

MediTrack

Research Report

DNB311 Part A

Parkinson's & Mobility

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Abstract

This report researches and explores Parkinson's Disease and its symptoms, systems and opportunities for design intervention. Parkinson's disease effects millions of people worldwide and there are still areas that have no developed support, meaning Parkinson's sufferers must endure these aspects of their life with no support.

Interviews, Surveys and Observations were conducted to gain understanding and experiences of people living with Parkinson's, learning of pain points and areas of struggle, with the hope of gathering enough information and experiences to help design a product that could address one of these areas

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Introduction

Parkinson's disease (PD) is a nervous system disorder, with symptoms that effect movement. Symptoms begin gradually, often starting with very minor shakes or tremors. Parkinson's typically affects those later in life, however early onset cases do manifest, albeit somewhat uncommon. These are the most common physical symptoms:

- **Involuntary Tremors:** This is the most common symptom of Parkinson's. It occurs most strongly at rest and decreases with movement. As the disease progresses, tremors become stronger and People Living with Parkinson's (PLWP) struggle to perform more and more tasks.
- **Bradykinesia:** Slowness of movement can manifest in walking, with slow and shuffling short steps. Dexterity decreases, making manipulating objects more difficult. Many PLWP experience freezing, in which they struggle to start a sequence of movements.
- **Rigidity of Muscles:** This causes movement to be even harder. PWLP struggle to move their limbs, due to muscles being stiff and locking up. Even if someone else tries to move them, it is incredibly difficult.

However, these symptoms vary so much from person to person, so one product or treatment will not (and so far has not,) fully address and fix the problems that these symptoms cause.

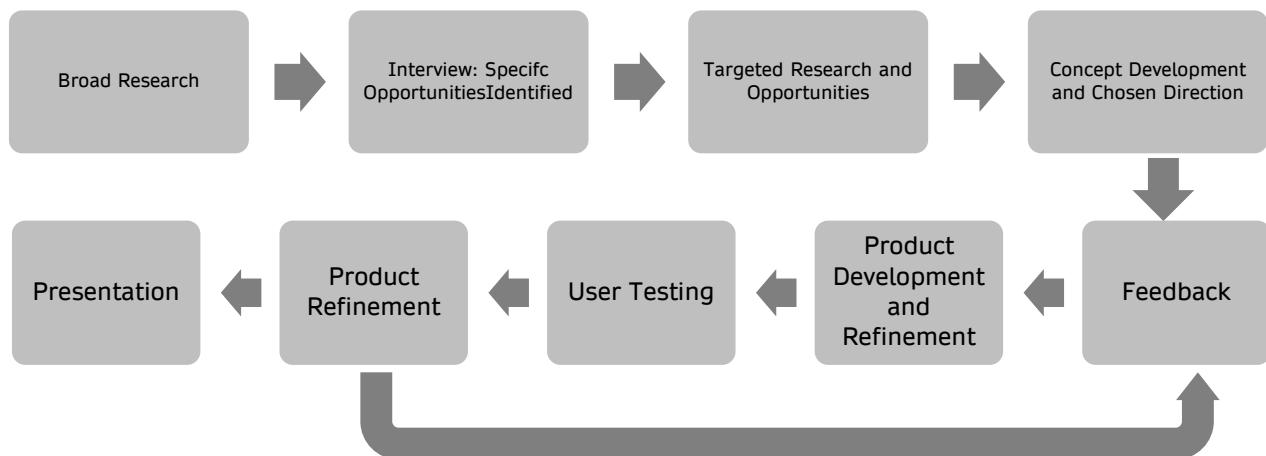
Parkinson's disease has no cure, but there are a wide range of systems, specialists and medications that help to manage the disorder, decrease the effects of the symptoms and improve the overall quality of life. But many aspects and areas in the Parkinson's system lack developed support, whether it be healthcare/specialist support or product interventions. This is an important area to study as some PLWP have no support in these areas and are left to suffer with no or poorly suited treatments or products.

While there are some products designed to address and decrease of Parkinson's symptoms, they are not effective for all PLWP, and there are still many areas left to address.

Aim

The aim of this project is to understand Parkinson's disease and the system that endeavours to manage and treat it, gathering an intimate understanding of its symptoms and how they affect people physically and mentally, exploring real data as well as personal experience from PLWP as well as family and carers. I aim to particularly focus on the area of Mobility with Parkinson's possibly addressing problems of movement, quality of life, independence, relationships with medical systems and mental health. I aim to target areas with little or no support, addressing important issues in specific areas to decrease pain points that PLWP, carers and specialists experience.

Project Structure



Literature Review

Parkinson's is a neurodegenerative disease, meaning that it is not curable, and it results in the degeneration of movement and cognitive functioning. As it progresses, symptoms worsen and they lose bodily function until the person's body cannot sustain itself and they pass away. PD develops in stages, usually in short periods of decline then a long plateau, followed by another short period of decline.

An article by *Cherney, K., Hammond, N. MD, (2021)*, depict the typical stages of symptoms many PLWP experiences

Stages of Parkinson's

Stage 1: Often, these symptoms are not noticed, and Parkinson's is not diagnosed. Motor symptoms may include a slight tremor, posture changes as well as RBD (REM Sleep Behaviour Disorder). If Parkinson's is diagnosed, medications can be very effective in reducing symptoms

Stage 2: This is the stage where PD is most commonly recognised and diagnosed. The person will begin to experience stronger tremors, muscle stiffness and slowness of movement. They may experience themselves taking longer to complete tasks, but the symptoms at this stage still allow them to live relatively normal lives, with little effect to their day-to-day

Stage 3: Many symptoms of this stage are the same as Stage 2, but people tend to experience balance losses and slower movement and reflexes. Medication is still effective in decreasing symptoms to a level where they can function and perform regular tasks, but at a much slower rate.

Stage 4: Walking and other assistant devices are now necessary to move and walk. People experience major difficulties getting out of bed, sitting or standing. They now experience freezing in assisted walking and other movement functions. They can no longer complete daily tasks, due to their loss of movement and dexterity. Dementia begins to affect up to 80% of Parkinson's patients and begin to lose brain function.

Stage 5: The final stage. Most people can no longer walk, they require assistance for all tasks. Many will experience confusions, delusions or hallucinations. For the majority of PLWP, Dementia is now much stronger. At this stage, there is not many opportunities for treatment, they can only really be kept comfortable.

A person's experience with Parkinson's can vary so greatly, different symptoms can emerge early, late or not at all, this is just an example of a typical experience.

Common Symptoms

A Medical Article by Y. Brazier and S. Han (MD) outlines common symptoms of Parkinson's disease, and early signs that can suggest its beginning stages. These are some early signs:

- Movement changes, such as tremors
- Coordination and balance impairments that can cause a person to drop things or fall over
- Loss of sense of smell
- Voice tremor or softer voice
- Cramped and smaller handwriting
- Fixed facial expressions due to changes in the nerves that control face muscles
- Sleep problems resulting from restless legs and other factors
- Gait changes, so a person leans forward slightly or shuffles when walking

While there are no known cures for Parkinson's and its declining process, some scientists have discovered that symptoms can emerge from the lack of dopamine. Dopamine is a neurotransmitter, that helps send information to the section of the brain that controls coordination and movement. If dopamine levels are low, these neurotransmitters die, making movement control hard.

Some studies have shown that exercise is one of the few things that has shown promise in preventing symptoms from appearing and worsening. Exercise has shown to produce dopamine, and if done enough, dopamine levels are kept high, preserving neurotransmitters and preventing symptoms like tremors from occurring. *Oliveira de Carvalho, A., Souza Sá Filho, A., Murillo-Rodriguez, E., Barbosa Rocha, N., Giovanni Carta, M., and Machado S. (2018)*

This could be a reason for the commonness of Parkinson's in the elderly, as they decrease with their physical activities and exercise, dopamine levels decrease and symptoms can begin to develop.

While dopamine can treat physical symptoms, it does not treat or slow the neurodegeneration caused by Parkinson's. There is currently no medication or treatment that can do this.

Parkinson's is not just a motor disorder, with physical symptoms. There are a range of mental and non-motor symptoms that can develop, often before the motor symptoms. Some of these symptoms include:

- Fatigue
- Depression
- Anxiety
- Dementia (in later stages)
- Pain
- Restlessness
- Insomnia

While a non-motor symptom can appear on their own, they can often be as a result of other non-motor and motor symptoms, which can cause a recurring loop of more and

more symptoms, as the person's condition worsens. Between motor and non-motor symptoms, non-motor has the least treatment by far. Studies and trials have been completed, but evidence has shown very little results to show promising medication and therapies to address these. Most drugs are still in trials stages, and current medication is normally used to treat non-Parkinson's related symptoms, like Serotonin and Pramipexole, which has shown mediocre results in Parkinson's related depression.

Todorova A., Jenner P., Ray Chaudhuri (2014).

A study by *Postuma RB., Gagnon JF., Bertrand JA., Génier Marchand D., Montplaisir JY. Parkinson (2015)* found that Parkinson's Disease and interestingly, **risk** of PD is very high in people who experience REM Sleep Behaviour Disorder (RBD). RBD has proven to be a possible warning sign of PD, which, if identified, could prevent symptoms appearing if managed and treated effectively.

RBD is a disorder that causes a person to act out their dreams, which often manifests violently in PLWP. This is dangerous as the patient, often elderly with bradykinesia and muscle stiffness can badly injure themselves

Medications

Levodopa is the common, effective, and widely used drug prescribed in treating the physical symptoms. Levodopa is absorbed in the small intestine, transported to the brain, and then is converted to dopamine. As mentioned before, dopamine is a neurotransmitter, which decreases motor symptoms like tremors.

As noted by *Fung V, Hely M, Moore GD, Morris J. (2001)*, Levodopa can last up to days in patients in early stages of PD. But as symptoms develop and worsen, the duration of the drug worsens to lasting less than a few hours. Levodopa's side effects mainly consist of nausea, this due to the dopamine stimulating the part of the brain commonly known as the "Vomiting Centre", or the Area Postrema.

Dementia often manifests in PLWP in the later stages in hallucinations, bouts of confusion, forgetfulness, loss of cognitive function etc. Sometimes, antipsychotic drugs may be prescribed to treat hallucinations, delusion and confusion. Unfortunately these drugs aim to do the opposite of Levodopa, by blocking dopamine to reduce brain stimulation. This causes the motor symptoms to return, causing making any function difficult and possibly making any present dementia symptoms worse.

Research

The study conducted aimed to provide a better understanding of the Parkinson's system and identify specific areas with lacking support and development. I also wished to gain understanding and perspective from PLWP, carers and family to understand their experiences and learn some of their specific pain points and areas with lacking support.

I completed two rounds of research. The first being a broad study of the whole Parkinson's system and finding possible directions, then focussing on those specific directions in my second round.

Methods

Interview: I conducted an interview via Zoom, as no in person meetings were allowed at the time. My interviewee was a QUT professor and Parkinson's specialist, who often works with Neurologists and specialists in treating PLWP. I chose this research method as it did not bind my interviewee to a specific topic. They were free to branch and elaborate. My interviewee knew more about the topic than I, and allowing them to give me knowledge and information that they thought was relevant was incredibly valuable in my research

Surveys: Using a Parkinson's Support Facebook group, I posted a link to an online survey I made using SurveyMonkey. I asked for opinions and experiences related to the directions I received in the interview. Again, I did not want to restrict my data, so all questions had a short-response answer box, allowing the people who completed the survey to provide personal and relevant information. I received 5 responses, much less than I would have liked. I attempted to join more Parkinson's groups, but as I do not have Parkinson's or am I a support worker, I was not allowed in most groups. Nonetheless, the data gathered was valuable in understanding unique experiences of people with and around Parkinson's

Observation: I conducted an observation of a woman whose husband recently passed away from Parkinson's. She showed me some methods and techniques she used in manoeuvring and managing a late-stage Parkinson's sufferer. I chose this method, as it involved someone I have a close connection with and I could learn unique data on the limits and struggles PLWP have. I chose an in-person method, as she could physically demonstrate, in her own home, many different aspects of looking after and caring for someone with Parkinson's. Sitting in lounge chairs, dining chairs, toilet techniques, how to sit and get up from bed, all of this knowledge was extremely valuable in learning the extent of how someone with Parkinson's can move and how to manage that.

Analysis and Findings

Since I did not gather any quantitative data, there was no way I could identify specific trends using numeric data. Due to the nature of Parkinson's and varying experience, this would likely not have been beneficial anyway.

I mostly analysed my data by finding common themes and topics brought up in my research methods. I also took note of areas and topics that were repeatedly brought up in the interview and observation.

60% of survey responses noted something to do with movement issues, specifically the desire to walk and move normally using walkers. The combinations of current drugs and walking aids is obviously not enough for some PLWP to move and function at a level they are happy with.

I noticed a few responses to questions that shone an interesting light on the mindset someone can develop while rereferring from PD.

In response to the question "What PD symptom has the least developed support?", one survey participant said, "too many to answer" and another responded, "Understanding of patient symptoms" (See Appendix 1.). While these responses did not answer my question, an underlying sentiment of hopelessness became apparent. These participants clearly feel lost and hopeless in dealing with their disorders, experiencing disappointment from the healthcare systems in providing adequate care.

My Parkinson's specialist interviewee was much clearer in his responses. He clearly outlined a few key areas that require development and could involve product intervention.

One main area was movement. This could include a specialized chair to aid sitting or standing and a Parkinson's specialized walker to address gait problems. However, he also noted that there is a multitude of products already developed or in development that aim to address these issues. The problem now, is making them accessible and affordable.

He brought up the concept of exercise for PLWP, and some common forms used to encourage them to get involved. This includes gym, dancing, swimming etc. A current issue entails getting PLWP getting involved and moving.

He also went on to discuss a disconnect problem between neurologists and their patients regarding medication. Neurologists have no way of knowing how medication is taken, to the guidelines they provide. The extend of the information the neurologists receive is a verbal confirmation from the patient that the medication has been taken at the right doses and the right times. Poor information to the neurologist could result in a faulty prescription which is dangerous to the patient.

My observation interviewee showed me methods she developed to assist and manoeuvre her husband, noting specific problems he had and showed me devices and equipment they used to manage his condition. They owned a chair that could assist in rising. This was an effective product in assisting him to stand without physical assistance from his wife. However, in his later stages he could no longer operate the buttons himself or remember the correct way to stand.



Toronto Leather Riser Recliner

She also mentioned an experience with a handheld tremor correcting spoon, similar to the device pictured below. This product is designed to cancel out Parkinson's tremors,



LiftLabs Liftware Steady

allowing them to feed themselves. The interviewee's experience of the product was not successful. The spoon was not as effective as expected and did not allow the PLWP to feed themselves (possibly due to the design of the product and the fact that it was introduced at such a late stage of Parkinson's development.) The PLWP tried the product once and it was ineffective, so they never tried it again. The design of the product made them feel like a hospital patient, incapable of doing things for themselves. My

interviewee specifically noted this as an important experience in interacting with Parkinson's technology.

Discussion

Main points in my research point to a solution being in walking, standing and sitting mobility, as these are areas that PLWP struggle the most with. Every research method I conducted mentioned problems like these and the desire for a product that could address them.

Due to existing product research and the interview with the Parkinson's Specialist, many of these products already exist, specifically targeting the areas that research findings identified. A main issue now is price, as these products can be exorbitantly expensive, far beyond what the elderly can afford. Additionally, these products are not currently connected with the health system, they are rarely supplied by health insurance, hospitals or aged care. Most products supplied, are not Parkinson's specific, ultimately reducing their potential effectiveness.

Research has shown that exercise can act in the same way as Levodopa, boosting dopamine levels to the brain. Currently many different activities and methods are being used to try and get PLWP moving, with mixed results. However, this challenge requires a system intervention much more than a new product. New systems of keeping active need to be trialled, then implemented before a product can be developed to aid it.

Medication is a far more important and central part of treating Parkinson's than was originally anticipated, much more than any Parkinson's specific product. PLWP depend on medications like Levodopa to function at a normal rate or at all. Their lives revolve around the highs and low points of the medication effectiveness. There is currently no system or product that manages this, while also giving quantitative data to people that require it. Specialists such as neurologists need to have access to the data of medication taking, to be able to provide and mediate effective treatments, otherwise PLWP could be under or overmedicated, which can greatly affect their quality of life.

While it is easy to treat PLWP as patients, they are people with specifically raw emotions and strong tendencies to develop mental health disorders. Often, they feel as they have no control in their lives and treatment, having all parts of their lives controlled and all tasks done for them. Interviews have shown that keeping some sort of independence or control in the lives of the PLWP can sustain their mental health and prevent other non-motor symptoms from occurring. Maintaining their feeling of humanity and value is intrinsically important in the condition of their mental health and maintaining their quality of life.

Design Implications

One of the greatest and important implications for design is the need for a device that allows PLWP some control over their life, rather than making an automated system that could make them feel incapable or inhuman. Creating a device that is aesthetically pleasing that encourages users to want to use the product will be important, as it can provide no benefits if it is not used. It cannot look like a “care” device, as this will affect product adoption for the product and potentially others that aim to assist PLWP.

People with Parkinson's can live independently, with partial care, in aged care facilities and full-time high care, depending on their situation and PD stage, so designing a product that will be effective and add value to a wide range of contexts will be challenging, ensuring that the user still has enough control over the product and its system and process, but not so much control that they cannot use it in later PD stages.

In all forms of research, Literature Reviews, Interviews, Surveys and Observations, it has become overwhelmingly apparent that PD manifests in different ways and varying levels in all people. No one product is going to be effective for all, so choosing a specific group and targeting them will be a way to design a strong and effective design solution

Design Opportunities

Movement and Mobility: There are possible areas with design opportunities that could aid in providing some sort of mobility back to the person. These could include a new walker that addresses gait problems and shuffling, by having a wide area for legs to move as well as showing some sort of marker to step over once a freezing episode occurs. Another opportunity could be in a chair, that aid the person in standing up in an anatomically correct and fluid motion, allowing the user to take over and stand effectively and correctly. This same premise could also be adopted into an exoskeleton leg support system, providing strength in times it is needed, allowing the user to sit and stand in all places.

Exercise: There are opportunities in developing new ways to get PLWP moving, whether that be through a PD specific smart watch or a fun, interactive exercise system, for individual or group use. New systems that can creatively promote exercise, in forms that PLWP can do and are interesting in, could be greatly beneficial to their physical and mental health

Medication Management: A system that measures and records when and how much medication is taken, for the use of specialists, carers and family to monitor and ensure correct medication. This system would need to be somewhat analogue, allowing the user to complete the task themselves, rather than being fed the medication by a machine, allowing the person to maintain control of their medication while also ensuring it is done correctly.

With many of these opportunities, specifically movement and mobility, products have already been developed. Creating a new, creative and effective innovation would be a challenge, especially due to the recent spike in research and development in recent years.

The opportunity of new ways of exercise would be a valuable and interesting topic, but the system to support it is lacking, with very few resources and support for a product intervention to be effective and worthwhile. Perhaps in a few years, revisiting this topic will be worthwhile, as the exercise system around PD develops.

A medication management system that still allows the user to maintain control of the process poses many problems. Designing a system that can cope for many different scenarios and values would be difficult, so designing a product that can navigate and cope with these problems will be challenging.

Conclusion

As mentioned previously, PD is a unique experience for all. No one design solution will be effective in addressing problems and aiding issues for each PLWP. Currently, the Parkinson's system is lacking solutions and products in many areas, leaving PLWP to struggle without any sort of effective developed support.

Parkinson's is a neurodegenerative disorder that evolves as the condition worsens, finding medication, activities, therapies and treatments that can reduce and slow physical symptoms occurring can greatly increase their quality of life, until they can no longer function. Enabling them to live life with the least hinderance from PD is the ultimate goal for this project and the entire PD care system.

Movement issues are the most debilitating symptoms of PD, causing simple tasks to become impossible. Without specialised medication and PD equipment, people will not be able to function, greatly decreasing their quality of life.

Non-motor symptoms and mental health problems appear just as frequently as motor symptoms. As these cannot be addressed by a simple product intervention. All products designed for PD must consider these things, ensuring that their mental health needs are met, managed and cared for is vital in effective treatment and can reduce symptoms and increase quality of life

Opportunities identified for product development and intervention include movement, involving walking, gait, standing, sitting, manipulating objects and performing simple tasks. Maintaining the ability to live day-to-day life, greatly effects the persons overall wellbeing and mental health. Exercise is known to decrease motor symptoms in PD, but specialists have issues getting PLWP involved and active, design a product to help address this could have great effects on living quality and reduce reliance on medication. A medication management system could ultimately enable more accurate medication taking, ensuring it is as effective as possible and providing specialists with the correct information.

Based on the variety of research methods applied, there are some promising design opportunities in need of development. Parkinson's is a complex disease with varying experiences, but new systems and products can be developed to address symptoms and experiences unique to Parkinson's in order to decrease symptoms and provide the person with a high quality of life.

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Appendix

Survey Results

Q1. What is your role in the Parkinson's System? (PWLP, family, caregiver, etc)

- PLWP
- PLWP
- Caregiver
- PLWP
- PLWP

Q2. What PD Symptom do you feel is the most debilitating?

- Sudden weakness ("zombie days"), and trembling.
- Slow walking with short steps
- Weakness and lack of Control Over Movement
- Anxiety
- Cognitive decline

Q3. What PD symptom has the least developed support?

- Loss of smell
- Uncontrollable Movements, Loss of balance
- All of them. PD is not understood by most GPs, specialists, the general public!
- Understanding of patient's symptoms
- Too many to answer

Q4. What PD aiding products, medical or personal would you like see?

- Something to help stretch out my legs
- A reasonably priced rollator streamlined; I need it to go to the loo without falling.
- Too broad a question
- More emphasis on exercise immediately upon diagnosis, assistance with rising from chair, toilet, bed, car seat.
- Incontinence aids

Q5. I am to design a device that assists PD patients with mobility and quality of life. In what area would you recommend I research and attempt to design for? What area could have the most impact?

- Walking normally
- Walking, getting up from a chair or sofa with no armrests
- An aid to simultaneously assist with balance and movement while aiding lifting and moving items from one place to another
- A lightweight, strong walker that's height adjustable.
- Mobility