

HUMAN COMPUTER INTERFACE FOR ALL: UNDERSTANDING
BARRIERS AND BRIDGES IN TECHNOLOGY TO BRING
EQUITY TO PARKINSON'S PATIENTS

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ABSTRACT

This study was designed to investigate the daily challenges that Parkinson’s patients face and understand how they are related to technology and communication. A human-centered design was used in conjunction with the first three stages of the Design Thinking Process to empathize, define, and ideate. Nine participants were chosen who had all been diagnosed with Parkinson’s disease for at least two years. Participants were interviewed and questioned about their daily struggles at home and with technology relating to communication. Their interviews were coded and themed, and the results were grouped into five major themes that included symptoms, daily challenges, values, communication, and technology. The results indicated that all participants struggled with communication on multiple levels, including in person, written, verbally, and virtually. Voice command software was deemed useful only to those who were in the early stages of the disease. Virtual communication was found to be helpful to those that were aware of its capabilities and used it on a regular basis. Social interaction and a sense of community were determined to be key

issues to help participants feel accepted and fight depression. Pre-diagnosis lifestyle and values were found to correlate with post-diagnosis symptom experiences, indicating that an individualized approach focused on patients' values and pre-diagnosis lifestyles could be more beneficial than focusing on how to slow symptom progression. This exploratory qualitative study is the first stage of a multi-phase project encompassing a mixed methods approach. These findings will be used to lay the foundation for a solid understanding of what Parkinson's patients struggle with and how to begin development of a quantitative communication instrument for fighting Parkinson's disease.

APPROVAL PAGE

The faculty listed below, appointed by the Dean of the School of Computing and Engineering, have examined a dissertation titled “Human Computer Interface for all: Understanding Barriers and Bridges in Technology to bring Equity to Parkinson’s Patients,” presented by Anthony S. Weiss, candidate for the Master of Science degree, and certify that in their opinion it is worthy of acceptance.

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DEDICATION

This thesis is dedicated to my father, grandfather, aunt. All whom have been diagnosed with Parkinson's disease.

CHAPTER 1

INTRODUCTION

Parkinson's disease is a long-term degenerative disease that attacks the central nervous system with no known cure. There are more than 60,000 people diagnosed per year in the United States, and the disease affects over 10 million people worldwide. This attack on the nervous system decreases dopamine production by 80 to 100% and results in decreased motor controls and depression (Parkinson's Foundation, n.d.). As symptoms worsen, ability to adapt to technological advancement becomes exponentially more challenging because of physical and mental changes. This study was developed in an effort to understand the relationship between Parkinson's patients and how the technological gap affects their communication. A full breakdown of the symptoms, causes, treatments, and effects of Parkinson's disease can be seen in Figure 1 on the following page.

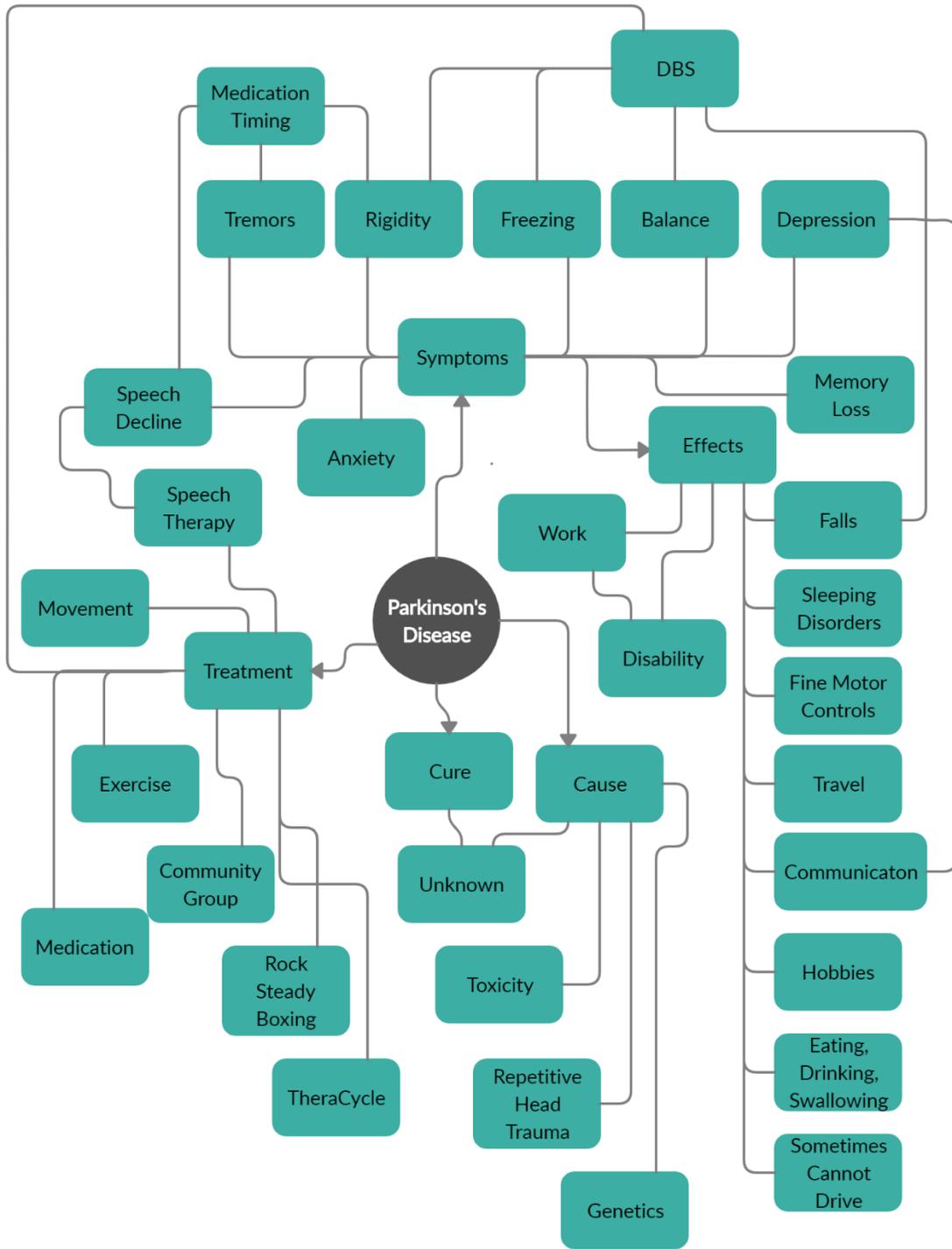


Figure 1.--Parkinson's Disease Breakdown

The key objectives of this study were to investigate challenges that Parkinson's patients face with technology and communication in everyday life and how to bring equity and access to them. A human-centered engineering design approach was used to incorporate elements of social science research through the study of Parkinson's patients in various communities, cultures, and geographical areas in the Kansas City metropolitan district. By intimately understanding these problems through the empathy stage of the Design Thinking Process, solutions can be developed and specifically targeted at the areas of highest need. This research study is laid out in the following manner.

Chapter 2, Literature Review: The literature review comprises all the preliminary research that was done for this project. This included understanding Parkinson's disease, different approaches to combat Parkinson's disease, touch sensor gestures, wearable sensor technologies, and human-centered research methods.

Chapter 3, Methodology: This chapter focuses on the methods used to carry out the research and testing of this study. A detailed description is given on how the participants were chosen, what the criteria of the study was, and how the interviews were conducted and structured. This chapter also focuses on the testing procedure that would have been used to test participants' gestures on touch screens using an iPhone and tablet. Due to the COVID-19 pandemic, extreme precautions were taken to protect these high-risk subjects, and in-person testing was not possible. However, the testing procedure that would have been used is still explained and laid out in detail.

Chapter 4, Results: This chapter is a compilation of the results found during the interviewing process. Interviews were coded and sorted into seventeen categories . These categories were then grouped into five major themes, which included symptoms, daily challenges, values, communication, and technology. The results display the findings and commonalities between the interviews, categories, and themes.

Chapter 5, Discussion: The results are discussed in further detail to break down their significance and what they mean for this study and the Parkinson's community as a whole. Study limitations, future work, recommendations, and the impact of COVID-19 on this study are all discussed here.

Chapter 6, Conclusion: This chapter summarizes the overall study details and results obtained. Future work is also included here.

CHAPTER 2

LITERATURE REVIEW

The literature review for this thesis is put together in order to discuss what living with Parkinson's disease is like, what specific tasks patients struggle with, what are some current devices and technological advancements to help aid Parkinson's patients, how wearable technology is evolving in healthcare, and what specific human-centered research methods have been successfully used in previous studies.

A thorough understanding of what Parkinson's disease is and does to those who are affected is extremely important. Examining how the disease develops over time and affects people at various stages can help identify when or if potential solutions can be implemented. The next area of research focused on existing solutions to help combat Parkinson's on a daily basis. Gaining understanding of current solutions provided insights and initial benchmarks to compare against new technological advancements. There are many medical studies investigating how to slow the neurological degeneration of the disease, but those were excluded from this study. Instead, research was focused on the patients themselves and how to help make their daily lives easier. Preliminary research was also done on how people with Parkinson's interface with touch sensor electronics. Topics included understanding limited range of motion, difficult gestures for Parkinson's patients, and any other challenges Parkinson's patients face when using a touch screen. Further investigating the area of touch sensor electronics, wearable sensors were researched to determine their role or potential future roles in the Parkinson's community. The last area of focus was an investigation on

what research methods could be used for this study. Human-centered research models, including the design thinking process, were explored in order to discover the best way to approach and interview participants.

Living with Parkinson's Disease

Parkinson's disease is a neurological degenerative disease that slowly decreases motor skills to those who are affected by the loss of dopamine producing cells in the substantia nigra area of the brain (Alsheri 2017). Parkinson's is the second most common neurodegenerative disease after Alzheimer's disease (Fargel et al. 2007). When this loss of dopamine occurs, it blocks any dopamine from reaching the basal ganglia, which halts the ability to move and affects the patient's motor skills (Castellana et al. 2019). These motor skills are typically offset by two commonly seen symptoms in Parkinson's disease – tremors and rigidity (Alsheri 2017). Tremors is the shaking phenomenon that occurs that causes a patient to move involuntary, typically seen in the hands and arms. Rigidity is often the stiffness and inability to move muscles, and this can be prevalent across the whole body (Alsheri 2017). This lack of dopamine and fine motor control skills make it very difficult to move and lead to other symptoms such as orthostatic hypotension (OH), rapid eye movement, constipation, anosmia, freezing of gait, anxiety, depression, balance and falling, sleep deprivation, hallucinations, speech degeneration, and swallowing degradation (Foongsathaporn et al. 2016). All these symptoms can predate the actual diagnosis by years or even decades. Once a patient is diagnosed, it is not uncommon for the disease to last for

three to four decades before death, often via pneumonia or other respiratory issues because of the inability to swallow or chew foods (Alsheri 2017).

Due to these symptoms, many of those affected with Parkinson's disease are unable to continue to function normally. Activities of daily living (ADL) become increasingly more difficult. Some of these basic household tasks and activities can be found in Table 1 on the following page (Olin, Aarsland, and Meng 2010). One of the most high-risk symptoms when performing ADL with Parkinson's is the falling that can occur from freezing of gait or loss of balance (Pimenta et al. 2019). Based on a study done by Foongsathaporn et al. (2016) on activities that increase the risk of falling in Parkinson's patients, it was determined that the majority of falls that occur happen performing ADL in the patient's home. It was discovered that most falls around the house were due to the freezing of gait, tripping, turning around, or bending over. It was also found that the three month fall rate of Parkinson's patients involved in the study were nine times greater compared to the control group (Foongsathaporn et al. 2016). In another study done by Wu, Hallet, and Chan (2015), freezing of gait was found to be more likely to occur when multitasking such as when using a cell phone while walking. Freezing periods lasted from a few seconds up to 30 seconds, depending on the patient (Wu, Hallet, and Chan 2015).

Table 1.--Common ADL That Become Increasingly Difficult
with the Progression of Parkinson’s Disease

Activities of Daily Living that Become Difficult with the Progression of Parkinson’s Disease		
Eating	Drinking	Bathing
Walking	Reading	Writing
Computer Skills	Dressing	Shopping
Taking Out Garbage	Pastime Hobbies	Games

Source: Olin, Aarsland, and Meng 2010

Two general scales are used to measure the severity of Parkinson’s disease. The Hoehn and Yahr scale (H-Y) and the Unified Parkinson’s Disease Rating Scale (UPDRS), both widely accepted (Asgari and Shafran 2010). The H-Y scale has five stages with 1 being normal and 5 being severe. The UPDRS is only a 4-stage scale with 1 being normal and 4 being severe. However, in addition, UPDRS – I is used for initial diagnosis and screening, UPDRS – II is used for the subjective patient diagnosis, and UPDRS – III is used for physician assessment (Shi et al. 2016). Foongsathaporn et al. (2016) used the H-Y scale in the study regarding how often Parkinson’s patients fall compared to their equivalent control group. It was found that H-Y stage 2 patients were twice as likely to fall as stage 1 patients, stage 3 patients were four times as likely to fall as stage 2 patients, and stage 4 patients were twice as likely to fall as stage 3 patients (Foongsathaporn et al. 2016).

In addition to falls, communication starts to become a big issue with the inability to properly speak loudly and clearly (Miller et al. 2011). A study done by Brabenec et al. (2017) stated that up to 90% of Parkinson's patients will eventually develop hypokinetic dysarthria (HD). HD affects all levels of speech, and symptoms can include reduced voice intensity, increased voice nasality, increased acoustic noise, harsh voice quality, rapid acceleration or deceleration of speech, and involuntary pauses (Brabenec et al. 2017). In addition, the study done by Miller et al. (2011) on Parkinson's patients performing speech-language therapy (SLT) in the United Kingdom, discovered that 87% of participants found SLT helpful in some way. The study also found that as many as 90% of the patients were dissatisfied with their current ability to communicate, and at least 50% were experiencing difficulties when communicating with strangers due to deterioration of the loudness of their voice (Miller et al. 2011). Miller et al. (2011) also found that ongoing advice and support as changes occur was the most valuable benefit to the patients participating in the SLT study, not the actual speech therapy treatments they received, which was second. This indicates that many of these patients just need support and encouragement to combat the depression and anxiety more than anything (Alsheri 2017).

Parkinson's disease has also consistently shown to be far more prevalent in men than in women. The National Parkinson's Foundation (n.d.) research has shown that men are 1.5 times more likely to develop it than women. Aside from being more prevalent in men, Parkinson's is typically seen much more frequently in elderly patients, with only 4% of cases being diagnosed under the age of 50 (Parkinson's Foundation, n.d.). Cases tend to sharply

increase after the age of 60 (Rodríguez-Violante, Velásquez-Pérez, and Cervantes-Arriaga 2019).

The National Parkinson's Foundation (n.d.) estimates that over 10 million people are suffering from Parkinson's disease worldwide. Out of these 10 million people, about 10% reside in the United States with nearly one million people currently diagnosed. The number of cases continue to grow as more than 60,000 people are diagnosed each year in America alone (Parkinson's Foundation, n.d.). This rate of growth has no indication of slowing down either. A study done in Mexico from 2014 to 2017 compared the incidence rates of Parkinson's patients from year to year, and it was found that each year the number of cases increased. In 2014 there were 5,057 new diagnoses, 7,273 in 2015, 8,009 in 2016, and finally 8,118 in 2017 (Rodríguez-Violante, Velásquez-Pérez, and Cervantes-Arriaga 2019).

In this same study, Rodríguez-Violante, Velásquez-Pérez, and Cervantes-Arriaga (2019) also stated that incident rates were found to be increasing in other countries as well. They found that China had the largest number of incidents of any country with 362/100,000 person-years from 1983 to 2009. Canada had the second highest number with 252/100,000 person-years, and India was the lowest at 5.7/100,000 person-years. Rodríguez-Violante, Velásquez-Pérez, and Cervantes-Arriaga (2019) also stated that their projections show the number of Parkinson's cases globally will double from 2005 to 2030.

Current Methods to Combat Parkinson's Disease

One of the most popular methods of helping enhance a Parkinson's patient's quality of life is exercise. It has been shown over and over again the Parkinson's disease symptoms

are greatly subsided by being able to get out and move (Müller and Muhlack 2008). The Theracycle is a perfect example of this. The Theracycle is a motorized stationary exercise bike designed specifically for Parkinson's patients and other neurodegenerative diseases such as Multiple Sclerosis, paraplegia, strokes, or brain injuries (PR Newswire 2019). This bike contains an electrical motor powered by a standard household outlet that provides a self-assisted pedal and arm motion for the riders. These motor-assisted movements allow for a full body workout for Parkinson's patients that otherwise might not be possible. Many studies have been done on the Theracycle, but one in particular by the Cleveland Clinic showed the Theracycle improved Parkinson's symptoms of rigidity, balance, and tremors drastically. In this study, the Cleveland Clinic also found that forced exercise increase patients' motor scores by 35% when measured on the USDRS – I scale. There was no increase in motor skills when Parkinson's patients used a standard stationary bicycle (PR Newswire 2019).

Another exercise-based program targeted specifically at Parkinson's disease is Rock Steady Boxing. This is an organization started in Indianapolis, Indiana, in 2006 with the goal of slowing the symptoms and progression of Parkinson's disease. The founder of the organization, Scott Newman, was also diagnosed with Parkinson's himself. This method of exercise gives people the ability to create large movements, work on balance, take out anger, and maybe more than anything create a community of similar individuals with a common purpose (Wilson 2018). In Kokomo, Indiana, the YMCA started hosting Rock Steady Boxing classes as well. The Director of Operations at the YMCA, Trish Severns, visited a class at the

Indianapolis Title Boxing facility and said, "I had no idea the impact these classes were making on people's lives...It's not just the class itself, but the sense of community it creates" (Sigler 2015). The Executive Director of the Rock Steady Boxing Team, Joyce Johnson, explains how the organization has begun to flourish from its original single location in 2006. "We started slowly, but as of July 2017, we have 405 affiliates in 47 states and seven countries" (Wilson 2018, 50).

A seven-year long-term study conducted at the University of Indiana by Stephanie Combs-Miller, PT, Ph.D., NCS, associate professor and Director of Research, found that Rock Steady Boxing did indeed help people's ability to move. Eighty-eight participants with Parkinson's were selected from around the state of Indiana – half were to attend Rock Steady Boxing classes, and half were to exercise elsewhere. This study showed that boxers were able to walk faster and had a greater level of overall functionality than those who did not attend the classes. Combs-Miller's study also confirmed that participants at Rock Steady classes had a "higher perception of their quality of life. And, they maintained it longer than patients participating in other forms of exercise elsewhere" (Wilson 2018).

Another common problem with Parkinson's disease is the inability to accurately measure symptoms. Many symptoms fluctuate in severity based on the time of day and the ingestion of medication. Due to this, it is often difficult for a physician to properly diagnose a Parkinson's patient based solely off the time they interact with them during an appointment. For this reason, many symptom severity diagnoses are based off self-reports, journals, or diaries (Chen et al. 2011). A system developed by Chen et al. (2011) called MercuryLive

uses a platform of wearable sensors to measure patients' symptoms continually and provide live updates to a clinical monitoring team. Accelerometers were placed in wearable sensors, and a live stream data push with video communication was set up to link the patient and the clinical monitoring team. Algorithms were created to estimate the symptom severity of three evaluation criteria based on the UPDRS rating scale. Tremors, bradykinesia and dyskinesia were the parameters measured. It was observed that this platform could be very beneficial to optimizing medication dosage times. Certain symptoms would occur more frequently on specific days and could be lessened by optimizing the time the medication was taken (Chen et al. 2011). This system was still undergoing extensive training and testing at the time of this article but has proved to be potentially very valuable.

Wearable sensors have been continually investigated to obtain live data from Parkinson's patients. Another study done by Casamassima et al. (2014) was done to measure the gait performance of multiple Parkinson's patients over time. This study showed through wearable sensors that Parkinson's patients demonstrated the ability of motor learning and improvement of motor function due to training. Motor learning is the practice, repetition, and experience of a certain task or skill, leading to a more permanent change in capability and, in this case, movement (Casamassima et al. 2014). Casamassima et al. (2014) used an interesting real-time feedback system for the coding of the study. Using signals from the patient's own body, artificial sensory information was added that involved cognitive components. This allowed specific body signals to be coded to sensory signals then fed back to real time (Casamassima et al. 2014).

Touch Sensor Gestures with Parkinson's Disease

Effectively understanding how to develop a friendlier user interface for Parkinson's patients based on their gesture limitations is one of the most important factors of this study. Given that most people in society use a smartphone, the potential that a Parkinson's patient will encounter difficulty using one at some point is very likely (Nunes et al. 2016). The current boom in technology is flooding all aspects of society; if Parkinson's patients are unable to keep up, they will certainly face difficulty as the world transitions to an internet-based communication hub powered by smartphones. Filling out questionnaires as well as scheduling appointments for doctor visits, physical therapy, and speech therapy are all heading to online interfaces, which cause challenges that are more significant for Parkinson's patients (Nackaerts et al. 2020).

The Population Division of the United Nations reported that the average age of people over the age of 60 has been increasing. In 1990, the number of people over the age of 60 was 9.2% of the world population, it was found to be 11.7% in 2013, and it is estimated to be 21.1% by 2050 (Gao and Sun 2015). Due to the fact that Parkinson's is far more prevalent in adults over 60 (Rodríguez-Violante, Velásquez-Pérez, and Cervantes-Arriaga 2019) and only 4% of those diagnosed with Parkinson's are under the age of 50 (Parkinson's Foundation, n.d.), the growing elderly population is an important statistic. Gao and Sun developed a study in 2015 that investigated how touch gestures differ between young and old adults. This study focused on a variety of touch gestures including clicking, zooming, dragging, and rotating. These gestures were measured on a variety of parameters to

investigate the differences the users experienced. It was found that on average, younger adults had a much easier time with these gestures compared to older adults. Older participants were more sensitive to errors when constraints such as button size, physical arrangement of the touch screen, angle of operation, and multi-finger touch were considered (Gao and Sun 2015). The optimal angle of inclination of the screen was found to be between 20 to 60 degrees depending on the participant (Gao and Sun 2015). Parkinson's patients will struggle more than a typical elderly person with a touch screen due to the natural decline of motor skills that come with aging in addition to the degeneration from the disease (Klein et al. 2017). This inability to use a touch screen will inevitably lead to a lack of communication and community for Parkinson's patients and could lead to isolation and depression (Alsheri 2017).

One study targeted specifically at Parkinson's patients was conducted by Nunes et al. (2016) and focused on how gestures were performed on smartphones. This focused solely on Parkinson's patients with the goal of understanding what gestures are best suited for their disabilities. This study tested Parkinson's patients on their ability to use only a smart phone on the follow gestures: dragging, tapping, swiping, and multi-tapping (Nunes et al. 2016). Similar studies on upper limb impairment and other disabilities have been conducted, but few were in regard specifically to Parkinson's disease. Many of these studies confirmed that older, disabled, and anyone with an upper limb disorders were significantly slower and less accurate than their younger and healthier counterparts (Nunes et al. 2016). A summary of the

twelve conclusive design principles from Nunes et al. study findings can be seen in Table 2 below.

Table 2.--Summary of Design Guidelines Regarding Gestures Related to Smartphones for Those Affected with Parkinson's Disease

1	Use tap targets with 14 mm of side
2	Use swipe gesture without activation speed
3	Controls with multiple taps are preferred
4	Drag gesture is not desirable
5	Multiple taps over drag is preferred
6	Adapt needs to the user
7	High contrast on element color
8	Display only useful information
9	Provide clear location of current location
10	Avoid time dependent controls
11	Prefer multi-modality over a single interaction
12	Consider smartphone design for older adults

Source: Nunes et al. 2016

Nackaerts et al. (2020) also conducted a similar study on Parkinson's patients' ability to cognitively think while using a smart phone. Swipe-Slide Pattern (SSP) was developed to more accurately model how a smartphone would be used and tested on Parkinson's patients. This SSP was designed to test their cognitive power while simulating a real-world scenario to see if participants could improve their skills over time. However, this series of commands was always visible to the subject, so their cognitive capacity may still have been inaccurately measured compared to a real-life scenario (Nackaerts et al. 2020). The study found that Parkinson's patients struggled with the ability to adapt to learning new tasks and muscle memory whereas other patients did not. It was found that even healthy elderly adults were able to improve or maintain their SSP performance after 24 hours, while Parkinson's patients were unable to. The severity of the disease and the length of time the subject had been diagnosed also correlated with their inability to improve (Nackaerts et al. 2020).

Memedi et al. (2013) also performed a study to research how Parkinson's patient's upper limb motor restrictions affected their ability to use a touchscreen. The data was collected using a handheld touchscreen that participants took home with them. The researchers asked participants to tap two 15 mm boxes on the screen for 20 seconds using a stylus. The boxes would alert the user to tap them at random times, the participants were to click as quickly and accurately as possible for the 20 seconds. This test was done four times daily at each participant's home for a week. The pixel coordinates and the timestamp of the taps were sent wirelessly to be analyzed by the research team immediately following the completion of a test. Memedi et al. (2013) found that scores were not correlated to the

UPDRS scale severity rating for upper limb restrictions. However, these results did show that it was very easy to distinguish between healthy elderly adults and Parkinson's patients at various stages of disease affectedness from only looking at the data (Memedi et al. 2013).

Wearable Sensors

The skin is the largest sensory organ in the body and has the ability to sense many different stimuli such as vibration, pressure, touch, and thermal presence (Kweon et al. 2019). This organ can be simulated in wearable sensor technology, which is growing at an exponential rate and is one of the largest potential contributors to improving healthcare. Because of their ability to constantly and wirelessly collect data, these sensors provide many opportunities within healthcare to improve patients' lives and study diseases, illnesses, and other medical conditions (Kristoffersson and Lindén 2020). Typically, these sensors are designed to be 3D and multitouch, meaning they can sense multiple forces at various locations on the screen (Kim et al. 2019).

A recent study in March 2020 found that out of 435 articles published on wearable sensor technology between 2010 and 2019, 47% were related to health and 39% were related to physical activity (Kristoffersson and Lindén 2020). The number of articles on wearable sensor technology has also been steadily increasing since 2010, indicating that more and more research is being done in this field. The United States was the country that produced the most published papers on the topic, followed by China and then the United Kingdom (Kristoffersson and Lindén 2020).

Traditionally, wearable sensors have been developed over the years using an indium tin oxide (ITO) as the electrode to detect a touch (“Graphene Electronics Market” 2017). However, different electronics and optoelectronic devices are being investigated for a better design that offers more conductivity, cheaper construction, and better mechanical and optical properties (Song et al. 2017). Due to variability and delicacy of these flexible wearable sensors, finding the right technology can be difficult. Song et al. (2017) investigated multiple different methods to understand their potential advantages and disadvantages. These technologies include carbon nanotubes, graphene, silver nanowire networks, and oxide/metal oxide multilayer systems. Even after investigating all these potential ITO substitutes, it was found that there was no better replacement, at least that performed as consistently as ITO. Even though ITO was not the top performer in surface uniformity, transparency, cost, and conductivity, overall its combined characteristics still made it the strongest candidate (Song et al. 2017).

Song et al. (2017) did propose a combination of the technologies to develop a new electrode. This was a transparent, flexible, multilayer electrode consisting of three layers: epoxy, copper, and ITO. When the ultrathin copper layer is adhered to the ITO, conductivity greatly improves. By then adhering these two layers to a photocurable epoxy layer, the optical transparency is enhanced by the destructive interference. The epoxy also increases the deformation of the sensor by increasing the ability to bend, twist, or stretch. This helps to reduce the potential for surface cracks when under pressure (Song et al. 2017). This multilayer electrode is applied to a transparent, flexible, interconnected web of wearable

touch and pressure sensors. Song et al. (2017) believe this new electrode will create many new opportunities in the field of wearable sensors and transparent electronics.

Wearable sensors have been developed to distinguish not only a single touch or tap for a capacitive touch but also thermal presence from temperature, pressure, and even humidity. Kweon et al. (2019) found that multiple existing studies had been developed on thermal touch presence to simulate the human skin. These findings included multisensory stimuli, such as both temperature and touch, can be detected at the same time through a complex ferroelectric carbon nanotube fabric. Kweon et al. (2019) used a multimodal sensor array through a single conductive layer into a surface capacitive array to create a hydrogel. This hydrogel was thought to be a perfect bridge between an electronic device attached to the human skin for sensory reception. Hydrogel is extremely transparent at almost 99% (Kweon et al. 2019), which would be ideal for optical properties. Furthermore, hydrogels offer an immense ability to stretch up to 150% and up to 600% strain, which allows for great deformation properties and the unique ability to conform to virtually any desired shape. This hydrogel was composed of poly vinyl alcohol (PVA), sodium tetraborate decahydrate hydrogel, borax, and poly sodium acrylate (SA). Kweon et al. (2019) believed this technology could greatly benefit wearable electronics, artificial electronic skin fabrication, window applications, and flexible circuits.

Graphene is another material that has been heavily researched as a potential replacement for ITO within wearable flexible sensors. Graphene offers mechanical flexibility and optical transmittance (Cataldi et al. 2017). A graphene touch sensor is typically

composed of two conductive sheets in parallel with one another. A small gap is allotted between the two sheets that senses a change in capacitance from a touch (Kang et al. 2017). The difficulty is when bending the electrodes, the conductive sheets often come in contact with each other and cause a short circuit. The bending can also cause difficulty in recognizing 3D multitouch applications. Kang et al. (2017) successfully tested and developed a wearable 3D multitouch graphene-based sensor that is transparent and flexible enough to wrap around complex human geometry such as the human hand. This graphene-based sensor is still in the development phase, but it is continually showing it could be the answer for the geometry constraints and inflexible struggles with current ITO 3D multitouch sensors. While this is still nowhere near the reliability of a flat ITO electrode sensor, these graphene-based nanotubes are showing potential (Kang et al. 2017).

Nanotubes, nanofibers, and nanoparticles are used to create electrodes for wearable textile fabrics. This raises another question on the durability, stretchability, and washability of these sensors if they can even be produced. Cao et al. (2018) developed a washable electronic textile (WET) that is constructed of three layers. The top layer consisted of a frictional fabric, such as silk. Secondly, the middle layer consisted of the electrode, which in this case was a carbon nanotube. Finally, the bottom layer was nylon fabric, which the carbon nanotube layer was printed on and adhered to. This design proved to have great washability with the addition of polyurethane to the carbon nanotube ink. Due to this durability and resistance to water contact, Cao et al. (2018) believe WET could be a great option for mass production for smart home controls. Tasks such as turning on the lights, microwave, fans, or

other similar household tasks could be done from anywhere in the house with a few simple motions.

Research Methods and Considerations

There are multiple methods available to researchers in science, technology and engineering to collect data and information for studies. Understanding social and behavioral aspects of Parkinson's patients' daily lives was one goal of this study. Due to this, it was important to focus on human-centered research methods, such as the Design Thinking Model and Transcendental method investigated below.

Before research can begin, an outline or plan must be implemented for the research process. Kate Shively, Krista M. Stith, and Lisa DaVia Rubenstein (2018) created a well-proven model called the Design Thinking Model (DTM). This design process is a grading, thinking, and evaluation technique that focuses on creativity, cognitive skills, and critical thinking rather than the end product (Shively, Stith, and Rubenstein 2018). Shively, Stith, and Rubenstein (2018) write that, in classroom settings in particular, many students are graded and assessed on topics or evaluation criteria that are not truly the primary purpose of the project (grammar, neatness, assessment scores), and many students are misled by this. Shively, Stith, and Rubenstein (2018) use the example of designing and building a small racecar that must roll a certain distance in a certain amount of time. Students create the racecar, and most will achieve the grading criteria and thus get a good grade. But what about the student who tested multiple different ideas for their car, brainstormed abstract methods, and thought deeply about their project – but did not meet the grading criteria? This student

would fail but probably have gotten more out of the project than the other students because of his or her ability to think critically, brainstorm, and problem solve in new or abstract ways (Shively, Stith, and Rubenstein 2018).

These same classroom evaluation principles can be extended to outlines and design modes for science, technology, engineering, and mathematics (STEM) projects to focus on creativity and critical thinking skills during the design phase. As seen in Figure 2 below, the DTM focuses on five key principles: empathize, define, ideate, prototype, and test. Using these five basic principles, Shively, Stith and Rubenstein (2018) believe a better design solution can be developed that will be more holistic in nature and address the true problem the subjects are facing.

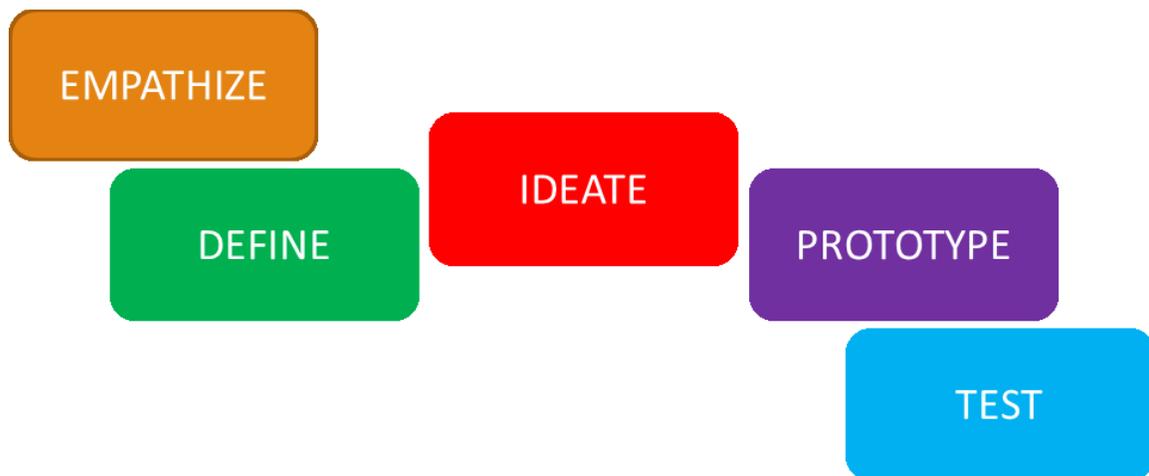


Figure 2.--The Five Steps to the Design Thinking Model (DTM)
Source: Shively, Stith, and DaVia Rubenstein 2018

Shively, Stith, and Rubenstein (2018) believe empathy is an important first step because it allows the researcher or designer to really understand the problem on a deeper

level and feel for those who are in need. This drives the solution development by directly interacting with those affected by the design decisions. Understanding what the other person experiences is key, and this can be done through immersion, observation, or engagement (Shively, Stith, and Rubenstein 2018).

The next step is to define the problem based off the research found in the empathizing stage. Defining the problem is what will drive the solutions and filter down the brainstorming results, so this area is important to spend time and focus on (Shively, Stith, and Rubenstein 2018). Ideate is the third stage and focuses on formulating as many ideas as possible based on the defined problem from stage two. Shively, Stith, and Rubenstein (2018) encourage brainstorming on distinct, diverse, creative, and many ideas.

The fourth stage is the prototype stage. This is where ideas are taken from the ideate stage and sketched, drafted, printed, built, and evaluated on their effectiveness to solve the problem. The fifth stage is testing the prototype. These final two stages go hand in hand and may require some iterations to finally pick the idea that is more feasible to solve the problem. These prototypes are then encouraged to be shared, observed, and tested by those who will be the final users. The end goal is to have one prototype that successfully passes the testing requirements and can be shared and evaluated by the researcher's target audience (Shively, Stith, and Rubenstein 2018).

Another social and behavioral research method is that known as the Transcendental Method, coined by Bernard Lonergan. Lonergan has four key principles to this research method: experiencing, understanding, judging, and deciding (Perry 2013). Lonergan believed

that these four principles can be generalized across the entirety of the human race because all people experience their own life and situations in a unique way tied to one's own culture, history, and perception. Perry breaks these four principles into easy to understand steps for the researcher: "Experiencing, be attentive. Understanding, be intelligent. Judging, be reasonable. Deciding, be responsible (Perry 2013)."

The goal of the Transcendental method is to get a deeper understanding by pushing the participants into somewhat of a self-reflective state by the approach of the researcher during an interview. Perry (2013) uses Figure 3 on the following page to describe the context of the entire situation and help the researcher understand what questions can and cannot be answered by using Lonergan's four key principles of experiencing, understanding, judging, and deciding. The three circles overlap into somewhat of a Venn Diagram and show how they are each related via the one circle in the middle. The middle circle represents questions that a person finds meaningful and may or may not be able to answer. The outer circles represent questions that people cannot answer yet, do not fully understand, or do not find meaningful (Perry 2013). The outer circles also help assess the context of everything going into the study. This includes the context of each question or inquiry and how that is instantly being processed (middle circle), the context of the participant, the context of the researcher, and the overall context of the situation. Perry (2013) notes that area of intersection between the inner and outer circles is known as the "horizon" and is the boundary between the participants current knowledge and interest in the study.

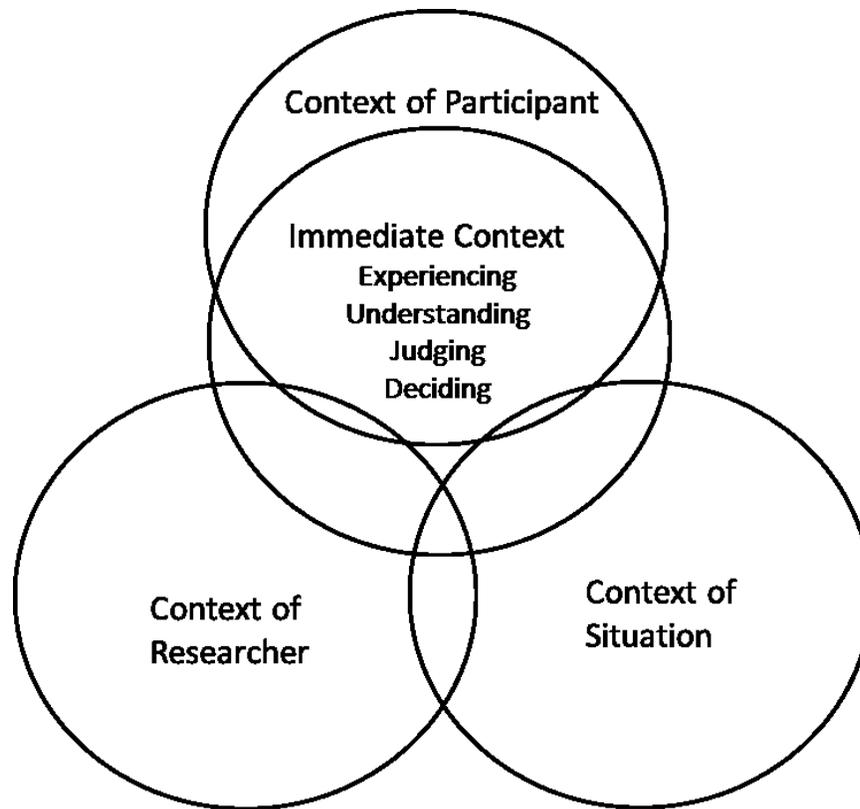


Figure 3.--Different Context Areas Assessed During an Interview Using Lonergan's Method
Source: Perry 2013

Perry (2013) also found during a follow-up interview with participants that by using Lonergan's Transcendental Research Method, participants were more conscious of their own thoughts, more curious, and more aware of the subject. She determined that this method helped participants process out loud, confirm their own thoughts by using targeted research questions, and improve their personal belief (Perry 2013).

In a study conducted in 2009 by Ahmed et al., using the cognitive interviewing methodology on palliative care screening measures in patients with advanced illnesses, it was found that participants were often impacted by the wording of the interview questions. This

study tested participants' ability to comprehend interview questions and process them. Most participants preferred questions that were not explicit to "yes" or "no" answers because they often wanted to elaborate their answers (Ahmed et al. 2009). This study also found that participants preferred questions that were worded more clearly and concisely. Participants did not like questions that were overly long and full of complex medical terms Ahmed et al. (2009) states some specific topics were more sensitive to the participants and potentially put them more at risk for emotional or psychological stress. These included religious views, finances, sexual intimacy, death, and questions pertaining to the progression or mental physicality of the illness (Ahmed et al. 2009).

Once interviews are completed, they are typically transcribed, decoded, and analyzed for commonalities using a qualitative research method (Connelly and Peltzer 2016). In order to ensure accuracy, Perry (2013) recommends that each interview be transcribed to read verbatim as it was recorded, and then verify the text by rereading the transcription and listening to the recording at the same time. After this, one should look for declarations in the text and make note of them, although it is important during this time to not decontextualize the data. The next step is to compare specific declarations found between multiple interviews and investigate how these are linked and or related across various participants. During this qualitative analysis, underdeveloped themes can arise for two major reasons: lack of in-depth interviewing and lack of interpretation and comprehensive analysis. It is also important to put time into the theming process to make sure the data is being interpreted and not just analyzed (Connelly and Peltzer 2016).

Sorting the topics into themes and categorizing them based on similarities is another method commonly used. Variables are tied to one another or linked to investigate relationships that are common and varying between them (Swygart-Hobaugh 2019). Common themes can be decoded further for additional categorization and subcategorizations and abstract correlations that may be relevant. Perry (2013) states that in her approach, she looks at the data first; only after processing themes does she begin to take a more abstract approach. Looking at each theme individually, in relation to each other, and in context of the research question and participant is vital to grasp a proper unpacking and decoding (Connelly and Peltzer 2016). Furthermore, mixed research methods can also be used to unpack the data and help answer the research question by using quantitative approaches for measurable items and qualitative methods for investigating in-depth context and meanings. This would be useful for studies that require explanations for variables measured using qualitative methods (Dowding 2013). Only then can the researcher fully understand the context of the broader situation.

CHAPTER 3

METHODOLOGY

This study focused on two main objectives: 1) understanding the struggles that Parkinson's patients have with everyday life, specifically related to technology and communication, and 2) bringing equity and access to these people. Parkinson's disease and other neurological disorders are extremely difficult to treat effectively and frequently require very specialized medical treatment. This treatment is often only found in very large metropolitan hospitals. It is not uncommon for these specialized facilities to be six hours or more apart from one another, just within the continental United States. With so many people in the world being affected by this disease or a similar neurological disease, these people need more access to the latest technological advancements, especially those in rural areas. A solid foundational understanding of the issues must be the starting point. To discover some of these issues Parkinson's patients struggle with, a series of interviews was conducted with nine participants to investigate and understand their lifestyle.

Before these interviews were conducted, a proper understanding of communication and Parkinson's disease as a whole had to be thoroughly comprehended. To address this, a concept map connecting the two was developed and can be seen in Figure 4 on page 31. This concept map was designed with the following question in mind: "How can we create a better communication platform for Parkinson's patients?" Using this question as a guide, different communication devices, methods, and motives were established and linked with specific struggles that Parkinson's patients have. By interconnecting the two beforehand, it gave an

even stronger visual representation of what was known and what is commonly overlooked. For instance, it was known that Parkinson's patients have trouble with mobility and movement, so they have difficulty using smartphones and computers. However, by developing this concept map, many new correlations were found, and a more holistic understanding of their challenges was discovered.

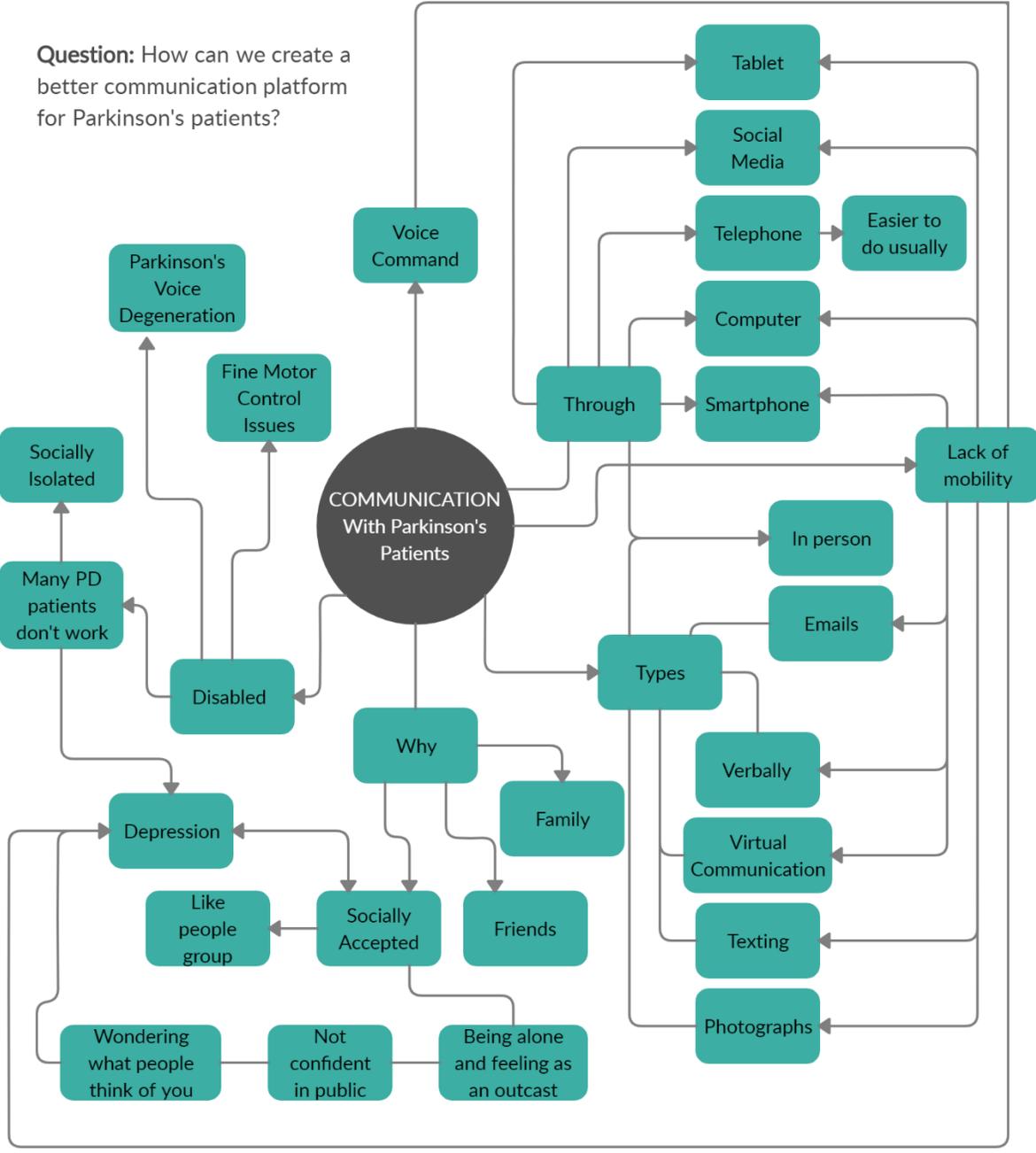


Figure 4.--Concept Map Relating Communication Methods to Parkinson's Disease Symptoms

Participants

Participants were recruited through snowball sampling and voluntary response sampling methods. This was accomplished by inquiring at Parkinson's community groups around the rural Kansas City area. A few members of the groups were informed about the study that and asked to spread the word to fellow members and find out if anyone would be interested in participating. If someone was interested in participating in the study, they were provided with the research team's contact information. This helped to alleviate any pressure that potential subjects might feel from the research team and instead allowed them to take time and decide whether they wanted to participate in the study on their own.

Participants were selected based on their age, diagnosis severity, gender, and demographic location. In order to more thoroughly understand how participants' activities and touch screen usage varied based on age, a large range of ages was necessary. With the average age of a Parkinson's disease diagnosis being 60 (The Michael J. Fox Foundation, n.d.), participants were selected in the age range of 30 to 80 years old. The primary target range was 50 to 70 years old since that is where the highest density of Parkinson's patients lies but extrapolating on each end of this range was important to understand all who are affected by Parkinson's disease. A reliable and accurate representation of the population studied is important for consistent results (Bender 2015). Gender of participants was split relatively even down the middle, with five men chosen and four women chosen. Even though men are on average 1.5 times more likely to get Parkinson's disease in the United States than women (Parkinson's Foundation, n.d.), an even spread was important for this particular study

because age and severity of disease were deemed as most relevant study parameters rather than gender differences.

For this study, nine participants were selected. Only a small number of participants was necessary to begin to explore and understand the needs and gaps Parkinson's patients face with technology. The participants were selected based on three major criteria – the participant is between the ages of 30 to 80 years old, the participant has been diagnosed with Parkinson's for at least 3 months, and the participant lives at least 30 minutes from a Parkinson's treatment facility. Finding a varying spread of disease severity was preferred, but no one was turned away based on these criteria. The participants selected for interviews had a mean average age of 65.9 years old and had an average diagnosis of 11.1 years, with 2 years being the shortest and 25 years being the longest. Based on the results and themes observed from these interviews, a more targeted survey and secondary interviews will be conducted in the future focusing on a mixed methods approach that builds on the exploratory qualitative approach used for these interviews. This is discussed in more detail in future considerations and the proposed mixed methods approach is shown in Figure 12.

Research Design and Interviews

Semi-structured interviews were chosen as the primary method for obtaining information from the participants. This was deemed as the best way to gather information from Parkinson's patients because they could be done in person or over the phone and allow verbal communication. Verbal communication is typically the easiest way for most Parkinson's patients to communicate because it is simplistic and uses the least amount of fine

motor control skills, except for advanced Parkinson's where even speaking becomes difficult. But even in advanced or severe cases, speaking is usually easier than typing, texting, or using a computer. This method also allowed the participants to speak freely and provide as little or as much detail as they desired.

Interviews were conducted via phone conversation only because of the COVID-19 pandemic. This outbreak made it impossible to interact personally with any Parkinson's patients because of their high-risk condition. Instead of interacting with patients in person, all interviews were conducted by phone and recorded and then transcribed within the next week.

Participants were asked a series of open-ended questions that pertained to activities in their daily lives and how they interacted and struggled with Parkinson's. Many of these questions eluded to how often or if a participant used a touch screen device and how they experienced that interaction. In general, participants were extremely interactive and positive, wanting to provide as much feedback and information as possible to help combat this disease.

Interview questions were formulated using the Transcendental Method for Research with Human Subjects (Perry 2013). This approach used a holistic cognitive process to focus on experiences, understanding, judging, and deciding. This method focused on centering the contents of human consciousness and allowing the participant to expand on their experiences based on their own personal background, history, and culture. The goal was to phrase questions to help subjects reach a somewhat self-reflective state where they could deeply and cognitively think about the question. This was accomplished through the wording of the

questions and by focusing on these three key points. 1) Keep the questions simple to understand and avoid complex terminology and medical terms. 2) Help the participants to feel an emotional connection to the question. Make the questions more personal by using phrases such as “how does that make you feel?” 3) Give the participants a complete overview of the project and let them know their input is valued and important and will be used to help fight this disease.

Many Parkinson’s patients struggle with depression and a lack of feeling desired or accepted because of their slow decline (Castellana et al. 2019). The severity of this depression is typically measured on the Hamilton Rating Scale (Dipasquale et al. 2017), and in one study by Broen et al. (2015) a score on the Hamilton Rating Scale of greater than or equal to twelve was considered to be suffering from relevant depressive symptoms. This same study also claimed that 35% of Parkinson’s patients show signs of depression (Broen et al. 2015). By reminding the participants that they are valuable people and their input and information will be used to fight Parkinson’s made all the difference. Many participants reached out completely on their own a second or even a third time to provide additional information because they were excited to be part of the fight.

Testing Procedures

In the original plan for this study, in-person testing was to be done in conjunction with in-person interviews. However, because of the impact of the global pandemic caused by the COVID-19 virus, in-person testing was unable to be completed. The University of Missouri-Kansas City was completely shut down and migrated to online classes prior to the

mid-semester spring break. Due to the restrictions and necessary precautions to slow the spread of COVID-19, a mandatory quarantine was put in place for Kansas City and the surrounding counties. This put a halt to any in-person research on gestures and touch sensor applications that was to be conducted during this time. Nevertheless, the testing procedures that would have been carried out had the COVID-19 pandemic not occurred are still outlined here and will be conducted in the future as this research continues into a doctorate.

In-person testing was designed to help understand how Parkinson's patients struggle with hand gestures while using a touch screen device. This was done by obtaining information on what gestures Parkinson's patients preferred and how different parameters such as button size or location affected this. In addition, these gestures would be tested using styluses of various diameter to see if gesture performance could be improved.

Participants would have been asked to use a tablet and a standard iPhone to see how they performed doing simple and common gestures. The four main gestures to be measured included tapping, zooming (two finger pinching), dragging, and holding. These gestures would have been measured on both devices to see how screen size affected ability to complete a task. Each participant would have been asked to complete gestures by doing a small series of simple repetitive tasks and evaluated on the amount of time they took. The number of errors or attempts it took to complete the task would also be measured. An error would be considered any time a participant was unable to drag, hold, tap, or zoom to the specified position. In order to more accurately measure the time each task took to complete; a slightly longer duration would be used. This could be done by increasing the number of

repetitions for a gesture movement. For example, a pinching zoom motion would be done two to three times in series per task, instead of a single pinch motion.

The four measured gesture exercises would have been completed two different times with three different sized buttons. The buttons were to be circular and range in size from 3, 6, and 10 mm in diameter on the standard iPhone screen to 8, 14, and 20 mm on the standard tablet screen. These various button sizes will give a more thorough understanding of how speed and accuracy can be assessed and potentially improved upon in the finalized design. Each task series would have been completed with two different styluses. A finer thin diameter traditional stylus and a larger fatter diameter stylus would both be used to see which was more desired by the participants. Table 3 on the following page displays an example data collection chart for a 10 mm button size using the iPhone. This collection sheet would be modified for the 3 and 6 mm button sizes for the iPhone and for the three button sizes on the tablet.

Table 3.--Example Collection Chart for the Gesture Tests

iPhone, Button Size: 10 mm						
Subject: Interviewee 1	iPhone		iPhone (Thin Stylus)		iPhone (Thick Stylus)	
	Time	Errors	Time	Errors	Time	Errors
Tap (1st Trial)						
Tap (2nd Trial)						
Drag (1st Trial)						
Drag (2nd Trial)						
Zoom, Single Hand (1st Trial)			N/A	N/A	N/A	N/A
Zoom, Single Hand (2nd Trial)			N/A	N/A	N/A	N/A
Zoom, Two Hands (1st Trial)			N/A	N/A	N/A	N/A
Zoom, Two Hands (2nd Trial)			N/A	N/A	N/A	N/A
Hold (1st Trial)						
Hold (2nd Trial)						

The first gesture, tapping, was to be performed by typing a small phrase of approximately 15 to 20 characters using both sides of a standard keyboard layout. This would give a better idea of how the participants used both hands and if they were able to type normal, everyday responses. The phrase “you get back home” was the decided upon phrase to be used because this uses 8 keystrokes on the right hand, 6 on the left hand, and 3 spaces to be used by either hand. This arrangement felt to be the most ideal because it used both hands but slightly favored the right hand, which is the dominant hand in 90% of people (Price 2009). This would make a difference for Parkinson’s patients whose non-dominant hand is usually more handicapped.

Next, zooming was to be performed with a double-handed and single-handed zoom (if possible). Zooming would have been tested by taking two dots, pinching them together, and then bringing them apart. This would be done twice per test with the participant's dominant hand using their thumb and index finger. A secondary zooming test would be conducted, but the participants would be able to use both hands and any fingers they desired. Zooming would only be tested using hand gestures; it would be excluded from the stylus experiments as it is not possible with only one stylus. Each series, single and double-handed, would be done two times with the three different button sizes (3, 6, 10mm for iPhone and 8, 14, 20 mm for the tablet).

Dragging would have been completed by moving a series of four dots across the screen from left to right. This task could be completed with the participants' hand of preference. Errors will be recorded if they did not complete the drag in one motion and the dot would go back to the start, prompting the participant to try again. This will be done two times for three different dot sizes.

The last gesture, holding, would have been to press down on the screen for three seconds with constant pressure using the participants' thumbs. Again, this would be done two times for three different button sizes. This gesture was chosen specifically for Parkinson's patients because of their tremors and rigidity which constantly make this a task difficult due to sensitivity issues, inability to move fingers, and involuntary movements. For these reasons, the holding gesture may need to be excluded as a potential design parameter of a Parkinson's centered communication platform.

CHAPTER 4

RESULTS

The results section in the continuing pages is outlined as follows. First, the participant analysis provides an overview of the participants and statistical analysis of the age, diagnosis length, and symptom experiences. Next, the coding and theming process used to break down the interviews is described. Lastly, the results, themes, and findings of the study as gathered from the interviews and presented.

Participant Analysis

The nine participants had an average age of 65.9 years old with a standard deviation of 9.0 years. The oldest participant was 79 years old, and the youngest was 48 years old. The average age diagnosed with Parkinson's disease was 54.7 years with a standard deviation of 11.1 years. The eldest person diagnosed was 69 years old, and the youngest was diagnosed at 35 years old. The average number of years with Parkinson's disease was found to be 11.1 years with a standard deviation of 7.6 years. The longest diagnosis was 25 years, and the shortest was 2 years.

Out of the nine participants, four had undergone Deep Brain Stimulation Surgery (DBS). These participants had an average age of 61.5 when the surgery occurred with a standard deviation of 15.4 years. These patients on average had battled Parkinson's disease for 13.8 years with a standard deviation of 6.2 years before having the surgery. Since their surgery, they have on average battled Parkinson's for 4.25 years with a standard deviation of 2.8 years – indicating that all of the DBS surgeries had occurred recently.

When asked about tremors and rigidity, 56% of the participants said that they currently or previously experienced tremors, while 67% said they experienced rigidity. Only 33% of the participants said that they experience freezing on a regular basis, and 67% of those participants had also underwent DBS surgery. When comparing tremors, rigidity, and freezing among DBS and non-DBS patients, it was shown that rigidity was by far the most common symptom of DBS patients with 75% experiencing this regularly. In addition, 50% of DBS patients also said they experience freezing. When looking at symptoms of non-DBS patients, the most common symptoms were tremors and rigidity at 60%. Freezing was only found to be mentioned by 40% of non-DBS patients.

From a communication standpoint, 89% of participants said that their communication with family and friends had been affected in one way or another due to Parkinson's disease. The most favorable form of communication (excluding in person communication) was found to be verbal with 57% of participants choosing this as their top choice, while virtual communication came in second at 22%. All the participants had come in contact with a smartphone or touchscreen on at least one occasion, but only 22% did not use a smartphone on a daily basis. Whether they used a smartphone daily or occasionally, 100% of participants had experienced difficulty in some way. The problems expressed across the entire group included inability to quickly move off a key, hitting the wrong buttons, sensitivity issues, difficulty dragging, swiping, or zooming, and generally not understanding how the technology works. Additionally, every interviewee offered their appreciation in some manner

for the work being done at the end of the interview, and 100% of participants voluntarily offered future assistance if more questioning or testing was needed.

Participants' locations were primarily rural, with the exception of three participants who lived in the greater Kansas City metro. The other six participants all lived in rural or small towns around the Kansas City area, but not within the metropolitan district. A smartphone was regularly used by 100% of participants that lived in the Kansas City metro area, while only 40% of those that lived in rural areas. With regards to voice command software, 66% of those in the Kansas City metro area said they regularly use it in contrast to 40% in rural areas. Virtual communication was regularly used by 100% of participants living in the Kansas City metro area; again, rural areas showed reduced usage with only 20%. When asked about technology, 80% of those living in rural areas experienced difficulty using it due to lack of experience and understanding from age. Only 33% of those living in the city expressed difficulty understanding technology due to age or generational gap. This solidifies the point that those who have Parkinson's in rural areas need better equity and access than those in a metropolitan area.

Coding and Theming Process

Results were obtained by coding and theming the nine interviews to look for similarities, differences, and other correlations that may have appeared. Each interview was transcribed from its original audio recording, and any personal information such as name, medical information, or employer was removed. From here, a qualitative coding analysis of each interview was performed to look for similarities between how the participant answered

questions throughout the interview (Bir et al. 2019). This gave insight into the specific values, struggles, and treatments that existed for each participant. For instance, some interviewees frequently commented on exercise as a way to combat Parkinson's disease, while those participants who struggled with speech decline commented more on their voice and communication struggles.

Each interview was compared in a matrix based on the analysis from the individual interview coding, as well as common phrases or words that appeared multiple times throughout the interview (Bir et al. 2019). Using this data, the interviews were assigned categories determined by the researcher. For example, one participant may use the word "slowness" frequently throughout the interview; therefore, their interview would be placed in the "impaired movement" category. If this same participant also indicated they have difficulty typing with touchscreens, their interview would also be placed in the category "struggle with touchscreens". During this coding process, seventeen categories were determined to be relevant to this research study. After analyzing these seventeen categories, five major themes were found. Each category was assigned to one of the major themes, which were Symptoms, Daily Challenges, Values, Communication, and Technology. These themes and their respective categories can be seen in Tables 4 through 8 on the following pages.

Table 4.--Symptoms Theme and Its Respective Categories

Symptoms	Interview Count
Impaired movement	5
Declining speech	3
Shaking and tremors	4
Short-term memory loss	2

Table 5.--Daily Challenges Theme and Its Respective Categories

Daily Challenges	Interview Count
Getting dressed and starting the day	5
Fine motor skills	5
Technology interactions - due to age	4

Table 6.--Values Theme and Its Respective Categories

Values	Interview Count
Exercise frequently	4
Communication with family	4
Community and social interactions	2

Table 7.--Communication Theme and Its Respective Categories

Communication	Interview Count
Written communication is challenging	6
All communication is challenging	3
Communication with family and friends affected	4

Table 8.--Technology Theme and Its Respective Categories

Technology	Interview Count
Struggle with touchscreens	6
Find voice command software useful	4
Frequently use virtual communication	3
Believe technology can help fight Parkinson's	4

All interviews in an assigned category were compared against one another to identify additional commonalities and findings. Each of the category findings were then compared against the other category findings within that major theme to see how or if those categories related in any way. The streamlined coding process can be seen on the next page in Figure 5.

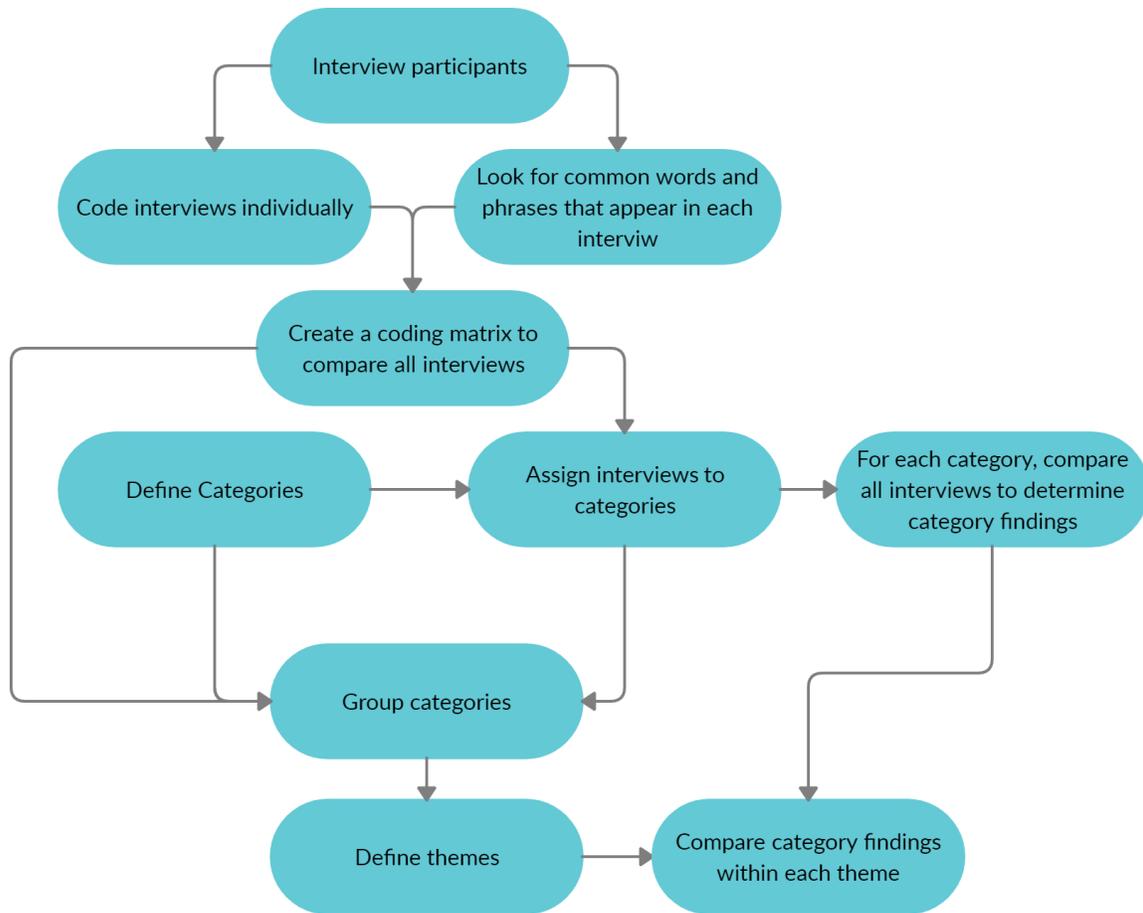


Figure 5.--Coding and Theming Process Flow

Symptoms

Impaired Movement

Three out of the five patients who fell in the impaired movement category expressed difficulty with their morning routine. In addition, getting dressed was noted as one of, if not the most, difficult task that these three participants faced daily. Four out of the five participants also stated their preferred method of combatting Parkinson’s disease was exercise and moving. One participant said, “The more I can move myself and exercise

myself, it seems to help.” These participants were consistent in using movement to describe their symptoms and as a way to combat the disease. This indicated that these participants were focused on movement for more than just one reason, and it was something they often thought about. Four of the five participants indicated that they experience slowness, and all or many of their activities took longer than they used to. These individuals also said their previous hobbies before Parkinson's disease were related to outdoors and an active lifestyle. From this, it can be concluded that if someone values outdoors and an active lifestyle before Parkinson's disease, they are more likely to care about their inability to move and use some form of exercise as treatment to fight the disease.

Declining Speech

Three interviews were chosen to be placed into the category relating to speech decline. These participants expressed difficulty with their speech to multiple questions during their interview. When asked if Parkinson's had affected their ability to communicate with people, one participant said, “Yes totally. My speech has changed, and my voice has gotten a lot quieter. And people can never understand what I say. They say, ‘say that again’ or ‘repeat yourself.’ It’s so frustrating.” All of these patients had also undergone DBS surgery and had a standard deviation in the number of years since their DBS surgery of 2.0. This indicates that DBS may have an effect on a patients’ speech.

Shaking and Tremors

Participants in this category were chosen based on their explanation of symptoms relating specifically to shaking and tremors. These participants used the words “shake” or

“tremor” multiple times within their interview. Three out of four participants selected in this category described difficulty with fine work, whereas it was only specifically mentioned two times by all other participants combined. Participants in this group also said that while typing on a keyboard or touchscreen, with or without a stylus, they often hit multiple keys on accident. Finally, all of these participants stated they believed virtual communication was helpful in some fashion.

Short-term Memory Loss

Short-term memory loss was experienced by two of the nine participants. One of these patients had undergone DBS, and the other had not. They complained that during their Parkinson's progression, they each began to experience a loss of words and an inability to remember short tasks that occurred sometimes only 15 minutes prior. These participants commented on their inability to move as well. One of these participants expressed a “lack of mobility,” and the other expressed slowness in their movements. Both participants expressed trouble getting dressed and that their morning routine is difficult to get started due to the lack of movement. No other correlations were found with memory, other than movement. This was surprising due to the fact that 83% of 20-year Parkinson's survivors are affected by dementia (Guzzeti et al. 2019). Two participants in this group had been diagnosed with Parkinson's for 20 years or longer, and only one mentioned memory loss. Long-term memory loss was not shown to be affected in any of the participants.

Symptoms Theme Overview

Four categories were determined under the symptoms theme, and when compared against one another, some interesting findings arise. Firstly, those who are most concerned about movement have a history of being “active” individuals. This indicates that because they were so active before being diagnosed, continuing to be active is important to them. Thus, those who care about movement seem to continue to exercise and find it helpful. Speech is most affected by those who have undergone DBS surgery and seems to be connected with rigidity. Those who struggle with tremors seem to care most about tasks associated with their fine motor skills, most likely because the shaking makes those tasks so hard. The symptoms findings also seem to suggest that DBS surgery helps with tremors and shaking, but at the expense of rigidity and speech decline. Short-term memory loss did not seem to correlate with any of the other symptoms or DBS. Overall, the symptoms that each participant spoke about most seemed to be those that were meaningful to them based on their past or present experiences. A distribution of the various symptoms experienced by all participants in the study can be seen on the next page in Figure 6. Note that multiple symptoms could have been experienced by the same participant.

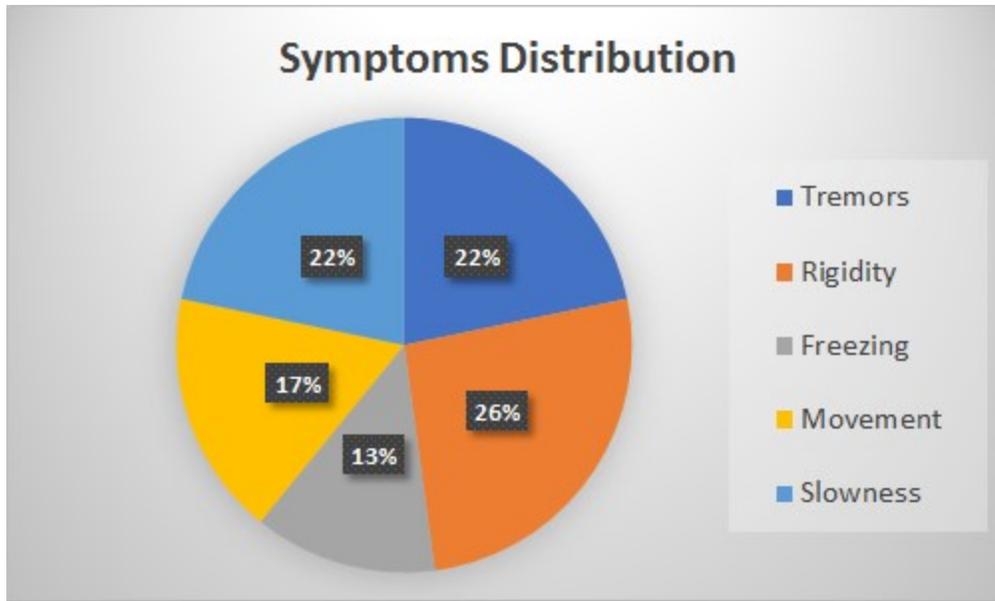


Figure 6.--Symptoms Distribution Experienced by All Participants

Daily Challenges

Getting Dressed and Starting the Day

When looking at the challenges that participants described through the interview process, most struggles were related to getting dressed in the mornings and changing clothes. Five of the nine participants indicated at some point in their interview that they experienced hardships changing clothes and getting started in the mornings. One participant said, “Simply getting up in the morning and getting out of bed and walking down the hall is really tough.” Another said, “Getting dressed. That’s my biggest challenge. Yeah. Changing clothes.” Three of the participants said that the challenge of getting dressed was specifically related to the mornings due to the absence of medication in their system from sleeping. Four of the five participants in this category indicated they experience rigidity as their most common

symptom. All five participants said that their hobbies before Parkinson's included exercise and being very active, indicating that movement is something that was very important to these people pre- and post-Parkinson's.

Fine Motor Skills

Difficulty with fine motor skills was found to be experienced by five of the nine participants. This category was the only one in which the majority said they experienced tremors: four out of the five said they have tremors related to Parkinson's. Two of the five participants expressed difficulty with general tasks such as tying knots, tying shoes, or doing handcrafted work, while three participants said their difficulties with fine motor skills were more related to smartphones, touchscreens, and typing problems. When asked about challenges relating to Parkinson's, one participant said, "Now a lot of things, especially finite work, are impossible for me." When asked about touchscreen gestures, one participant said, "Anything that involves fine motor skills is tough enough, but when you have to use more than one finger in a fine motor skills motion, it's exponentially harder." Another said, "My fingers are so difficult to push the buttons on a smart phone." This all suggests a normal interaction with a smartphone would be nearly impossible for someone with Parkinson's, based upon the inability to use fingers or digits to hit these small buttons, especially on a relatively small screen.

Technology Interactions – Due to Age

The next category that arose was based on the difficulty to use technology solely due to age and the generational gap rather than Parkinson's. This was experienced by four out of

the nine participants. The average age of all participants was 65.9, and the average age of this category was 69.8. Out of this group, only one participant said they regularly use a smartphone and all of these participants lived in rural areas outside the Kansas City metro area. Two of the participants said they use a flip phone rather than a smartphone, and one participant said they use a flip phone but are starting to use a smart phone occasionally also. However, all four said they had attempted to use a smartphone at some point since being diagnosed with Parkinson's. During the interview process, each of these four participants indicated that the reason they have difficulty using a smartphone is largely because they do not understand the technology due to their generational gap. When asked if they used a smartphone, one participant said, "I attempt to use a smartphone, and it's not because of Parkinson's, it's just that I'm too old of a generation to understand how these things work." When asked about voice technology, another participant said, "I was slow to get to technology." Three out of the four participants also said they do not use voice command software either. Results from this category indicate that a generational gap combined with Parkinson's makes it more difficult to interface with new and advanced technology.

Daily Challenges Theme Overview

Each participant was asked what challenges they experience on a daily basis. These challenges were grouped and can be seen in Figure 7 on the following page. When analyzing these challenges, three categories were determined and analyzed. This theme offered some surprises as the most common answers had to do with morning routines and getting dressed. This category did not have any correlations to the other two categories that could be found.

Fine motor skills were impaired for five participants, and those that experienced fine motor control issues also stated they had trouble with touchscreens. Out of the five participants with fine motor control issues, three had technology interaction issues due to age, which was 75% of that category. This implies that if a Parkinson's patient has not used a touchscreen prior to being diagnosed, their ability to adapt and use the technology would be significantly more difficult because of the generational gap. This combined with sensitivity and fine motor control issues would make for a very steep and frustrating learning curve. This also indicates that Parkinson's patients may greatly benefit from a more user-friendly and simpler interface platform.

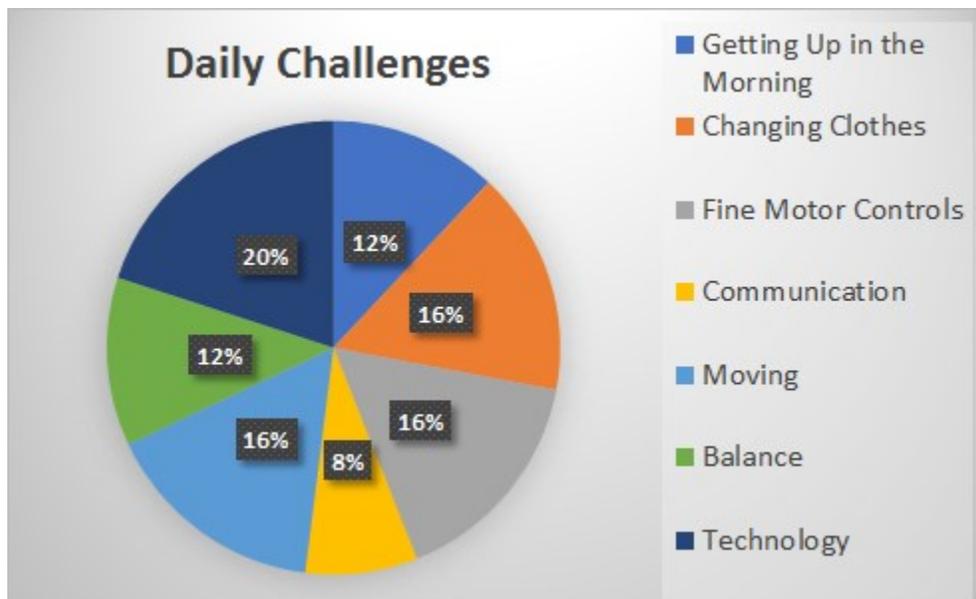


Figure 7.--Biggest Challenges that the Nine Participants Experienced During a Normal Day

Values

Exercise Frequently

This category was selected based on whether the participant continued to perform exercise frequently after being diagnosed with Parkinson's. No questions were directly asked about exercise, so any information that was provided here was voluntary. Four interviews were selected for this category. At least three of the four regularly attend Rock Steady Boxing classes, and all four thought that exercise helped fight Parkinson's disease. One participant said, "I realized as long as I had exercise for the rest of my life, it would help keep me more normal, and it does." These four participants also all mentioned at least once that they enjoy the atmosphere, community, group, or the "social interaction" of a gathering of "like-minded" people. One participant, when asked a follow-up question about whether the Rock Steady Boxing Classes were more about the workout or the community and atmosphere, said, "For the boxing gym, it's both. For my other gym, it's just about a workout." This suggests a deeper underlying theme: Parkinson's patients can benefit from exercise, but Parkinson's patients also desire a community of like-minded people to feel, as one participant stated, "normal" and accepted.

Communication with Family

For this category, four interviews were selected based on the following criteria: the participant values communication, and this person specifically mentions communication with family, kids, and grandkids. The four interviews selected all mentioned communication specifically with their family at least twice, and one participant even brought it up six times

during the interview. These instances appeared when asking participants about hobbies, communication platforms, what brings joy to their life, and when talking about general tasks, such as time spent with their kids or grandkids going to the pool and fishing. All four of these participants also said they have used virtual communication software to communicate specifically with their kids and grandkids. One participant said it even helped with depression and the emotional battle with Parkinson's. Out of the nine participants that were asked about virtual communication, six people found it helpful and four were tied to reasons relating to seeing family and grandkids. This would suggest that virtual communication with loved ones could be a very beneficial and powerful communication method for Parkinson's patients who are battling depression.

Community and Social Interaction

Two participants were selected for the community and social interaction category. This category was based on if participants indicated that social and community interaction was important outside of the realm of exercise and family. The words "community", "group", and "social" were used as keywords for this category. These words appeared seven different times for one interviewee and five different times for another, which was significantly higher than for any of the other participants. These participants both expressed that they found it enjoyable and helpful to be around other people with Parkinson's. One participant said, "Maybe it's the older I get, or maybe it's Parkinson's in general, but the need to socialize and socialize with the people that understand what I'm going through is very important." After their first experience with a community group, another participant stated, "It was a real eye-

opener because I hadn't been to any support groups because I was still kind of pretending that I didn't have it." Neither of these participants mention communication with family or kids or grandkids, but their answers suggest they were finding the same sort of emotional and supportive connections through social and group interactions that those in the category of family communication were experiencing. This further illustrates that Parkinson's patients need communication and social interactions with people who care and can relate to them and their struggles.

Values Theme Overview

When examining the three categories in the values theme, the biggest correlation was that of a sense of belonging and community. Rock Steady Boxing classes were found to be beneficial to Parkinson's patients for two reasons: the workout helped with their movement, and it was a community of like-minded people fighting for the same cause. This sense of community was also seen in communication with family and small group interactions. None of the participants who spoke about Parkinson's groups focused on what the group was or did but instead focused on it as a place of social interaction with other people struggling with the same issues. This indicates a sense of motivation to fight the disease – people are stronger together. This was further exemplified by the importance of communication with family, kids, and grandkids. All hobbies and values that the nine participants partook in prior to being diagnosed with Parkinson's disease was divided into the pie chart shown in Figure 8 on the next page. Many of these had significantly changed since their diagnosis with Parkinson's. Being active was mentioned as a general hobby, but it was tied with exercise as

the most recurring activity. Crafts denotes tasks such as sewing, woodworking, scrapbooking, or other hobbies done with your hands.

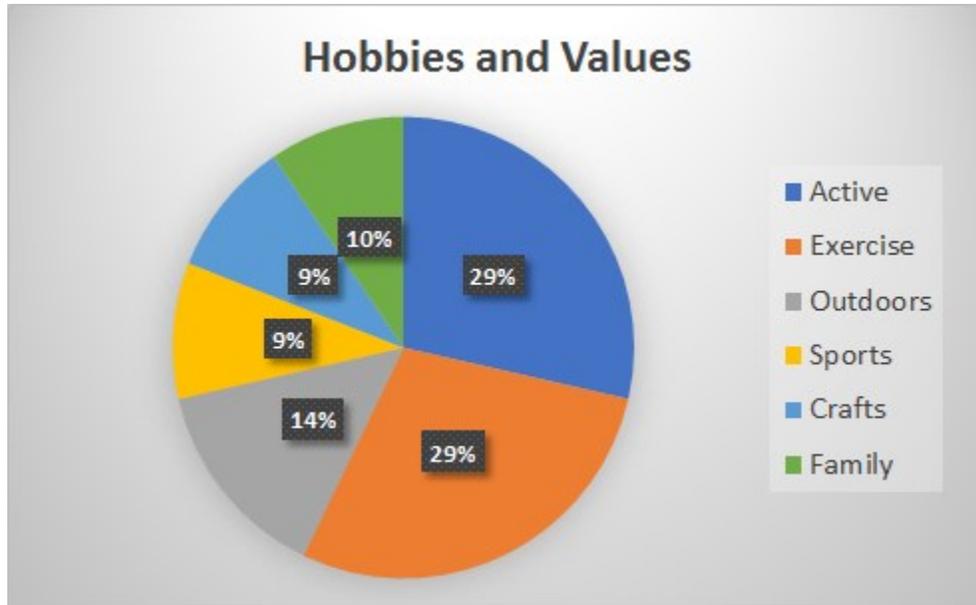


Figure 8.--Hobbies and Values of the Nine Interviewees Prior To Being Diagnosed with Parkinson's

Communication

Written Communication Is Challenging

The next category analyzed was regarding written communication. Six out of nine of the participants were categorized based on whether they found texting, email, using a keyboard, or handwriting difficult. Out of these six participants, all mentioned directly or inferred that written communication has become more difficult for them since being diagnosed with Parkinson's. When asked about using a keyboard, five out of six participants said they either cannot use a keyboard anymore or can only use one with difficulty.

Participants in this group also used the word “difficult” twice as much as participants not in this group – indicating that the effects of Parkinson’s may be more significant than just written communication. Furthermore, participants in this category also mentioned their trouble with speech 4.3 times more than those without written communication struggles. This implies that those who struggle with written communication may be more affected in all forms of communication, or at least realize how difficult life is without the ability to communicate, thus causing them to talk about it more. All participants that had undergone DBS surgery were in this group, indicating that DBS may have an effect on the ability to move your hands and fingers in a way needed for texting, writing, or typing. Three of the six participants said that their biggest issue is that they often hit multiple keys on accident when typing or texting. One participant said, “It’s that ability just to touch it. And instead of it being 1 G, it is 3 G’s or 15 G’s because of the inability to softly tap that key.”

All Communication Is Challenging

Interviewees that indicated they had difficulty with all forms of communication was the next category, which was three out of the nine participants. The first significant commonality was that all participants had DBS surgery, at least three years ago. Age did not seem to have any significance, but length of diagnosis did. These participants’ diagnosis length all fell within the top four when compared to other participants. Each one of these participants commented that their ability to communicate had been significantly altered. One participant said, “My speech has been terribly affected. My handwriting is terrible. My fingers are so stiff, I can't really type anything. It’s very difficult for me to communicate with

anybody. It's very frustrating." When asked if Parkinson's had affected their ability to communicate, another participant said "yes, totally" and "it's so frustrating". All these participants also indicated they have rigidity or stiffness, and tasks that were most difficult for them were movement-based. Two out of the three participants indicated they lived in rural areas as well. All participants indicated difficulty talking and stated voice command software is very hard to use. For these reasons, only one of the three participants uses it frequently. When asked about if they used voice command software, they said, "Yes, and it gets about the 50%. And I still have to go back and fix the words. It's horrible."

Communication with Family and Friends Affected

The last communication category analyzed was that relating specifically to family and friends and how Parkinson's had affected that relationship. Three interviews were put in this category, and each participant expressed at some point during the interview process that they had difficulty communicating with family and/or friends. Participants expressed hardships because they could not see their loved ones, talk to their loved ones, or were experiencing an "off period" and could not move or perform as they normally would.

Communication Theme Overview

When comparing the three categories of the communication theme, it was shown that Parkinson's disease had a huge effect on communication. Every participant in this study said they struggled at least some with communication due to Parkinson's. Those that struggled with written communication were much more likely to have trouble with their speech and verbal communication. Half of the participants who struggled with written communication

also struggled with all forms of communication. This could be because they were more aware of their communication limitations, or their disease progression was simply just more advanced. Every participant who struggled with all forms of communication said their relationships and communication with family and friends had been affected. This could lead to increased isolation as there is limited access to social and community groups that help people cope with their disease. Lastly, voice communication was suggested to be only partially effective because of the difficulty understanding those whose speech had been affected. Every participant with speech problems indicated that they also had written communication problems and editing misinterpreted words by the voice command software was “horrible” as one participant stated. This theme indicates that those with Parkinson’s disease will face communication struggles at some point in their diagnosis, and if one communication platform is affected, there is a strong chance other or all platforms will also be affected. A breakdown of all the participants’ answers to what their preferred method of communication was is shown in Figure 9 on the next page. Those that preferred virtual communication indicated it was because they have trouble with their speech.

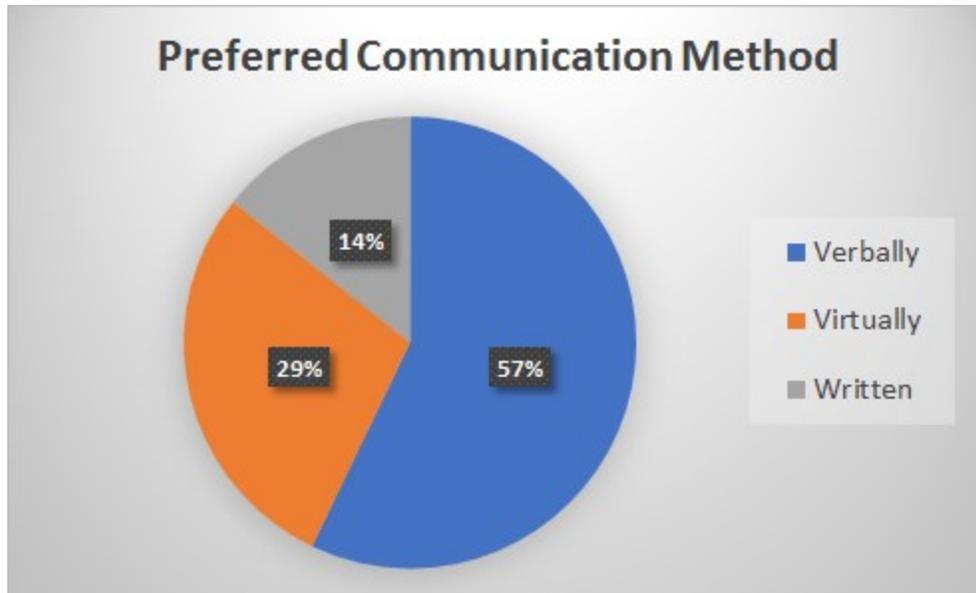


Figure 9.--Preferred Communication Method for All Participants

Technology

Struggle with Touchscreens

When asked about smartphones and tablets, six out of nine participants said they experienced difficulties specifically with touchscreens. Out of these six, four participants said they regularly use a touchscreen, one said they occasionally use a touchscreen, and one said they rarely use a touchscreen. Two participants commented on specific gestures, and both said that zooming with two fingers in a “pinching” motion was the most difficult gesture. These two participants also both indicated that tapping is much easier and that all gestures were easier if the screen was on a flat surface. Three of the participants said that having a steady screen closer to them made things easier. When asked about this, one participant said, “If I laid it on the desk and only had to reach two or three inches, it would be okay. But to

me, the further out you reach, the more your hands tremor.” Another participant said, “But it is difficult for me to use a keyboard, to use a touch phone, an iPhone, an iPad. Especially if I hold the thing up with one hand to type with another hand, it’s like shaking, shaking.” Four of the participants indicated that they often use additional touchscreens other than their phones, such as a tablet, and two of them said the larger screen size does make things easier to interface with. Overall, this indicates that many Parkinson’s patients struggle with touchscreens, and having a steady platform, closer, with larger buttons and screen size may be helpful.

Find Voice Command Software Useful

Four out of nine participants indicated that voice command software was potentially useful for Parkinson’s disease. However, out of these four, only three attempted to use some form of voice command software frequently. Two participants said that the software works great for them, and two said it has a lot of difficulty understanding them due to their speech limitations. Three of the four participants in this category only used voice command for simple tasks, such as asking questions to a device or in their car. One participant attempted to heavily use voice command software to help them specifically with Parkinson’s. When asked about what they believed would be most beneficial to help fight Parkinson's disease, this participant said that “voice recognition would be huge”, and if it could be linked to household tasks, it would be “amazing”. Based on these results, it seems that voice command could be useful for Parkinson's patients, but because many of these patients struggle with speech, it may not be the most practical method of communication.

Frequently Use Virtual Communication

Three participants were placed into the virtual communication category based on whether they regularly used virtual communication software. Participants in this group had an average age of 56, nearly 10 years younger than the average age of all nine participants. This indicates that age may have a significant effect on Parkinson's patients' ability to use more advanced technology. Not only did all three of these participants frequently use virtually communication software, but they also believed it was very helpful overall. Two out of the three participants in this category also had difficulty with speech, and both indicated that the reason virtual communication was helpful was because of the ability to speak and be seen. When the listener was able to see their lips move while they spoke, this greatly increased the listener's ability to understand them. When asked if they found virtual communication helpful, one participant said, "Yes. Because not only can I see what they're saying, they can see my mouth – what I'm trying to say." Another participant, when asked the same question, said, "Yeah, I think that they can much more easily make out what I'm saying." The third participant said they believe virtual communication was beneficial because of the social interaction. When asked if they thought virtual communication was helpful, they said, "It's probably more of the social aspect." All of this would suggest that virtual communication could be a very powerful tool for Parkinson's patients.

Believe Technology Can Help Fight Parkinson's

Four participants indicated throughout their interview that they believed technology overall could be beneficial to help combat Parkinson's disease and were therefore put into

this category. These participants hinted in many of their answers that they would like to see more technological advancements in Parkinson's disease research. One participant suggested an Apple Watch style or similar wearable device that could be communicated with verbally – something that could be worn at all times to help with basic tasks at home. Another participant said they would like to see specific voice recognition software developed on an individual basis. All the participants in this category used a smartphone daily and texted, called, and emailed from it regularly. All but one participant used voice command software on occasion, and all but one participant used virtual communication frequently. This suggests that there is a strong correlation between those who use technology and those who believe in the value of technology. If a Parkinson's patient more frequently interfaces with technology, they appear to be more apt to believe in its value to combat Parkinson's disease. Contrary to this, out of the nine participants, only three said they do not regularly use a smartphone. All three of these patients never used voice command software at all, and only one of the three occasionally used virtual communication. This further suggests the divide – if Parkinson's patients do not regularly use technology, they do not understand or believe in its ability to help them.

Technology Theme Overview

Technology was broken down into four categories and focused on three main forms of user interaction. These three forms were touchscreens/smartphones, voice command software, and virtual communication. Comparing these four categories, it can be seen that age does affect technology usage and interfacing, and if technology is not regularly used,

there is less likely to be a belief that it is useful. This theme also indicates that those who are trying to use technology the most still have difficulty with it. Two participants fell within all four technology categories, and each one of these participants commented on the difficulties with each platform. However, both also indicated they found all platforms useful and regularly use or attempt to use them. This would suggest that those who use technology see its benefits but also realize and endure the struggles. Those that do not regularly interface with technology seem to either not fully understand it or find it too difficult to use. Overall, the struggles that Parkinson's patients face with technology were not all that different based on their technological usage or their severity and length of diagnosis. The real issue seems to be the lack of a communication platform that allows for their symptoms to be catered to.

Technology communication was divided into three platforms: smartphones, virtual communication, and voice command. The distribution of which platforms each participant used is shown in Figure 10 on the following page. Each of the nine participants was only counted one time.

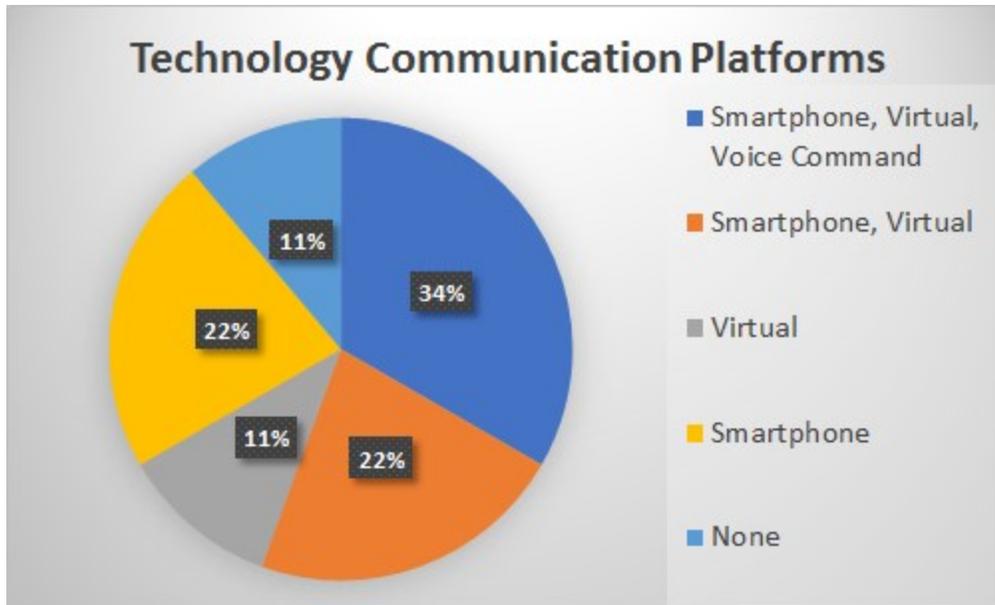


Figure 10.--Distribution of Technological Communication Platforms for Each Participant

CHAPTER 5

DISCUSSION

The results of the study provide insight into the difficulties that Parkinson's patients face with technology and communication in everyday life. This discussion will highlight the major takeaways from the results and describe why these findings are relevant to the Parkinson's community. The limitations of the study will also be discussed, along with potential future solutions on how to bring equity and access to Parkinson's patients locally and globally.

Geographical location definitely had an effect on participants' technology usage. Those that were living in rural areas were at a significant technological disadvantage, which is not surprising due to the lack of resources many small towns and rural areas have. Technology generally never spreads as quickly in rural areas as it does in a metropolitan area, and when discussing a disadvantaged people group, the effects were even more drastic. Rural Parkinson's patients struggled more with using technology, understanding technology, believing in technology, and overall had a higher rate of suffering from communication. The need for equity and access in these communities cannot be ignored. If these were the results from rural areas locally, what would the effects look like in rural areas across the country or even the globe? The results speak for themselves.

Rigidity, stiffness, and slowness were heavily favored as the most common words used to describe the symptoms that participants were experiencing on a daily basis. Most Parkinson's patients indicated that their "off time" or "difficult times" were in the mornings,

which usually occur at home and when their medication is absent from their system. When asked about the most difficult task that they face, five of the nine participants mentioned getting dressed and getting their day started. This would indicate two things: 1) Parkinson's patients need and could greatly benefit from a technological platform to help them start their day, and 2) to truly understand struggles a Parkinson's patient faces, their home lifestyle must be carefully analyzed on all levels.

The same symptoms may be experienced from person to person, but how that symptom is perceived and the effect it has on each person may be different. This opens a new way of looking at the design process. Instead of focusing on what symptoms are and how we can treat them, maybe a better method of research would be to find out how their life has been affected. For example, one participant had a great love of hiking and fishing but also focused their struggle descriptions on their movements and rigidity. The inability to move is indeed a problem, but maybe the bigger issue is how to restore these hobbies and value areas to bring back joy that has been subject to the continuation of their diagnosis. Understanding what each person finds value in could possibly be the easiest and most individualized way of restoring joy to Parkinson's patients outside of a cure.

During the next phase of the project, these values and symptom descriptions will be compared to previous hobbies and lifestyles pre-Parkinson's diagnosis. Further investigation could lead to a great discovery if in fact Parkinson's patients' perceptions and experiences of symptoms are most related to their pre-diagnosis lifestyle, values, and hobbies. This would have potential to individualize treatment and change how the disease is fought and thought

about for each person. By understanding these correlations between pre-diagnosis lifestyles and post-diagnosis symptom experiences, their needs and desires concerning technology could be drastically changed. This will be done in the next phase of the project using a mixed methods approach focusing on both quantitative and qualitative data, which is further discussed in future considerations.

Another method of bringing joy and equity to the Parkinson's community could be through virtual communication. This was shown to be an effective way of communicating for Parkinson's patients because it gives Parkinson's patients the ability to see, be seen, and be heard without the hassle of moving, getting dressed, and leaving their homes. There are multiple softwares such as Zoom Video Conferencing, Microsoft Teams, Slack Technologies, and many more that allow online meetings and screensharing. What if these platforms could be used in a way to specifically benefit Parkinson's patients? This brings to light ideas such as in-home workouts or group and community events. This would eliminate Parkinson's patients' need to travel all the time and would allow them the ability to be part of a class, group, or other event from home if they were in an "off period." Of course, in-person interactions are great and should still be done when possible but having a reliable secondary option would be beneficial.

These results also indicate how important social interaction, being understood, and being able to fit in with "like-minded" people is for Parkinson's patients. Parkinson's disease takes so much away from those affected by disrupting their lives, work, families, and hobbies – it changes everything. Depression and isolation will continually attack and try to take away

a person's identity. However, social interactions and a good community foundation can help to fight this, whether that is with family, friends, or other Parkinson's patients: finding people who will listen and understand is key. Creating a space of acceptance where Parkinson's patients do not have to be afraid, ashamed, or embarrassed by their disease and corresponding symptoms could be a great amendment to their lives. A virtual communication platform would especially be useful and could be accessible at all times, even for those in rural areas with a less dense population of Parkinson's patients or for those with long commutes to metropolitan areas.

Family and friends can encourage Parkinson's patients to get access to this virtual communication software and communicate through it with them, especially for those that have a speech issue. This could alleviate a lot of communication frustrations for a Parkinson's patient by allowing the other party to pick up on their words through lip reading. These results also indicate that seeing someone, even on a screen, could help with depression and social isolation. With the ever-expanding globalization of our world, more families, kids, and grandkids are growing up apart from one another. This is difficult for any parent or grandparent, but for those who find themselves isolated and fighting depression, this would be especially hard. By using a virtual communication platform specifically designed to address the sensitivity and rigidity issues Parkinson's patients face, many of these challenges could be alleviated.

Voice command software could be another wonderful tool, as indicated by multiple participants, but due to many of their speech degeneration problems, this was not as effective

of a communication platform. This could be because this technology just is not quite advanced enough yet, or many Parkinson's patients' speech is just too affected to make this a reliable form of communication. These results indicated that DBS had a correlation with speech degenerations, strong enough that voice command software was not reliable enough to use. Voice command software could still be useful for those in the early stages of Parkinson's disease or those that do not have as severe of a speech degeneration problem. Time will tell; it certainly is an attractive idea if the technology is able to recognize a specific person's voice, even when slurred and softly spoken.

It cannot be understated how large the gap is between Parkinson's patients and their ability to regularly and effectively use technology to communicate. The average age of diagnosis in this study was 54.7 and the average length of diagnosis was 11.2 years. That means the average diagnosis would have taken place roughly around 2009. At that time, smartphones and touchscreens were just starting to come into play. With how much technology has changed in the past 11 years, it is now a cornerstone to modern life. Social networks, messaging platforms, transportation, delivery, and many other services all rely on smartphone applications; as these functions become more essential, Parkinson's patients will continue to fall further behind (Klein et al. 2017). With the average age of diagnosis being 54.7 for this study, just the generational gap due to their age alone is nothing short of significant. In addition, their involuntary movements and impaired fine motor skills do not provide them much of a fair chance. Several of the participants commented on their inability to understand technology due to never having used it, completely independent of their

Parkinson's symptoms. Similar results were also found in a study done by Albani et al. (2019) on Parkinson's patients' lower and upper limb movements with wearable and optical technology. The participants who did not regularly use technology were less likely to believe that technology was or could be helpful to them. Due to this lack of experience and the ever-evolving beast we call technology, it is no surprise many of these patients just stay grounded in what they know and what has worked for them all these years. However, if a simple technological communication platform was designed for and explained specifically to Parkinson's patients, their thoughts might be different. This could lead to a completely new world of dealing with and fighting Parkinson's disease for those that do not regularly interface with communication technology.

Study Limitations and COVID-19

Two significant limitations were present in this study: firstly, the impact of the COVID-19 pandemic and secondly, the limited sample size. The original scope of this study included in-person interviews and in-person touch sensor gesture testing. However, due to the mandatory national quarantine and stay at home order for the majority of the Spring 2020 semester, no in-person interviews were able to be completed. This meant no visual assessments of symptoms could be done, and no gesture testing could be done. Parkinson's patients are an extremely high-risk group because of their age and already weakened immune system, so extreme precautionary measures had to be taken to protect them. This quarantine also shut down many community groups and Parkinson's-related events, which made reaching out to potential interviewees and Parkinson's groups more challenging. This was

somewhat expected, since this is a group that already struggles with both communication and technology. In the end, the required number of participants was still obtained, and the interviews were completed over the phone. Even before the spread of COVID-19, the sample size of this study was limited to ten people, which is a relatively small sample size by comparison to the number of Parkinson's patients. Therefore, results will need follow-up confirmation from a larger sample size and different geographical locations.

Due to these two limitations, the focus was shifted from a touch sensor gesture research study to a human-centered design research study paired with the first two stages of the Design Thinking Process. The original goal was always to understand the true struggles Parkinson's patients face with communication and technology. However, when it was realized that in-person testing would be impossible, the study objectives no longer focused on touch screen gestures – instead, they were aligned to focus on barriers that affect technology and communication and how to formulate a bridge for Parkinson's patients. This resulted in a more thorough investigation of challenges, which ultimately led to a better understanding of how to set up gesture testing.

Future Considerations

This study is just the beginning of a multi-phase project that starts with this exploratory qualitative analysis completed for the master's thesis and will extend into a mixed methods approach and final design during a doctorate program. The project life cycle can be seen in Figure 11 on the next page, displaying the key phases of the project. Below that, Figure 12 outlines the mixed methods approach spanning the time frame of the master's

thesis and into a PhD dissertation. The results and information gathered in this research will be used to design a secondary interview questionnaire and survey that will be distributed to a larger sample size focusing on quantitative data provided through targeted questions developed from the exploratory qualitative phase. Using a mixed methods approach, both quantitative and qualitative data will be analyzed to help generate targeted questions to the participants. This information would then be used for concept generation and brainstorming purposes, enabling the creation of a product that would serve to bridge the technological communication gap. From here, the product would be tested, and the cycle would repeat itself with field testing, revisions, and amendments to the design based on comments and user feedback. The end goal would be to have a human computer communication platform bringing equity and access to all Parkinson's patients across all locations to help them better fight the battles they face on a daily basis.

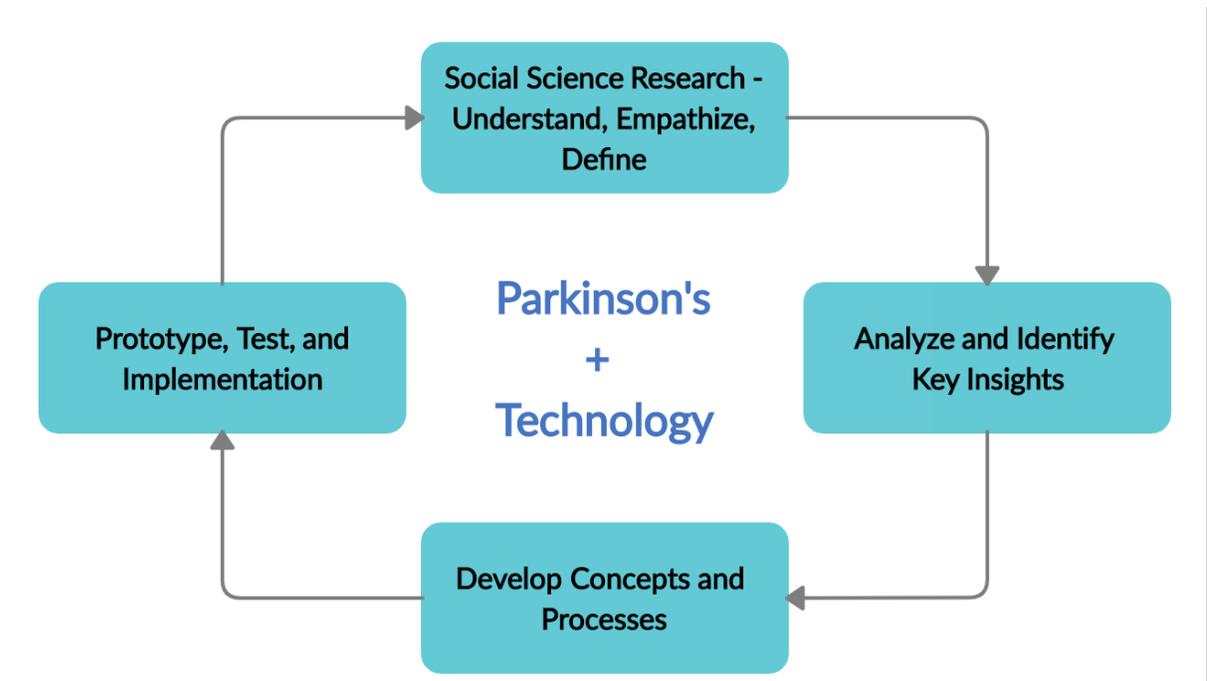


Figure 11.--Project Process Life Cycle



Figure 12.--Mixed Methods Approach and Project Timeline

CHAPTER 6

CONCLUSION

This study was designed to help gain insight into the challenges that Parkinson's patients face on a daily basis related to technology and communication. A human-centered design was used, along with the Design Thinking Process, to formulate the research methods used. Nine participants were interviewed, and the results were coded and themed to look for commonalities that existed. During this process, the interviews were sorted based on the answers that participants provided. Seventeen categories were determined, and then sorted and grouped into five major themes. These major themes included communication, technology, daily challenges, values, and symptoms. All interviews within a category were compared, and all categories within a theme were compared to formulate the results.

The results concluded that Parkinson's patients do in fact face significant barriers when it comes to technology and communication. Geographic location does matter and those in rural areas are much more affected due to these barriers. Participants commented on their inability to communicate in person, verbally, virtually, or in writing. Hobbies were found to have been significantly changed by the disease, but values remained concrete. The ability to carry out some of these values, however, was affected. Basic daily tasks that related to fine motor skills and movement were found by most participants to be difficult. Rigidity and stiffness were the most common symptoms experienced and the most devastating when using a smartphone or touchscreen. All participants that used a touchscreen found it difficult due to their Parkinson's symptoms, and some participants additionally struggled with lack of

experience and understanding of the technology. Voice command software was found to be helpful only for participants who did not have speech degeneration or for those in the early stages of the disease. Virtual communication was found to be very helpful and possibly the best communication platform for most of the participants. Social interaction, community, and a sense of belonging was also expressed to be of great importance by all but one of the participants.

It must be remembered that many of those who are diagnosed with Parkinson's cannot perform daily tasks easily such as driving, moving, talking, or typing, especially when the severity of the disease begins to become serious or critical. Bringing equity and access to these people through a human-centered design approach of a new communication platform is one way that can begin to help bridge the existing gap. This research is starting on a relatively local scale by only extending out to the rural Kansas City area with nine participants. Being able to understand the specific problems that rural and isolated Parkinson's patients have locally in the United States is the first step to taking this to a national and eventually international level.

Overall, Parkinson's patients' ability to use technology as an effective communication platform is significantly inhibited. They have limited access to any specialized technological communication platforms that provide equity to them. This subset of disabled people could arguably be one of the most affected groups when discussing communication in general, and certainly with regards to technology. These results show just how significantly this small sample size around the Kansas City metropolitan area need

better equity, and if this study was to be extended to more rural areas of the United States or even globally, the need for a better communication platform could be exponentially greater. It cannot be denied no matter how large the sample size or the location it is taken from, Parkinson's patients need more help. Parkinson's patients are an incredible people group who have suffered enough – it is time to give back to what many of them have given to us. Their perseverance, motivation, and continued fight for a cure is nothing short of inspiring.

APPENDIX
CONSENT FORM



Consent to Participate in Research

Study Title: *Bridging the Gap Between Parkinson's Disease and Technology*

Authorized Study Personnel

Principal Investigator: Dr. Darran Cairns, Ph.D. Office: (304) 216-9363
Secondary Investigator: Anthony Weiss, Office (785) 215-2730

KEY INFORMATION

You are being asked to take part in this research study because you have Parkinson's Disease. Research studies are voluntary and only include people who choose to take part. The purpose of this research is to better understand how Parkinson's patients interact with touch sensor technology. The total amount of time you would be in this study is 20 to 30 minutes. During your participation you will be involved in answering a series of about 20 questions about your daily life with Parkinson's disease. Taking part in this research involves the following risks or discomforts: answering questions about your disability and providing examples of specific household or daily tasks that you struggle with. The potential risks are only associated with the privacy and confidentiality of this information. The research team will do our best to keep this information confidential, but it cannot be guaranteed. There are no benefits to you for taking part in this study. You have the alternative of not taking part in this study.

Please read this consent form carefully and take your time making your decision. As the researcher(s) discusses this consent form with you, please ask him/her to explain any words or information you do not clearly understand. Please talk with your family and friends before you decide to take part in this research study. The nature of the study, risks, inconveniences, discomforts, and other important information about the study are listed below.

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to understand how Parkinson's patients interact with technology in their daily lives, specifically touch sensor technology. Through gaining a better understanding of what challenges exist with touch sensor technology and Parkinson's disease, a better platform/interface can hopefully be developed to help combat the difficulties of living with Parkinson's.

You are being asked to be in this study because you have been diagnosed with Parkinson's disease and are between the age of 30 to 80.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

Approximately 5 to 10 people will take part in this study at UMKC.

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Consent to Participate in Research

WHAT IS INVOLVED IN THE STUDY?

You will be asked to complete a phone interview of about 20 questions pertaining to your daily life with Parkinson's disease. These questions will ask about struggles you have with specific household/daily tasks and how often, if at all, you use technology such as smart phones, tablets, kindles, or tablets.

HOW LONG WILL I BE IN THIS STUDY?

The interview will take about 20 to 30 minutes to complete over one session.

WHAT ARE THE RISKS OF THE STUDY?

This research presents risk of loss of confidentiality, emotional and/or psychological distress because the interviews involve some potentially sensitive questions about your work habits and disability struggles.

Every effort will be made to keep your information confidential; however, this cannot be guaranteed. If information was to be accidentally disclosed, it could pose risks to your employment/employability, due to the disclosure of specific tasks that may be difficult to complete, such as computer-oriented work.

Some of the questions we will ask you as part of this study may make you feel uncomfortable. You may refuse to answer any of the questions and you may take a break at any time during the interview. You may stop your participation in this study at any time.

ARE THERE BENEFITS TO TAKING PART IN THE STUDY?

There are no benefits from taking part in this study.

WILL MY INFORMATION BE KEPT CONFIDENTIAL?

The University of Missouri System, Authorization No. 00-018 requires research data to be retained for 7 years after the final report.

Reasonable steps will be taken to protect your privacy and the confidentiality of your study data. Your name and contact information is only used for completing the phone interview and will not be stored with your interview data. The interviews will be transcribed after the initial recording (within 5 to 10 days) to discuss and look for common themes in. Any potentially confidential or identifiable information from the interview will be removed. After the transcription is complete your contact information and the audio recording itself will be deleted.

All information provided during the interviews will be recorded and saved to the investigators personal password protected computer. In addition, the information will be placed in a folder that is password protected so there is a second level of security. The individual file will be password protected as well. No flash drives or external storage devices will be utilized.

The only persons who will have access to your research records are the study personnel, the Institutional Review Board (IRB), and any other person, agency, or sponsor as required by law. The information

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from this study may be published in scientific journals or presented at scientific meetings but the data will be reported as group or summarized data and your identity will be kept strictly confidential.

WHAT ARE THE COSTS TO YOU?

There is no cost to you to be in this research study.

WHAT ABOUT COMPENSATION?

There will be no compensation given for participation in this study.

WHAT SHOULD YOU DO IF YOU HAVE A PROBLEM DURING THIS RESEARCH STUDY?

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

UMKC appreciates people who help it gain knowledge by being in research studies. It is not UMKC policy to compensate human subjects in the event this research results in injury/harm. The University, in fulfilling its public responsibility, has provided medical, professional and general liability insurance or self-funded coverage for any injury/harm in the event such injury/harm is caused by the negligence of the University, its faculty and staff. In the event you have suffered an injury/harm as the result of participation in this research study, you are to advise the researcher listed on page one and contact the University Risk Management Office, telephone (573) 882-1181 who can review the matter and provide further information.

WHAT ABOUT MY RIGHTS TO DECLINE PARTICIPATION OR WITHDRAW FROM THE STUDY?

You can decide not to be in this research study, or you can stop being in this research study ("withdraw") at any time before, during, or after the research begins for any reason. Deciding not to be in this research study or deciding to withdraw will not affect your relationship with the researcher(s) or with the University of Missouri Kansas City.

WHOM DO I CALL IF I HAVE QUESTIONS OR PROBLEMS?

You may ask any questions concerning this research and have those questions answered before agreeing to participate in or during the study.

For study related questions, please contact the researcher(s) listed at the beginning of this form.

For questions about your rights as a research participant, or to discuss problems, concerns or suggestions related to your participation in the research, or to obtain information about research participant's rights, contact the UMKC Institutional Review Board (IRB) Office

- Phone: (816) 235-5927
- Email: umkcirb@umkc.edu

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Consent to Participate in Research

STATEMENT OF CONSENT

The purpose of this study, procedures to be followed, risks and benefits have been explained to you. You have been allowed to ask questions, and your questions have been answered to your satisfaction. You have been told whom to contact if I have questions, to discuss problems, concerns, or suggestions related to the research, or to obtain information. You have had the consent form verbally read to me and agree to be in this study, with the understanding that you may withdraw at any time. Do you agree to participate in this study?

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VITA

Anthony “Tony” Weiss was born in Edgerton, Kansas, in 1992. He grew up for the majority of his childhood in nearby Baldwin City, Kansas, where he graduated from Baldwin High School in 2011. Following this, Tony enrolled for the fall of 2011 at Pittsburg State University to study biology and run track and cross country. After two years, Tony switched his focus to engineering and graduated in 2016 with a B.S. in Mechanical Engineering Technology. He then went on to work for Black and Veatch as a design engineer in Kansas City. After working for one year, he decided to go back to school and pursue his Mechanical Engineering degree from the University of Missouri at Kansas City. Tony graduated with his B.S. in Mechanical Engineering in the spring of 2019. Currently, Tony is still working at Black and Veatch and will graduate with his M.S. in Mechanical Engineering in May of 2020. Tony’s hobbies include the outdoors, waterskiing, traveling, running, and soccer. His future plans following his graduation in 2020 are still yet to be determined.