# CURRENT KNOWLEDGE AND ATTITUDES ABOUT PARKINSON DISEASE AMONG

## COLLEGE STUDENTS

By

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# CURRENT KNOWLEDGE AND ATTITUDES ABOUT PARKINSON DISEASE AMONG COLLEGE STUDENTS

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Abstract: Parkinson disease (PD) is a progressive neurological disorder characterized by a variety of symptoms that affect many aspects of an individual's daily functioning. Multiple studies have investigated college students' awareness and perceptions of a variety of diseases such as epilepsy, stroke, or dementia. However, there is little to no existing research about current perceptions and knowledge about PD among college students. Therefore, the aim of the present study is to identify the current level of knowledge and attitudes about PD among college students enrolled at Oklahoma State University (OSU). This study utilized a three-part survey that consisted of a demographic survey, a knowledge survey, and an attitudes survey. The threepart survey was conducted online. Participants included 206 undergraduate students representing different ages and majors. Results indicated that participants were more aware of externally observable symptoms of PD when compared to some of the nonmotor symptoms. The results also indicated an overall positive attitude from the participants towards individuals who have PD. In conclusion, the current study findings indicated a great need for more educational programs to be implemented in order to alleviate current lack of knowledge about different symptoms as well as replace misconceptions and negative attitudes with the current facts and knowledge about PD and its possible management.

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#### **INTRODUCTION**

## PD Definition, symptoms, and etiology

Parkinson disease (PD) is a progressive neurological condition that affects motor function and is typically characterized by muscle rigidity, slowness, and tremor (Armstrong & Okun, 2020). Parkinson disease occurs due to a lack of dopamine in the substantia nigra, a structure within the basal ganglia crucial to smooth motor function. The basal ganglia refer to a group of subcortical structures that play a role in the initiation of movement, muscle tone, and the maintenance and inhibition of extraneous movements. The lack of dopamine affects the muscles' ability to perform voluntary movements, thus leading to possible slowness of movements and rigidity. Parkinson disease typically causes both motor and nonmotor symptoms; however, often times the nonmotor symptoms appear years and sometimes decades before the onset of motor symptoms (Armstrong & Okun, 2020).

There are many PD-related nonmotor symptoms including rapid eye movement (REM) sleep behavior disorder, olfactory loss, constipation, and depression (Armstrong & Okun, 2020). Although all of the above-mentioned symptoms are not specific to PD, when they co-occur the risk of a diagnosis is greater. Based on a recent review by Armstrong and Okun (2020), an estimated 30-50% of individuals with PD have REM sleep behavior disorder. Some motor symptoms associated with PD include bradykinesia (i.e., slowness and smaller movements when performing a task), a gradual onset of resting tremors (i.e., tremor that occurs when limbs are at rest), and stiffness. When diagnosing an individual with PD, there are key features that must be taken into consideration as neurologists often test for presence of bradykinesia and rigidity or tremor. Other symptoms of PD that may be present include soft voice, gait changes, decreased facial expression, and depression (Armstrong & Okun, 2020). In conclusion, PD is a

multimodality disorder and, typically, presence of symptoms such as changes in gait, bradykinesia, rigidity, and rest tremors are used by neurologists for its clinical diagnosis.

## PD Prevalence and Incidence Across the Globe

A comprehensive review published by the GBD 2016 Parkinson's disease collaborators focused on the global and regional prevalence of PD from 1990 to 2016. The findings showed that over the past generation, the prevalence of PD has more than doubled to over six million globally (GBD 2016 Parkinson's Disease Collaborators, 2018). Although much of this could be attributed to the fact that people are living longer lives, there are possibly other factors such as an individual's lifestyle habits or the improved understanding of symptoms of PD that could also explain the increased worldwide prevalence of PD. Of all the neurological disorders studied in this extensive review, PD has been reported to be the fastest growing neurological condition (GBD 2016 Parkinson's Disease Collaborators, 2018).

Specific to the United States, a study found the overall incidence rates of PD increased by 24% per decade from 1976 to 2005 in men but not to the same extent in women (Savica et al., 2016). The authors attributed this gender difference to several factors. The increase in incidence could be the result of better understanding of the different symptoms, improved clinical assessment, and the overall increase in awareness over the decades. The fact that it is occurring in men primarily may imply that the habits and lifestyle men have maintained may contribute to the development of PD (Savica, et al., 2016). A similar study conducted by Marras et al. (2018) investigated the prevalence of PD across the United States and Canada. This was a longitudinal study, and it evaluated the prevalence of PD in men and women over the age of 45 over the span

of four years (Marras et al., 2018). The results showed that for women the number of cases increased from 109 in the first year to 3,204 in the fourth year (Marras et al., 2018). The number of cases for men increased from 207 in the first year to 3,728 in the fourth year (Marras et al., 2018). Similar to the study by Savica et al. (2016), this study also reported an increased prevalence rate in men when compared to women.

Further in South Korea, a similar increase in PD for both prevalence and incidence occurred throughout the country over the span of the five-year study (Park et al., 2019). In contrast to previous studies, both incidence and prevalence of PD was greater among women than men. There was a steady increase in incidence of PD. For women, the increase was 27.7 cases per 100,000 individuals and among men it was 20.0 cases per 100,000 individuals, over the span of five years. There are several reasons as to why there was a greater increase in incidence and prevalence among females in South Korea. Some of the factors that the authors discussed to be behind the increased prevalence of PD among Korean women were increased age, possible exposure to pesticides and toxins, and possible dietary deficiencies (Park et al., 2019). In conclusion, the existing studies suggest gender differences across different geographical regions in terms of prevalence of PD. Further, the progressive nature and recent increase of incidence of PD worldwide make it even more critical that people receive a timely diagnosis of PD and begin treatment and management of their symptoms as early as possible and work towards delaying the progression of the condition.

#### PD Awareness – Knowledge, Attitudes, and Stigma

One key component to ensuring people receive timely treatment once diagnosed with PD relies on the level of knowledge and awareness people have about PD. Multiple researchers have examined the level of knowledge and awareness about PD symptoms during the last 15 years (Mokoya et al., 2017; Moore, 2006; Pan et al., 2014). Among these existing studies, one study conducted by Moore (2006) investigated the knowledge and attitudes toward PD among two groups in Australia: people with PD and adults without PD. The results revealed that both groups were more likely to view PD with stigma when they held more negative attitudes toward the disease. The author discussed the importance of increased awareness about PD to help reduce the social stigma and discrimination against those who have a PD diagnosis. Although some participants without PD demonstrated an adequate level of knowledge, as suggested by correctly identifying PD symptoms on the questionnaire, there were others who had many misconceptions about PD that contributed to its stigma (Moore, 2006).

Another study conducted by Pan et al. (2014) investigated the knowledge and attitudes about PD among neurologically healthy older adults. The authors discovered that traditionally undeserved minorities are more likely to delay diagnosis of PD and less likely to receive the care necessary to treat their disease. One explanation for this is that there is a lack of knowledge and awareness within these communities, due to the limited resources and education programs available to them. About one-third of the members had little to no knowledge of the disorder as many did not correctly identify the possible symptoms of PD. In addition to lack of knowledge, many cultural groups and populations demonstrated negative attitudes or perceptions about PD. Further, Pan et al. (2014) found some of the Chinese American and African American

participants held certain attitudes that could discourage health-seeking behavior should they begin to present signs of PD.

In a similar study investigating knowledge and attitudes of PD in South Africa, findings showed that this population had a relatively high level of knowledge, but still lacked an understanding of key features of PD such as its etiology (Mokoya, Gray, & Carr, 2017). Similar to Moore's (2006) study, this study focused on interviewing two groups of people: those who had PD and those who did not have PD. The results showed that people without PD had more positive attitudes toward the disease than those with PD as they expressed less concern when presented with 15 different aspects of the disorder. In contrast, participants with PD had relatively negative attitudes compared to people without PD, and this correlated with lower levels of knowledge regarding PD symptoms. It was also interesting to note that the participants without PD who demonstrated higher levels of knowledge about PD symptoms, also had more negative attitudes than those with relatively less knowledge about the disorder (Mokoya et al., 2017). A possible explanation could be that individuals with relatively higher levels of knowledge about symptoms of PD may feel less encouraged about the long-term outcomes, may have more realistic expectations, and may hold more negative attitudes as a result when compared to those who are less knowledgeable about the possible manifestations of PD. In conclusion, previous studies indicated there is an overall low level of knowledge when it comes to PD and its symptoms, among both those who have PD and those who are neurologically healthy, often resulting in misconceptions and stigma surrounding the disorder.

## Awareness About Neurological Disorders Among College Students

Specific to PD, a majority of existing research has focused on older adults' knowledge and perceptions of PD symptoms. To the best of our knowledge, there are no studies currently existing about the perceptions and attitudes of young adults (or those attending college) regarding PD. This is in sharp contrast to multiple studies that have examined attitudes of other common neurological disorders such as dementia (Cowan, 2019; Werner et al., 2019; Werner et. al, 2020), epilepsy (Young et al., 2002; Youssef, et al., 2009), and cardiovascular disease (CVD) (Obembe, et al., 2014; Smith & Spillman, 2003).

## Perceptions About Dementia Among College Students

In one of the existing studies, Cowan (2019) investigated undergraduate college students' and community members' awareness and attitudes toward dementia at a university in the Midwest United States. The study utilized surveys and immersive experiences to compare participants' initial understandings and attitudes of dementia before and after an informational program. There were a total of 101 participants, 68% being university students and 32% non-students. The results showed that there was an improvement in the participants' comfort level of being around a dementia patient as well as their knowledge on the disease during the post-experience period (Cowan, 2019). In conclusion, the study showed the benefits of informational events as they improved the awareness and attitudes toward dementia.

Another study investigated attitudes toward dementia among Greek and Israeli college students (Werner et al., 2019). The findings showed that there were low levels of stigma in both groups, but that the Israeli students held significantly higher levels of stigmatic beliefs about dementia than the Greek students. One explanation for this revolves around a bias that is more common in the Greek culture to possess. This bias is one where individuals often want to appear accepting and socially desirable, which in turn, may be why they expressed fewer stigmatic beliefs about dementia (Werner et al., 2019).

A similar study focusing primarily on the attitudes toward dementia among college students found that the age of onset of a person's Alzheimer's had an impact on participants' attitudes toward Alzheimer's disease dementia (Werner, Raviv-Turgeman, & Corrigan, 2020). The results found that there were relatively lower levels of stigma towards older individuals with Alzheimer's disease (AD), however, there were markedly higher negative attitudes toward a person with young-onset dementia. The study concluded that positive emotions and a willingness to help were much lower among college students when interacting with an individual with young onset dementia than one with late onset dementia (Werner et. al, 2020).

## Perceptions and Attitudes Towards Epilepsy Among College Students

Specific to attitudes and perceptions about epilepsy, Young et al. (2002) investigated Canadian college students' knowledge of epilepsy over a span of three years. A standardized questionnaire about the knowledge level and perceptions toward epilepsy was utilized and presented to different groups of college level students in different settings each year. The first year, the questionnaire was presented to a psychology class consisting of 55 participants. The second year, it was given immediately after class to a wide range of students with different majors totaling to 136 participants. The third year, the questionnaire was given to a single large class consisting of 59 participants divided into two groups. During the third year, one group

received an informational brochure to utilize while filling out the survey, while the other group did not. The results indicated that during the third year, the group that did not receive an informational brochure yielded similar results to the first- and second-year participants. These results indicated a low level of knowledge of epilepsy, but an overall positive attitude toward the disorder. Further, the group that received the brochure performed markedly better than the other groups in their overall knowledge score (Young et al., 2002).

In a similar study, Youssef et al. (2009) focused on college students' attitudes and knowledge about epilepsy in Trinidad and Tobago. The study utilized a standardized questionnaire that focused on the level of knowledge of epilepsy and the attitudes toward the disorder. There were 355 participants, 90% were of the ages 18-24 years. Of these participants, 86% had heard about epilepsy, more than half knew someone with epilepsy, and about 44% of the participants had witnessed someone having a seizure previously. Although many participants indicated some familiarity with epilepsy, researchers discovered that knowledge about epilepsy was relatively low and the overall attitudes were generally positive. One interesting finding was that even though attitudes were positive as people were open to learning more about epilepsy and open to relationships with someone with epilepsy, there was still a high stigma or a mark of disgrace surrounding epilepsy. Much of this stigma was dependent on participants' religion as Hindu students demonstrated markedly higher perceptions of stigma when compared to Muslim and Christian students. Approximately 50% of students expressed possible discrimination against people with epilepsy in the society (Youssef et al., 2009). Overall, studies have reported mixed levels of knowledge and expressed different levels of stigma for people with epilepsy among college students.

#### Perceptions and Attitudes Towards Cardiovascular Disease Among College Students

Apart from dementia and epilepsy, there are some existing studies that have examined more chronic and debilitating disorders such as cardiovascular disorders (CVD). One such study examined knowledge of CVD risk factors among college students and how increased knowledge may be associated with changes in one's lifestyle (Smith & Spillman, 2003). This study took place at Miami University (Florida) and participants were randomly selected. There were a total of 500 participants, including 280 female and 220 male students. The study utilized a survey consisting of two parts, a general personal health questionnaire as it related to CVD and a knowledge test of CVD. Authors reported that, overall, the students had a low level of knowledge specific to risk factors and many did not correctly identify symptoms on the questionnaire. In addition, many participants in the study felt that lifestyle changes to avoid CVD need to be implemented later in life rather than during early adulthood.

Almost a decade later, researchers investigated the knowledge level related to stroke among college age students and staff at a Nigerian university (Obemebe et al., 2014). In this study, there were 949 participants, including 500 students under the age of 40 and 494 staff members of the university. In this cross-sectional study, respondents were selected to represent the 13 faculties: Basic Medical Sciences, Dentistry, Clinical Sciences, Science, Pharmacy, Arts, Technology, Environmental Design and Management, Agriculture, Administration, Social Sciences, Law, and Education. The study utilized a questionnaire that evaluated knowledge about different warning signs and risk factors of stroke. The results revealed that the most commonly identified risk factor of stroke was hypertension (87.4%). In contrast, a high cholesterol diet was the least identified risk factor (37.8%). The findings also revealed that college students had less knowledge about risk factors and symptoms associated with stroke

when compared to the staff participants. However, the overall awareness for stroke was low for all groups regardless of their education level (Obemebe et al., 2014).

It is evident that research on college students' knowledge and awareness about different disorders is not a new phenomenon. However, there is a significant gap of research regarding college students and their awareness of PD. Parkinson disease is the second most common disorder affecting older adults. As the average lifespan of humans has increased, more and more people are likely to be affected by this condition in the future. Therefore, it is crucial to begin spreading awareness of PD, to increase knowledge about different aspects of PD among people of all age groups, and to reduce the stigma associated with its many symptoms. To the best of our knowledge, no published studies currently exist about the level of knowledge and attitudes toward PD among college students based in the United States. Therefore, the purpose of this study was to utilize surveys to examine the current perceptions and attitudes regarding PD among college students enrolled at Oklahoma State University (OSU). The findings from this study can help identify current gaps in knowledge about PD which in turn will allow a more curated development of community-based education programs. Due to the relatively long lifespan of humans in the past decades, PD is going to be seen increasingly more in the population in the coming years. Because of this, increased awareness and knowledge of PD symptoms among adults can be helpful to improve attitudes, minimize misconceptions, and encourage early diagnosis and intervention.

#### **METHODS**

## **Participants**

The current study had an online survey design. The study was approved by the OSU Institutional Review Board (IRB-201-114; approved 02/25/21) prior to data collection. Data were collected between March and May 2021. To participate, individuals had to be 18 years or older and enrolled as an undergraduate student at OSU. Participants were recruited via email, inclass presentations, and social media posts. A total of 206 undergraduate participants completed the online survey including 121 females and 85 males. Ages of participants ranged from 18 to 49 years with an average age of 21. Specific to ethnic backgrounds, 78% of participants were White/Caucasian, 6% were Hispanic/Latino, and 5% were Asian. Of the different colleges within OSU, 9.7% of participants were in the College of Education and Human Sciences, 13.6% were from the College of Engineering, Architecture and Technology, 13.6% were from the College of Agriculture, 14.6% were from Spears School of Business, and 30% were from the College of Arts and Sciences. About 18% of participants did not specify their major. About 34.83% of participants were seniors, 25.84% were juniors, 12.36% were sophomores, and 25.84% were freshman.

## **Study Surveys and Measures**

The current study included modifications from existing PD surveys (Adubi et al., 1997; Cheon et al., 2008; Freed, 2020; Miller, 2012). The study included three different surveys about the knowledge and attitudes toward PD. All participants first completed an informed consent followed by a demographic questionnaire, a survey about knowledge of PD-related symptoms, and a survey examining perceptions and attitudes toward PD. These surveys can be found in the appendices. The surveys were presented in the same order to all participants via a Qualtrics link. Participants could access the survey either through a link or QR code sent via email. All participants who completed the surveys were eligible to be in a raffle to win one of ten e-gift cards.

#### RESULTS

## **PD Knowledge of Symptoms**

The current study aimed to identify the level of knowledge, perceptions, and attitudes of PD among undergraduate students attending OSU. The PD knowledge survey displayed a list of all the symptoms associated with PD for the participants to select if they knew the symptom is associated with PD. Results indicated that the most commonly identified symptoms were rest tremors (96.39%), lack of dexterity (80.72%), and changes in physical gait (77.11%). Table 1 shows the top 15 symptoms of PD identified by the participants. In addition to the actual possible symptoms of PD, the survey included three false symptoms. These false symptoms were included to determine whether or not participants would select these symptoms due to their lack of knowledge about PD. Among the three false symptom of PD. However, this symptom is actually associated with another neurological disorder (multiple sclerosis). Thus, sometimes participants demonstrated a lack of accurate knowledge about possible PD symptoms by selecting a false symptom on the survey.

The survey included motor and nonmotor symptoms of PD. It was interesting to note that some of the least commonly identified symptoms were the nonmotor symptoms of PD. These included vomiting (10.24%), double vision (12.65%), and intense or vivid dreams (12.65%). Table 2 shows the top 10 least identified symptoms of PD by participants. Based on the survey results, it can be concluded that college students identified more of the externally observable and more frequently discussed symptoms of PD such as changes in physical gait and rest tremors. However, a majority of participants demonstrated lack of knowledge about the existing nonmotor symptoms of PD such as double vision, loss of smell, and changes in sleep as evident with lower percentages on the survey.

Symptoms	Percentage of participants who selected
	the symptom
Rest tremors (shaking of hands, fingers,	96.39
legs)	
Lack of dexterity (holding tools such as a	80.72
brush or pen with hands)	
Changes in physical gait (reduced steps,	77.11
shuffling, freezing)	
Changes in handwriting	75.30
Dyskinesias (out-of-control movements of	73.49
hands and legs)	
Muscle aches	70.48
*Relapsing and remitting of symptoms	62.65
(some weeks with severe symptoms and	
some weeks with less or no motor	
symptoms	
Muscle cramps	62.05
Voice tremors	61.45
Loss of speech clarity	60.84
Morning stiffness	59.04
Changes in swallowing	58.43
Fine movements (buttoning, tying	51.20
shoelaces)	
Toileting/difficulty toileting	51.20
Eating problems	51.20

Table 1. Summary of 15 most frequently associated Parkinson Disease (PD) symptoms

Note. Symptom with an asterisk was a false-positive item is not at all associated with PD

Symptoms	Percentage of participants who selected
	the symptom
Sleep talking and moving	17.47
Change in smell	15.66
Nausea	15.06
Constipation	15.06
*Onset of bipolar disorder (a mental	15.06
disorder marked by alternating periods of	
elation and depression)	
Change in taste	13.86
Excessive sweating	13.25
Intense or vivid dreams	12.65
Double vision	12.65
Vomiting	10.24

Table 2. Summary of 10 least frequently associated Parkinson disease (PD) symptoms

Note. Symptom with an asterisk was a false-positive item is not at all associated with PD.

#### **Perceptions and Attitudes toward PD**

In addition to examining the level of knowledge about different PD symptoms, the current study also aimed to identify the attitudes and perceptions regarding PD among OSU college students. Results indicated that there was an overall positive attitude toward those who have PD. The attitudes survey consisted of six different categories with 23 statements overall. The categories were Perceived Barriers: (A) Personal Relationship, (B) Perceived Barriers: Social Limitations, (C) Perceived Severity, (D) Perceived Susceptibility, (E) Perceived Benefits, and (F) Cues to Action. A Likert scale was utilized to measure the participants' attitudes toward each statement presented. The possible responses for each statement ranged from strongly disagree, disagree, neutral, agree, and strongly agree.

## A. Perceived Barriers: Personal Relationship

The first section titled "Perceived Personal Relationship" focused on statements about different psychological and emotional implications associated with having a diagnosis of PD. Results indicated that a large majority of participants were very aware of the possible psychological and emotional implications of PD. Figure 1 shows the participants' attitudes toward statements about barriers concerning one's personal relationship with PD. Approximately one-third of participants agreed that PD causes one to lose their independence. In terms of the mental health impact due to PD, about 84% believed the disorder would have an effect. Furthermore, approximately 62% of participants felt that it would be very difficult to accept having PD. These findings show that a majority of the participants demonstrated understanding of the physical, emotional, and mental severity of the disease as it relates to one's self-esteem and lifestyle changes that may subsequently occur with a PD diagnosis.

## B. Perceived Barriers: Social Limitations

In contrast to the psychological and emotional changes associated with PD, the college students in the current study did not seem to either understand or have a clear idea about possible social barriers of PD. Figure 2 includes a summary of different ratings for PD-associated social limitations by the college students. About one-third of participants revealed they were not open to marrying someone with young onset PD (30s-40s). Similarly, over half of the participants felt there is a high stigma associated with PD. Although these two findings suggest possible stigma and negative perceptions about people with PD, approximately 62% of participants did express they would be willing to be friends with someone who has young onset PD. In conclusion, based on the ratings for social barriers, it appeared that the current college participants had some reservations or feelings of stigma around some of the social aspects of living with PD or having a spouse or partner with PD when compared to having friendships.

#### C. Perceived Severity of PD

The third part of the attitude survey focused on the possible severity of PD and its impact on one's daily functioning. Specific to this section, a majority of participants demonstrated adequate awareness regarding PD. Figure 3 depicts a summary of the ratings for perceived severity of PD. The majority (87%) of participants expressed that PD is a serious disease. In addition, one-third of participants acknowledged the effects PD has on an individual's ability to communicate. Similarly, over two-thirds of participants agreed that PD affects one's physical mobility. In summary, participants were relatively more aware about the physical and serious aspects of the disorder when compared to the possible impact on one's lifespan following a PD diagnosis.

## D. Perceived Susceptibility

The fourth section of the attitudes survey aimed to investigate participants' thoughts on how susceptible they feel they are to developing PD symptoms later in life and the results varied among the participants regarding these statements. Figure 4 includes a summary of ratings regarding perceived susceptibility for developing PD later in life. About half of the participants disagreed that a healthy diet and regular exercise can prevent them from developing PD, when these things can help with PD prevention. One interesting finding revolved around the typical age of onset for PD. The results were fairly equal for participants either agreeing or disagreeing that those who have PD are most likely in their 60s and 70s. One-third agreed that this was true, about one third disagreed, and one third did not specify their opinion on the statement. Although results for this statement were mixed, more than half of the participants expressed that they did not believe they were likely to get PD in the future. In conclusion, these findings showed that participants felt that diet and exercise had no implications on PD prevention. In addition, many did not believe they were susceptible to getting PD as only 8% of participants agreed that they were likely to develop the disorder in the future.

## E. Perceived Benefits following PD

Similar to the results for perceived susceptibility, the section about perceived benefits following a PD diagnosis were mixed. The findings indicated that participants were aware that receiving treatment for PD is better than not receiving treatment. However, it was also evident that participants were unsure of the effectiveness of treatment. Figure 5 includes a summary of ratings for statements related to perceived benefits after getting a diagnosis of PD. About one-third of participants felt that the treatment for PD is not very effective, while almost 50% stayed neutral on the statement, and only about 20% felt that treatment was very effective. In contrast to this, approximately 47% of participants agreed that PD symptoms can be effectively managed by a combination of physical therapy, speech therapy, and psychological support. These two findings imply that there are mixed opinions when it comes to the effectiveness of treatment which could be due to an overall lack of knowledge and information regarding the effectiveness of therapy in PD. To summarize, the participants' responses toward the perceived benefits when it comes to PD indicated a need for more clear and detailed education and awareness of PD symptoms to minimize the lack of understanding and mixed opinions.

## F. Cues to Action

In terms of participants' likelihood for seeking out help or knowledge should they be diagnosed with PD, results indicated that participants were very likely to familiarize themselves with their diagnosis. Figure 6 shows the results of participants' attitudes with regard to their response if they themselves were to develop PD in the future. Almost three-fourths of participants indicated that they would want to find answers on their own first if they were to show signs or symptoms of PD. This could look like researching online, reading books about PD, or talking to professionals or family members. Similarly, 93% of participants indicated they would consult a healthcare professional if they suspected having PD. A little less than half of participants stated they would seek out help if they suspected having PD. Overall, participants expressed they would seek out help and familiarize themselves with the disorder should they ever present symptoms of PD



Figure 1. Summary of Ratings for Perceived Personal Barriers Faced by People with PD

Note. SD = Strongly disagree; D = Disagree; N = Neutral; A = Agree; SA = Strongly Agree



Figure 2. Summary of Ratings for Perceived Social Limitations Faced by People with PD

Note. SD = Strongly disagree; D = Disagree; N = Neutral; A = Agree; SA = Strongly Agree



Figure 3. Summary of Ratings for Perceived Severity of Parkinson Disease

*Note. SD* = *Strongly disagree; D* = *Disagree; N* = *Neutral; A* = *Agree; SA* = *Strongly Agree* 



Figure 4. Summary of Ratings for Perceived Susceptibility of PD

Note. SD = Strongly disagree; D = Disagree; N = Neutral; A = Agree; SA = Strongly Agree



Figure 5. Summary of Ratings for Perceived Benefits of PD

Note. SD = Strongly disagree; D = Disagree; N = Neutral; A = Agree; SA = Strongly Agree



Figure 6. Summary of Ratings for Cues to Action as it Relates to PD

Note. SD = Strongly disagree; D = Disagree; N = Neutral; A = Agree; SA = Strongly Agree

#### DISCUSSION

The aim of the present study was to examine the current perceptions and attitudes regarding PD among college students enrolled at Oklahoma State University (OSU). To the best of our knowledge, there are no current studies that have investigated college level students' knowledge and attitudes toward PD based in the United states including Midwest regions such as Oklahoma.

#### **PD Knowledge**

#### Motor vs Nonmotor Symptoms

The current study showed that participants displayed more knowledge when it came to the PD-related motor symptoms in comparison to the nonmotor symptoms. Findings from the study indicated that participants selected all of the common motor symptoms on the survey [rest tremors (96.39%), lack of dexterity (80.72%), and changes in physical gait (77.11%)]. In contrast, nonmotor symptoms of PD were among some of the least commonly identified symptoms. Some of these included vomiting (10.24%), double vision (12.65%), and intense or vivid dreams (12.65%). These findings are not surprising as the symptoms of PD that are most heavily shown in media and taught within classroom settings are often the motor-related symptoms. Further, the nonmotor symptoms are not always inherently associated with PD, but when presented all together with the motor symptoms, they are indicative of PD (Armstrong & Okun, 2020).

Although there are not as many studies examining PD knowledge specifically among college students, there are multiple studies that have examined these same concepts in older age groups, both with and without PD. Although the demographic differs, there are many similarities

between the current study and existing studies. Moore (2006) surveyed neurologically healthy adults via telephone on their knowledge and attitudes toward PD. The results showed that there was a low level of knowledge overall; however, the most commonly identified symptoms related to PD were motor symptoms such as rest tremors and joint stiffness (rigidity) (Moore, 2006). These findings remain consistent, as now, fifteen years later, young adults are still likely to identify motor symptoms more easily when compared to the nonmotor symptoms. A possible explanation of more awareness of PD motor symptoms could be the fact that they are externally more observable when interacting with a person than some of the nonmotor symptoms such as anosmia (lack of ability to smell), sleep problems, or changes in vision.

Cheon et al. (2008) investigated awareness of nonmotor PD symptoms among individuals with PD and their family members. Interestingly, of the 74 patients and 54 family members evaluated, 28 patients and five family members were not aware of the correlation between any of the nonmotor symptoms and PD (Cheon et al., 2008). Further, findings from the existing studies and the current study show relatively less awareness among neurologically healthy participants about some of the key nonmotor symptoms of PD such as changes in smell, sleep changes, and changes in vision.

Therefore, it can be concluded that knowledge surrounding PD is lacking among both those who are diagnosed with PD as well as close family members and caregivers of people with PD. Although there are some identifiable symptoms of PD (typically motor), there are many signs and symptoms associated with the disorder that are completely unknown to many. It is widely known now that nonmotor symptoms of PD often present before the motor symptoms (Armstrong & Okun, 2020). Therefore, it is critical that community-based education and

awareness programs include both nonmotor and motor changes of PD and their possible implications for overall awareness and understanding about the PD pathophysiology.

#### Communication Disorders Associated with PD

Another interesting finding of the current study is that a large number of participants correctly identified several speech and voice changes associated with PD. These included voice tremors (61.45%), loss of speech clarity (60.84%), and changes in swallowing (58.43%). This could be possibly in part due to the participants' background as Communication Sciences and Disorders was one of the highest participating majors in this study. According to Ramig et al. (2018), about 89% of people with PD have a speech disorder and these changes in speech are some of the first signs to appear in people with PD. Due to the high prevalence of speech disorders in those who have PD, there are many treatment programs including the Lee Silverman Voice Training and SPEAK OUT!<sup>®</sup> and LOUD Crowd<sup>®</sup> programs that focus on the speech and voice functioning of people with PD (Levitt & Walker-Batson, 2015). Increased awareness about different speech changes may be due to the fact that many informational brochures and educational programs about PD focus on these symptoms when creating awareness among people with and without PD. Overall, the current study findings are encouraging as more than 50% of the participants correctly identified the possible speech changes associated with PD.

## False Symptoms

In order to further test participants' knowledge level of PD, we also included three false symptoms on the knowledge survey. These symptoms were added as a buffer to identify if people were knowledgeable about all possible symptoms or if participants were likely to select everything included on the survey as a symptom of PD. The three false symptoms were: relapse and remission of symptoms, onset of bipolar disorder, and neologisms (meaningless or nonsensical words coming up in one's verbal expression). Relapsing and remitting of symptoms was among the top 15 most commonly selected symptoms associated with PD as approximately 63% of participants chose this. This symptom is actually associated with multiple sclerosis, another progressive neurological disorder. The second false symptom on the survey was the onset of bipolar disorder. This was selected by about 15% of participants. This symptom was identified as one that was least associated with PD. Bipolar disorder is not associated with PD pathophysiology and is more common with other psychiatric conditions. Finally, the symptom of neologisms was selected by about 29% of participants and this symptom is typically associated with individuals who have aphasia and in some cases of dementia. The selection of these false symptoms suggests that at least some of the study participants may have had some misunderstandings or misconceptions surrounding the possible symptoms of PD. With these results in mind, it is important for education surrounding PD to provide clarity regarding the possible symptoms of PD when compared to other neurological disorders.

#### **Attitudes toward PD**

#### Impact of PD

The participants of the current study expressed overall positive attitudes toward PD. For example, one major finding was that 84% of participants indicated that PD has an impact on one's mental health. As mental health awareness has been on the rise, this finding is encouraging

as participants understood the difficulties that come with this diagnosis as well as how isolating it can be mentally. A large majority of participants also recognized the devastating losses one may experience with this diagnosis such as a loss of independence and routine. One-third of participants agreed that PD causes one to lose their independence. Finally, about 62% of participants admitted that it would be difficult to accept a diagnosis of PD further implicating their understanding of how difficult living with this diagnosis can be. These survey findings are encouraging as participants display empathy and understanding of what life with PD may look like. Overall, these findings suggest there is a compassionate and sympathetic outlook among college students when it comes to the personal effects PD may have on a person.

## Relationships with individuals with PD

Although participants displayed great understanding and an openness to the effect PD has on an individual, there were some mixed opinions regarding the social and relational aspects of PD. There appeared to be a hesitancy on whether or not these participants would engage in any type of relationship with someone who may have a diagnosis of PD. Over half of the participants expressed there was a high stigma associated with PD. This percentage played a major role in the likelihood of participants associating with someone who has PD. For example, one-third of participants revealed that they were not willing to marry someone who has young onset PD (30s-40s). This could be due to a variety of reasons. One possible reason could be the understanding about the difficult impact of PD on one's daily functioning and people may not be open to take on that burden of being a care partner or spouse. Another reason could be because of the high stigma associated with PD. The ratings differed based on the type of relationship. Although very few participants were willing to marry someone with young-onset PD, about 62% of participants expressed that they would be willing to be friends with someone who has young-onset PD. What these two contrasting findings suggest is that there may be some hesitancy when it comes to marrying or having a more long-term relationship with someone who has PD. A friendship appeared to be more acceptable than a spousal relationship for the majority of the study participants. In conclusion, the type of relationship was an important factor for the college students when referring to people with PD.

#### Severity and Susceptibility of PD

Another interesting finding was that participants recognized the severity of PD. However, they did not feel they themselves were susceptible to a diagnosis of PD. About 87% of participants expressed that PD is a serious disease. This is a huge percentage and is consistent with other findings regarding the severity of PD such as almost 75% of participants indicated that PD affects one's ability to communicate effectively and two-thirds of participants indicated that PD affects one's mobility. Although participants displayed a strong understanding of the severity of PD, this knowledge did not seem to have an impact on whether or not they believed they themselves were susceptible to a diagnosis of PD. A large number of responses to the perceived susceptibility statements were "neutral". The only statement that did not have a high "neutral" response was when about half of participants indicated that they were likely to receive a diagnosis of PD. This finding was interesting as the participants were college aged students and the idea of being diagnosed with any disease may have seemed improbable to them at this time.

Although participants did not express a likelihood of being diagnosed with PD,

participants did express a willingness to seek help and knowledge should they ever be diagnosed with the disease. Almost three-fourths of participants indicated they would want to find answers on their own first if they were to show signs and symptoms of PD and about 61% of participants indicated they would consult a healthcare professional if they suspected having PD. The responses for these specific statements indicated that participants are not afraid to seek out help should they begin to present with signs of PD, showing that perhaps the stigma and shame surrounding a diagnosis of PD may be diminishing with younger generations. These findings are encouraging as the current study participants, being college students, showed that they would be more proactive and take actions to seek immediate care if they were to develop PD. One thing to consider is the questions did not specify a specific time frame for the cues to action, so participants could have interpreted these cues to action questions as relating to themselves now as college students which could have affected their responses. In conclusion, a majority of participants expressed an understanding of the severity of PD and indicated they would be willing to seek help should they experience signs and symptoms of PD.

## **Study Limitations**

There were several limitations to this study. The first limitation is that there was a relatively low number of participants. Although the current study had 206 participants, a greater number of responses would have allowed better generalization of study findings. The data collection for the study coincided with the COVID-19 pandemic and major changes in students' schedules and in-person interactions during the semester. The study was conducted during March to May 2021 where many students were either enrolled in all online courses or courses with

different formats. As a result, the study was dependent on survey responses based on emails and flyers shared directly with the students and with the course instructors. Additional participants could have been possibly recruited if the author could have visited different classrooms and shared the study information in-person.

In addition, due to the current pandemic it is possible that some participants may have felt very overwhelmed with the state of the world and their circumstances during this time and may not have considered participating in this online study as a top priority. Another possible limitation could be the survey design as there may have been biases present among the participants especially with the "neutral" opinion being an option. The inclusion of a "neutral" option could have allowed participants to have a default option should they want to appear favorable during the survey and not share their true thoughts on the subject. A final limitation to the study revolves around the fact that there was the inclusion of only three false symptoms. Studies similar to the current study often have a much larger number of "incorrect" or "false" answers in order to alleviate participants could have chosen these false symptoms because they were not looking closely at every symptom listed.

#### CONCLUSION

The aim of this study was to identify the current knowledge, perceptions, and attitudes toward PD among college students at OSU. The findings of the current study show that there is a need to spread awareness about PD in a college environment. Although knowledge levels of the motor symptoms of PD was good, there is still a great need in increasing awareness of all possible symptoms associated with PD. Participants displayed an overall positive attitude towards individuals with PD, but the lack of knowledge of PD often made it difficult for participants to have a clear opinion on some of the statements as indicated by them selecting the "neutral" option for these specific statements. It is important for this demographic to be aware of the symptoms associated with PD as this allows the opportunity for students to be able to help family members that may begin to present these symptoms and it will be beneficial later in their life should they ever present symptoms of PD. Future studies can focus on the development of informational and educational programs for community adults including college students to increase awareness about symptoms and resources for PD as well as reduce societal and cultural misconceptions about different aspects of PD.

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# APPENDICES

# Appendix A. Demographic Questionnaire

# **Demographic Questionnaire**

# Participant Group: Adults 18 years or older

1. Age:				
2. Gender: □ Male	□ Female	□ Prefe	r not to indicate	
3. Race/ Ethnicity (ch	neck all the boxes t	hat apply	to you):	
African American	Asian		Hispanic/Latino	Native American
Pacific Islander	□ White/ Ca	ucasian	□ Other (	)
□ Prefer not to indica	ite			
4. List your current a	cademic status:			
Freshman				
Sophomore	Junior	□ S€	enior	
Other				
5. List your major:				
6. Do you have a fam	nily member/ friend	l (current/	past) with a diagno	osis of Parkinson disease?
□ Yes		No		
7. List your current o	ccupation (if applied	cable):		

# Appendix B: PD Knowledge Survey

# Sources: The following checklist was developed based on findings reported by the following sources.

Abudi, S., Bar-Tal, Y., Ziv, L., & Fish, M. (1997). Parkinson's disease symptoms- Patients' perceptions. *Journal of Advanced Nursing*, 25, 54-59.

Cheon, S-M., Ha, M-S., Park, M.J., & Kim, J. W. (2008). Nonmotor symptoms of Parkinson's disease: Prevalence and awareness of patients and families. *Parkinsonism and Related Disorders*, *14*, 286-290.

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**Instructions:** Please review the checklist below with a list of different PD symptoms. Some of the symptoms may or may not be related to PD. Please check ALL of the symptoms that you think may be related to Parkinson disease (PD).

Check all the boxes	Possible Chang	es
that you think are	_	
related to		
Parkinson Disease		
	I. Mot	or Changes
	i.	Rest tremors (shaking of hands, fingers, legs)
	ii.	Dyskinesias (out-of-control movements of hands and legs)
	iii.	Changes in physical gait (reduced steps, shuffling, freezing)
	iv.	Reduced arm swing
	v.	Changing positions (e.g., from sitting to standing, from lying
		to sitting)
	vi.	Relapsing and remitting of symptoms (some weeks with
		severe symptoms and some weeks with less or no motor
		symptoms)
	vii.	Walking outside home (walking on pavements/walking
		surfaces outside home)
	viii.	Muscle ache
	ix.	Muscle cramps
	х.	Fine movements (buttoning, tying shoelaces)
	xi.	Changing position in bed
	xii.	Ability to clip one's own nails using a clipper
	xiii.	Dressing self
	xiv.	Getting in/out of bed
	XV.	Toileting/ Difficulty toileting

xvii.       Eating problems         xviii.       Changes in swallowing         xix.       Changes in handwriting         xx.       Lack of dexterity (holding tools such as brush, pen with hands)         II.       Communication Changes         i.       Quiet voice (reduced loudness)         iii.       Monopitch (same pitch across all sentences)         iiii.       Voice getting deeper         v.       Voice getting quieter         vi.       Voice tremors         viii.       Constant throat clearing         viii.       Mumbling         ix.       Imprecise consonants         x.       Tight mouth         xii.       Loss of speech         xiii.       Loss of clarity         xiii.       More effort to maintain intelligible speech         xiv.       Neologisms (meaningless or nonsensical words in a language)         xvi.       Reduced breath support         xvi.       Reduced control of exhalation         xviii.       Shallow breathing         xviii.       Shallow breathing         xix.       Mild changes in nasality (extra air coming out)
xviii.       Changes in swallowing         xix.       Changes in handwriting         xx.       Lack of dexterity (holding tools such as brush, pen with hands)         II.       Communication Changes         i.       Quiet voice (reduced loudness)         ii.       Monopitch (same pitch across all sentences)         iii.       Voice getting husky         iv.       Voice getting deeper         v.       Voice getting quieter         vi.       Voice tremors         viii.       Constant throat clearing         viii.       Mumbling         ix.       Imprecise consonants         x.       Tight mouth         xii.       Slowness of speech         xiii.       Loss of clarity         xiiii.       More effort to maintain intelligible speech         xiv.       Neologisms (meaningless or nonsensical words in a language)         xvv.       Palilalia (repetition of words)         xvii.       Reduced breath support         xvii.       Shallow breathing         xviii.       Shallow breathing         xviii.       Shallow breathing
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xviii.       Shallow breathing         xix.       Mild changes in nasality (extra air coming out)
xix. Mild changes in nasality (extra air coming out)
III. Non-motor Changes
i. Dribbling of saliva
ii. Change in taste
iii. Change in smell
iv. Vomiting
v. Nausea
vi. Constipation
vii. Bowel incontinence
viii. Incomplete bowel emptying
ix. Urinary urgency
x. Nocturia (or excessive nighttime urination)
xi. Unexplained pain
xii. Unexplained weight loss
xiii. Memory changes
xiv. Loss of interest
xy. Hallucinations (experience something that really doesn't
exist such as seeing a person, animal, or an object)
xvi. Difficulty in concentrating
xvii. Feeling sad

xviii.	Feeling anxious
xix.	Change in sexual interest
XX.	Sexual dysfunction
xxi.	Orthostatic dizziness or hypotension (sudden drop in blood
	pressure when standing up from sitting or lying down)
xxii.	Daytime sleepiness
xxiii.	Insomnia
xxiv.	Intense, vivid dreams
XXV.	Sleep talking and moving
xxvi.	Restless legs
xxvii.	Swelling of legs
xxviii	. Excessive sweating
xxix.	Double vision
XXX.	Delusions (false beliefs)
xxxi.	Onset of bipolar disorder (a mental disorder marked by
	alternating periods of elation and depression)

Rate your level of confidence about your responses to the above-mentioned questionnaire.

- a.) I'm highly confident
- b.) I'm somewhat confident
- c) Neutral
- d.) I'm less confident
- e.) I have no idea
- f.) Other (please specify)\_\_\_\_\_

# Appendix C. PD Attitudes Survey

Please respond to the statements below based on your experiences at this time. Please rate each question on a scale of strongly agree (SA), somewhat agree (SWA), neutral (N), somewhat disagree (SWD), and strongly disagree (SD).

## **Perceived Barriers**

Personal Relationship:

- 1.) Individuals who have Parkinson disease become very lonely.
- 2.) It would be easy to accept having Parkinson disease.
- 3.) Having Parkinson disease does not affect one's personality.
- 4.) Parkinson Disease causes people to lose their independence.

#### Social Barriers:

- 5.) There is a high stigma surrounding Parkinson disease.
- 6.) I am open to marrying someone with young onset Parkinson disease (30s-40s).
- 7.) I would prefer not to be friends with someone who has young onset PD.

## **Perceived Severity**

- 8.) Parkinson disease is a very serious disease.
- 9.) People with Parkinson disease have the same lifespan as people without PD.
- 10.) Having Parkinson disease affects one's physical mobility.
- 11.) Having Parkinson disease does not affect one's ability to communicate effectively.
- 12.) Having Parkinson disease does not affect one's mental health.

## **Perceived Susceptibility**

- 13.) I feel I am very likely to get Parkinson disease.
- 14.) As long as I eat well and exercise, I can prevent Parkinson disease.
- 15.) I have no family history of Parkinson disease, therefore I will not get it.
- 16.) Most people with PD are in their 60s and 70s.

## **Perceived Benefits**

- 17.) Treatment for Parkinson disease is not very effective.
- 18.) The progression of Parkinson disease can be managed by early intervention therapy.

19.) Parkinson disease symptoms cannot be effectively managed by a combination of physical therapy, speech therapy, and psychological support.

20.) People with Parkinson disease can reduce their disease progression with early diagnosis and receive timely treatment and management.

# **Cues to Action**

21.) If I had Parkinson disease signs and symptoms I might want to find answers on my own first (look online, read books, search research articles, talk to professionals or family members).

22.) If I had Parkinson disease, I would go to a healthcare professional and get educated on the disease.

23.) If I developed signs and symptoms of Parkinson disease, I would not talk to my doctor immediately.

Rate your level of confidence about your responses to the above-mentioned questionnaire.

# a.) I'm highly confident

b.) I'm somewhat confident

c) Neutral

d.) I'm less confident

e.) I have no idea

f.) Other (please specify)\_\_\_\_\_