ParkinsonPal

(Image generated by Meta AI)

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Project Phase: Phase 1 - User Research

Contribution of Individuals

Name	Contribution statement
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Honor Code:

As participants in the group project, we recognize the importance of integrity, originality, and ethical conduct in academic and creative pursuits. This honor code serves as a commitment to uphold these values throughout the project.

1. **Respect for Originality:** We will endeavor to create original work for all submissions related to the project. When inspiration is drawn from existing sources, appropriate recognition and citation will be given.
2. **Acknowledgment of External Assistance:** If we seek and receive help from external sources, including online resources, texts, experts, or artificial intelligence tools like ChatGPT, we will transparently acknowledge this assistance in our submissions.
3. **Collaborative Integrity:** As this project involves group work, we commit to contributing fairly and honestly to our team's efforts. We will openly communicate our ideas, respect the ideas of others, and ensure that all members' contributions are duly recognized in the contribution statement. In the case of unfair or unequal contributions by member(s), we will highlight this in the contribution statement section.
4. **Adherence to Guidelines:** We will adhere to all the guidelines and requirements set forth for the project, understanding that these are in place to ensure a fair and equitable experience for all participants.
5. **Consequences for Non-Compliance:**
   1. **First Violation:** Failure to adhere to any part of this honor code will result in an automatic failure for the project phase in which the violation occurred.
   2. **Repeat Violation:** A second violation will result in a failure for the entire project and referral to the disciplinary committee for further action.
6. **Digital Signature Commitment:** By digitally signing this document, we individually affirm our commitment to these principles. We understand that failure to adhere to this honor code may result in consequences as determined by the teaching team and the university.

Digital Signature:

By typing our names below, we digitally sign and commit to the Honor Code of this course/project.

- Member 1:   Hussain Sulaiman Zia   27/02/25
- Member 2:   Azaan Imran   27/02/25
- Member 3:   Zainab Humayun   27/02/25
- Member 4:   Rumaan Mujtaba   27/02/25
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1. Problem description

Parkinson's disease (PD) is a progressive neurological disorder that affects movement, cognition, and daily life. People with PD often struggle with tremors, stiffness and loss of balance. Additionally, they may face memory problems and cognitive decline, which can affect their ability to manage medications, appointments, and exercise routines - all key factors in maintaining their health and well-being. These challenges impact their independence and place immense emotional strain on their caregivers and loved ones.

Managing Parkinson's symptoms requires consistent medication, regular exercise, and symptom tracking. However, cognitive and motor impairments can make it difficult for patients to stay on top of these tasks. Caregivers and family members also face challenges in providing timely assistance and monitoring the patient's condition.

2. Introduction - (~1 page)

Parkinson's disease (PD) is a progressive neurodegenerative disorder that causes hindrance in movement and may result in tremors, problems with balance and coordination, which is due to loss of dopamine-producing neurons in the brain. Negative Impact of PD worsens over time and age. Although it can be in younger people, it is quite rare. Apart from problems with motor functions, PD may also result in psychological symptoms including worry and sadness, as well as dysautonomic symptoms including low blood pressure, constipation and abnormal sensations, muscle spasms, impaired sense of smell, and a skin condition called seborrhoeic dermatitis. A systematic review analyses that Parkinson's disease in Pakistan has risen over the past decade, and amongst 1016 cases 93.2% were diagnosed in hospitals while 6.8% were due to door-to-door surveys. It is also observed that PD is more common in males, 88.5%, than in females, where it is 11.14%, which aligns with that found in the global spectrum. The average age of individuals affected due to PD is 50 to 70 years. The highest number of cases was recorded in Lahore (85 cases), while the lowest was in Lower Dir and Malakand (14 cases) (Jamali et al., 2024). Another study has found that PD has affected almost 1 million individuals in the country altogether(Tufail, 2019).

In Pakistan a study was conducted on 70 PD patients between ages 50-70 years at Neuro-Medicine Ward, Jinnah Postgraduate Medical Center, Karachi, between August 2019 and February 2020 based on prevalence of non-motor symptoms in Parkinson's diseases in Pakistan which showed that the non-motor effects were in percentages: Depression 54.3%, anxiety 41.4% (Ahmad & Zubair, 2016). It also showed that while depression remained constant, anxiety decreased and insomnia increased. This study concluded that these were common symptoms and required focus on early diagnosis. The disease can be treated in multiple ways i.e., pharmacological approaches including levodopa with carbidopa, dopamine agonists, and monoamine oxidase-B inhibitors (*Pakistan Parkinson's Society - Treating Parkinson's Disease*, n.d.-b), advanced surgical interventions like Deep Brain Stimulation (DBS) are available for severe cases, showing significant benefits in selected patients (Syed et al., 2020).

Supportive therapies such as physical, occupational, and speech therapy, along with psychological support, play a crucial role in patient care (*JCPSP | Journal of College of Physicians and Surgeons Pakistan*, n.d.). However, limited awareness, late diagnoses, and a shortage of specialized neurologists hinder effective management. Ongoing studies aim to explore genetic predispositions, develop neuroprotective therapies, and improve early diagnosis. Further efforts are needed to assess emerging treatments like stem cell therapy (*Parkinson's Disease | Stem Cell Treatment in Pakistan*, n.d.), and enhance healthcare infrastructure to support PD patients more effectively.

As technology grows there is a growing need and accessibility to smartphones and technology which has allowed multiple global advancements in Parkinson's apps including the APDA Symptom tracker app(*American Parkinson Disease Association: Hope in Progress*, n.d.), The PPMI Mobile App by Michael J. Fox Foundation for data collection(*PPMI Mobile App | Parkinson's Disease*, n.d.), etc. Moreover, in Pakistan Trequant Wearable Device to measure tremor and identify tremors allows lifestyle adjustments (*This Pakistani's Tremor Tracking Wearable Helps People with Parkinson's Disease*, n.d.) thus, some progress in using technology and apps to allow patients some ease and accessibility and lifestyle improvement. Our research includes conducting interviews of PD patients and doctors and understanding the major problems faced by various patients.

3. Literature review/Previous work - (no word limit)

In this period of technological advancements and inclusivity, there has been vast research on making the world more accessible for those suffering from various diseases, etc and hence, several assistive tools have emerged that aid patients diagnosed with Parkinson. This includes mobile apps developed to help people with Parkinsons along with wearable devices designed for them.

A study conducted on digital interventions for Parkinson's Disease (Lee et al., 2022) helped gain valuable insights about the existing apps that aim to help patients. The paper explores the design and the different features of the existing apps; making observations about how most apps are directed towards the self-care of the patients. This includes medication reminders, exercise tracking, data collection, and also visual representations of the data trends. The study further emphasized that while most apps feature 'self-maintenance', it is not sufficient for the smooth tracking of patient data as they focus majorly on how people, diagnosed with PD, can ensure that they follow what they have been advised. The study included apps that monitored the motor symptoms but not the non-motor symptoms which mainly included disturbance in sleep, cognitive unfitness, and mood changes. This is a problem that needs to be addressed as these symptoms contribute a lot to the fitness of the patient. Failing to do so would result in patients going into depression and anxiety that would further deteriorate their health. Moreover, the study also explains how most existing mobile apps adhere only to medication reminders. It tells how physical activity is really important for the patients and how sometimes, they would be motivated enough to do the exercises but would be unable to follow the exercises correctly which again is a problem that could be addressed in our app. Provide an exercise plan for the users so they can learn and

practice physical exercise wherever they want to. This would help them learn the exercises that are good for their movement.

Some apps provide these exercises for the patients but then they are solely based on the exercise trait and don't feature any other characteristics (Landers & Ellis, 2020). Continuing the same theme, there is another study conducted on the monitoring of Parkinson's patients remotely during the COVID-19 period (Motolese et al., 2020). The monitoring was done by repeated sampling of the current experiences and behaviours, also defined as ecological momentary assessment. The study discusses how the traditional monitoring of the patients could be ineffective in some cases such as noting down patterns or trends on a very day-to-day basis. As a result of this, using a smartphone to write a diary on the patient's behaviour is much more beneficial. It records the severity of the patient, which is highly crucial when assessing the patient after a long time. Daily monitoring of the motor and non-motor symptoms leads to more precise information to the medical helpers which in result, leads to better and more accurate patient care. Conclusively, some apps exist out in the world that can be used for telemedicine and are yielding positive results but they, more or less, focus on one aspect of the disease, leaving the others. A product that allows to achieve all of these, would most certainly be very appreciated and useful.

Motor Symptoms

Researchers have conducted studies as well using the existing knowledge about the improvement of symptoms associated with Parkinson's. This is a very crucial understanding to have when designing an app for patients. It helps in finding out whether the given solution would affect the patients or not. A similar study is done regarding the physical exercise that aids in improving the conditions of the patients (Afshari et al., 2017). The study finds out that exercising leads to self-efficacy of the patients. Physical therapy of the patients leads to improvement in the motor symptoms thus leading to better motor control. The study further discusses that it also leads to improvement in non-motor symptoms as well. The data they collected showed that people who did exercise, reported a change for better in their non-motor symptoms such as mood and sleep, helping them to achieve a better quality of life. On the other hand, people whose activity was less or no, reported anxiety and depression. This information discussed is really necessary as it tells that providing a plan for people to follow would not only help their movement symptoms but also their non-movement symptoms. Retaining this information, we can aim to design technology that can help out the patients and help them improve their quality of life.

Secondly, people with Parkinson's have difficulty with voice control and clear speech, their speech is soft and difficult to understand for most. Different programs using voice assisted technology (VAT) have been created to assist PD patients in daily tasks.

A research conducted on Parkinson's patients reported about 80 percent of them to have experienced voice changes due to the disease signifying the need of VAT to enable communication among these patients (Landers & Ellis, 2020). It is reported that using VAT more than 70 percent of the PD patients

were able to complete almost all digital tasks such as sending emails, using online apps or making video calls. VAT proved useful medically as well by making it easier to set reminders for medication and scheduling appointments with doctors. Despite facing speech difficulties, the majority of the patients report that they seldom had to repeat themselves while using voice assisted technology and were able to use it consistently, thereby supporting the accuracy of such technology.

Existing Apps for Treatment of Motor Symptoms - Pros and Cons

Today apps exist in order to help the patients with their physical activity as well. An example of the existing app that aids patients with their physical activity is 9zest Mobile App. A study was conducted on the usability of the app to test out its efficacy on the patients diagnosed with PD (Landers & Ellis, 2020). Their methodology was to invite people who had downloaded the app to participate in the study being conducted for various aims. The data was then recorded and analyzed. The key findings of the study were that a majority of people were content with the app-guided exercises. They felt that not only were the exercises safe, but they were also very relevant to their condition. Another important finding to be noted is that most of the people also informed that they felt that they felt noticeable improvement in their condition by following the exercise programs given by the app. The study is crucial as it tells that there has been effective use of the exercises that are offered by the app.

Non-Motor Symptom - Sleep Disorders

Parkinson's patients face trouble falling and staying asleep paired with limited mobility that makes it hard to turn over in bed causing agitating sleep disruptions. Sleep disorders such as insomnia, restless leg syndrome and REM (Rapid eye movement) sleep behaviour disorder are common among PD patients. Prescribed medications and mood instability worsen sleep patterns (Bollu & Sahota, 2017).

Existing Apps for Sleeping Disorders - Pros and Cons

To help cater similar issues, apps like Sleepio are designed to help PD patients. Sleepio is a digital cognitive therapy program that is personalized to the needs of the user, it builds slow and gradual week by week progress to make it easy for the user to keep up (Desotell, 2022). It sends helpful suggestions that are mostly basic and probably well known to the user already, however the cognitive exercises train its users to battle negative thought cycles that ultimately lead to mental relaxation thereby improving sleep.

Another study conducted on another one of the aforementioned apps related to sleeping disorders in PD patients.. The authors conducted research on the first app that was developed specifically for patients diagnosed with Parkinson's disease, known as SleepFit (Mascheroni et al., 2021). The study was done in collaboration with doctors to get better and accurate results of the usage of the app. The principal findings of the research highlight that the app was a success as it was very user interactive and since it was developed specifically for patients with PD, it took into account their input which made the app

very user-friendly for them. Furthermore, the users found the app accessible as well, given the motor impairments. They could easily reach the target locations of their smartphones and navigate through the app. The app was beneficial as it took input from the users and could be used to monitor the sleeping patterns of users for their follow-up checkups.

Research has been done to assess the use of technology in improving the lifestyle of PD patients (Triantafyllidis et al., 2023); the findings supported the claim that the apps designed for patients with PD and similar neurological diseases helped with physical activity as were proved useful for the patients to get better exercise adherence, refined movement metrics, reduced fatigue, educated the patients while also letting them monitor the treatment and the disease symptoms separately. However, it is reported that most of these apps were primarily focused on helping with physical symptoms with little support for cognition, education and overall quality of life. The research suggests that doctors, patients and caretakers should be closely involved with the design team when creating such applications allowing modifications to be made according to their needs and requirements. Additionally, the interface of these programs is designed considering high literacy groups while ignoring the user category that falls in the low literacy group, as a result only a restricted amount of users from the user group are able to effectively use the apps.

Ideal Design

Furthermore, studies provide insights into the rationale behind app interface choices. A study conducted shows how health apps, that have a complex interface, are not suitable for some groups such as the elderly (Peng et al., 2016). Since most of the people diagnosed with PD are elderly, the interface needs to be simple and easily accessible so it doesn't obstruct the usage of the app. The study uses the phrase '*digital literacy*' which will be kept in mind while designing the app for the patients. Digging a little deeper into the fine details, the study explains that once users are comfortable in sharing their data and personal information, they find the reminders of the apps to be very helpful. A feature such as setting goals and tracking them makes it much more interactive and personal for the user and helps promote self-efficacy.

Despite its benefits, Sleepio and similar programs like Calm have a user interface that is too complex for Parkinson's patients. Elderly people struggle with the sign up and login due to poorly designed login pages, the questionnaires that such apps have are mostly too long and technical for old people (2024 reviews). Users are asked to keep track of the time they go to bed and how long it takes for them to sleep, this can be inconvenient as users will have to keep looking at the watch til they nearly doze off to sleep. While these apps focus on sleep efficiency, they are not designed to help improve sleep duration which is a primary concern for Parkinson's patients. Some of these apps have lengthy unskippable videos purposed to teach users improved methods to achieve a healthy sleep pattern, old people have trouble remaining focused on the video content due to its length or sometimes are unable to even watch it to the end.

Voice assisted technology (VAT) though highly accurate is not affordable for all PD patients and a considerable group of PD patients will be unable to benefit from it. VAT is designed in a manner to cater needs of medium to high literacy groups, patients who are not literate will not be able to effectively use such technology as they may find it too complex.

Conclusively, an interactive design will be crucial to establish a more personalised experience for the users. Amalgamating all of these needs that are absent in other apps, we aim to design an app that fits all these requirements that would help patients diagnosed with PD to not only learn about their symptoms, but also aid them in taking care of themselves.

<u>Conclusion</u>

In our project, we aim to create an application to aid Parkinson's patients. The user interface will be kept simple and the solutions offered will be specialised to the needs of Parkinson's patients. Instead of just being able to communicate with an LLM, our users will be able to stay in direct contact with their doctors for medical support. Our project aims to provide complete experience for the patients, helping them in ways where other products lack. Keeping the demographics and other factors, our product can be very useful to even people with limited skills in their arsenal. Moving into an age of technology, our product can be used as telemedicine to provide services to the patients diagnosed with Parkinson's so that not only are they able to promote their self-efficacy but also provide them with the health care they require.

4. Existing Products

There are several apps available commercially that aid people living with Parkinson's to either track their symptoms or help them with the non-motor symptoms such as sleep disorders or mood swings. These apps have specific features such as reminders for medication, the ability to journal their symptoms and guide to physical exercises. Although these apps exist, each app has complications as well. To keep the discussion short but a little descriptive, let's analyse some products that are available as of now:

<u>Parkinson's ON:</u>

Parkinson's ON offers a wide range of features such as medication reminders, the ability to log and track your symptoms and a smart way of scheduling the medications. Furthermore, it empowers people with Parkinson's so they can be self-effacing. Although it offers various features, it still fails to deliver some crucial features required in uplifting the quality of life of the patients, such as giving recommendations based on the symptoms, and providing insights which could be helpful for the patients or their caretakers to track their progression. (2025)

My Moves Matter:

This app allows its users to log their symptoms and their daily activities. Moreover, it is also really useful for the females who are diagnosed with Parkinson's, as it features a way of tracking the menstrual cycle as well. However, one of its complications includes a difficult and challenging interface that people find difficulty interacting with and lacks useful insights. (2025)

Neuro Heroes:

This application features live classes for the physiotherapy session for the patients. Experts hold classes for patients to watch and do as they teach. Moreover, it requires no equipment as the classes are simple, needing no special equipment for the patients. It has cons as well which is that it is a paid subscription, making it limited to people with enough resources and secondly, the classes aren't recorded so if a patient wants to refer to it later, he won't be able to do that. (2025)

Beats Medical:

Finally, this one offers therapies to people diagnosed with Parkinson's Disease. It is designed to aid the patients with their symptoms by providing guides regarding physical, speech and language symptoms of the patients. The cons of Beats Medical is that it doesn't cover the non-motor symptoms of the patients and it is paid, which means it's not accessible for people with limited resources.

What is common amongst the above apps is that they are specific to only one aspect of the disease and do not provide comprehensive support within a single app. Secondly, most of the apps are either costly or have an interface not designed specifically for the elderly/parkinson patients and they face issues in interacting with the interface according to the study (Orozco et al., 2020).

We aim to develop Pakistan's first ever complete app for patients diagnosed with Parkinson's disease, in hope of improving their quality of life and ensuring better care of the patients.

5. User research method

The user research method we mainly used is semi-structured interviews. We did not use surveys as there are very few people in Pakistan with Parkinson's disease who could answer the questions or effectively use technology so it would have been an inconvenience. The interviews on the other hand allowed us to understand the user problems, needs, and pain points. It also allowed us to connect with the patients and clarify any confusions by asking follow up questions.

Given that our user group was small, interviews were the most suitable method, as they allowed us to gather in-depth insights from a limited number of participants. Additionally, interviews allowed us to

observe the patients as well, helping us understand the physical and cognitive challenges they face in their daily lives as Parkinson's majorly affects the motor skills of the patients.

Conducting semi-structured interviews also meant that we could tailor the interviews to meet the patients' context. For instance, we could ask questions in Urdu, or explain the question (give examples) to make it easier for the patient to comprehend and also feel comfortable answering.

6. User details

Our primary user group consists of patients in the early stages of Parkinson's disease (PD) in Pakistan. We chose this group because early intervention can help better manage the progression of the disease and improve their quality of life. Patients in this stage start losing their independence, struggling with tremors, stiffness, and mild mobility issues. Many lack access to individualized care due to limited healthcare infrastructure and financial constraints. We want to focus on this group, hoping to develop an affordable, accessible solution that will help them maintain their independence, manage symptoms, and stay socially active.

7. Method plan

Interview Protocol

Due to the small size of our user group, finding participants for our primary research was quite challenging. We connected to most of the patients through friends and family, usually reaching out to their caretakers first before meeting them. We had a list of tentative questions (attached in the appendix), starting with the patient's initial diagnosis and early symptoms. Then we would move onto the effects Parkinson's has had on their day-to-day lives and any mental stress they faced due to the disease. They were also asked if they faced any problems when using electronics like mobile phones.

We also reached out to doctors (neurologists and physiotherapists), primarily through cold calls to hospitals and clinics, requesting an interview for our research. The questions scripted for them started with the symptoms of Parkinson's and the diagnostic process, and then continued to the effects it had on patients' daily life, physical and mental well-being. We would then ask about the disease's progression, and any treatments to manage the symptoms.

Focus Settings

The interviews were conducted over a period of two weeks, taking place in various settings. They were mostly in-person, at the patients home with a family member present. In our opinion, this was the best setting for the interviews, as it ensured the patients comfort and was a familiar environment. There were exceptions to this, like one interview at an old age home where a staff member was present and two interviews taken online.

Contextual Inquiry

A proper Contextual Inquiry was not feasible during our research, because of privacy concerns. Families would not have been comfortable with us visiting their home just to observe their elderly loved ones doing daily tasks. However, since most of the interviews were conducted in-person at the patients' homes, we were able to gather some insights by witnessing their physical and cognitive challenges in real time.

Interview Documentation

For all interviews, we first asked the caretakers/family and the patients for consent before starting to record. In some cases, the family were not comfortable with the patient being captured on video, so we either only recorded the audio or pointed the camera away from them. Keeping ethical considerations in mind, we did not record the patients or capture any pictures outside of the interview. During interviews, other group members present would take notes and immediately after we would discuss any observations we made.

8. Your Findings/Results

Through our research and analysis, we identified three major pain points amongst our user group:

- Patient's do not prefer going for physiotherapy.
- Doctors find it difficult to track the disease progression in patients.
- Patient's dislike the lack of independence

Patient hesitance in going for therapy

Patient beliefs

Patients in this study believed that going for physiotherapy as they are already walking and staying relatively active, which is essentially what the physiotherapists make you do.

"I do not go for physiotherapy, I do hand movements and I have a little walk outside with my friend, but nothing too heavy. Cause my dad has it… so what they make you do is walk indoors, raise your legs using a scarf and rotate your shoulders" (Patient4_Naheed_Rehman, 27/02/2025)

"I walk in my corridor, take 3 or 4 rounds and do some exercises while sitting down" (Patient8_Rehana_Iqbal, 27/02/2025)

What is surprising is that a lot of the patients reported that physiotherapy had made their conditions worse which could be linked to either of the reasons: a) during the start of the physiotherapy, patients felt more tired which is normal,b) patients saw little to no improvement and got demotivated, c) patients were advised exercises without proper evaluation. Adverse events (AE's) do occur during physiotherapy and is majorly due to the lack of personalized plans (Caniça et al., 2022).

"Physiotherapy didn't work much for me and I was not very happy with that. Sometimes I used to go but I was not very with that, I do exercises at home but don't go anymore"(Patient3_Siddiqa_Hussain, 20/02/2025)

"No, I feel it's non effective"(Arshia Khalid, 26/02/2025)

"When she took physiotherapy, she was in the worst agony we have seen her in" (Caretaker3_Nighat_Hussain, 266/02/2025)

However, while the patients' experiences are important, the physiotherapists and neurologists differ in their opinions about at home therapy. While they do agree that the patients' should stay active in their daily routine, passive exercises are not possible. Some parts of the body need to be moved to keep the range of motion (RoM) complete.

"We need to stretch the flexors and strengthen the extensors to ensure that the body does not become rigid… have to make sure the joints motion is complete… people in early stages can do some of these at

home, but at later stages you need a professional to help you rotate your arm otherwise if you do not move it for a whole day, it will become rigid…" (Physiotherapist1_Dr_Ishfaq, 19/02/2025)

Difficulty in Tracking Progression

Irregular doctor visits and self managing the symptoms

Doctors often find it difficult to track the progression of the disease in follow-up meeting or regular check-ups as most patients that were part of this study claimed that they do not go to see the doctor on the regular basis and prefer to manage their symptoms on their own.

"The medication that I took didn't really help that much…I know this is the problem that I have so I'm just dealing with it." (Patient4_Naheed_Rehman, 27/02/2025)

" I used to go to the doctor before but now I don't, my son is a doctor too he manages all my medications… changes the dosage when required" *(Patient8_Rehana_Iqbal, 27/02/2025)*

Availability of Medicinal Drugs and Treatment

Given that this study is based in Pakistan, there are issues with the availability of medications, which makes patients hesitant to even start certain treatments due to concerns about continuity. Considering that the Parkinson Disease (PD) medications have severe side effects, immediate discontinuity can pose some risks.

"The prescription that the doctor gave isn't available in the market. I know of a story where someone was taking a medication which became unavailable and he was sleeping 18 hours a day... I do not want to get into a situation where I have to rely on a drug" (Patient7_Maajid_Maqbool, 28/02/2025)

Other than these, people also heavily rely on homeopathic drugs as alternative treatment for the disease, despite unclear scientific backing. This reflects a broader issue of healthcare accessibility in Pakistan, where patients often self-manage their treatment.

"I did not try physiotherapy but sometimes when my old friends come, they give their suggestions to do this and that, try homeopathic drugs. I tried them but nothing I did benefitted me."(Patient6_Yasub_Dogar, 26/02/2025)

" I did not really try any exercises as such, but lately I have resorted to homeopathic medicines. … In UK, they use waves and pinpoint them in the precise area of the head and the tremor goes away due to them. But these (treatments) are not available in this country and to go there (abroad), it takes time and is quite expensive. (Patient7_Maajid_Maqbool, 28/02/2025)

Inconsistency in Treatment

In Pakistan most people with PD don't have a specific doctor that they visit, and this means that every time they go to a new doctor, they have to explain their symptoms and progression to the doctor. This is

a painstaking task and most patients often end up telling the doctor of only recent stuff and may miss out on some information about their medication or any alternative treatments that they may have tried in the past.

"Many times you ask someone oh how is your father doing and they really don't know how to explain what exactly is going on." (Doctor1_Khalid_Jamil, 18/02/2025)

Doctor Khalid also highlighted in an informal conversation that people often change doctors, so it easier to have something in front of you to see the progress.

Loss of Independence and Psychological Impact

PD is highly distressing for the patients as they eventually become dependent on their caregivers or families. Small everyday tasks can become distressing when one has to constantly ask for help, which leads to feelings of frustration, guilt, and helplessness.

"The forks and the knives are heavier that parkinson patients use but my father used to get annoyed, if he can't eat he would get annoyed" (Patient4_Naheed Rehman, 27/02/2025)

"I try to not ask for help, like i can't open bottles so I have to ask someone to do it for me but I try to do things on my own" (Patient6_Yasub_Dogar, 26/02/2025)

"I still try to do household work, cook when I get the time and am feeling better" (Patient8_Rehana_Iqbal, 27/02/2025)

"I walk a lot because I'm scared of losing mobility completely" (Patient5_Asfa_Farooq, 21/02/2025)

It was also apparent that some participants did not want to express how much their life has been impacted by the disease. One of the patients expressed reservation in letting us speak with their family and upon our arrival were also adamant on arranging the seats for us. This shows how PD patients prefer to control the narrative around their condition and appear independent.

At another instance, a patient, when asked about if their hobbies or lifestyle have been affected, mentioned how they are nothing without their hobbies and that while it had posed challenges they were still able to engage in all the activities she did prior to her diagnosis. The caretaker differed and clarified how many of the hobbies that were mentioned were things the patient can no longer do such as sewing or going out for social work. This discrepancy highlights the psychological aspect of disease acceptance, where some individuals may downplay the impact of Parkinson's either as a coping mechanism or to avoid appearing dependent.

"My mother may not want to admit it but parkinson has affected her life a lot and she can't do those (hobbies) anymore" (Caretaker2_Nighat_Hussain, 20/02/2025)

PD takes an immense psychological toll on patients, with depression and anxiety being among the most common non-motor symptoms. Many patients in the study reported feeling embarrassed in public hence,

leading to a decline in self-confidence and social withdrawal. Patients frequently reported avoiding social interactions because they struggle with tremors, speech difficulties, or slowed movement, making them feel self-conscious in public settings.

"Initially, when this diagnosis came, I used to be very fit in the army days. I was part of the Special Services Group. I used to think, "Allah what has happened to me? Why of all the people me?" So yes the feeling was there. I was not in a deep depression but was definitely demoralized."
(Patient6_Yasub_Dogar, 26/02/2025)

"It goes without saying it's quite embarrassing for her to be seen in a wheelchair and feels depressed."
(Caretaker1_Ruqhia_Nazeer, 26/02/2025)

Parkinson and Technology

This study found that the participants faced trouble using their mobile phone as the interface is not PD friendly. The icons are too small for the patients hence, due to tremors they often press the wrong button and have to rewrite stuff multiple times. While some patients do use voice features more often than typing, there is also reasonable evidence to believe that the voice feature might not work efficiently for patients who have problems with their speech.

"It is pressing the wrong place which is a real challenge…if something can speed up my typing that would be great" (Patient7_Maajid_Maqbool, 28/02/2025)

"Sometimes my hand starts to shiver after I'm on my phone too long" (Patient4_Naheed_Rehman, 27/02/2025)

"When I type, sometimes I press the digit next to the one that I had to press accidentally" (Patient6_Brig_Yasub_Dogar, 26/02/2025)

Technology to Bridge the Gap Between Doctors and Patients

Almost every person nowadays has access to a mobile phone and the internet, making technology a potential tool for bridging the gaps in Parkinson's care. During this study, we identified numerous shortcomings in patient care and disease management that could be addressed through well-designed digital solutions. Neurologists and caretakers also wish for there to be technology that while cannot replace them, would ease their daily tasks.

This would also be feasible as most participants in this study claimed that they do still use the mobile phone, despite having several issues with the interface.

"It would be really helpful, if you could see things charted down: their mobility, gait, speech. Many times caretakers really don't know how to explain how the patient is doing" (Doctor1_Khalid_Jamil, 18/02/2025)

"All depends on what and how helpful it is going to be" (Caretaker1_Ruqhia_Nazeer, 26/02/2025)"

Minor Findings:

Social Life and Hobbies

Almost all participants reported that their social life has deteriorated, as they are unable to move around as much or to stand for long periods of time so can't engage in sports or household chores (standing in the kitchen).

"I was a very mobile person, I used to go to these clubs or out of city but now because I can't drive and because of the effort it takes in preparations but I still try to keep relatively active otherwise I will go back into depression" (Patient6_Brig_Yasub_Dogar, 26/02/2025)

"It has definitely affected her social life, she used to go out alot and do alot of social work which she can't anymore because she can't stand for that long" (Caretaker2_Nighat_Hussain, 20/02/2025)

Hobbies and socializing is one thing that helps patients feel more active and keeps their mind engaged so also helps control some of the tremors. The participants who have continued to engage in hobbies also seemed to be doing better than those who have let themselves go. At a visit to the the old age home, the caretaker Muhammad Awais also mentioned how all residents have a "gametime" where they play 'Ludo' and other board games.

"In the evening there is a gametime for all the residents.. they play ludo, and sometimes they watch tv" (Caretaker2_Muhammad_Awais, 20/02/2025)

"Without my hobbies I would not be able to survive" (Patient3_Siddiqa_Hussain, 20/02/2025)

"My mother plays solitaire in the newspaper… at this stage many patients really deteriorate but she is way better because she keeps her mind and body active and goes out even if it's for a little while" (Caretaker2_Nighat_Hussain, 20/02/2025)

During an interview with the neurologist, he mentioned how PD patients are also given visual mental cues which help engage their brain and so they are able to overcome the rigidity or sudden stops.

"Sometimes they are walking and then they are frozen, if you put a piece of paper in front of them and ask them to cross it, their brain comes to action and they will cross it" (Doctor1_Khalid_Jamil, 18/02/2025)

9. Needs and desires

When analyzing the issues faced by Parkinson's patients, caregivers, and doctors, we were able to identify certain needs and desires.

Needs

- Better tracking of disease progression

  Parkinson's is a progressive disease, meaning the symptoms will worsen over time. Tracking these changes is essential for adjusting treatment and improving patient quality of life. However, the progression will be different for every patient, there is no set rate at which their condition deteriorates. Regular checkups are needed for the doctor to be able to track how the disease is progressing, and to then suggest appropriate interventions. However, once the initial shock of the diagnosis subsides, and patients come to accept the fact that they have an incurable disease, they stop keeping a regular appointments schedule.

- Access to effective physiotherapy

  Regular exercise and physiotherapy helps Parkinson's patients maintain mobility, balance, and coordination, reducing fall risks and improving overall well-being. This helps them preserve their independence for as long as possible, reducing stress and allowing them to live a normal life. However, not all patients receive the level of physiotherapy they need, and generic exercise programs may fail to address the symptoms and disease progression for individual patients.

  Most patients we interviewed did not receive regular physiotherapy from any professional. They mostly just relied on exercising individually, taking daily walks and receiving massages at home.

- Managing medication

  Medication is one of the most effective ways to manage Parkinson's disease symptoms, helping patients maintain motor function, reduce stiffness, and improve their quality of life. However, these medications need to be taken at set timings and in precise dosage to be effective. Improper management can lead to severe fluctuations in symptoms and increased side effects, a serious one being hallucinations. Neurologists need to monitor patients every now and then, tracking their symptoms, to correctly adjust medication doses and minimize these effects.

Desires

- Maintaining independence

  As Parkinson's progresses, both the motor and nonmotor symptoms get worse. They face difficulties in performing daily activities (like cooking or changing clothes) due to tremors and stiffness. Their reliance on caregivers increases with time, causing frustration and impacting

self-esteem. They fear becoming a burden on family members. Patients fear losing their independence as the disease progresses.

- Participating in Social Activities

Patients who used to be very active socially before, feel uncomfortable going out due to symptoms like tremors, slowness of movement and speech difficulties. They face multiple challenges like fear of embarrassment due to these visible symptoms and trouble communicating. Fatigue limits their ability to attend events away from home. Many patients suffer from depression and anxiety, leading to social withdrawal. They reminisce of the 'good old days' but sadly feel that such pleasures are now out of reach.

10. New and Final problem statement + Description <(max 400 words)>

After the interviews and observations of the patients and the doctors the new problem statement that we devised is that there exists a need for technological solutions to address disease management and progression tracking. Currently the interactions between the doctors and the patients is largely manual and inconsistent given that patients do not go for regular appointments and only end up going when they have some serious issue. This coupled with Doctor Khalid Jamil's complaint about patients not being able to explain how they are doing goes to show that these irregular appointments mean that any self medication (homeopath, changing dosage without consultation) or other changes in mobility, gait etc that are not recent get left out of the conversation.

From the literature review, we have seen that there are no apps currently that take a one stop approach to the lifestyle apps designed for parkinson patients. Each app has its own shortcomings or even though these apps are specifically made for the patients, they find the user interface too complex or its features difficult to interact with.

Specifically in the context of Pakistan, technology is an underused resource and while many assistive and lifestyle apps do exist in many parts of the world, these have not yet made their way into Pakistan. Every patient experiences Parkinson's in a unique way, facing differing severities of symptoms and requiring individualized medications and therapy routines. However, we do not utilize technology to provide such personalized treatments.

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Appendix

Patients Interview Questions

- What were the first symptoms you noticed before your diagnosis?
- What are the most challenging motor symptoms you experience?
- Do you experience anxiety or worry?
- How often do you feel sad or depressed?
- How has Parkinson's disease affected your relationships?
- Have you tried any alternative treatments (e.g., physiotherapy, speech therapy)?
- How does Parkinson's affect your daily activities (e.g., dressing, eating, walking)?
- Do you find it difficult to use mobile phones now?
- How does Parkinson's impact your ability to work or engage in hobbies?
- How has Parkinson's affected your mental health and emotional well-being?
- Is there anything you wish people better understood about living with Parkinson's?

Caretakers Interview Questions

- How long ago were they diagnosed with Parkinson's?
- How often are the patients taken for physiotherapy or any other type of therapy? (duration + type?)
- Are there any adaptations or tools they use to make daily life easier (e.g., special utensils, walking aids)?
- How often do you take them out for activities?
- How often do you go for doctor appointments?
- How do you tell the doctors about the patient's disease progression?
- Do you use any technology or apps to manage the daily activities as a caretaker?
- Would you want to automate some of your caretaker responsibilities?
- Do the patients use mobile phones regularly? How easy/difficult is it for them? (Plz elaborate) Do they experience problems with memory or concentration?
- Is there anything you wish people better understood about living with Parkinson's?

Doctor Questions

<u>Early Symptom Recognition</u>

- From your experience, what are the most common early symptoms of PD that patients present with? What subtle or less recognized early symptoms do you actively screen for in patients who might be at risk of PD?
- How often do patients initially present with non-motor symptoms like sleep disturbances, loss of smell, or constipation *before* they experience noticeable motor symptoms?
- In your experience, how often do patients dismiss their early symptoms, and what are the common reasons for this? How can we improve patient education to address this?

<u>Diagnostic Process and Challenges</u>

- What is the typical diagnostic process for PD, and how has it evolved in recent years?
- What are the biggest challenges you face in diagnosing PD in its early stages? Are there any limitations in current diagnostic tools or protocols?
- "How do you track disease progression in the early stages, and what milestones indicate a shift in treatment approach?"

<u>Patient Communication and Support</u>

- How do you communicate a PD diagnosis to a patient, especially in the early stages when symptoms might be mild?
- How do you ensure patients understand the disease, its progression, and the available treatment options?
- What resources or support systems do you recommend to patients newly diagnosed with PD? How do you address the emotional and psychological impact of the diagnosis?
- Are there specific lifestyle changes or therapies that you recommend to patients for delaying progression?
- How important is physical activity in managing early Parkinson's symptoms?

Physiotherapist Questions

- How does Parkinson's disease affect a patient's mobility and overall physical health?
- How do motor symptoms (e.g., tremors, rigidity, freezing) impact daily activities like dressing, cooking, or using a phone?
- What non-motor symptoms (e.g., fatigue, depression, cognitive issues) affect a patient's quality of life the most?
- How do you currently track patient progress outside of therapy sessions?
- What common exercises do you recommend for mobility, strength, and balance?
- What are some common obstacles that Parkinson's patients face when trying to follow a physiotherapy routine?
- What are the biggest reasons why patients lose motivation or stop following therapy plans?
- Do patients typically use assistive devices or apps for exercise reminders, movement tracking, or symptom management?
- What motivates Parkinson's patients to stay active and engaged in therapy?
- What advice do you give to caregivers and family members to help support a Parkinson's patient?
- What advice would you give to someone newly diagnosed with Parkinson's regarding physiotherapy?

The consent form used.

CONSENT

I hereby give consent…

…to use my audio/video recordings for educational/research purposes   ◌ YES   ◌ NO

…to publicize pictures from my recordings in written papers   ◌ YES   ◌ NO

Date: ……. - …. - 2025

Gender: Male/Female

Name: …………………………………………………………………………

Age: …………………………………………………………………………

Email: …………………………………………………………………………

Signature: …………………………………………………………………………