

# More than Tremors- Combating the Unspeakable

Providing **E**vidence-based and **C**ulturally **S**ensitive **R**esources  
for Asian Parkinson's Patients

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## Abstract

Parkinson's Disease (PD), an age-related neurodegenerative condition ranking second only to Alzheimer's, is commonly associated with motor symptoms, notably tremors. However, the presence of non-motor symptoms is equally significant, and the lack of observable motor issues can lead to delayed diagnosis and treatment. Particularly within the Asian community, PD remains a seldom-discussed topic despite its increasing prevalence and incidence. This project, a collaborative effort between Tufts University School of Medicine and Asian Women for Health, aims to address this gap by creating a 20– 25-minute documentary and a comprehensive resource guide tailored for PD patients and caregivers. The initiative is designed to educate on Parkinson's Disease, foster healthy behaviors among Asian patients, provide health resources in the patient's and caregivers' native languages (e.g., Chinese/ Mandarin), and encourage participation in clinical trials. The documentary features interviews and live clips of a patient and his wife, along with insights from a physician, physical therapist, and PD researcher. Additionally, a separate video featuring an interview with the PD physician and a resource guide available in Chinese (with translations planned for English and other languages) complement the project's overarching goal of enhancing awareness and support within the Asian PD community in the United States.

### Background

Parkinson's Disease (PD) is an age-related, progressive neurodegenerative condition characterized by uncontrollable movements (Hayes, 2019). Ranking as the second-most common neurodegenerative disease after Alzheimer's, PD manifests with both motor and non-motor symptoms. Motor symptoms encompass tremors (e.g., uncontrollable shaking of hand), body stiffness, slowness of movements and challenges in balance and coordination. The non-motor symptoms include but not limited to, depression, anxiety, hallucinations, dementia, apathy, sleep disorders, insomnia, constipation, erectile dysfunction, REM sleep behavior disorder (RBD), orthostatic hypotension and a loss of the sense of smell (Frucht, 2004). Progressing in severity, PD may impede walking, talking, and independence of doing daily activities due to its functional debilitating symptoms. Globally, an estimated 10 million people are living with Parkinson's, with one million in the U.S., and an annual incidence of approximately 90,000, notably rising in people over 65 years old (Parkinson's Foundation, 2023). While predominately affecting the elderly population, PD can also strike individuals as young as in their 20s, though rare (Post et al., 2020).

Though incurable, Parkinson's symptoms can be alleviated through regular exercise (e.g., aerobic exercise, strength training and flexibility training), medication (e.g., dopamine replacement therapy), and surgical interventions (e.g., deep brain stimulation) (Ellis et al., 2021). Early and correct diagnosis and treatments of PD are crucial for the patient's well-being and beneficial in reducing symptoms (Murman, 2012) and restoring normal day-to-day functions. Regrettably, underserved minority groups, such as first-generation elderly Chinese and Vietnamese immigrants, face the risk of delayed diagnosis and undertreatment (Pan et al., 2014).

Despite PD's global growth in prevalence and likely rise of incidence (Dorsey et al., 2018), the disease remains unfamiliar in the Asian community, seldom discussed, even among the patients and their family and friends. Previous interviews of the ACCESS-PD study, which is discussed later in the paper, discovered that some patients had never heard of Parkinson's before their diagnosis. Misconceptions persist, with some erroneously associating shaking as the sole symptom, and others struggling to distinguish PD from Alzheimer's. As a movement disorder, Parkinson's Disease is often solely linked to its motor symptoms, leading to potential delays in diagnosis and treatment for those with minor motor symptoms (Wan et al., 2019).

### Misunderstanding of PD Symptoms and Diagnosis Latency

Chinese patients experience delays in diagnosis of the disease, partially due to having minor motor symptoms and physicians' lack of knowledge in PD symptomology (Wan et al., 2019), and partly due to the patient misinterpreting their symptoms as a normal part of aging (Nomoto et al., 2023). One study on public knowledge regarding PD in Asia shows an important gap in knowledge that can lead to delays in seeking a diagnosis, medical care, and treatment (Tan et al., 2015). The results of the study suggested that 83.7% of people incorrectly believed that all PD patients experience tremors, which implied that if a patient does not have tremors as a symptom, they are less likely to seek medical consultation with a neurologists or movement disorder specialist for clinical diagnosis of Parkinson's (Wan et al., 2019). Moreover, the study shows that around half of the people surveyed wrongly believed that PD is currently curable (Tan et al., 2015). These misconceptions point to the need for educational programs and interventions for health promotion among Asian communities.

### Knowledge Gap

There are many inconsistencies in the current knowledge base about PD. For example, information available online regarding to the longevity and complications of PD medication (i.e. Carbidopa- Levodopa) seem confusing with some claiming that long-term use of levodopa and other dopaminergic treatments leads to loss of effectiveness or efficacy (Marsden, 1994) and complications such as levodopa-induced dyskinesia (Kwon et al., 2022), which was observed in 50% of the patients after 5 years, and 80% patients after 10 years of levodopa use (S.-H. Lee & S. Lim, 2017), while others claim that long term use of the medicine does not lead to loss of effectiveness (APDA, 2019). Those state that higher doses of medication or new medication is needed as the disease progresses, independent of the length of Levodopa usage. There is also no significant evidence that people who start Levodopa early are more likely to have worse disease outcomes (Katzenschlager & Lees, 2002). Inconsistencies in information contribute to the confusion and lack of knowledge of PD.

Furthermore, there is a notable lack of diversity in Parkinson's clinical trials, with a predominant focus on Caucasian participants. The underrepresentation of Asian patients in these research studies compromises the generalizability of findings to the Asian community and other minority populations in the United States. Adding to this challenge is the scarcity of information and resources available in patients' native languages, such as Chinese or Vietnamese, in contrast to the abundance of English resources. Moreover, even when resources are available and pertinent to Asian patients, many are exclusively accessible online, posing a barrier for elderly patients who may lack the necessary computer skills and equipment to access them.

### Exercise and Complementary Medicine

Compelling evidence supports that regular exercise enhances the physical performance of individuals with PD (Crizzle & Newhouse, 2006). This encompasses physical therapy

interventions that improve physical function and reduce disabilities among patients (Ellis et al., 2021). Recent research also suggests that consistent and rigorous exercise may even contribute to slowing the progress of the disease (Crotty & Schwarzschild, 2020). This information holds particular significance for PD patients and their families, considering the absence of a current cure with medications merely alleviating symptoms impeding disease advancement. Offering patients the prospect of slowing disease progression not only motivates them to engage in regular exercise but also fosters a more optimistic outlook towards their condition. Moreover, public awareness should emphasize the promotion of healthy exercise behaviors, as studies indicate that elevated levels of moderate to intense physical activity in mid or later life correlates with reduced risks of developing PD (Fang et al., 2018) and thus may protect against the disease (Xu et al., 2010). Additionally, there is supportive evidence for the effectiveness of traditional Chinese exercise methods, such as Tai Chi, in enhancing motor functions and balance among PD patients (Yang et al., 2015).

In addition to exercise, complementary medicine such as acupuncture exhibits promising potential in treating Parkinson's disease, albeit with some controversy. Academic endeavors have sought to unravel the efficacy of acupuncture in managing Parkinson's. Notably, a systematic review and meta-analysis, incorporating 982 relevant articles and 25 randomized controlled trials (RCTs), yielded favorable results for acupuncture as a treatment for PD. It shows that acupuncture is significantly more effective in relieving symptoms when combined with conventional treatment, compared to conventional treatment alone (S. H. Lee & S. Lim, 2017). A more recent systematic review in 2022, encompassing 17 RCTs, reinforced the positive impact of acupuncture on both motor and non-motor symptoms in Parkinson's patients (Pereira et al., 2022). Despite the wealth of evidence suggesting the potential benefits of acupuncture in

alleviating both motor and nonmotor symptoms of the disease (detailed in Appendix 2), reservations persist in scientific discourse, largely due to the absence of "high-quality evidence" derived from well-designed RCTs, specifically those featuring double blinding, has substantial sample sizes, and accounting for placebo effects. Given the lack of a cure for Parkinson's and the associated complications and worsened side effects linked to long-term use of PD medication, especially in advanced stages, discerning whether acupuncture qualifies as an evidence-based alternative or complementary treatment is crucial. Advocating for acupuncture as a viable option becomes imperative to ensure patients are informed about potential alternative treatments in their Parkinson's journey.

### Field Organization

Asian Women for Health (AWFH), a peer-led and community-based nonprofit organization founded by Chien-Chi Huang, serves as a dynamic network committed to advancing the health and well-being of Asian women through education, advocacy, and support (AWFH, 2023). This diverse collective unites individuals from various backgrounds to collectively address individual, community-wide, and systemic barriers affecting Asian women and their loved ones. AWFH has forged a meaningful partnership with Professor Alice Tang at the Tufts University School of Medicine on the "ACCESS-PD: Advancing Comprehensive Care and Enhancing Service Standards for People of Asian Descent living with Parkinson's Disease" project. This initiative aims to comprehend the barriers hindering timely diagnosis and treatment for Asian Parkinson's disease patients through a combination of qualitative interviews and a quantitative survey for care-partners. It encompasses interviews with 12 Chinese and English-speaking Parkinson's patients, 9 care-partners of Chinese and Vietnamese descent, as well as 8 clinicians and 3 community advocates.

## Project Objective

This Applied Learning Experience (ALE) project, undertaken in collaboration with, Asian Women for Health (AWFH) and Tufts University School of Medicine, is financially supported by the Michael J. Fox Foundation (MJFF). It concurrently serves as a vital component in fulfilling the deliverable requirement for the Applied Learning Experience (ALE) within the Master of Public Health (MPH) degree program at Tufts University. A documentary and resource guide are created in order to address the issues identified earlier in the introduction section of the paper.

The purpose of this documentary is to:

- a) Educate the general Asian population about Parkinson's Disease (PD), especially its non-tremor and non-motor symptoms.
- b) Assess and advocate for Asian PD patients' overarching needs.
- c) Promote evidence-based health information and resources such as acupuncture and exercise methods and programs (physical therapy and Tai Chi etc.).
- d) Encourage participation in clinical trials among Asian PD patients.

The documentary is planned to be 15-20 minutes long. With the resource guides/toolkits developed for PD patients and caregivers, it is developed for the purpose of educating the Chinese population about Parkinson's Disease, promoting healthy behaviors such as exercising, providing health resources in their native languages (i.e., mandarin etc.) and encouraging participation in clinical trials since MJFF has identified Asians as being chronically underrepresented in clinical trials in terms of Parkinson's Disease.

## Methods

## Activities



The following are the main activities that were involved in this project:

- Developed a timeline for the project.

*Documentary related activities*

- Learned to shoot good videos and make a documentary via an online class.
- Brainstormed documentary ideas individually and with other staff at AWFH.
- Wrote a short introduction to the documentary and resource guide project to send to key stakeholders for the purpose of study recruitment.
- Developed a draft script for the documentary.
- Contacted potential key characters in the film to participate in the interviews and filming.
- Recruited participants (1 patient, 1 caregiver, 1 physician, 1 PT, 1 researcher), scheduling and coordinating with them.
- Recruited a professional videographer and video editor.
- Developed interview questions, including translation in both Chinese and English.
- Worked with media relations at the hospitals and obtained consent with them and the participants.
- Conducted interviews, filming, and audio recording in person with the participants.
- Developed a comprehensive script for the documentary based on interview transcripts, available in both simplified Chinese and English.
- Transcribed and translated interview transcripts.
- Video editing and subtitling in Chinese and English.
- Sending edited videos to the AWFH team to collect feedback and revise the films.

*Research and Resource Guide related Activities*

- Researched facts related to PD including evidence of the effectiveness of acupuncture on PD for making evidence-based recommendations.
- Research on resources available for patients in Chinese.
- Communicate with other employees at AWFH to assign research responsibilities.
- Wrote a report/summary on the systematic reviews of the effectiveness of acupuncture.
- Developed a resource guide for the patients in Chinese based on research conducted.

### Process

The project timeline spanned from September to December 2023, beginning with my enrollment in an online Udemy class on documentary filmmaking. In September, I began brainstorming ideas, crafting a short plan, and outlining a production timeline. Team meetings were convened to explore potential incentives for participants. I composed a brief introduction to the documentary project, along with a script draft for recruitment purposes. Key participants, initially planned as two patients, two care-partners, and two experts, were contacted for consent, with interviews scheduled for those who are willing to participate. Leveraging previous contacts, patients, and caregivers were engaged, while experts were recruited through varied outreach methods such as phone and in-person contacts.

A professional videographer and editor were hired to facilitate the documentary production. The participation of a patient, his wife, Parkinson's physician Dr. Luo, Tufts Medical Center's physical therapist Esteban Chapeta PT, DPT, and PD researcher Dr. Alice Tang was secured. Tailored interview questionnaires (see Appendix 4) were developed in either Chinese or English and sent for review and approval. After obtaining consent and collaborating with hospital communication departments, interviews were conducted in natural settings, recorded professionally in both audio and video formats. Translations were facilitated for interviews

conducted in English, with a comprehensive script drafted for video editing in both Chinese and English using Otter.ai and Google Translator (see Appendix 1).

Editing commenced using Final Cut Pro, incorporating additional footage (B-rolls) from Boston Chinatown, Boston Commons, Tufts University School of Medicine, and purchased video clips. Each interview recording was meticulously reviewed and analyzed, edited to seamlessly intertwine relevant narratives. An additional video was filmed post-interview with Dr. Luo due to the wealth of valuable information provided, warranting a separate production. Drafts of edited videos were shared with AWFH for feedback.

Beyond video production, extensive research on Parkinson's disease and the effectiveness of acupuncture was conducted using online platforms like Google Scholar and PubMed, employing the search term "Acupuncture and PD." A summary of evidence regarding acupuncture's effectiveness in Parkinson's, sourced from scientific literature, was compiled (see Appendix 2). This evidence was integrated into the videos and a resource guide, the latter developed based on cumulative research and project progress (see Appendix 3).

## Results

This initiative resulted in two informational videos, a summary of evidence from systematic reviews on the efficacy of acupuncture in Parkinson's, and a resource guide.

### *Parkinson's Documentary – More Than Tremors- the Unspeakable*

Five sets of interview questions were generated, each tailored for the respective participant (see Appendix 4). A comprehensive script for the documentary, encompassing narratives, interview transcripts, and timestamps, was created (see Appendix 1). The final video product culminated in a 23-minute film, featuring Mandarin narrations, as well as interview recordings and live-clips

from those interviewed, presented in either Chinese (patient and wife) or English (all physicians/researchers). The film is segmented into four thematic sections, along with an introduction, discussion, and summary—covering Seeking Care and Diagnosis; Treatment and Living with PD; Difficulties in Seeking Care; and Clinical Trials and Hope. Subtitles in both Chinese and English were included to enhance accessibility. The documentary will be accessible on various online platforms, including YouTube, LinkedIn, WeChat channels, and Bilibili. Moreover, it will be featured on the AWFH website and potentially distributed by collaborating partners such as Beth Israel Deaconess Medical Center, Tufts University, and MJFF.

#### Educational Video- Learning About PD with Dr. Luo, its symptoms, diagnosis, treatments, and clinical

An additional 23-minute video has been created, featuring an interview with Dr. Luo, alongside the main documentary. This supplementary video, presented in English, is also available with Chinese and English subtitles and may undergo translation into Vietnamese. Dr. Luo provides a comprehensive overview of Parkinson's Disease, elucidating its symptoms, dispelling associated myths, and detailing the diagnostic process. She delves into treatment modalities, including medications and alternatives such as exercise, notably Tai Chi, and complementary medicine like acupuncture. Dr. Luo further emphasizes the significance of Asian patients' involvement in clinical trials, offering encouragement and valuable recommendations to prospective participants.

#### Summary of Systematic Reviews

In addition, a Summary of Systematic Reviews and Analysis of the Clinical effectiveness of Acupuncture on PD is written (appendix 2). This analysis explores the potential benefits of acupuncture as a complementary treatment for PD, emphasizing its positive effect on both motor

and non-motor symptoms. The analysis is supported by 10 different meta-analysis, summaries, and clinical studies. It counts the difficulties of ruling out the placebo effect in acupuncture studies and future studies with larger sample size and well-designed methods is recommended. It discusses the safety of acupuncture as understood by previous studies and the intriguing prospect of acupuncture potentially slowing down disease progression for PD, which needs to be further studied and analyzed. Ultimately, the summary concludes that acupuncture is a promising alternative treatment for Parkinson's disease and may offer valuable support and relief for patients, especially in the early stage of the disease. In combination with traditional therapy and regular exercise, it presents an additional avenue for improving health outcomes in Parkinson's patients.

### Resource Guide

A resource guide for patients has been developed, initially in Chinese and subsequently translated into English (see Appendix 3). Plans are underway for potential translations into other Asian languages. This resource guide underscores the significance of exercise for individuals with Parkinson's disease and incorporates QR codes linking to publications from the American Parkinson's Disease Association (APDA) that align with the guide's language and content. It features essential information, including APDA hotlines, valuable resources, and recommendations related to Tai Chi, acupuncture, and the Mediterranean diet, all supported by evidence from relevant studies. Furthermore, the guide actively promotes participation in clinical studies and directs patients to websites where they can explore and engage in ongoing clinical trials.

### Discussion and Recommendation

The initiative resulted in significant outcomes, including two informative videos/films, a resource guide for patients, and a comprehensive summary of the effectiveness of acupuncture on PD. All the products and deliverables that are produced as part of this initiative, except for the written summary, which served its purpose by providing an evidence base for the recommendations made in the other products, will undergo refinement and finalization by other employees and volunteers at Asian Women for Health before their online launch and distribution through conferences and community outreach events. Following the dissemination of the films and resource guides, the overarching goals include educating the general Asian population about Parkinson's Disease (PD), especially its non-tremor and non-motor symptoms; advocating for Asian PD patients' overarching needs; promoting evidence-based health information and resources to the Asian communities; and encouraging participation in clinical trials among Asian PD patients. AWFH envisions the film becoming available for the public sometime in June or July next year. Subsequently, the impact of these deliverables can be potentially assessed through metrics such as the number of views, likes, and comments they received on each platform where they are published.

### Confusion and Difficulties around Diagnosis and Care

Through the interview with Dr. Luo and the patient and previous research, I learned that Parkinson's is currently diagnosed through clinical exams and there is no one test that can diagnose the disease. Tests such as Dopamine Transporter Scan, DAT scan, and a skin biopsy to look for abnormal protein (i.e. alpha-synuclein deposits) in the skin can only help support the diagnosis. Due to the lack of a physiological gold standard for the diagnosis, many patients can be misdiagnosed, compromising the quality of care they receive.

During previous interviews for the ACCESS-PD study, two patients mentioned that their physicians confirmed Parkinson's diagnosis through prescribing Carbidopa-Levodopa and observing whether the patient's symptoms improved. While one cannot judge the procedure of clinical diagnosis without having been through the physician's training, hearing about this method of diagnosis sheds light on the confusion and mistrust some patients and care-partners have regarding their Parkinson's diagnosis.

For example, the couple I interviewed was previously diagnosed by a neurologist but was unsure whether Parkinson's Disease was the correct diagnosis and is seeking a second opinion from physicians at a different hospital (i.e., MGH). This uncertainty stemmed from being told by two neurologists that he did not have PD, only to receive a PD diagnosis from another, as his hand symptoms improved after taking prescribed medication. To add to the confusion, some symptoms improved while others did not – his hands gained strength, but walking felt weaker (possibly even worse after taking the meds), and he is still experiencing stiffness in the waist. He attributed his symptoms to causes other than PD, citing a previous injury from falling down the stairs a few years ago. This highlights the importance of having a biomarker/physiological gold standard and a corresponding test. The most reliable methods have been recently identified by the Parkinson's Progression Markers Initiative (PPMI) at MJFF as  $\alpha$ -synuclein seeding amplification assay ( $\alpha$ Syn-SAA), which detects abnormal proteins in the skin with a sensitivity of 88.7% (Siderowf et al., 2023).

### Comparing Medical Systems in the U.S. and China

The referral system in the U.S. poses a potential barrier to patients receiving a prompt and accurate diagnosis, as patients cannot directly consult a neurologist without a referral from their primary care physician (PCP). In my interview with Dr. Luo from BIDMC, she emphasized that

obtaining a referral to a neurologist, preferably a movement specialist, should be the initial step for individuals experiencing PD symptoms. However, the referral process can be time-consuming, involving multiple days or even weeks of waiting for an appointment with the PCP. Furthermore, there is a risk of misdiagnosis if the PCP lacks proper training to recognize early symptoms, particularly the non-motor symptoms of Parkinson's disease. Complicating matters, some neurologists are in-network with specific PCPs, while others are not, and insurance networks further restrict patient choices. Additionally, cultural factors may make some Asian patients hesitant to request a referral, fearing they may burden their physicians or consume too much of their time. Therefore, it is crucial to educate physicians about Parkinson's, enabling them to make appropriate referrals when identifying potential symptoms.

Fortunately, the patient I interviewed successfully obtained a referral to a neurologist at MGH through his primary care physician to confirm his PD diagnosis. However, he faces a waiting period of 5 months for the appointment. In contrast, in China, appointments are typically scheduled as same-day walk-ins. While occasional advanced appointments may require up to 2 weeks, the consultation duration is brief, often just 5 minutes, depending on the appointment type. Notably, there is no need for a referral to see a neurologist in China.

One can imagine how a referral system can be a barrier for patients to be seen by a neurologist. However, there are pros and cons associated with both systems, as a research study on PD diagnosis latency in China claims that the freedom of consulting a neurologist without a referral does not necessarily shorten the time from first medical consultation to PD diagnosis (Wan et al., 2019). Most patients still seek a primary or secondary care physician instead of a neurologist or movement disorder specialist on their first visit (Wan et al., 2019). The study indicates that no patients who had gait disturbances and bradykinesias seek a neurologist as an initial visit for



their symptoms, whereas 33.90% of those who had tremors and 6.25% of those who had rigidity did, which again points to patients' association of tremors with PD but not so much other motor symptoms. The study finds that the median diagnosis latency for the patients that they surveyed is 15 months (Wan et al., 2019), on the other hand, a study conducted in the U.S. discovered that the average was 1.8 years which translates to around 21.6 months (Surathi & Feinstein, 2020). However, we cannot compare these two statistics with each other in a meaningful way because one is median one is mean, and they both have small sample sizes and are conducted in a small set of patients that cannot be generalized to the national level. More studies are needed before any policy recommendations are made.

### Clinical Trials

It is crucial for Asian PD patients to participate in clinical trials, addressing the underrepresentation of this population in U.S. research studies. With no current cure for PD, participating in research studies not only advances potential treatments but also enhances the applicability of the study results to diverse American populations. Translated consent forms help to improve Asians' involvement in clinical trials. Providing translated consent forms facilitates increased participation among Asians in clinical trials. Moreover, combating the stigma associated with PD is essential. Most interviewed patients revealed that they refrain from discussing their PD diagnosis with extended family and friends, fearing negative perceptions. Raising awareness about PD within the community and portraying Parkinson's patients and care-partners positively in the media can contribute to reducing the stigma associated with the disease.

### Diet

The care-partner whom I interviewed mentioned that they couldn't find information regarding what kind of food to eat that is good for Parkinson's. Upon brief research, it seems that a

balanced whole-food Mediterranean-style diet may be linked to not only lower odds of having Parkinson's and later PD onset (Alcalay et al., 2012), but also associated with a slower disease progression (Bisaglia, 2022). This diet is rich in whole grains, fresh vegetables and fruits, berries, nuts, fish, olive oil and red wine.

## Conclusion

There are more than 20 million Asians living in the United States, of which 5 million are Chinese. Many of them are first-generation immigrants who don't speak much English. Because of their language difficulties and cultural barriers (ex. don't want to bother others), as well as inconvenience presented in the American medical system such as the referral system, they can encounter challenges while seeking health care.

Moreover, no physiological gold standard for the diagnosis of Parkinson's disease is currently available, and clinical diagnoses are not foolproof. Improving the accuracy of diagnosis and the quality and effectiveness of treatments may be the key focus of further research. Fortunately, MJFF recently announced that they have found a biomarker of Parkinson's disease-abnormal  $\alpha$ -synuclein and developed the tool to identify it, the  $\alpha$ -synuclein seeding amplification assay ( $\alpha$ Syn-SAA). Hopefully soon, the causes of Parkinson's disease will become better understood and diagnosis will no longer be a difficulty.

In addition to following the doctor's instructions, active and regular exercise is also the key to overcoming it. As Asians, especially Chinese, excellent traditional exercises like Tai Chi is recommended to help improve the body's flexibility and balance, as well as acupuncture to help relieve symptoms. Following a healthy and preferably Mediterranean diet may be linked to better disease outcomes. In addition to these external treatments, perhaps equally important is whether a patient can correctly understand and face Parkinson's disease. As Dr. Luo said in the interview,

an optimistic attitude is crucial when dealing with PD. Just a few days ago, the patient interviewed sent me a video of himself with a group of old friends. He played the harmonica, and they sang. As a Christian, his faith in Jesus also helped him to view the disease and sufferings on earth with a more optimistic attitude. Perhaps one day, Parkinson's disease will no longer be incurable or difficult to talk about; until that day, we have an eternal hope.

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## Appendices

### Appendix 1 – Documentary Script

#### 不仅震颤 — 难以启齿的它

一部献给亚洲帕金森病患者及照顾者的记录短片

Luna Luo

More than tremors — the unspeakable

A short documentary dedicated to Asian Parkinson's patients and Care-partners

【以黑屏开头，显示帕金森病 (PD) 的事实和数字】

【唐人街开幕】字幕：中国城，波士顿。

旁白：说到帕金森，你会想到什么？

你可能会想到不受控制的震颤，你也可能以为它是一种老年性疾病。事实上，作为一个本科心理学专业的人，我修过一些神经科学的课，也在课上了解讨论过帕金森。然而，在采访帕金森病人和家属之前，我也以为帕金森只有震颤，而且离像我这样的年轻人很远很远。直到我有机会采访了一些在美国的华裔帕金森病人和家属，才发现，原来 20,30 岁的年轻人也是可以得帕金森的，虽然很罕见。比如说，在 TED 上演讲的年轻女孩——

【插 TED 片段】，比如说著名的演员 Michael J. Fox 【放照片】，而且，不是所有病人都

有震颤，也不是所有有震颤症状的人都有帕金森。但由于人们只将 PD 与震颤联系在一起，有时没有这个症状的病人会被误诊或延误诊断。而且我也发现好像很多病人很难向人启齿自己确诊帕金森的事实，即便是对自己的亲人和朋友。

【标题：不仅震颤 — 难以启齿的它】

【第一部分，就诊，诊断/ Seeking Care and Diagnosis】

【黑幕：请你给我定义一下什么是帕金森？！/ What is PD? Please give me a definition!】

旁白：根据美国帕金森协会的权威解释，帕金森是一种神经退行性疾病，主要影响大脑中可以产生多巴胺的神经细胞，使其不能正常分泌多巴胺，从而导致病人的运动障碍，以及一些非运动障碍的症状，例如抑郁和焦虑以及记忆力和认知功能的丧失。它不是老年痴呆，而是仅次于老年痴呆第二常见的神经系统疾病。

叔叔：(0:30-

2:30) 症状以及确诊的过程。不确定自己有没有帕金森因为没有手抖症状以及其他原因。

对帕金森的疑惑：(2:57-4:38) 诊断没有生理上的金标准。

Alice：我决定从事这一领域的研究，因为我的母亲患有帕金森病，而且她很晚才被诊断出来。实际上，她没有那种典型的震颤，所以在其他症状变得更严重、更明显之前，她多年来一直未被诊断出来。因此，事后看来，我们意识到，在确诊之前的许多年里，她已经经历了该疾病的许多非运动症状。

旁白：为了寻找（叔叔）这些关于诊断的问题的答案，我们来到了哈佛大学的主要教学医院之一，贝斯以色列女执事医疗中心，采访神经科的运动障碍专家罗岚医生。

*罗岚医生: Lan Luo, MD, MS ( Medical Director, DBS Program; DBS 项目主任;*

*Movement Disorders Specialist, Department of Neurology, Beth Israel Deaconess Medical Center.*

*运动障碍专家 · BIDMC (哈佛医学院教学医院)神经科;*

*Instructor, Neurology, Harvard Medical School; 讲师 · 神经学 · 哈佛医学院) :*

【帕金森的症状和诊断】

- Not all PD patients have tremors as a symptom (the dr didn't directly mention this but it is important to mention this point in both videos). (3:20- 5:19)

对于帕金森病的症状，很多人认为这只是单纯的运动问题，运动症状构成了该病的唯一症状。

然而事实并非如此，帕金森病既是运动障碍又是非运动障碍。

对于运动症状，患者可能有四种主要的症状，

这些是：静止性震颤；姿势不稳定，这意味着平衡能力差；动作缓慢，

例如，使用手（例如用勺子吃饭）时，人们的手动灵活性可能会非常慢；

另一个症状是肢体僵硬，他们的手臂或腿会感觉非常僵硬，很难活动。

另一方面，对于非运动症状，病人通常会出现认知能力下降、思维或记忆障碍等问题。

还有可能出现幻觉：幻视或幻听。

焦虑和抑郁也是患者中常见的症状，还有体位性低血压，这意味着血压波动，有时人们的血压可能会降至很低，导致昏厥或头晕，头重脚轻的感觉。

然后是嗅觉障碍，例如患者可能会闻不到味道；和勃起功能障碍等，都是患者可能出现的症状。(7:50 -)

- 例如，震颤患者，他们不一定患有帕金森病，但可能患有帕金森氏症，或者其他症状类似帕金森病的疾病，例如多系统萎缩症。(9:05)
- **The clinical test is not obsoletely accurate.**
- **Some task can help, such as DAT scan (9:25) and skin biopsy to look for abnormal protein in the skin.**

诊断帕金森病的方法实际上是通过临床检查。病人会去办公室看神经科医生或运动障碍专家时，他们将对患者进行非常详细的病史询问和体格检查。会询问他们一些问题，例如他们是否有颤抖或手抖的问题？也会向患者询问关于其他一些运动和非运动症状的问题。

然后你接受一个详细的身体检查，是否有行动迟缓、静止性震颤、身体失衡，

僵硬等之前我提到的症状，这些都是帮助帕金森病诊断的重要线索。

当然，有些病症可能模仿帕金森病，例如，震颤患者，他们不一定患有帕金森病，但可能患有帕金森氏症，或者其他症状类似帕金森病的疾病，例如多系统萎缩症。临床诊断并不绝对准确。

我们也有一些测试可以帮助诊断帕金森病，例如多巴胺转运蛋白扫描或 DAT

扫描、DAT，然后还有一种称为皮肤活检的方法，用于寻找皮肤里的 $\alpha$

突触核蛋白沉积物或异常蛋白质。

**旁白：**就像叔叔在采访中提到的，帕金森的诊断没有一个生理上的金标准，加上Dr. Luo 说的，对帕金森的临床诊断很难做到万无一失，如何提高诊断的准确性以便提高治疗的质量和效果也许是下一步研究的关键。所幸的是MJFF

通过不懈的努力，宣称他们已经找到了帕金森的生物标记——异常的 $\alpha$ -

突触核蛋白，以及找寻它的工具。希望在不久的将来人们会越来越了解帕金森病的病因，诊断也不再是一个困难。

Reference: <https://www.michaeljfox.org/news/breaking-news-parkinsons-disease-biomarker-found>

## 【第二部分·治疗方法 & 与其共存/Treatment & Living with PD】

叔叔：

- 走路，打太极 (8:30-9)
- 弹琴 (10 : 15)
- 现在吃药，理疗，下个月试试针灸按摩 (11:15)
- 心情要好一点，乐观，不要害怕 (07:55-9)



- “药还是有用的，就是腿一直没力气（16:17- 17:35）
- 政府保险做到比较好，要配合医院，心理上不要太担心，食物，运动。
- 要靠自己，靠国家
- Luna:药可能过一段时间就没效果了。。（我错了）

罗医生：其实是随着疾病（实际上是帕金森病）的进展，我们发现人们需要更高剂量的药物，并且在此过程中可能会出现其他症状，促使添加药物的需要。所以这并不是说药物停止起作用。只是随着病情的进展，治疗方案中本来就应该加入更多的药物。

旁白：刚刚陈先生提到了做理疗，我们接下来到塔弗茨医学院的复建中心来采访一个物理治疗师，看看他对帕金森病和物理治疗的理解（something like that...）

### Physical Therapist 物理治疗师：

(Esteban Chapeta, PT, DPT, Physical Therapist at Tufts Medical Center):

【Introduction, Effects of PD, kind of exercise】

我叫埃斯特万。我是一名物理治疗师。我在塔夫茨医疗中心从事门诊物理治疗工作。

我在这里呆了大约一年，当我在物理治疗学校时，我也在这里进行了轮换。

病人经常出现步态障碍、冻结、行动困难等症状。

这导致他们对自己的行动能力失去信心并居于自身的限制。

因此，当他们来这里接受治疗时，我所做的就是尝试恢复功能，并给予他们信心，让他们能够继续尽可能多地运动，以增加力量。

我也只是处理他们向我提出并向我表达的日常问题和问题。我根据他们的需求制定独特的治疗课程。

我们楼下的物理治疗健身房里有很多我用来治疗帕金森病的设备，其中之一是我们的治疗台，是可以上下升降的，这让他们更容易在躺下后再起来，我们称之为转移。

帕金森氏症患者经常会出现躯干僵硬，所以他们在这个区域僵硬。

所以我做的很多动作都是普通人认为理所当然的旋转动作。

例如，后备箱旋转会以这种方式到达汽车座椅后面，他们将很难做到将背部伸到头顶上的柜子中，他们将很难做到这一点。仅仅步行就是他们可能遇到的问题。

(Including the separate clip of him demonstrating)

我想特别是对于亚洲人群来说，语言障碍常常阻碍他们进入医院。

如果他们需要，我们在这里可以提供口译服务。

### 罗医生：运动治疗·药物和 alternative treatments

- Importance of exercise and active lifestyle (-07:30)
- Medication (09:49)
  - The lasting of the medicine (2:35-3:00)

### DBS and its risk (10:48-12:15)

帕金森氏症的治疗包括三种主要方法。一是锻炼，我之前提到过。

经常锻炼的人往往比久坐的人病程更慢。

那么，运动，我的意思是，比如说运动，包括有氧运动，柔韧性的训练，力量的训练，这些都是相当重要的。其他方法包括药物治疗，其主要是多巴胺能药物。

这些有助于补充帕金森病患者缺乏的多巴胺。另一种第三种治疗选择是深部脑刺激手术 DBS。

### Acupuncture (12:55 - 14:05)

### Taiji (14:05 – 14:33)

- 让患者尝试一下辅助医学是可以的，只要是相对安全、风险低、没有那么多不良反应的东西就行。针灸方面，科学文献中有大量与其相关的研究。然而，就结果而言，例如，对于帕金森病的运动症状，结果好坏参半，一些研究表明，它确实有助于帕金森氏症的四种核心主要症状中的一些，而其他研究表明它并没有真正提供太大的改进。所以，我认为患者尝试一下是可以的，我的一些病人觉得它很有帮助。还有研究表明，针灸可以帮助改善帕金森病的非运动方面，例如焦虑。我认为，如果患者愿意的话，针灸绝对是一种可能的治疗方法。至于你问题的另一部分，太极拳，太极拳运动，我认为这对于帕金森病患者来说是一项很好的运动。《新英格兰医学杂志》上发表的一项规模最大的研究发现，太极练习实际上有助于改善平衡能力，并且有助于帕金森氏症患者。所以，我向所有帕金森病患者强烈推荐练习太极。

阿姨：

- a. 他做得还多一些”（13：40-50）
- b. 对身体不如以前有压力，鼓励他(-14:41)
- c. 往好的方面想，多鼓励，乐观。心理治疗优于药物治疗。吃药的话，自己要多查找资料，不能光听一个医生说的。不能不听医生的，也不能太听。（21:30-22:30）

### 【第三部分· 寻求帮助的困难/Difficulties in Seeking Care】

旁白：在美国生活着超过 2000 万的亚裔，其中有 500 万是华裔。他们其中有很多是像叔叔一样不太会说英文的第一代移民。因为他们语言上的障碍和文化上的差异，以及美国医疗系统存在的一些问题，他们在就诊和寻求医疗帮助常常会出现困难。

罗医生：我觉得特别是对于中国人来说，人们不知道到哪里寻求帮助。

因此，他们不知道可用的社区资源。他们不确定是否要求初级保健医生(家庭医生)

转诊去看神经科医生，这应该是出现可能是帕金森病的症状后的第一步。(1:40 -2:20)

(17:00-18:00)

是的，所以我认为亚洲社区或华人社区最重要的一些担忧，特别是就帕金森病而言，如果，你知道，在他们出现一些PD的症状后，他们绝对应该联系神经科医生。

与神经科医生、最好是运动障碍专家联系，我认为这是帕金森病的重要的护理目标之一。

PT: 挑战：我认为患者教育就是其中之一。

当我评估患有帕金森病的人并提出这个话题时，我得到的答案是：

“哦，我的医生告诉我我患有帕金森病。

对，我吃这个药来治帕金森病，但我真不知道为什么吃它。”

这可能是医疗保健整体上需要改进的一个领域。

如果我们了解帕金森病的疾病过程以及出了什么问题，我认为这可以让他们更好地了解自己的身体和生活中发生的事情。

叔叔：（20:30-21:25）

1. 不满意，诊断上没有金标准，医生意见不统一。
2. 脚的症状没有消除

### 3. 医院之间的数据没共享

阿姨：想到MGH再看看，要明年 (-16:16)

## 【四·临床试验的需要&对未来的展望/ Clinical Trials & Hope】

罗医生：

### 1. Her current research

#### 2. 我怎么强调参与临床研究的重要性都不为过。

我认为有时人们，特别是亚裔社区或华人社区并没有意识到参与研究的重要性。

目前，我们还没有治愈方法，这是一种进行性疾病。

我认为应该有越来越多的人参与到研究中来。

#### 3. 他们应该首先询问神经科医生或运动障碍专家，询问他们所在机构进行的临床试验。

例如，我总是建议这甚至可以是第一步。

#### 4. Importance of having a translated consent form:

所以，我认为为了有更多的患者参与到帕金森病的研究中来，这是第一步是得有同意书的翻译版本。

我认为我们在让有色人种参与临床试验和拥有更多样化的人群研究群体方面做出了越来越多的努力。因为如果我们只在一个同质的人群中做实验，我们真的不能说结果可以推广到整个美国人口。这就是为什么华人社区应该更多地参与到临床实验中。

我认为从这个角度来看，参与研究确实是个好主意。

叔叔：希望看到未来怎样的科学研究和突破？(9:02--)

Alice: 我认为仍有许多领域需要研究。首先，我们需要更好地了解语言障碍、文化耻辱和系统性因素如何影响亚洲帕金森病患者获得医疗保健和护理质量，以及如何缩小存在的差异。其次，我们需要开展更多研究专门针对亚洲社区的教育计划和宣传活动的有效性，以提高对帕金森病及其症状以及早期诊断和治疗重要性的认识。第三，我们需要学习如何让亚洲社区更积极地参与帕金森病研究。这可以包括参与新药物或治疗方法的临床试验或其他类型的研究。因此，其中一部分是减少医生研究人员在招募亚洲患者时面临的障碍。医生在就诊期间很难与患者沟通。他们可能会犹豫是否招募他们来学习，因为如果他们不具备适当的语言技能和文化能力，知情同意过程本身可能会非常困难且耗时。但我们知道，让亚裔人参与研究非常重要。因此，我们需要找到方法来消除招聘中的这些障碍，并努力使我们更具包容性。最后，我们需要培训医疗保健专业人员，使其具有文化能力和敏感性以及为帕金森病患者提供护理的影响，并减少医疗保健系统中存在的一些障碍，这些障碍导致病人不能安排与医疗保健提供者的预约，或者难以在就诊期间提出问题。

## 【结尾】

### 【秋日树叶进 Voice】

叔叔：

“帕金森不帕金森不要去计较这个名字了”，药还是有用的，就是腿一直没力气 (16:17-17:35)

- a. 政府保险做到比较好，要配合医院，心理上不要太担心，食物，运动。
- b. 要靠自己，靠国家
- c. 还有什么想分享，或者对观众说的吗？(10:25-11:55)

- a. 配合医生
- b. 得帕金森的都是伟人呢！（霍金有帕金森？（ChatGBT：不，他没有！） 11:20- 11:30）

PT: 有帕金森病患者来找我说, 我不做任何运动。我不离开我的家。

我在家里做饭、打扫卫生、洗澡等基本事情上都遇到了困难。

因此, 我致力于的一件事是步态训练, 或者说(提高)他们行走的能力, 以便他们能够自信地离开家, 而不是感到害怕。

罗医生:

人们应该联系社区中的神经科医生, 在他们出现帕金森氏症症状后, 我们将去找运动障碍专家。然后, 就研究而言, 如果有能力的话, 一定要参与临床研究, 最后, 我建议每个人保持坚韧的态度。

我想鼓励大家, 拥有一个坚韧的态度是帕金森病取得良好或成功结果的关键特征之一, 这意味着你不应该让这种疾病压倒你, 而是用一个更加乐观的心态来看待它。

我认为制定一个严格的锻炼计划是克服PD的另一个关键组成部分。

Alice: 患有帕金森病对于患者及其家人来说都是一个挑战。

但要知道, 在这段旅程中您并不孤单。

亚洲社区的强大韧性、力量和支持可以帮助您克服所面临的障碍。

重要的是, 让亚洲人参与帕金森病新疗法和生物标记物的研究。

通过积极参与研究和宣传工作, 您不仅可以为自己, 也可以为子孙后代带来改变。

因此, 我希望我们能够共同打破一些障碍, 提高帕金森病亚裔患者的护理质量和生活质量。

旁白: 帕金森病不止是手抖而已, 还有许多别的不为人知的症状, 了解帕金森非运动症状能帮助我们早发现, 早诊断, 早治疗。除了遵循医嘱之外, 积极规律的运动也是战胜它的关键。作为亚裔, 特别是华人, 我们很荣幸有像太极这样的优秀的传统运动来帮助提高身体的灵活性和平衡性, 也可以尝试通过针灸来帮助缓解症状。除了这些外在的治疗, 也许同样重要的, 是我们能否正确的认识和面对帕金森病, 就像罗医生说的, 一个乐观的心态对待帕金森病至关重要。就在前几天, 陈叔叔给我发了一个视频是他和一群老朋友一起, 他吹口琴, 他们唱歌。我想, 作为一个基督徒, 他对耶稣的信仰, 也帮助他能够以一个更加乐观的态度看待这在地上的疾病和苦难。也许终有一天, 帕金森病不再是不可治愈的, 也不再使病人难以启齿; 直到那天, 我们一直有一位永恒不变的盼望。

[The End/ Credits]

[Starts with black screen showing Parkinson's disease (PD) facts and figures]

[Opening of Chinatown] Subtitles: Chinatown, Boston.

Narrator: When you think of Parkinson's disease, what comes to mind?

You might think of uncontrolled tremors, or you might think it's an age-related disease. In fact, as an undergraduate psychology major, I took some neuroscience courses and learned about Parkinson's disease in the classes. However, before interviewing Parkinson's patients and their

families, I also thought that Parkinson's only had tremors, and that it was far, far away from young people like me. It wasn't until I had the opportunity to interview some Chinese Parkinson's patients and their families in the United States that I discovered that young people in their 20s and 30s can also get Parkinson's disease, although it is very rare. For example, the young girl who spoke at TED - [insert TED clip], for example, the famous actor Michael J. Fox [show photo], and not all patients have tremors, and not all people with tremor symptoms All have Parkinson's disease. But because people only associate PD with tremors, patients without this symptom are sometimes misdiagnosed or delayed. And I also find that it seems that many patients find it difficult to disclose the fact that they have been diagnosed with Parkinson's disease to others, even to their relatives and friends.

[Title: More than Tremors—the Unspeakable]

[Part 1, Seeking Care and Diagnosis]

[What is PD? Please give me a definition!]

Narrator: According to the authoritative explanation of the American Parkinson's Association, Parkinson's is a neurodegenerative disease that mainly affects the nerve cells that can produce dopamine in the brain, making it unable to secrete dopamine normally, resulting in the patient's movement disorders and some non-motor symptoms. Symptoms of disorders such as depression and anxiety and loss of memory and cognitive function. It is not Alzheimer's disease, but the second most common neurological disease after Alzheimer's disease.

Uncle: (0:30-2:30) Symptoms and the process of diagnosis. I'm not sure if I have Parkinson's disease because I don't have any symptoms of hand tremors or other reasons. Hawking has Parkinson's disease? (ChatGBT: No, he didn't!)

Confusion about Parkinson's: (2:57-4:38) There is no physiological gold standard for diagnosis.

Alice: I decided to pursue research in this area because my mother has Parkinson's disease and she was diagnosed very late in life. Actually. She didn't have the classic tremors, so she went undiagnosed for years until other symptoms became more severe and obvious. So, with the benefit of hindsight, we realize that she had experienced many of the non-motor symptoms of the disease for many years before her diagnosis.

Narrator: In order to find answers to (uncle)'s questions about diagnosis, we came to Beth Israel Deaconess Medical Center, one of Harvard's major teaching hospitals, to interview Dr. Luo Lan, a movement disorder expert in the Department of Neurology.

Dr. Luo Lan:

**【Parkinson's Symptoms and Diagnosis】**

- Not all PD patients have tremors as a symptom (the dr didn't directly mention this but it is important to mention this point in both videos). (3:20- 5:19)

When it comes to the symptoms of Parkinson's disease, many people believe that it is simply a motor problem, with motor symptoms constituting the only symptoms of the disease. However, this is not the case; Parkinson's disease is both a movement disorder and a non-movement disorder. For motor symptoms, patients may have four main symptoms, these are: resting tremor; postural instability, which means poor balance ability; slow movements, for example, people have manual dexterity when using their hands (such as eating with a spoon) Sex may be very slow; another symptom is stiffness. Their arms or legs will feel very stiff and difficult to move. On the other hand, for non-motor symptoms, patients often experience cognitive decline, thinking or memory impairments, and other problems. Hallucinations may also occur: visual or auditory hallucinations. Anxiety and depression are also common symptoms among sufferers, as is orthostatic hypotension, which means blood pressure fluctuates and sometimes people's blood

pressure may drop very low, causing fainting or dizziness, a light-headed feeling. Then there are olfactory disorders, for example, patients may not be able to smell; and erectile dysfunction, etc., are all symptoms that patients may experience. (7:50- )

- For example, people with tremors, they don't necessarily have Parkinson's disease, but they may have Parkinson's disease, or other conditions with symptoms that mimic Parkinson's disease, such as multiple system atrophy. (-09:05)
- The clinical test is not obsoletely accurate.
- Some tasks can help, such as DAT scan (9:25) and skin biopsy to look for abnormal protein in the skin.

The way to diagnose Parkinson's disease is actually through a clinical examination. When a patient goes to the office to see a neurologist or movement disorders specialist, they will take a very detailed history and physical examination. They will be asked questions such as do they have tremors or hand tremors? Patients will also be asked questions about a number of other motor and non-motor symptoms. Then you undergo a detailed physical examination to see if you have slowness of movement, resting tremor, body imbalance, stiffness and other symptoms I mentioned before. These are important clues to help diagnose Parkinson's disease. Of course, there are conditions that may mimic Parkinson's disease, such as people with tremors who don't necessarily have Parkinson's disease but may have Parkinson's disease, or other conditions with symptoms that mimic Parkinson's disease, such as multiple system atrophy. Clinical diagnosis is not absolutely accurate. We also have tests that can help diagnose Parkinson's disease, such as a dopamine transporter scan or DAT scan, DAT, and then there's something called a skin biopsy that looks for alpha synuclein deposits or abnormal proteins in the skin.

Narrator: As my uncle mentioned in the interview, there is no physiological gold standard for the diagnosis of Parkinson's disease. In addition, Dr. Luo said that it is difficult to make a foolproof clinical diagnosis of Parkinson's disease. How to improve the accuracy of diagnosis? Improving the quality and effectiveness of treatment may be the key to further research. Fortunately, through unremitting efforts, MJFF announced that they have found the biomarker of Parkinson's disease-abnormal  $\alpha$ -synuclein, and the tool to find it, the  $\alpha$ -synuclein seeding amplification assay ( $\alpha$ Syn-SAA) ,In one experiment, this method proved to be 93% ,sensitive. Hopefully, in the near future, the causes of Parkinson's disease will become better understood and diagnosis will no longer be a difficulty.

Reference: <https://www.michaeljfox.org/news/breaking-news-parkinsons-disease-biomarker-found>

[Part 2, Treatment & Living with PD]

uncle:

- Walking, doing Tai Chi (8:30-9)
- Play the piano (10:15)
- Take medicine and physical therapy now, and try acupuncture and massage next month (11:15)
- Be in a better mood, be optimistic, don't be afraid (07:55-9)
  - o "Don't worry about the name Parkinson's or not." The medicine is still useful, but my legs have always been weak (16:17- 17:35)
  - o Government insurance is better. Cooperate with the hospital and don't worry too much about food and exercise.
  - o Rely on yourself and the country
  - o Luna: The medicine may lose its effectiveness after a while. . (I was wrong)

Dr. Luo: It's actually as the disease, actually Parkinson's disease, progresses, we find that people need higher doses of medication, and other symptoms may develop along the way that prompt the need for additional medication. So it's not that the medication stops working. But as the disease progresses, more drugs should be added to the treatment plan.

Narrator: Mr. Chen just mentioned physical therapy. Next, we went to the Rehabilitation Center of Tufts Medical School to interview a physical therapist to see his understanding of Parkinson's disease and physical therapy (something like that...)

Physical Therapist Physical Therapist:

(Esteban Chapeta, PT, DPT, Physical Therapist at Tufts Medical Center):

**【Introduction, Effects of PD, kind of exercise】**

My name is Esteban. I'm a physical therapist. I work in outpatient physical therapy at Tufts Medical Center. I stayed here for about a year and did a rotation here while I was in physical therapy school.

Patients often experience symptoms such as gait disturbance, freezing, and difficulty moving. This causes them to lose confidence in their ability to move and to live within their own limitations. So when they come in for treatment, what I do is try to restore function and give them the confidence to continue moving as much as they can to gain strength. I also just deal with the day-to-day questions and issues that they bring to me and express to me. I develop treatment sessions unique to their needs.

Our physical therapy gym downstairs has a lot of equipment that I use to treat Parkinson's disease, and one of them is our treatment table, which goes up and down, which makes it easier for them to lie down and get up again, which we call for transfer. People with Parkinson's disease often experience stiffness in the trunk, so they are stiff in this area. So a lot of the moves I do are spin moves that normal people take for granted. For example, the trunk rotates in such a way that it gets behind the car seat and they're going to have a hard time reaching their back into the overhead cabinets, which they're going to have a hard time doing. Just walking is a problem they may have.

(Including the separate clip of him demonstrating)

I think especially for the Asian population, the language barrier often prevents them from getting into the hospital. We are here to provide interpretation services if they need it.

Dr. Luo: Exercise therapy, medications and alternative treatments

- Importance of exercise and active lifestyle (-07:30)

- Medication (09:49)

The lasting of the medicine (2:35-3:00)

DBS and its risk (10:48-12:15)

Treatment for Parkinson's disease includes three main approaches. One is exercise, which I mentioned before. People who exercise regularly tend to develop the disease more slowly than those who sit for long periods of time. Well, exercise, I mean, for example, exercise, including aerobic exercise, flexibility training, strength training, these are all very important. Other approaches include pharmacotherapy, which is primarily dopaminergic drugs or medications. These help replenish the dopamine that people with Parkinson's disease lack. Another third treatment option is the deep brain stimulation procedure DBS.

Acupuncture (12:55 - 14:05)

Taiji (14:05 - 14:33)

• It's OK to let patients try complementary medicine, as long as it's something relatively safe, low-risk, and doesn't have as many adverse effects. When it comes to acupuncture, there is a wealth of research related to it in the scientific literature. However, in terms of results, for example, for the motor symptoms of Parkinson's disease, the results are mixed, with some studies showing that it does help some of the four core primary symptoms of Parkinson's disease, and other studies showing that it Doesn't really offer much of an improvement. So, I think it's OK for patients to give it a try, and some of my patients find it helpful. There is also research showing that acupuncture can help improve non-motor aspects of Parkinson's disease, such as anxiety. I think acupuncture is definitely a possible treatment if the patient is willing. As for the other part of your question, Tai Chi, Tai Chi exercise, I think it's a great exercise for people with Parkinson's disease. One of the largest studies published in the New England Journal of Medicine found that Tai Chi exercises actually help improve balance and help people with Parkinson's disease. Therefore, I highly recommend practicing Tai Chi to anyone with Parkinson's disease.

Aunt:

a. He has done more" (13:40-50)

b. If the body is not as stressed as before, encourage him (-14:41)

c. Think on the bright side, be encouraging, and be optimistic. Psychotherapy is better than medication. When taking medicine, you need to look up more information yourself and don't just listen to what a doctor says. You can't disobey the doctor, and you can't listen too much. (21:30-22:30)

[Part 3, Difficulties in Seeking Care]

Narrator: There are more than 20 million Asians living in the United States, of which 5 million are Chinese. Many of them are first-generation immigrants like Uncle Chen who don't speak much English. Because of their language and cultural barriers, as well as some problems in the American medical system, they often have difficulties in seeking medical treatment and seeking medical help.

Dr. Luo: I think especially for Chinese people, people don't know where to go for help.

Therefore, they are unaware of available community resources. They were unsure whether to ask their primary care physician (family doctor) for a referral to a neurologist, which should be the first step after developing symptoms that may be Parkinson's disease. (1:40 -2:20)

(17:00-18:00) Yeah, so I think some of the most important concerns in the Asian community or the Chinese community, especially in terms of Parkinson's disease, is if, you know, after they develop some of the symptoms of PD, they You should definitely contact a neurologist. Liaison with a neurologist, preferably a movement disorders specialist, I think is one of the important goals of care in Parkinson's disease.

PT: Challenges: I think patient education is one of them. When I evaluate people with Parkinson's disease and bring up this topic, the answer I get is: "Oh, my doctor told me I have Parkinson's disease. Yes, I take this medicine to treat Parkinson's disease, but I really don't know why I'm eating it." This may be an area where health care in general needs improvement. If we understand the disease process of Parkinson's disease and what's going wrong, I think it can give them a better understanding of what's going on in their bodies and in their lives.

Uncle: (20:30-21:25)

1. Not satisfied, there is no gold standard for diagnosis, and doctors' opinions are not uniform.
2. The symptoms of the feet are not eliminated



3. Data is not shared between hospitals

Auntie: I want to see MGH again next year (-16:16)

[4. The need for clinical trials & prospects for the future/Clinical Trials & Hope]

Dr. Luo:

1. Her current research

2. I cannot stress enough the importance of participating in clinical research. I think sometimes people, especially in the Asian community or the Chinese community, don't realize the importance of participating in research. Currently, we have no cure and this is a progressive disease. I think more and more people should get involved in research.

3. They should first ask a neurologist or movement disorder specialist about clinical trials conducted at their institution. For example, I always recommend that this could even be the first step.

4. Importance of having a translated consent form:

Therefore, I think that in order to have more patients participate in Parkinson's disease research, the first step is to have a translated version of the consent form. I think we're making more and more efforts to include people of color in clinical trials and to have more diverse populations studied. Because if we only do an experiment in a homogeneous population, we really can't say that the results can be generalized to the entire U.S. population. This is why the Chinese community should be more involved in clinical trials. I think participating in research is a really good idea from this perspective.

Uncle: What kind of scientific research and breakthroughs do you hope to see in the future?  
(9:02-- )

Alice: I think there are still many areas that need to be researched. First, we need to better understand how language barriers, cultural stigma, and systemic factors impact access to and quality of care for Asian patients with Parkinson's disease, and how to reduce existing disparities. Second, we need more research on the effectiveness of educational programs and awareness campaigns specifically targeting Asian communities to increase awareness of Parkinson's disease, its symptoms, and the importance of early diagnosis and treatment. Third, we need to learn how to engage Asian communities more actively in Parkinson's disease research. This can include participation in clinical trials or other types of research for new drugs or treatments. So part of that is reducing the barriers that physician-researchers face in recruiting Asian patients. Doctors have difficulty communicating with patients during visits. They may be hesitant to recruit them to study because the informed consent process itself can be difficult and time-consuming if they do not have the appropriate language skills and cultural competence. But we know it's important to include people of Asian descent in research. So we need to find ways to remove these barriers in recruitment and work to make ourselves more inclusive. Finally, we need to train health care professionals to be culturally competent and sensitive to the impact of providing care to patients with Parkinson's disease and reduce some of the barriers that exist in the health care system that prevent patients from scheduling appointments with health care providers appointments, or difficulty raising questions during the visit.

**【end】**

**【Autumn leaves enter Voice】**

Uncle: "Don't worry about the name Parkinson's or not." The medicine is still useful, but my legs have always been weak (16:17- 17:35)

a. Government insurance is better. Cooperate with the hospital and don't worry too much about food and exercise.

b. Rely on yourself and the country

c. Is there anything else you want to share or say to the audience? (10:25-11:55)

a. Cooperate with the doctor

b. Those who suffer from Parkinson's disease are all great people! (11:20-11:30)

PT: I have people with Parkinson's disease come to me and say, I don't do any exercise. I don't leave my home. I had trouble doing basic things like cooking, cleaning, and showering at home. So one of the things I work on is gait training, or (improving) their ability to walk so that they can leave the house confidently and not be afraid.

Dr. Luo: People should contact a neurologist in their community, and after they develop symptoms of Parkinson's disease, we will go to a movement disorder specialist. And then, as far as research goes, definitely participate in clinical studies if you're able to, and finally, I advise everyone to be resilient.

I would like to encourage everyone that having a resilient attitude is one of the key characteristics of a good or successful outcome with Parkinson's disease, which means that you should not let the disease overwhelm you, but rather look at it with a more optimistic mindset. I think having a rigorous exercise program is another key component to overcoming PD.

Alice: Living with Parkinson's disease can be a challenge for both patients and their families. But know that you are not alone in this journey. The resilience, strength and support of the Asian community can help you overcome the obstacles you face. It is important to include Asians in research into new treatments and biomarkers for Parkinson's disease. By actively participating in research and advocacy efforts, you can make a difference not only for yourself, but for future generations. So my hope is that together we can break down some barriers and improve the quality of care and quality of life for Asian patients with Parkinson's disease.

Narrator: Parkinson's disease is not just about hand tremors, but also has many other motor and non-motor symptoms. In addition to following the doctor's instructions, active and regular exercise is also the key to overcoming it. As Asians, especially Chinese, we are privileged to have excellent traditional exercises like Tai Chi to help improve the body's flexibility and balance, as well as acupuncture to help relieve symptoms. In addition to these external treatments, perhaps equally important is whether we can correctly understand and face Parkinson's disease. As Dr. Luo said, an optimistic attitude is crucial when dealing with Parkinson's disease. Just a few days ago, Uncle Chen sent me a video of him and a group of old friends. He played the harmonica and they sang. I think that as a Christian, his faith in Jesus also helped him to view the diseases and sufferings on earth with a more optimistic attitude. Perhaps one day, Parkinson's disease will no longer be incurable or difficult to talk about; until that day, we have an eternal hope.

## **Appendix 2 – Summary of Acupuncture Systemic Reviews**

### **Summary of Systematic Reviews and Analysis of the Clinical effectiveness of Acupuncture on PD Evidence and Reasoning for Using Acupuncture in addition to medicine.**

1. Although the use of medication such as levodopa lessen the risk of complications such as dyskinesia and motor fluctuation. Long term use of levodopa and other dopaminergic treatments leads to loss of efficiency and complications, which was observed in 50% of the patients after 5

years, and 80% patients after 10 years of levodopa. Therefore, the use of medication should not start early unless the symptoms have interfered with the patient's life (is this a valid statement?).

2. Acupuncture is most used as a complementary therapy in PD patients. And it has been reported in clinical trials to have potential therapeutic effect for Parkinson's patients such as improving motor symptoms, decrease need of drug dosage, decrease medicine side effects and improving sleep and other non-motor symptoms (1,5,11).
3. A systematic review/ meta-analysis published in 2017 which included 25 clinical trials conducted between 2000-2014 examined the effectiveness of acupuncture for Parkinson's patients (1). The analysis concluded that acupuncture is more effective than no treatment or with conventional treatment alone (dopaminergic treatments). And there are significant evidence supporting the effect of acupuncture plus conventional therapy on PD than conventional therapy alone.
4. A more recent systematic review (2022) that includes 17 RCTs mentioned that all the studies they reviewed concludes a positive effect of acupuncture on improving the motor and non-motor symptoms in PD (2). The review, however, concluded that it is difficult to validate the results of these RCTs because most of them were unable to rule-out placebo effect, except one (3). This study published in 2018 seems to be able to find an objective way to measure the patient's tremor through fMRIs.
5. Furthermore, another study conducted in 2019 suggests that acupuncture can help reducing the pain that a PD patient is experiencing. It also explains the neurological mechanism behind treating pain in PD patients using acupuncture (4). According to the research, acupuncture can increase the connectivity in brain areas relate to brain areas that is associated with reducing pain and alternating pain matrix persistently for 3 months after stopping treatments.
6. In terms of non-motor symptoms, a meta-analysis in 2022 concluded that acupuncture is effective in relieving some non-motor symptoms associated with PD such as insomnia and depression (5) and it might improve cognition and quality of life as shown in better UPDRS scores. Another 2023 article suggests that acupuncture is a promising therapeutic approach for PD induced constipation (11).
7. A mice study in 2020 suggests the potential pathway that acupuncture has in improving motor symptoms and reduce anxiety (6). It suggests that acupuncture can result in restoration of the gut microbiota which leads to decrease of neuroinflammation.
8. Regarding the safety of acupuncture, a recent meta-analysis reports no adverse events among the articles been reviewed. Furthermore, 2 overviews of 11 and 12 systematic reviews published in 2020 both concludes that acupuncture can be a safe alternative treatment for PD (8,9).
9. Moreover, a review of studies published between 2000-2020 even suggests that acupuncture may reduce neurodegeneration thus delay the progression of Parkinson's (10), which can be very exciting if verified by clinical studies since we have not yet found a treatment to delay the progression of disease.

## **Conclusion and Recommendation**

1. Acupuncture has positive effect in relieving symptoms relate to Parkinson's, both motor and non-motor, and it should be recommended to the PD patients in addition to conventional therapy. Evidence-based alternative treatments such as acupuncture may be used in early phrases of the progressive PD course before the use of dopaminergic treatments such as levodopa. It can also be used in combination with medication for an improved health outcome among PD patients.
2. Further research with larger sample size and well-designed RCTS should be conducted to compare different methods of PD alternative treatments such as acupuncture, massages, physical therapy, traditional Chinese medicine, and TaiChi/Chigong. This can potentially cross-check the placebo effect for acupuncture since it is very hard to design a double-blinded study in this context. To reduce placebo effects, research can also be conducted among a population that has no previous knowledge of Acupuncture and thus without an expectation of how it may improve

the symptoms. However, it is not necessary to consider placebo effect in PD patients because the goal of the therapy is not curing the disease but help reducing the symptoms, i.e. make the patient feel better. Thus, even if they feel better because of a placebo effect, the goal is still met.

3. A clinical study should measure whether acupuncture can indeed, slow down disease progression (10).

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## Appendix 3 - Resource Guides for PD Patients in Simplified Chinese and English



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[pdbp.ninds.nih.gov](http://pdbp.ninds.nih.gov)

### 资源分享

美国帕金森协会 (APDA) 热线  
**1-800-223-2732**

帕金森基金会热线  
**1-800-473-4636**

帕金森宝典APP (按时吃药好帮手)  
[www.411pd.org.tw/411pd/tw/](http://www.411pd.org.tw/411pd/tw/)

APDA的出版物 (中英文)  
[awfh.org/APDAPublications](http://awfh.org/APDAPublications)



扫描此二维码以获取更多关于帕金森病的信息



**AWFH** 是一个致力于通过社区参与、教育和代表性来促进亚洲女性的健康和福祉的非盈利组织。

### 你知道吗？

打太极拳可以帮助维持甚至改善帕金森患者的平衡和协调能力



## 运动有益健康



扫描此二维码以获得  
APDA的运动健康手册

### 你知道吗？

吃药只能缓解症状，但是经常规律的**有氧运动**，**力量训练和拉伸**可以帮助大脑和身体的运作以**推迟病情的恶化!!**

平衡营养的**地中海饮食结构**（新鲜莓果，蔬菜，鱼肉，粗粮，坚果，橄榄油，红酒）也许也可以推迟帕金森病情恶化哦！





**AWFH** is dedicated to advancing the health and well-being of Asian women and people from diverse, underrepresented backgrounds through community engagement, education, and representation.



## A Resource Guide for Patients with Parkinson's Disease

There are nearly **10 million** Parkinson's patients worldwide - **You are not alone!**  
Asking for help is a sign of strength, not weakness.  
Please ask for help when you need it!



### Did you know?

Acupuncture may improve motor and non-motor symptoms of PD.

Abnormal alpha-synuclein ( $\alpha$ -syn) is currently the most reliable biomarker for Parkinson's Disease, with one study showing that it is present in 93% of patients.

### Information

**American Parkinson Disease Association (APDA) Hotline**  
1-800-223-2732

**Parkinson's Foundation Hotline**  
1-800-473-4636

**Parkinson's Guide APP**  
(good helper to take medicine on time)  
[www.411pd.org.tw/411pd/tw/](http://www.411pd.org.tw/411pd/tw/)

**APDA publications (Chinese & English)**  
[awfh.org/APDAPublications](http://awfh.org/APDAPublications)

### Are you willing to participate in clinical trials?

Clinical trials require Asian patients. Participation in clinical trials helps improve treatments for Parkinson's disease and provides access to the latest treatments. If you would like to participate, please consult your neurologist or visit the following website:

- **Michael J. Fox Foundation Clinical Trial Finder**  
[www.michaeljfox.org/trial-finder](http://www.michaeljfox.org/trial-finder)
- **National Institutes of Health (NIH) Clinical Trial Registration Method**  
[www.clinicaltrials.gov](http://www.clinicaltrials.gov)
- **Parkinson's Disease Biomarker Project**  
[pdbp.ninds.nih.gov](http://pdbp.ninds.nih.gov)



Scan this QR code to get more information about Parkinson's Disease



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### Did you know?

Tai Chi can help maintain and even improve balance and coordination in people with Parkinson's Disease.



## Exercising Is Good for Your Health!



Scan this QR code to get APDA's Sports and Health Handbook

### Did you know?

Medication can only relieve PD symptoms, but regular aerobic exercise, strength training, and stretching can help the brain and body function and delay disease progression.

**A balanced Mediterranean diet that is rich in berries, fresh vegetables and fish, whole grains, olive oil, and red wine may help slow the disease progression**





Questions for Patients (Family members can also answer questions for patients):

1. When were you diagnosed? How were you diagnosed?
2. What were the symptoms at the time (when diagnosed), and have they changed now?
3. Do you have any confusion/questions about Parkinson's disease?
4. When you have these doubts, will you share them with others or seek help from them?
5. Would you share your Parkinson's diagnosis with others? (Why?)
6. Did you encounter any difficulties in life, physical or psychological, before and after your diagnosis? Is there any way to adjust it?
7. Who is mainly taking care of you now?
8. What treatment are you receiving now? How's the effect?
  
9. After you were diagnosed, have you done anything to relieve symptoms and improve your quality of life, such as massage, physical therapy, rehabilitation or appropriate regular exercise?
10. Some academic research results support the use of acupuncture and Tai Chi in the treatment of Parkinson's disease. Have you tried any traditional Chinese medicine methods, such as Tai Chi or acupuncture, or taking traditional Chinese medicine? Does it help with symptoms and conditions?
11. Are you satisfied with your experience of medical treatment and treatment in the United States? Did you encounter any difficulties? Is there anything that can be improved?
12. What kind of outside help do you think a Parkinson's patient needs most?
13. What scientific research and breakthroughs would you like to see in the future?
14. Is there anything else you would like to share or say to the audience?

Questions for families:

1. What are your thoughts or feelings about your family member's diagnosis of PD?
2. What kind of support do you currently provide to he/her? What about psychological support?
3. Do you think there are any changes in your husband before and after the diagnosis? How has this diagnosis affected your lives?
4. Did you encounter any difficulties in taking care of your husband? Do you need any help?
5. Are you satisfied with your wife's medical experience and treatment effects?
6. Is there anything that American society, government, hospitals, or the Chinese community can do for patients and their families?
7. Is there anything else you would like to share or say to the audience?

Interview Questions for Dr. Luo:

1. Can you tell me what are some common myth associates with PD among Asians (especially Chinese)? (0:45 -2:20)
  - a. There is medication available.
  - b. Where to turn for help
  - c. The lasting of the medicine (2:35-3:00)
    - it's not that Parkinson's medications stop working, but rather that as the disease progresses over time, higher doses of medication may be needed, and additional medications may need to be added to treat other symptoms that develop.
2. What are some symptoms of PD besides tremors? Do all PD patients have tremors? Motor & non-motor. (3:20- 5:19)
  - Not all PD patients have tremors as a symptom (the dr didn't directly mention this but it is important to mention this point in both videos).

- Parkinson's disease has both motor and non-motor symptoms.
3. Some people think PD is dementia, is that true? (5:20-6:00)
    - About 30-60% of Parkinson's patients may develop cognitive issues over time.
  4. Can people inherit Parkinson's? (6:00 - )
    - 10% of Parkinson's cases may be linked to genetic mutations.
  5. Importance of exercise and active lifestyle (-07:30)
    - Lifestyle factors like exercise can impact Parkinson's progression.
  6. Currently, what is the most reliable way to diagnose PD? (7:50- )
    - Patients have tremors may not necessarily have PD, but it can be parkinsonism or other diseases such as multiple system atrophy. (-09:05)
    - The clinical test is not completely accurate
    - Some tests can help, such as DAT scan (9:25) and skin biopsy to look for abnormal protein in the skin
  7. What are some current treatments for Parkinson's? (09:49)
    - a. Exercise
    - b. medication
    - c. DBS and its risk (10:48-12:15)
  8. There are some studies that provide evidence supporting using Acupuncture and doing Taiji for Parkinson's patients. Would you recommend these methods?
    - a. Acupuncture (12:55 - 14:05)
    - b. Taiji (14:05 – 14:33)
  9. Can you touch on the disease progression of Parkinson's? (-15:50)
    - Parkinson's has no set timeline and progression varies between individuals.
  10. Do you recommend patients to start medication ASAP, or should they wait until the disease becomes more severe? (-17:00)
    - Take the medicine when the symptom has impacted the person's life.
  11. From your experience interacting with Asian patients, especially Chinese patients, what are some of their most urgent needs that you see?
    - *Improving awareness of available community resources and care options for Parkinson's. Many are not aware of where to turn for help.*
    - *Going to see a movement specialist, preferably in a major university medical center.*
    - *Increasing understanding that Parkinson's is not simply an aging problem and can affect younger individuals too.*
    - *Ensuring they follow up with specialists like neurologists after initial symptoms arise rather than waiting.*
  12. What are clinical trials? How can Asian patients be more involved in clinical trials? (19:20-23:10)

- a. Importance of participating in clinical trials (Participating in clinical research studies to help advance treatments)
  - b. How to involve, some recourses (websites) (20:? -21:45)
  - c. (in the documentary, mentioning the MJF biomarker study)
13. Are there any encouraging thing or words that you want to tell the Asian patients and their caregivers? (23:12- 24:20)
14. Anything else that you want to tell the me/ the audience? (Take home points)
- a. Reaching out to a neurologist or movement disorder specialist after developing Parkinson's symptoms
  - b. Participate in the research if able.
  - c. Maintaining a resilient attitude and exercise routine can help manage the disease.
15. Early symptoms for PD that people should keep in mind of. (-26:46)
- a. Prodromal symptoms like changes in smell or vivid dreams could indicate early Parkinson's.
  - b. Recommendation (-27:20)
    - get a thorough evaluation with a clinician with a neurologist or neurologist or movement disorder specialist.
16. Some people think that PD is only an old-person's disease. Is that true? (-28:12)
- age is a risk factor in developing Parkinson's disease.
  - So, people as young as in their 30s or so my coworkers have seen people in their 20s with Parkinson's disease. So those are called the young onset PD.
17. What research are you currently doing? Can you tell me more? (in the separate recording)

Transcripts- Dr. Alice Tang:

1. Can you tell us about the Parkinson's research projects that you are currently doing?

So I am working with a neurologist at Tufts Medical Center and a community based organization called Asian women for health. And we're conducting a study to examine factors associated with access and quality of care about Asian living with Parkinson's disease. So were conducting the study in two phases. So the first in the first phase, we interviewed four groups of people. So we interviewed Asian patients living with Parkinson's disease, their family members who support them, their health care providers who treat them and then community advocates who work primarily with the Chinese and Vietnamese communities in the greater Boston area. And the purpose of those interviews is to learn more about the challenges and barriers that they face when accessing care for their Parkinson's disease. And then in the second phase, we're gonna do a larger survey among the family members to learn more about how those barriers are associated with more access to quality of care.

2. You mentioned to me that your mom has Parkinson's. Can you please describe how she was diagnosed and if it is related to the PD research that you are doing?

I decided to pursue this area of research because my mother has Parkinson's disease and she was diagnosed very late. Actually. She didn't have that classic tremor, so she remained undiagnosed for many years before her other symptoms became more advanced and more obvious. So in hindsight, we

realized that she had been experiencing many of the non motor symptoms of the disease for many years prior to her diagnosis.

3. What kind of research is needed going forward and how can the Asian community participate in them?

think there are many areas of research that are still needed. First, we need to better understand how language barriers cultural stigmas and systemic factors affect access to health care and quality of care for Asian patients living with Parkinson's disease, and how the disparities that exist can be mitigated Second, we need to develop more research on the effectiveness of educational programs and awareness campaigns targeted specifically at the Asian community to enhance knowledge about Parkinson's disease, its symptoms and the importance of early diagnosis and treatment. And third, we need to learn how to engage the Asian community more actively in Parkinson's Disease Research. And this can include participation in clinical trials for new medications or treatments or other types of studies. So part of this is reducing the barriers that physician researchers face in recruiting Asian patients. Physicians struggle to communicate with their patients during their clinic visits. They may be hesitant to recruit them for their studies because the informed consent process itself can be very difficult and time consuming if they don't have the appropriate language skills and cultural competency. But we know it's very important that people of Asian descent are represented in the research. So we need to find ways to remove those barriers in recruitment, and be more inclusive in our efforts. And then finally, we need to study the impact of training healthcare professionals to be culturally competent and sensitive and delivering care to patients with Parkinson's disease and to reduce some of the barriers that exist within the healthcare system that might prevent patients from being able to do simple things like scheduling an appointment with their healthcare provider, or ask questions between their clinic visits.

4. Are there some encouraging words that you want to say to the Asian patients and their carers?

Living with Parkinson's disease can be challenging for both patients and their family members. But just know that you're not alone in this journey. The recently added strength and support within the Asian community are powerful tools that can help you overcome the barriers that you face. It's important that Asians are included in research on new treatments and biological markers for Parkinson's. By actively participating in research and advocacy efforts, you can make a difference not only for yourself, but for future generations. So I hope that together we can break down some of the barriers and improve quality of care and quality of life for people of Asian descent who are living with Parkinson's disease.

Transcripts- Physical Therapist

1. Can you do a short introduction of yourself?

Sure. My name is Esteban. I'm a physical therapist. I work outpatient physical therapy here at Tufts Medical Center. I've been here for about one year, while I was in physical therapy school, I did a rotation here as well.

Cool. Thank you so much for participating today. First, I want to ask you if you know anything about Parkinson's disease?

yes, I know a lot about Parkinson's disease. I could go on for hours discussing the topic and patient care pathophysiology. What enjoy general what we do here for Parkinson's patients are, is increasing functional mobility, safety and independence with their daily activities.

Do you have any experience working with Asian Parkinson's patients?

I currently have two patients with Parkinson's with an Asian background. And have had that I can remember off the top of my head at the moment, a few more in the past as well.

So what's your How has your experience been working with them?

I really liked the population, it's nice to see the progress with them. When it comes to physical therapy and the interventions that we do here. If you give it enough time, you have a great noticeable change in their function, which is rewarding for me as a therapist.

How is... I think you've mentioned this a little bit already, but how is physical therapy helpful for Parkinson's patients?

Yes. So, they have often gait impairments, episodes of freezing, trouble moving. And that causes them to lose confidence in their mobility and limit themselves. And so when they come here to therapy, what I do is try to restore function, and give them that confidence to continue moving as much as they can increase strength. And I also simply deal with the day-to-day issues and problems that they come to me and express to me. So I make my therapy sessions unique to their needs.

Thank you so much. Is there anything that you see particular challenging for patient patients? One second. Or like any challenge that's well put particular to this population? Absolutely.

I think patient education is one of them. When I'm evaluating someone with Parkinson's disease, and I bring up the topic, an answer I get is, oh, my doctor told me I have Parkinson's. And yes, I take this medication for Parkinson's, but I don't really know why. And that may be an area of healthcare that needs to be improved on as a whole. If we understand the disease process and what goes wrong with Parkinson's disease, I think it gives them a better understanding of what's going on in their own bodies and in their own lives.

Yes, thank you for sharing. Can you just briefly show me some work outs or like postures that the patients can practice as a whole?

Sure. I don't have the proper equipment here at the moment. We have a lot of equipment downstairs in the physical therapy gym that I use with Parkinson's disease, one of which are our treatment tables are twins that go up and down, it gives them easier access to lay down to get back up what we call transferring. Parkinson's patients often experience trunk rigidity, so they're stiff in this area here. So a lot of movements I do are rotational movements that your average person would take for granted. So for example, trunk rotation would be reaching behind a car seat this way, they would have trouble doing that reaching overhead into a cabinet extending their back, they would have trouble doing that. And simply walking is an issue that they that they can run into.

Thank you. Can you told me a story of a patient and physical therapy doesn't have to be specific or identifiable?

A story from a therapy session or something that a patient with Parkinson's has told me has happened to them in the past?

Anything that you think will be good to share? Any... like a story of how physical therapy has helped the patient?

Sure, absolutely. Okay. I've had patients with Parkinson's come to me and say, I don't do any exercise. I don't leave my house. I struggle with basic things in my house cooking, cleaning, showering. And so one thing I work on is gait training, or their ability to walk, to be able to leave the house with confidence, and not feel afraid of doing so. Even though they're dealing with a progressive disease that unfortunately, only gets worse with time.

Thank you. Do you want to say anything to the Asian Parkinson's pay community? Or do you want to say anything to patients, especially Asian patients to encourage their usage of physical therapy?

Yes, very much. So. We see heavy Asian population here just being in Chinatown. And we encourage anyone having trouble or dealing with Parkinson's to come see us in physical therapy. We have had fantastic results in the past. Again, improving function restoring function. And they don't need to feel alone dealing with their Parkinson's. We're here to help physical therapist spend a lot of time in school learning about this. And one of my coworkers is even neurological specialists with which Parkinson's is a

nervous system disease. So we are all well educated on the subject. If they need any help, they can come see us here at Tufts physical therapy.

Thank you so much. Anything else you want to tell me or share to the audience?

Yeah, I guess in specific to the Asian population, oftentimes a language barrier hinders them from coming into the hospital. We use interpreter services here if they need. Alright, thank you so much for us. Yeah.