# Understanding Knowledge, Attitudes, and Beliefs about Parkinson's Disease in the Philadelphia Community

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## Introduction

Parkinson's disease (PD) is the second most common neurodegenerative disease and affects nearly 1 million Americans. According to one study, forty percent of those suffering from PD are not aware that they have the disease. Of those who are diagnosed with PD, only a small proportion receives treatment. Treatment improves quality of life in those with PD. However, patients from traditionally underserved communities are less likely than whites to receive treatment.

### Aims

In efforts to develop strategies that could reduce the treatment disparities in those with PD, we aimed to understand knowledge, attitudes, and beliefs about PD and PD treatment among different racial and ethnic groups.

# **Study Design & Methods**

#### Recruitment

Older adults ages 55 years and older from senior centers were invited to participate through flyers

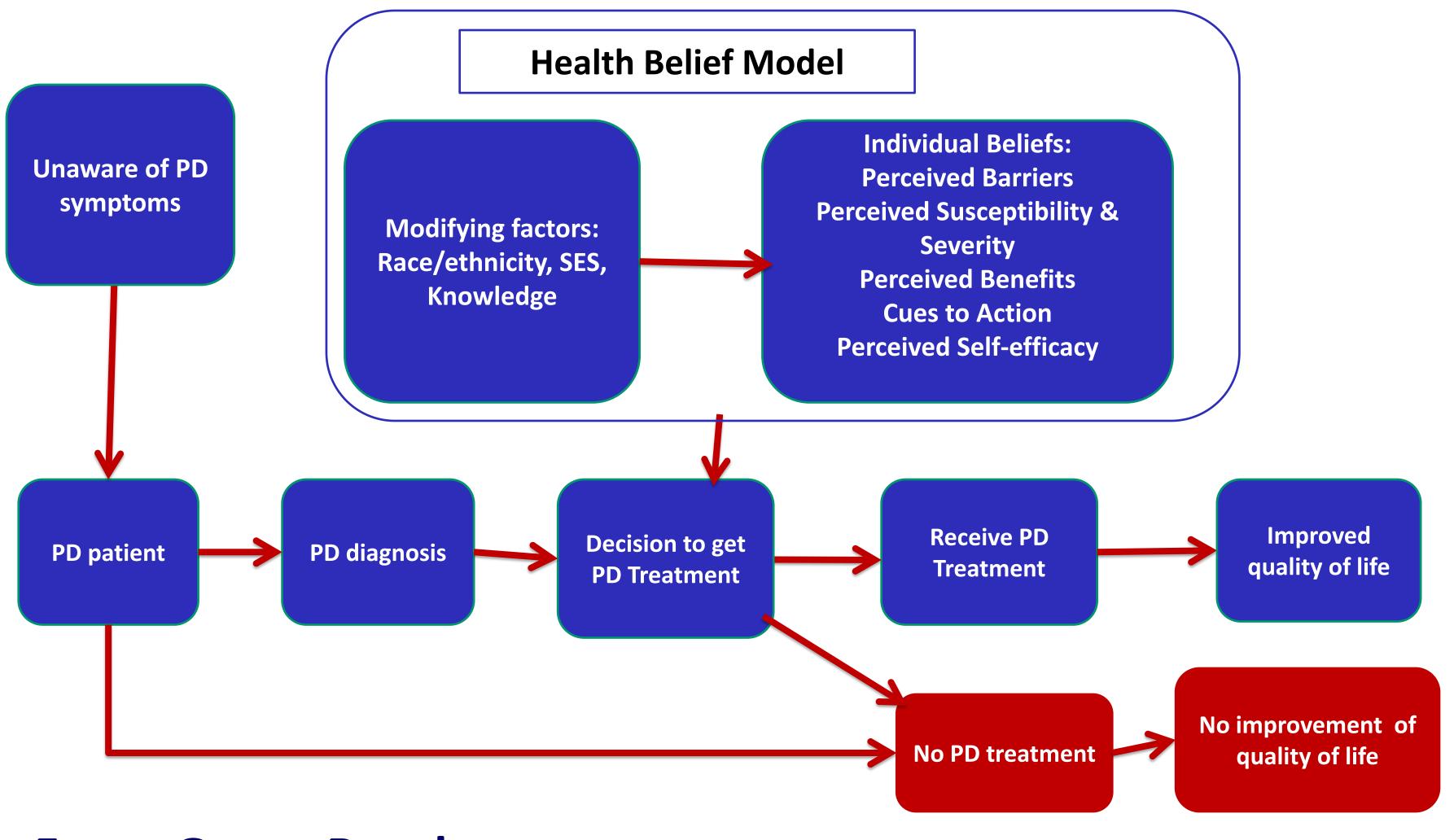
#### Focus Groups

- Cross-sectional study involving 10 homogenous focus groups of 6 to 8 White, Black and Asian (Chinese descendants) older adults
- Participants were asked to respond to video clips showing people with PD at various stages
- Participants were led in a discussion with questions about PD.

#### PD Knowledge and Attitudes Questionnaire

- Questionnaire given in English and Chinese to both senior center members and individuals attending PD support groups as a comparison.
- Twenty questions about knowledge of PD and the attitudes associated with PD

## **Problem Overview – Barriers to PD Treatment**



## Focus Group Results

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Focus Group Results Summarized					
Common Themes among all race/ethnic groups	<ol> <li>Fear of knowing whether one has PD</li> <li>Uncertainty about available PD treatment</li> <li>General feeling of pessimism towards PD</li> <li>Lack of knowledge about PD symptoms</li> <li>Not knowing where to go for help</li> <li>Importance of community support</li> </ol>				
Differing Themes between race/ethnic groups in the perception of barriers to PD treatment	<ol> <li>Whites more likely to mention lack of awareness or pessimistic outlook of PD.</li> <li>Blacks more likely to mention insurance and mistrust.</li> <li>Asians more likely to mention language barriers.</li> </ol>				

# PD Knowledge and Attitudes Questionnaire Results

Table 1. Demographics

Categories	White (N=60)	Black (N=48)	Asian N=44)	
Average Age (yrs)	76.9	76.7	74.9	
% Female	65.5	83.3	56.8	
Highest Level of Education % Middle School and less % Between Middle and High School % 2-yr College and beyond	8.5 l 69.5 22	17.4 71.7 10.9	30.8 15.4 53.8	
Socio-economic Status % Low % Middle % High	28.1 36.8 35.1	30.4 43.5 26.1	10 77.5 12.5	

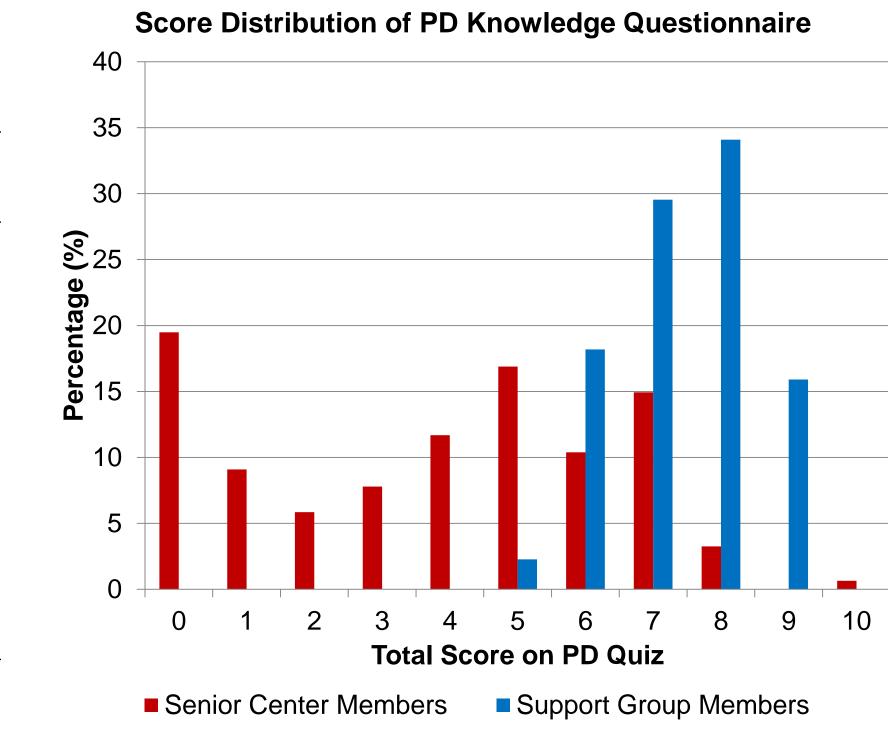


Table 2. Distribution of Scores from PD Knowledge Questionnaire

Level of PD Knowledge	% Senior Center	% Support Group	<i>p</i> -value	
	Members	Members		
Little/No Knowledge ( score ≤ 2)	33.3	0		
Some level of Knowledge	46.8	20.5		
(3 ≤ score ≤ 6)				
High (score ≥ 7)	18.8	79.5	< 0.001	
Mean Score	3.76	7.43	< 0.001	

Table 3. Perceived Barriers to Treatment (Multiple Logistic Regression)

Variable	% Yes	% No or undecided	Unadjusted Odds Ratio	Adjusted** Odds Ratio	95% CI	<i>p</i> -value
Race						
White* (N = 56)	16.1	83.9	1	1		
Black $(N = 42)$	23.8	76.2	1.72	1.7	0.6 - 4.7	0.33
Asian $(N = 43)$	30.2	69.8	2.31	5.7	1.59 - 20.5	0.008
Level of Education						
College* $(N = 37)$	10.8	89.2	1	1		
High School (N = 75)	26.7	73.3	2.9	7.4	1.86 - 29.07	0.004
Middle School (N = 25)	32	68	3.76	4.3	1.16 - 15.97	0.029

<sup>\*</sup> denotes Reference Group

#### **Additional Observations**

- Asians are less likely to seek medical treatment compared to Whites & Blacks
- Asians are more likely than Whites & Blacks to perceive PD as highly severe disease
- Those who are older are less likely to perceive PD treatment to be beneficial
- Blacks and Asians are more likely to perceive PD as part of normal aging than Whites

## Summary

- There is an overall lack of knowledge and awareness about PD and PD treatment in the community.
- Barriers to care that were identified by focus groups and questionnaires include:
- 1. Believing there is very little that one can do to help people with PD.
- 2. Fear of accepting the fact that one has PD
- healthcare system and language barriers
- 4. Lower educational attainment and Asian (Chinese) ethnicity

# **Future Direction**

- Provide information about community health resources and clinics particularly to non-English speaking populations.
- community awareness about Parkinson's disease symptoms and treatment community organizations with appropriate translation services as needed.
- Increase community provider awareness of 3. Concerns about insurance coverage, trust in treatment disparities and how beliefs about PD may contribute to these disparities to improve patient-provider communication

<sup>\*\*</sup> Adjusted for Age, Gender, Socioeconomic Status.