Knowledge and attitudes about Parkinson's disease among a diverse group of older adults

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Abstract

Underserved minorities are vulnerable to diagnostic delays and under-treatment of Parkinson's disease (PD). The purpose of this mixed-methods study was to understand knowledge and attitudes about PD among a racially/ethnically diverse group of community members. In the qualitative arm, 10 homogeneous focus groups of 6 to 8 White, African-American and Chinese-Americans older adults at senior centers in Philadelphia were conducted. Next, for the quantitative piece, a questionnaire of knowledge and attitudes about PD was administered among a larger group of senior center members. Themes were identified from the focus group discussions. ANOVA and chi-square tests were used to assess differences in PD knowledge and attitudes among the different racial/ethnic groups. Logistic regression analyzed for independent factors associated with barriers to treatment. Seventy-five adults participated in the focus groups (23 Whites, 36 African-Americans and 16 Chinese-Americans) and 154 completed the questionnaire (62 Whites, 47 African-Americans and 45 Chinese-Americans). One common theme about developing PD was fear of losing independence. Racial/ethnic groups identified unique barriers to care: mistrust in the healthcare system by African-Americans and language difficulties by Chinese-Americans. 80% of all participants had no to some knowledge of PD. African-Americans and Chinese-Americans were more likely to perceive PD as a part of normal aging than whites. Chinese-Americans were more likely to perceive barriers to treatment than whites. A diverse sample of older adults demonstrated low levels of PD knowledge through both qualitative and quantitative methods. Many barriers to PD care were identified. Targeted community outreach and education efforts should incorporate information about PD and how to receive care.

Keywords

African-American; barriers to care; Chinese-American; focus groups

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Introduction

Parkinson's disease (PD) is a degenerative disorder of the central nervous system characterized by tremor, bradykinesia (or slowness), rigidity, and postural instability that affects 1 million older Americans. Epidemiological studies estimate that 17 new cases of PD per 100,000 persons are identified each year (Twelves et al. 2003). Adjusted for age and gender, the incidence of PD (per 100,000) by race is approximated to be 13.6 in Non-Hispanic Whites, 11.3 in Asians, and 10.2 in African-Americans (Van Den Eaden et al. 2003). Timely identification of PD is important because treatment can improve quality of life, delay disability, and potentially improve survival (Nutt & Wooten 2005).

Unfortunately, community-based prevalence studies have shown that between 12–78% of individuals with PD were previously undiagnosed (de Rijk et al. 1995; Dotchin et al. 2008; Kis et al. 2002; Melcon et al. 1985; Tison et al. 1994). Traditionally underserved minorities are more likely to have missed and delayed diagnosis of PD than whites (Dahodwala et al. 2011; Schoenberg et al. 1985). Furthermore, once identified with PD, underserved minorities are less likely to receive medication or physical therapy, specialty care, PD surgery, high quality PD care or participate in PD clinical trials (Cheng et al. 2008; Dahodwala et al. 2009; Eskandar et al. 2003; Schneider et al 2009; Willis et al. 2011).

Knowledge and attitudes about PD may play a role in the currently unexplained reasons behind diagnostic delays and treatment disparities in PD. In a study of Alzheimer's disease, higher levels of knowledge about the disease were associated with greater help-seeking behavior (Werner 2003). Prior studies of PD knowledge and attitudes in the community have shown that reported knowledge of PD is low (Werner & Korczyn 2010), and many associate stigma with the disease (Moore & Knowles 2006). These may act as additional barriers to care, particularly for underserved minorities.

Reducing diagnostic delays and treatment disparities may lead to improved quality of life for minorities with PD. A greater understanding of the barriers to care will play an integral role in creating interventions to achieve those goals. Healthcare educators can also improve cultural competency training programs, an important part of healthcare provider education, through the knowledge gained about health beliefs among different racial/ethnic groups.

The Health Belief Model (HBM) is a framework that assesses beliefs among older adults of different racial and ethnic backgrounds (Glanz et al. 2008). Health behavior researchers have used the HBM since the 1950's to explain health-related behaviors and to guide health behavior interventions. It consists of six major constructs: perceived susceptibility (belief of whether one is susceptible to a disease or condition), perceived severity (belief of the seriousness of a condition or disease), perceived benefits (belief that taking action would reduce a disease or threat), perceived barriers (the potential negative aspects of a particular health action), cues to action (strategies that activate readiness in an individual to take action), and self-efficacy (the confidence that one has in executing a particular health behavior to produce the expected outcomes). Each of the constructs of the HBM model serves as a general explanation for an individual's health belief and behavior. Low perceived susceptibility, low perceived severity, low perceived benefits, high perceived barriers and

low cues to action discourage health seeking or promoting behavior. We used this model as a theoretical framework to guide our study. The specific goals of the study were to determine the level of PD knowledge among a diverse group of community-dwelling older adults and understand attitudes about PD using both qualitative (focus groups) and quantitative (questionnaire) methods.

Subjects and Methods

Study Design

A mixed-methods cross-sectional study involving focus groups (qualitative) and administration of a questionnaire (quantitative) was conducted through local Philadelphia senior centers in neighborhoods serving primarily White, African-American and Chinese-American (primarily Mandarin and Cantonese-speaking who are first-generation immigrants) older adults.

IRB Approval/Ethics

This study was approved by the Institutional Review Board at the University of Pennsylvania with a waiver of written informed consent. Verbal informed consent was obtained prior to the focus group sessions and questionnaire completion.

Recruitment

Approximately 20 senior centers were invited to collaborate with this study. Of the 20 that were invited, 10 agreed to participate. We contacted the senior centers in Philadelphia by email and phone based on geography, anticipated response rates and population served. All centers are multi-service community centers for adults over the age of 55 that provide educational, recreational and social services. Centers that did not participate were not notably different by geography or population served. Non-participating centers cited a full calendar of existing activities or organizational re-structuring during the time of the study as reasons for refusal.

Study subjects were recruited by posting flyers at each center and with the assistance of senior center program directors. Subjects who met the criteria of being 55 years of age or older and able to speak and write in English or Chinese were eligible for participation in the focus groups and/or questionnaire portion.

Demographics

Participants reported basic demographic information including age, race, gender, financial status and level of education. Socioeconomic status (SES) was determined by the individual's response to the question: "At the end of the month, how much money do you have left over?"(Cornoni-Huntley et al. 1993). Those who selected "some money left over" were categorized as high SES. Those who selected "just enough to make ends meet" were categorized as middle SES. Those who selected "not enough to make ends meet" were placed in the last category as low SES.

Focus Groups (Qualitative)

We selected 5 centers based on the demographics of the population served by the centers for the focus groups. Our goal was to select centers that were primarily comprised of African-American, Chinese-American or White older adults in order to ensure homogenous focus groups (that is, one racial/ethnic group per focus group). Two to three focus groups were held at 5 of the senior centers in Philadelphia. Each focus group session lasted for approximately an hour and was conducted in English or Mandarin. Discussion questions for each focus group session were delivered in two sets. The first set asked more general and open-ended questions to gauge participants' overall views regarding the brain and the aging process. In between the first and second set of questions, participants were asked to watch two short video clips depicting individuals with first mild and then moderate to advanced PD. Since the symptoms of PD are visual (e.g. tremor, slowed movement, shuffling steps) and we wanted to assess the ability of community members to recognize these symptoms, we showed the PD videos to both provide an additional lens to study PD knowledge and to provide a context for discussion for participants who may have had limited familiarity with PD. The videos were introduced with the general statement, "Now I'm going to show you a short video and I will ask you questions about the video after it is finished." The first video clip showed three different patients with mild PD doing normal activities (e.g. reading a magazine, walking outside) that displayed a mild rest tremor, slowed movements including slowed gait, decreased arm swing and stopped posture. The second video showed more advanced cases of PD with more severe symptoms of tremor, slowness and gait/posture changes.

Participants were then asked to discuss their thoughts about the video clips. The second set of questions assessed the participants' knowledge and attitudes about PD. All of the questions posed to the focus group subjects were developed according to the six concepts from the HBM. At each focus group session, a member of the research team kept field notes and recorded non-verbal cues such as murmurs or changes in an individual's expression. Each session was audio-taped. The moderator was responsible for asking the key questions and keeping the discussion on topic.

PD Knowledge and Attitude Survey (Quantitative)

At 10 senior centers, individuals over the age of 55 who could speak and write in English or Chinese were invited to complete a survey of PD knowledge and attitudes. The survey consisted of ten questions testing PD knowledge and ten questions to assess attitudes associated with PD (Table 1). These questions were developed based on a review of the literature, and then reviewed by an expert panel of PD neurologists, nurses, social workers and support group participants for content and wording. In the knowledge section, both incorrect answers and answers in which participants selected "I don't know" were grouped together for analysis. Items in the attitudes section were grouped according to HBM concepts (Table 1), and response options were scored on a 5-point Likert scale that measured level of agreement. Since our sample consisted of older adults without PD, the HBM construct of perceived self-efficacy (which would assess the confidence someone with PD has to execute a health behavior) was not measured. The survey was then translated into

Chinese, and back-translated into English to verify that the original intent of each question remained the same.

To establish a comparison group for PD knowledge, the knowledge portion of the questionnaire was also administered to a group of PD support group members (both patients and caregivers).

Data analysis

Focus groups—Recordings from each focus group session were transcribed and combined with the field notes. Through an iterative process, investigators categorized the focus groups responses. First, one researcher (SP or JS) reviewed each transcript and summarized the data according to emerging themes. Then, the senior investigator (ND) also reviewed the transcripts to identify themes. Finally, all three investigators met as a group to discuss and categorize responses into major themes. The following factors helped determine relevance of responses: 1) the frequency that something was mentioned; 2) level of agreement with other participants; 3) level of detail in response; and 4) any associated emotions. A constant comparative analytic framework was used focusing on the similarities and differences in themes by race/ethnicity (Krueger & Casey 2009).

PD Knowledge and attitude survey—The number of correct answers out of 10 questions determined level of PD knowledge: little or no knowledge by 2 or less, some knowledge by 3 to 7 and high knowledge by 8 to 10 correct answers. Data were fitted into an ordinal logistic regression model to determine the independent association of demographic factors with level of PD knowledge (dependent variable).

The attitudes associated with PD were scored so that higher values reflected attitudes that would discourage health seeking or promoting behavior. Chi-square tests were used to determine any group differences in responses. Separate logistic regression models were created with each of the five categories of attitudes associated with PD as the dependent variable, and age, gender, race, socioeconomic status and level of education as independent variables. All data analysis was run using SAS® Software version 9.1 (SAS Institute Inc., Cary, NC, USA).

Results

There were 75 focus group participants with a mean age of 74.1 years (s.d. 8.0) and 78% were women. The racial/ethnic breakdown was as follows: 31% White, 48% African-American and 21% Chinese-American. The 154 survey participants had a mean age of 76.1 (s.d. 7.9) and 68% were women. They were 40% white, 31% African-American and 29% Chinese-American. Table 2 describes the demographic characteristics of the focus group and survey participants in detail.

Focus groups

Numerous themes emerged from the focus group discussions related to PD knowledge, attitudes and actions in response to PD signs or symptoms. Most themes were similar across racial/ethnic groups. Table 3 lists the common themes and sample quotes for each theme.

While there was at least one participant from each focus group that identified PD as the cause of the symptoms when shown videos of more advanced cases of PD, there were multiple other explanations for the observed symptoms. These included old age, arthritis, osteoporosis and stroke. Furthermore, there was a great deal of uncertainty about causes of PD and treatment options.

Although most focus group members agreed that they would seek medical care for symptoms of PD, there were several racial/ethnic differences when participants responded to the discussion question of why an individual with PD signs or symptoms would not seek medical care. African-Americans mentioned lack of insurance and religious concerns. One discussion at an African-American group focused on mistrust in doctors: "Cause everyone don't believe in doctors" (Focus Group (FG) 6, Participant (P) 4); "I don't either. They don't do nothing. Make you worse. Misdiagnose you. Turn you into an experiment" (FG6, P6). Whites, on the other hand, mentioned that some people might not be aware that they have the signs or symptoms of PD. One participant remarked, "Because you know why, people that do have it don't know [they] better to go to the doctor unless their family takes them. They don't know. They probably don't even know they have it (FG3, P2)." Focus groups with Chinese-American participants were more likely to discuss language barriers and lack of knowledge on where to seek treatment. A sample quote from a Chinese-American participant was: "I imagine that if I had Parkinson's, I wouldn't know where to go to seek medical care, which hospital to go to. A family doctor probably would not know (FG5, P7)."

In addition, there were more specific barriers to receiving treatment that participants noted. A Chinese-American focus group member commented: "There is a specific type of medicine. We cannot afford it, [they] won't give it to us (FG8, P2)." Another, African-American participant commented, "You can't do nothing about it [to treat PD] (FG7, P8)."

PD knowledge and attitude questionnaire

There was an overall low level of knowledge about PD among community members. One-third (33.3%) of community members had no to little knowledge of PD compared to 0% of support group attendants, almost half (46.8%) of community members had some knowledge of PD compared to 20.5% of support group attendants, and only 18.8% of community members had high PD knowledge compared to 79.5% of support group members. These differences were statistically significant ($X^2 = 55.4$, $p < 0.001$). Table 4 depicts the percentage of correct responses for each individual item. Support group members were significantly more likely to have a greater percentage of correct answers on each knowledge item except for tremor and diet. There were no significant differences in the level of knowledge among African-American, Chinese-American, and white subjects when comparing total scores ($X^2 = 3.6$, $p = 0.46$). However, Chinese-Americans were less likely to respond correctly when asked if medications can help symptoms of PD ($X^2 = 10.3$, $p = 0.01$).

After adjusting for demographics (age, gender, race, SES and level of education) and having a friend or family member with PD, only older age was found to be significantly associated with low level of PD knowledge. The odds of having little or no level of PD knowledge was 1.06 ([95% CI 1.01 – 1.11, $p = 0.03$) times higher for each year of increase in age.

Table 5 shows the responses of senior center participants to the attitudes and beliefs items about PD. Chinese-Americans were more likely than both white and African-American senior center members to agree that diet and exercise would prevent PD (42.2% vs. 15.0% vs. 25.0%, respectively; p<0.01). This suggests a low perceived susceptibility of PD. Additionally, Chinese-Americans were less likely than both whites and African-Americans to agree that people with PD live active lives (20% vs. 59.7% vs. 51.1%, respectively; p<0.01). This suggests a higher perceived severity of PD among Chinese-Americans compared to whites and African-Americans. Lastly, both Chinese-Americans and African-Americans were more likely to agree that PD is a natural result of aging than whites (44.4% vs. 22.7% vs. 5.1%, p<0.01), which suggests they may have fewer cues to action than whites.

After controlling for age, gender, education, and socioeconomic status, Chinese-American ethnicity and African-American race were still associated with certain attitudes and beliefs that could discourage health-seeking behavior. Chinese-Americans were more likely to perceive higher barriers to care (OR 4.98, 95% CI 1.24–19.96) and lower cues to action for care (OR 14.35, 95% CI 3.52–58.43) when compared to whites. While African-Americans did not have statistically significantly lower cues to action (OR 2.85, 95% CI 0.91–8.91) than whites, they were more likely to perceive parkinsonism to be a natural result of aging (OR 11.83, 95% CI 2.13–65.53), a subset of the cues to action category. On the other hand, Chinese-Americans were more likely to perceive PD as highly severe, which would promote healthcare seeking behavior.

In addition, individuals with lower educational attainment were more likely to perceive higher barriers to care (OR 9.57, 95% CI 1.89–48.32 for at least high school level of education compared to greater than high school; OR 6.18 95% CI 1.28–29.79 for less than high school compared to greater than high school), and older age was associated with lower perception of benefits of PD treatment (OR 1.07, 95% CI 1.01–1.13).

Discussion

The results of our study demonstrated a very low level of knowledge about PD symptoms, treatment and causes across a sample of community-dwelling African-American, Chinese-American and white seniors. In addition to low knowledge about PD, additional barriers to care that we identified through both focus groups and surveys included fear related to having PD and becoming a burden to their families. Several racial/ethnic differences in barriers to care were also identified and will be discussed below.

Knowledge level as a barrier to care

There have been several studies outside the United States that have also found low to moderate levels of knowledge about PD. One telephone survey conducted among Australian households asked similar questions related to PD causes, symptoms, diagnosis and management with an average of 66% of items answered correctly (Moore & Knowles 2006). Those study participants were younger than those in our sample. On the other hand, an Israeli study which asked participants how much they knew about PD, found that only 34% reported knowing much or very much about the disease (Werner & Korczyn 2010). In

addition, a recent focus group study in Tanzania found that most community members were unfamiliar with PD. Respondents listed witchcraft, AIDS/malaria, alcohol, not eating food, cold, head injury and high blood pressure among the possible causes of PD (Mshana et al. 2011). Similar to these studies, our current study confirms an overall low knowledge about PD in the community and the presence of several misconceptions about its cause, symptoms and treatment. This adds to the limited body of knowledge about PD knowledge by extending the findings to urban, American older adults of African-American, Chinese-American and white race/ethnicity. This is especially relevant because low levels of knowledge about disease can itself act as a barrier to healthcare. In a study of Alzheimer's disease, a neurodegenerative disease that can be considered analogous to PD, lower knowledge was associated with being less likely to seek health care (Werner 2003). Similarly, low health literacy (the skills needed to function effectively in the health care environment) is associated with lower levels of knowledge, poorer use of health care services and worse health outcomes across multiple health conditions (Berkman et al. 2011; Dewalt et al. 2004).

Attitudes about PD and health behavior

In addition to knowledge, several attitudes about PD could create additional barriers to receiving care. In order to study these attitudes, we used the HBM framework. Although this framework is one of the oldest and well-established models to study general health beliefs, it has several limitations. First, it does not take into account social factors such as the influence of the surrounding environment which may differ by race/ethnicity. Second, it does not provide specific strategies to change attitudes, beliefs or behaviors. Nevertheless, it provides a basis to understand the underlying motivation for specific health behavior which can then guide targeted interventions.

A common theme that emerged from all focus groups was a fear of losing independence and becoming a burden on loved ones. Our findings align with the study by Werner & Korczyn (2010) who identified that about 40% of adults feared the development of PD. The fear of developing Alzheimer's disease is similarly high in the general population (Cantegreil-Kallen & Pin 2012; Laforce & McLean 2005), and reported as one barrier to seeking care (Bond et al. 2005). The construct of perceived barriers is one of the most influential dimensions of the HBM in predicting behavior (Janz & Becker 1984).

Racial/ethnic differences

Few studies have evaluated perceptions of PD among diverse populations. However, many similar themes related to racial/ethnic differences in perception of normal aging, stigma, language and trust have been studied in other conditions. Research in Alzheimer's disease has described differences in perceptions between African-Americans and whites, including a lower perceived threat of developing the disorder among African-Americans (Roberts et al. 2003). Additionally, African-Americans are more likely to believe that Alzheimer's disease is a part of normal aging (Connell et al. 2009).

In mental health disorders, higher levels of stigma are seen among African Americans and Asians when compared to whites, and can translate to delays in seeking care and compliance

with treatment (Abdullah & Brown 2011). Not surprisingly, language barriers with healthcare providers were mentioned often during the focus groups of Asian community members who are first-generation immigrants. These language barriers are known to lead to additional barriers to care (Ponce et al. 2006). In addition, lower levels of trust in physicians among African-Americans compared to whites are not only prevalent (Doescher et al 2000), but may also partly explain differences in health service use (Ayanian et al 1999).

Limitations

Focus groups (qualitative)—Given the qualitative nature of focus groups and their small sample size, the results are exploratory and may not generalize to other communities.

PD knowledge and attitudes (quantitative)—The bias from the recruitment of older adults from senior centers could lead to generally more active and healthier study participants compared to those who choose to stay at home, resulting in information bias. It is also possible that those who volunteered to participate had a keen interest in brain and aging, or alternatively, had no knowledge and wanted to learn something new. Given this selection bias, it is important to note that the range of viewpoints among non-participants is likely even broader than what we found. Although we compared the level of knowledge about PD between community members and those living with PD, in the future it would be helpful to compare PD knowledge level with knowledge about other disease conditions as well. In addition, the sociodemographic characteristics of the comparison support group members were not matched to the senior center cohort.

Conclusions

There are several conclusions and future directions for research and community outreach that we propose. First, among a diverse sample of older, urban African-Americans, Chinese-Americans and whites there was a low level of knowledge about PD. Second, using the HBM framework, multiple barriers to care were identified: 1) moderately high perceived barriers to care related to fear and stigma due to PD across all racial/ethnic groups; 2) even higher perceived barriers to care among Chinese-Americans due to language barriers and African-Americans due to mistrust; and 3) lower cues to action among Chinese-Americans and African-Americans when compared to whites.

Therefore, educational campaigns to improve community awareness of PD and individual knowledge about PD symptoms and treatment may be appropriate to reduce health disparities. We need to improve access to translation services and provide written translated material for non-English speaking PD communities. Targeted programs for African-Americans and Chinese-Americans can focus efforts on perceived barriers to care and cues to action. Through partnership with community organizations we can begin to address deeper issues related to mistrust and stigma, and therefore build community support for those living with neurodegenerative diseases such as PD. Future research should continue to explore knowledge and attitudes about PD in diverse communities and develop strategies to reduce disparities in care.

Acknowledgments

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Table 1

PD knowledge and attitude questionnaire items

Knowledge	*Items*
	Response options: definitely true, somewhat true, I don't know, somewhat false, definitely false
Causes	PD is more common in the elderly; In most cases, the cause of PD is unknown; PD is contagious
Symptoms	Shaking (tremor) is a main symptom of PD; Memory loss is a main symptom of PD; Slow movements are a main symptom of PD
Diagnosis	There is a blood test which can diagnose PD
Management	Medications can improve the symptoms of PD; Exercise can improve the symptoms of PD; Diet can improve the symptoms of PD
Attitudes	*Items*
	Response options: strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, strongly disagree
Perceived barriers	There is a stigma or shame associated with having PD; I would be embarrassed to use a walker
Perceived severity	People with PD live long and active lives
Perceived susceptibility	My risk of getting PD is high; As long as I eat well and exercise, I can prevent PD; I worry about being diagnosed with PD someday
Perceived benefits	Treatment for early PD is very effective; Treatment for PD is not worth the side effects of medications
Cues to action	If I had signs or symptoms of PD, I would talk to my doctor; PD is a natural result of aging

Table 2

Characteristics of Focus Group and Questionnaire Participants from Philadelphia Senior Centers

Demographics	Focus group participants			PD Knowledge and attitude questionnaire participants		
	White (N = 23)	African-American (N = 36)	Chinese-American (N =16(	White (N = 62)	African-American (N = 47)	Chinese-American (N = 45)
Mean age (s.d.)	74.4 (9.8)[3]	75.0 (8.1)	71.4 (4.8)	76.8 (7.6)[1]	76.6 (8.8)[2]	74.8 (7.2)[1]
% Female (n)	52.2 (12)	94.3 (33)	75.0 (12)	65.5 (38)[1]	83.3 (40)	56.8 (25)
% Level of education completed (n)						
Less than 9 years	4.4 (1)	14.3 (5)	18.8 (3)	8.5 (5)	17.4 (8)	30.8 (12)[5]
Between 9–12 years	56.5 (13)	54.3 (19)	25.0 (4)	69.5 (41)	71.7 (33)	15.4 (6)
More than 12 years	39.1 (9)	31.4 (11)	56.3 (9)	22.0 (13)	10.9 (5)	53.8 (21)
% Socioeconomic Status (n)						
Low	9.1 (2)[1]	40.0 (14)	25 (4)	28.1 (16)[2]	30.4 (14)[2]	10.0 (4)[4]
Middle	54.6 (12)	45.7 (16)	68.8 (11)	36.8 (21)	43.5 (20)	77.5 (31)
High	36.4 (8)	14.3 (5)	6.3 (1)	35.1 (20)	26.1 (12)	12.5 (5)

Superscript number represents number of missing data for that cell

Table 3

Common themes about PD from African-American, Chinese-American and White focus group discussions

Categories	Common Themes	Sample Quote(s)[*]
Knowledge about Parkinson's Disease	Symptom attribution to multiple disorders (when shown videos of PD cases)	"Well stroke is the first thing that comes to mind." (AA, FG2, P2)
		"He might have a nervous breakdown or something." (AA, FG7, P8)
		"Shaking. Something to do with the nerves." (AA, FG9, P6)
		"They all seem like they look lonely." (AA, FG9, P6)
		"She's got osteoporosis." (W, FG3, P6)
		"A lot of people age differently." (W, FG3, P2)
		"Getting older." (C, FG5, P2)
		"Don't really know." (C, FG5, P4)
	Uncertainty about causes of PD	"It starts with the nerves." (AA, FG6, P3)
		"[He] dove into some water and hit his head. And they believe that is when it started." (W, FG3, P7)
		"It's probably hereditary." (W, FG3, P5)
		"It can come from arthritis too." (W, FG4, P8)
		"I think it comes from stress. Nervousness, stress." (W, FG4, P1)
		"It most likely has to do with the brain." (C, FG8, P3)
		"Using the brain too much. Thinking too much. Over-thinking. Overusing the brain." (C, FG5, P7)
		"Old age" (C, FG8, P4)
	Treatment awareness varies	"If not now, sometime down the line it will be. I think. I think [there's a] cure for anything 'cause they have all kinds of medications—they all kinds of [inaudible] and science you never know." (AA, FG2, P8)
		"Nowadays there's treatment for Parkinson's disease and you have to get the treatment." (W, FG 4, P1)
		"And there's nothing you can really do." (W, FG3, P3)
		"None, none." [in response to availability of medications] (C, FG8, P7)
Attitudes and beliefs about PD	Loss of independence	"It's disabling and you need help. And you have trouble speaking and eating." (AA, FG2, P5)
		"I'd feel helpless. I'd feel very helpless… so I would want to have a strong support with me." (AA, FG1, P2)
		"You have to depend on others to help you." (W, FG10, P4)
		"If you really can't do things by yourself, this will be inconvenient." (C, FG8, P8)
	Accepting	"I think I would try really hard to accept [a Parkinson's disease diagnosis]. You know? Because you can't do nothing about it." (AA, FG2, P1)
	Stigma/burden on family	"But again, it goes to being almost like a stigma on the family, and so people think, you know [do not seek help]." (W, FG10, P6)
		"…don't wanna put that burden on your family." (W, FG3, P2)
	Loneliness and depression	"Say if I did get this disease, I would feel as if I had no other choice, and also lonely" (C, FG8, P2)
		"[I would feel] very discouraging, very depressed. But, I even hate to say that some would want to really end their life." (W, FG10, P2)
Actions in response to PD signs or symptoms	Seek help	Go to the doctor. Get medicine." (AA, FG6, P4)
		"Go to a professional and get educated on the disease." (AA, FG7, P6)

Categories	Common Themes	Sample Quote(s)[*]
		"I would call my family at home to help." (AA, FG6, P2)
		"Listen to the doctor." (C, FG5, P4)
		"[Someone with suspected PD] should go to the doctor. Nowadays, there's treatment for Parkinson's disease and you have to get the treatment." (W, FG4, P5)
	Lack of desire to live	"I would probably become suicidal." (AA, FG6, P6)
		"I'd rather be dead." (W, FG3, P5)
	Multiple reasons someone with suspected PD may not seek help	"One is that the person does not have the knowledge that seeing a doctor can assist with helping him get better." (C, FG5, P3)
		"Well he must have lost faith in living, that's why he doesn't go." (C, FG5, P2)
		"Fear" (W, FG4, P6)
		"…they could be scared too." (AA, FG7, P1)
		"Some don't want to accept the fact that they're losing it." (AA, FG6, P7)
		It's not curable. That's why." (W, FG3, P5)

[*] Notation within parentheses: AA = African-American; C = Chinese-American; W = White; FG = Focus group; P = Participant

Table 4

Percentage of participants correctly answering PD knowledge items

Knowledge Item	African-American (n=47)	Chinese-American (n=45)	White (n=62)	Support group member (n=52)	p-value
More common in elderly	44.7	46.7	46.8	75.0	<0.01
Blood test is available	17.0	13.3	8.1	84.6	<0.01
Cause unknown	38.3	28.9	43.6	69.2	<0.01
Contagious	57.5	37.8	62.9	100	<0.01
Tremor is main symptom	48.9	51.1	54.8	71.2	0.10
Memory loss is main symptom	29.8	15.6	25.8	51.9	<0.01
Slowness is main symptom	48.9	46.7	43.6	78.8	<0.01
Medications help symptoms	63.8	33.3	59.7	90.4	<0.01
Exercise helps symptoms	46.8	42.2	37.1	98.1	<0.01
Diet helps symptoms	19.1	13.3	12.9	13.5	0.79

Table 5

Percentage of participants that either "Strongly Agree/Agree" of "Strongly Disagree/Disagree" with health beliefs that could lead to barriers in PD care

Health beliefs that prevent health seeking behavior for PD	African-American (N=47)	Chinese-American (N=45)	White (N=62)	*p*-value
High Perceived Barriers to Treatment				
Agree that stigma is associated with PD	34.2	34.1	25.9	0.58
Agree that embarrassed to use walker	32.6	22.2	20.3	0.32
Low Cues to Action				
Disagree that would talk to MD about PD	2.3	2.2	0	0.52
Agree that PD is a natural result of aging	22.7	44.4	5.1	<0.01
Low Perceived Susceptibility				
Disagree that risk of PD is high	17.8	20.5	31.6	0.22
Agree that diet and exercise prevent PD	25.0	42.2	15.0	<0.01
Disagree that worried about getting PD	38.6	20.5	40.4	0.08
Low Perceived Severity				
Agree that people with PD live active lives	51.1	20.0	59.7	<0.01
Low Perceived Benefits				
Disagree that treatment is effective	9.1	4.7	10.0	0.60
Agree that treatment not worth side effects	16.7	20.1	8.6	0.21