposed study timeline accounts for the addition of another focus group as needed for the study. This proposed timeline may need to account for any adjustments to the study based on data analysis and responses gathered from patients. For instance, if thematic saturation is not achieved within the current timeline of the study, more patients may need to be recruited and their responses added to the study. The recruitment period may need to be extended if not enough initial interest is gathered when recruiting clinic patients. Furthermore, more time may be needed during the video development phases depending on the feedback received. At the time of submission of this research thesis, this research study is in the beginning of its initial stages of patient recruitment with mailing of recruitment opt-out letters and initial phone calls to clinic patients to gauge interest.

Timeline:

	Year 1: 2022				Year 2: 2023	
	Q1	Q2	Q3	Q4	Q1	Q2
IRB submission						
Patient Interviews						
Provider survey						
Transcription and Coding						
Thematic Analysis						
Video Patient Recruitment						
Video Script Development						
Video Recording						
Focus Group 1						
Video Adjustment (if needed)						
Focus Group 2 (if needed)						
Video Adjustment (if needed)						
Manuscript Development						

Figure 14: A proposed timeline of this research study. Figure provided by Stephanie Bissonnette, DO, MPH, Assistant Professor of Neurology at Boston University School of Medicine. As indicated in the figure, this planned research study will occur throughout an approximate timeline of 12 to 18 months.

CHAPTER THREE: DISCUSSION

Potential study results and findings

Upon analysis of the data and patient responses collected in this study, we expect to find several different findings that may not only add to the gaps in the existing literature but also be consistent with some of the disparities in the existing literature mentioned above. First, when analyzing patient experiences with diagnosis of PD, we predict that patients will describe lower levels of self-efficacy with regards to disease management. Patients whose primary language is not English may report that the burden of barriers in communication may limit their understanding of their disease. Patient responses may also suggest a theme of dissatisfaction with the healthcare system overall; they may suggest that the healthcare system is complex or difficult to navigate, and they also may feel as if their visits with providers are not adequate. Another theme that we expect to identify is the difficulty involved in medication management. Patients may report factors such as the complexity of instructions for either one or multiple medications, due to factors such as lower levels of literacy or barriers in language. Another potential theme may be lack of closeness with their physicians. Obstacles such as language barriers, use of medical jargon, or cultural differences may affect patient interactions with the physician and lead to participants being unwilling to discuss more details with their physicians. Other common themes that may appear could be difficulty with medication adherence influenced by factors such as insurance status, language of the instructions written on the bottle, copay/cost, and transportation to reach the pharmacy.

In addition to these themes found in qualitative analysis, we predict that the data will suggest several different associations between factors. For instance, we predict lower health literacy and education levels will be predictive of longer length of time between symptoms and diagnosis and poorer medication adherence. Furthermore, we also predict that a patients' decision to start medication or exercise will be significantly associated with factors such as lower levels of health literacy, primary language spoken, and lower education status. Patients who may have more difficulty navigating the healthcare system, along with the steps needed to manage their disease, may be more delayed in taking action to do so, potentially due to a worsened experience with healthcare. Also, we predict the data will suggest that lower levels of health literacy and lower education status to be predictive of less satisfied patient experiences with providers and poor experience with initial diagnosis. Patients who struggle more in communication with their provider may be more likely to not adequately feel cared for and subsequently their mood states at time of diagnosis may be likely to be affected. In addition, factors such as lack of insurance or low-income status may also be significantly associated with an increased delay in beginning medication and exercise after diagnosis, due to patients potentially having more difficulty accessing these services. Additional factors such as a decreased level of social support may also be associated with both worsened diagnosis experiences and increased times between diagnosis and starting medication or exercise, as patients may not have the support needed in navigating the healthcare system. Ultimately, we predict that the data collected in this research study will not only agree with some previous studies regarding health literacy and language barriers, but also identify new

factors associated with under-represented patients' experiences with PD diagnosis and treatment.

Potential strengths and limitations of the study

The design of this research study has several different strengths and limitations. First, the application of both qualitative and quantitative methods in this research study allows this study to be potentially stronger, as opposed to using just qualitative or quantitative independently. The diverse assessment of multiple patient populations enables the findings of this research study to be potentially applicable to a wide range of patients with PD. The adaptive and flexible nature of the qualitative aspect of this research study also enables the study to account for feedback from patients during the progression of the study, potentially strengthening the study as changes are made in real time to improve aspects such as interviews or video development. Additionally, screening patients for participation in this research study with both a culturally competent cognitive assessment tool such as the RUDAS and a quiz to ensure patients understand that they are participating in research lowers the likelihood of cognitive impairments or manipulation of patients respectively. Furthermore, having various study team members eventually code and re-code the same transcripts will potentially lead us to have strong intercoder reliability during the coding process in this study.

However, several limitations may also arise in carrying out his research study, potentially affecting the data to be collected and the conclusions that the data may ultimately suggest. First, there may be potential bias in the qualitative process of the

study. For instance, during the initial onset of the open coding phase, study team members may be more inclined or predisposed to look towards certain themes over others based on their previous knowledge of the existing literature. In addition, at the time of their interviews, patients may be in varied states of their PD which could affect the responses that they provide. For instance, patients upset or more "off" (medications not working as well) on the day of their interviews may be more prone to speaking about various topics in the interview negatively, leaving mood and affect to be factors that potentially should be considered. Furthermore, there may be limitations caused by potential confounding variables in this research study. One confounding variable may be the existence of any comorbidities in patients participating in the study. Patients with other chronic diseases or health issues may subsequently have different responses during the interview portion of this study. For instance, a patient with both PD and diabetes mellitus may be spending more time with their physician due to more overall symptoms. These patients may also be required to take more medications, potentially affecting their attitudes and experience with medications and overall disease management. Another potential confounding variable that may need to be considered is the current ongoing COVID-19 pandemic. While significant progress and advancements such as the development of vaccines have been made since the pandemic's initial onset two years ago, the pandemic continues to have widespread effects, both at the global and individual level in several domains, including medicine. The current state of the pandemic may potentially affect participants' responses in this study and the data collected. For instance, participants' attitudes and outlook towards medicine and healthcare providers may have

been affected, or their experience with managing PD may have been made more difficult in these past two years. Additional areas such as their social support networks may also have been affected as a result of the pandemic-related public health measures (such as social distancing and quarantine). As a result of these limitations, further work may be needed in the future to improve or expand upon this current research study.

Clinical significance of the study and future work

The clinical research study team at BMC involved in this research study ultimately aims to develop the findings of this research study into educational videos for PD patients of varied backgrounds. The diverse patient population of BMC provides an ideal sample for this study but the findings from the data collected in this study may be generalizable to other institutions as well. As mentioned above, the existing literature has indicated a need for better understanding of how health disparities concerning factors such as health literacy and language barriers affect health outcomes associated with management of PD. A better understanding of how these health disparities impact PD patients from these populations may lead to improved interventions for these patients and their interactions with the healthcare system. In addition, the videos produced may be able to be utilized throughout the country and posted online to be available to patients upon their diagnosis with PD. These interventions, in turn, may help patients have improved management of PD, leading to improved health outcomes. The findings of this research study may also help provide a groundwork for other future researchers aiming to

use qualitative or mixed methods to investigate health disparities, either in PD or in other disorders.

Upon the conclusion of this research study, this study may be potentially improved in the future through applying the methods in this study to other patient groups in medically underserved communities. Doing so may improve the generalizability of this study for PD patients of other ethnicities and various cultural backgrounds, or for medical centers with different underserved communities. In addition, having a research study focusing on a patient population with shared experiences may gather more specific findings, such as having a similar study focusing specifically on patients of refugee or immigrant backgrounds, or having another study focus specifically on patients who are uninsured. Furthermore, another potential improvement that may be made to this research study is the incorporation of additional interview questions regarding cultural differences in how patients view specific topics such as medicine, health, aging, and chronic disease. Patients of different cultures, for instance, may hold different values and opinions on concepts such as illness, medicine, and life course. More extensive assessment of participants' cultural backgrounds, in the way that medical anthropologists have done, may help researchers better closely understand the interactions between various PD patients and the healthcare system. Furthermore, increasing the number of study team members involved in coding of the data may also help increase the intercoder reliability of the coding in this qualitative research study. Having more members code the same transcripts may lead to stronger reinforcement of themes that may have already previously been established or the suggestion of potential new connections between

various areas and themes in the study. Finally, another improvement that could be made would be the addition of another quantitative survey or scale to be used to assess patients in the study. Doing so would gather additional real-time data that could be triangulated alongside the qualitative responses collected in the study and the quantitative data gathered from chart-review, potentially strengthening the study even further.

Summary/Conclusion

Overall, this research study aims to ultimately explore how disparities in factors such as health literacy and language barriers affect disease knowledge and management in PD patients, and how to reduce their impact through the production of educational videos. Using both qualitative and quantitative methods, our research study specifically examined these disparities in patients who identified as Black or African-American, Hispanic or Latinx identity, and patients who primarily spoke Haitian-Creole or Spanish. We hope that the findings of this research study adds to the existing disparities literature and assist other researchers in their investigative studies regarding these topics; furthermore, we hope that the ultimate implementation and dissemination of these educational videos helps reduce the impact of the abovementioned health disparities on PD patients from these populations and improves not only their understanding of the disease but also their overall well-being and management of the disease.

BIBLIOGRAPHY

Al Shamsi, H., Almutairi, A. G., Al Mashrafi, S., & Al Kalbani, T. (2020). Implications of Language Barriers for Healthcare: A Systematic Review. *Oman Medical Journal*, *35*(2), e122. https://doi.org/10.5001/omj.2020.40

Ali, P. A., & Watson, R. (2018). Language barriers and their impact on provision of care to patients with limited English proficiency: Nurses' perspectives. *Journal of Clinical Nursing*, *27*(5–6), e1152–e1160. https://doi.org/10.1111/jocn.14204

AlYahmady, H. H., & Al Abri, S. S. (2013). Using Nvivo for Data Analysis in Qualitative Research. *International Interdisciplinary Journal of Education*, *2*(2), 181–186. https://doi.org/10.12816/0002914

Baker, D. W. (2006). The meaning and the measure of health literacy. *Journal of General Internal Medicine*, *21*(8), 878–883. https://doi.org/10.1111/j.1525-1497.2006.00540.x

Baker, D. W., Parker, R. M., Williams, M. V., Pitkin, K., Parikh, N. S., Coates, W., & Imara, M. (1996). The health care experience of patients with low literacy. *Archives of Family Medicine*, *5*(6), 329.

Bass III, P. F., Wilson, J. F., Griffith, C. H., & Barnett, D. R. (2002). Residents' ability to identify patients with poor literacy skills. *Academic Medicine*, *77*(10), 1039-1041.

Berkman, N. D., Sheridan, S. L., Donahue, K. E., Halpern, D. J., & Crotty, K. (2011). Low Health Literacy and Health Outcomes: An Updated Systematic Review. *Annals of Internal Medicine*, *155*(2), 97. https://doi.org/10.7326/0003-4819-155-2-201107190-00005

Braak, H., Del Tredici, K., Rüb, U., De Vos, R. A., Steur, E. N. J., & Braak, E. (2003). Staging of brain pathology related to sporadic Parkinson's disease. *Neurobiology of Aging*, *24*(2), 197–211. https://doi.org/10.1016/S0197-4580(02)00065-9

Braak, H., Ghebremedhin, E., Rüb, U., Bratzke, H., & Del Tredici, K. (2004). Stages in the development of Parkinson's disease-related pathology. *Cell and Tissue Research*, *318*(1), 121–134. https://doi.org/10.1007/s00441-004-0956-9

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101.

Carrasquillo, O., Orav, E. J., Brennan, T. A., & Burstin, H. R. (1999). Impact of language barriers on patient satisfaction in an emergency department. *Journal of General*

Internal Medicine, *14*(2), 82–87. https://doi.org/10.1046/j.1525-1497.1999.00293.x

Chan, A. K., McGovern, R. A., Brown, L. T., Sheehy, J. P., Zacharia, B. E., Mikell, C. B., ... & McKhann, G. M. (2014). Disparities in access to deep brain stimulation surgery for Parkinson disease: interaction between African American race and Medicaid use. *JAMA Neurology*, *71*(3), 291-299.

Chow, M. Y. K., Quine, S., & Li, M. (2010). The benefits of using a mixed methods approach – quantitative with qualitative – to identify client satisfaction and unmet needs in an HIV healthcare centre. *AIDS Care*, *22*(4), 491–498. https://doi.org/10.1080/09540120903214371

Christy, S. M., Gwede, C. K., Sutton, S. K., Chavarria, E., Davis, S. N., Abdulla, R., Ravindra, C., Schultz, I., Roetzheim, R., & Meade, C. D. (2017). Health Literacy Among Medically Underserved: The Role of Demographic Factors, Social Influence, and Religious Beliefs. *Journal of Health Communication*, *22*(11), 923–931. https://doi.org/10.1080/10810730.2017.1377322

Dahodwala, N., Karlawish, J., Siderowf, A., Duda, J. E., & Mandell, D. S. (2011). Delayed Parkinson's Disease Diagnosis among African-Americans: The Role of Reporting of Disability. *Neuroepidemiology*, *36*(3), 150–154. https://doi.org/10.1159/000324935

Dahodwala, N., Siderowf, A., Xie, M., Noll, E., Stern, M., & Mandell, D. S. (2009). Racial Differences in the Diagnosis of Parkinson's Disease. *Movement Disorders : Official Journal of the Movement Disorder Society*, *24*(8), 1200–1205. https://doi.org/10.1002/mds.22557

Dahodwala, N., Xie, M., Noll, E., Siderowf, A., & Mandell, D. S. (2009). Treatment disparities in Parkinson's disease. *Annals of Neurology*, *66*(2), 142–145. https://doi.org/10.1002/ana.21774

de Lau, L. M., & Breteler, M. M. (2006). Epidemiology of Parkinson's disease. *The Lancet Neurology*, *5*(6), 525–535. https://doi.org/10.1016/S1474-4422(06)70471-9

DeWalt, D. A., Berkman, N. D., Sheridan, S., Lohr, K. N., & Pignone, M. P. (2004). Literacy and health outcomes. *Journal of General Internal Medicine*, *19*(12), 1228–1239. https://doi.org/10.1111/j.1525-1497.2004.40153.x

Divi, C., Koss, R. G., Schmaltz, S. P., & Loeb, J. M. (2007). Language proficiency and adverse events in US hospitals: A pilot study. *International Journal for Quality in Health Care*, *19*(2), 60–67. https://doi.org/10.1093/intqhc/mzl069

Doyle, F.J. (2013). *Integrations of Delivery Systems – Lessons learned from the BHN experience.* [Powerpoint slides]. America's Essential Hospitals. https://essentialhospitals.org/wp-content/uploads/2013/12/52213-Webinar-Aetna-3-Slides.pdf

Erickson, S. M., Wolcott, J., Corrigan, J. M., & Aspden, P. (Eds.). (2003). Patient safety: achieving a new standard for care.

Fan, J. H., Lyons, S. A., Goodman, M. S., Blanchard, M. S., & Kaphingst, K. A. (2016). Relationship Between Health Literacy and Unintentional and Intentional Medication Nonadherence in Medically Underserved Patients with Type 2 Diabetes. *The Diabetes Educator*, *42*(2), 199–208. https://doi.org/10.1177/0145721715624969

Fleisher, J., Bhatia, R., Margus, C., Pruitt, A., & Dahodwala, N. (2014). Health literacy and medication awareness in outpatient neurology. *Neurology: Clinical Practice*, *4*(1), 71–81. https://doi.org/10.1212/01.CPJ.0000436211.73013.ab

Fleisher, J. E., Shah, K., Fitts, W., & Dahodwala, N. A. (2016). Associations and Implications of Low Health Literacy in Parkinson's Disease. *Movement Disorders Clinical Practice*, *3*(3), 250–256. https://doi.org/10.1002/mdc3.12272

Fullard, M. E., Thibault, D. P., Hill, A., Fox, J., Bhatti, D. E., Burack, M. A., Dahodwala, N., Haberfeld, E., Kern, D. S., Klepitskava, O. S., Urrea-Mendoza, E., Myers, P., Nutt, J., Rafferty, M. R., Schwalb, J. M., Shulman, L. M., & Willis, A. W. (2017). Utilization of rehabilitation therapy services in Parkinson disease in the United States. *Neurology*, *89*(11), 1162. https://doi.org/10.1212/WNL.0000000000004355

Gauthier, S. G. (2005). Alzheimer's disease: The benefits of early treatment. *European Journal of Neurology*, *12*(s3), 11–16. https://doi.org/10.1111/j.1468-1331.2005.01322.x

Glanz, K., Rimer, B. K., & Viswanath, K. (Eds.). (2008). *Health behavior and health education: theory, research, and practice*. John Wiley & Sons.

Greenfield, S., Kaplan, S. H., Ware, J. E., Yano, E. M., & Frank, H. J. L. (1988). Patients' participation in medical care. *Journal of General Internal Medicine*, *3*(5), 448–457. https://doi.org/10.1007/BF02595921

Grosset, K. A., Reid, J. L., & Grosset, D. G. (2005). Medicine-taking behavior: Implications of suboptimal compliance in Parkinson's disease. *Movement Disorders*, *20*(11), 1397–1404. https://doi.org/10.1002/mds.20525

Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J. G. (2009). Research electronic data capture (REDCap)—A metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Informatics*, *42*(2), 377–381. https://doi.org/10.1016/j.jbi.2008.08.010

Heale, R., & Forbes, D. (2013). Understanding triangulation in research. *Evidence Based Nursing*, *16*(4), 98–98. https://doi.org/10.1136/eb-2013-101494

Hironaka, L. K., & Paasche-Orlow, M. K. (2008). The implications of health literacy on patient-provider communication. *Archives of Disease in Childhood*, *93*(5), 428–432. https://doi.org/10.1136/adc.2007.131516

Hughes, A. J., Daniel, S. E., Kilford, L., & Lees, A. J. (1992). Accuracy of clinical diagnosis of idiopathic Parkinson's disease: A clinico-pathological study of 100 cases. *Journal of Neurology, Neurosurgery & Psychiatry*, *55*(3), 181–184. https://doi.org/10.1136/jnnp.55.3.181

Institute of Medicine. Health Literacy: A Prescription to End Confusion. Washington, DC: National Academies Press; 2004.

Kalia, L. V., & Lang, A. E. (2015). Parkinson's disease. *Lancet (London, England)*, *386*(9996), 896–912. https://doi.org/10.1016/S0140-6736(14)61393-3

Kalia, S.K., Sankar, T., & Lozano, A.M. (2013). Deep brain stimulation for Parkinson's disease and other movement disorders. *Current opinion in neurology, 26*(4), 374-380.

Kalichman, S. C., Ramachandran, B., & Catz, S. (1999). Adherence to combination antiretroviral therapies in HIV patients of low health literacy. *Journal of General Internal Medicine*, *14*(5), 267–273. https://doi.org/10.1046/j.1525-1497.1999.00334.x

Karliner, L. S., Kim, S. E., Meltzer, D. O., & Auerbach, A. D. (2010). Influence of language barriers on outcomes of hospital care for general medicine inpatients. *Journal of Hospital Medicine*, *5*(5), 276–282. https://doi.org/10.1002/jhm.658

Kutner, M., Greenburg, E., Jin, Y., & Paulsen, C. (2006). The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy. NCES 2006-483. *National Center for Education Statistics*. https://eric.ed.gov/?id=ED493284

Mendorf, S., Witte, O. W., Grosskreutz, J., Zipprich, H. M., & Prell, T. (2020). What Predicts Different Kinds of Nonadherent Behavior in Elderly People With Parkinson's Disease? *Frontiers in Medicine*, *7*. https://www.frontiersin.org/article/10.3389/fmed.2020.00103

Mosher, H. J., Lund, B. C., Kripalani, S., & Kaboli, P. J. (2012). Association of Health Literacy With Medication Knowledge, Adherence, and Adverse Drug Events Among Elderly Veterans. *Journal of Health Communication*, *17*(sup3), 241–251. https://doi.org/10.1080/10810730.2012.712611

Naqvi, R. M., Haider, S., Tomlinson, G., & Alibhai, S. (2015). Cognitive assessments in multicultural populations using the Rowland Universal Dementia Assessment Scale: A systematic review and meta-analysis. *Canadian Medical Association Journal*, *187*(5), E169–E175. https://doi.org/10.1503/cmaj.140802

Nwabuobi, L., Agee, J., & Gilbert, R. (2021). Racial and Social Disparities in Health and Health Care Delivery among Patients with Parkinson's Disease and Related Disorders in a Multiracial Clinical Setting. *Journal of Cross-Cultural Gerontology*, *36*(3), 253–263. https://doi.org/10.1007/s10823-021-09436-w

Oates, D. J., & Paasche-Orlow, M. K. (2009). Health Literacy. *Circulation*. https://doi.org/10.1161/CIRCULATIONAHA.108.818468

Onofrj, M., Thomas, A., & Bonanni, L. (2007). New approaches to understanding hallucinations in Parkinson's disease: Phenomenology and possible origins. *Expert Review of Neurotherapeutics*, *7*(12). https://doi.org/10.1586/14737175.7.12.1731

Pan, S., Stutzbach, J., Reichwein, S., Lee, B. K., & Dahodwala, N. (2014). Knowledge and attitudes about Parkinson's disease among a diverse group of older adults. *Journal of Cross-Cultural Gerontology*, *29*(3), 339–352. https://doi.org/10.1007/s10823-014-9233-x

Paasche-Orlow, M. K., & Wolf, M. S. (2007). The Causal Pathways Linking Health Literacy to Health Outcomes. *American Journal of Health Behavior*, *31*(1), 19–26. https://doi.org/10.5993/AJHB.31.s1.4

Parkinson study group, Jankovic, J., McDermott, M., Carter, J., Gauthier, S., Goetz, C., Golbe, L., Huber, S., Koller, W., Olanow, C., Shoulson, I., Stern, M., Tanner, C., & Weiner, W. (1990). Variable expression of parkinson's disease: A base-line analysis of the datatop cohort. *Neurology*, *40*(10), 1529–1534. https://doi.org/10.1212/wnl.40.10.1529

Peek, M. E., Wilson, S. C., Gorawara-Bhat, R., Odoms-Young, A., Quinn, M. T., & Chin, M. H. (2009). Barriers and Facilitators to Shared Decision-making Among African-Americans with Diabetes. *Journal of General Internal Medicine*, *24*(10), 1135. https://doi.org/10.1007/s11606-009-1047-0

Post, R. M., Leverich, G. S., Kupka, R. W., Jr, P. E. K., McElroy, S. L., Altshuler, L. L., Frye, M. A., Luckenbaugh, D. A., Rowe, M., Grunze, H., Suppes, T., & Nolen, W. A. (2010). Early-Onset Bipolar Disorder and Treatment Delay Are Risk Factors for Poor Outcome in Adulthood. *The Journal of Clinical Psychiatry*, *71*(7), 5308. https://doi.org/10.4088/JCP.08m04994yel

Poureslami, I., Rootman, I., Doyle-Waters, M. M., Nimmon, L., & FitzGerald, J. M. (2011). Health Literacy, Language, and Ethnicity-Related Factors in Newcomer Asthma Patients to Canada: A Qualitative Study. *Journal of Immigrant and Minority Health*, *13*(2), 315–322. https://doi.org/10.1007/s10903-010-9405-x

Saadi, A., Himmelstein, D. U., Woolhandler, S., & Mejia, N. I. (2017). Racial disparities in neurologic health care access and utilization in the United States. *Neurology*, *88*(24), 2268. https://doi.org/10.1212/WNL.0000000000004025

Schyve, P. M. (2007). Language Differences as a Barrier to Quality and Safety in Health Care: The Joint Commission Perspective. *Journal of General Internal Medicine*, *22*(2), 360–361. https://doi.org/10.1007/s11606-007-0365-3

Seo, J., Goodman, M. S., Politi, M., Blanchard, M., & Kaphingst, K. A. (2016). Effect of Health Literacy on Decision-Making Preferences among Medically Underserved Patients. *Medical Decision Making : An International Journal of the Society for Medical Decision Making*, *36*(4), 550. https://doi.org/10.1177/0272989X16632197

Sheridan, S. L., Halpern, D. J., Viera, A. J., Berkman, N. D., Donahue, K. E., & Crotty, K. (2011). Interventions for individuals with low health literacy: A systematic review. *Journal of Health Communication*, *16 Suppl 3*, 30–54. https://doi.org/10.1080/10810730.2011.604391

Sveinbjornsdottir, S. (2016). The clinical symptoms of Parkinson's disease. *Journal of Neurochemistry*, *139*(S1), 318–324. https://doi.org/10.1111/jnc.13691

Tansey, M. G., & Goldberg, M. S. (2010). Neuroinflammation in Parkinson's disease: its role in neuronal death and implications for therapeutic intervention. *Neurobiology of disease*, *37*(3), 510-518.

Tversky, B. (2011). Visualizing Thought: Topics in Cognitive Science(2010). *Topics in Cognitive Science*, *3*(3), 499–535. https://doi.org/10.1111/j.1756-8765.2010.01113.x

Udow, S. J., Hobson, D. E., Kleiner, G., Masellis, M., Fox, S. H., Lang, A. E., & Marras, C. (2018). Educational Needs and Considerations for a Visual Educational Tool to Discuss Parkinson's Disease. *Movement Disorders Clinical Practice*, *5*(1), 66–74. https://doi.org/10.1002/mdc3.12563

Virenfeldt, J., Rudolf, F., Camara, C., Furtado, A., Gomes, V., Aaby, P., Petersen, E., & Wejse, C. (2014). Treatment delay affects clinical severity of tuberculosis: A longitudinal cohort study. *BMJ Open*, *4*(6), e004818–e004818. https://doi.org/10.1136/bmjopen-2014-004818

Virmani T., Moskowitz C. B., Vonsattel J.-P. and Fahn S. (2015) Clinicopathological characteristics of freezing of gait in autopsy-confirmed Parkinson's disease. *Movement Disorders.* 30, 1874–1884. https://doi.org/10.1002/mds.26346

Wong, L. (2008). Data Analysis in Qualitative Research: A Brief Guide to Using Nvivo. *Malaysian Family Physician : The Official Journal of the Academy of Family Physicians of Malaysia*, *3*(1), 14–20.

Zipprich, H. M., Mendorf, S., Schönenberg, A., & Prell, T. (2021). The impact of poor medication knowledge on health-related quality of life in people with Parkinson's disease: A mediation analysis. *Quality of Life Research*. https://doi.org/10.1007/s11136-021-03024-8

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