Parkinson’s Disease in African Americans: A Review of the Current Literature

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Abstract. Parkinson’s disease (PD) is the second most common neurodegenerative disease, though evidence suggests that this disorder does not affect all racial groups similarly. Research in African Americans, in particular, has been conflicting. Some studies have found similar prevalence rates in African Americans and whites whereas other studies have found much lower prevalence and incidence rates in African Americans. A few studies identify potential factors underlying these discrepancies, including biologic differences as well as disparities in healthcare access. However, African Americans remain underrepresented in research studies, which make understanding the underlying reasons for these differences difficult. The purpose of this paper is to summarize existing research in African Americans with PD, highlight some of the reasons why differences exist in diagnostic rates of PD in this population, and briefly discuss interventions that may need to be made in order to ensure adequate care is provided to these patients.

Keywords: Parkinson’s disease, African Americans, healthcare disparities, epidemiology

Parkinson’s disease (PD) is the second most common neurodegenerative disease, with an estimated 930,000 persons affected in North America by 2020 [1]. While there are genetic mutations that are linked to this disorder, most cases are idiopathic [2]. PD is a well-studied disorder; however most of our understanding of this disorder and its diagnostic criteria is from studies that have been performed using patients of European descent. This creates a challenge in understanding risk factors and differences in disease presentation in non-white populations. African Americans have been historically underrepresented in medical research in general, and this holds true in PD studies [3]. In other chronic diseases, African American patients have been shown to have risk factors, rates, and severity of disease that differs from those in whites [4, 5]. To date, most investigations regarding this apparent disparity in PD focus on potential systemic and structural factors in healthcare quality and access, while only a few studies focus on potential phenotypic or genetic differences. The purpose of this review is to summarize the findings to date (Table 1) and highlight gaps in knowledge regarding African Americans with PD.

STUDIES OF PREVALENCE

The prevalence of PD in the United States has been estimated to be 572 per 100,000 [1], and incidence at 37.55 per 100,000 person-years for women and 61.21 per 100,000 person-years for men [6]. These prevalence and incidence estimates are based on studies that included all racial groups. Differences in prevalence in African Americans compared to whites with PD were recognized as early as the 1970s, when Kessler noticed rates of PD in African Americans were much lower compared to white...
## Table 1
Research in African Americans with Parkinson’s disease

| Author, year | Population characteristics | Findings |
|--------------|----------------------------|----------|
| Kessler II, 1972 [8] | Participants: Baltimore hospital discharges from 1965 to 1967 | Significantly lower numbers of African Americans with PD |
|               | Total subjects: 459 PD patients, 409 white, 50 African American |          |
|               | Age: <45 years |          |
| Pressley JC et al., 2005 [23] | Participants: National Health Interview Survey, 1986–1994 | PD less likely to be listed on death certificates of those with lower socioeconomic status and less education |
|               | Total subjects: 751 persons with PD, 283 with death certificates |          |
|               | - 37 African American, 676 white, 38 Hispanic/other |          |
|               | Age: <45 years |          |
| Schneider MG et al., 2009 [3] | All PD clinical trials published between 1985 and 2007 evaluated for minority enrollment | 17% of PD clinical trials reported minority enrollment 8% of participants in these studies were non-white |
| Cheng EM et al., 2008 [44] | Participants: VA patients in the LA area with ICD.9 diagnosis of PD verified by chart review with documented race/ethnicity | Disparities in treatment of depression in African Americans with PD in the VA system |
|               | Total subjects: 374 patients |          |
|               | - 309 White, 23 African Americans, 30 Hispanic, 11 Asian, 1 Native American |          |
|               | Age: ≤64 years |          |
| Dahodwala N et al., 2009 [15] | Participants: Pennsylvania State Medicaid Claims | Newly diagnosed African Americans with PD are less likely to receive physical therapy or medications at their first appointment |
|               | Total subjects: 307 incident cases |          |
|               | - 86% white, 14% African American |          |
|               | Age: Mean age 55.1 |          |
| Yacoubian TA et al., 2009 [16] | Participants: Subjects using PD medications REGARDS study | Lower PD medication use in African Americans as compared to whites in the REGARDS study |
|               | Total Subjects: 24,424 enrolled in REGARDS |          |
|               | - 41.7% African American, 54.1% White |          |
|               | Age: >45 years |          |
| Gao X et al., 2009 [28] | Participants: Subjects enrolled in HPFS and NHS cohorts who had reported hair color, nested case-control with genotyping | Those with red hair and blonde hair had higher PD risk as compared to black hair |
|               | Total Subjects: 38,641 in HPFS, 93,661 in NHS |          |
|               | - PD in 264 men, 275 in women |          |
|               | - 272 cases genotyped |          |
|               | Age: mean age >43 years |          |
| Ross OA et al., 2010 [32] | Participants: DNA samples from 22 African American PD patients from Coriell Cell Repository collection | No frequent pathogenic mutations in African Americans with PD studied |
| Hemming JP et al., 2011 [42] | Participants: PD patients at a tertiary care center | African Americans with PD had higher Hoehn and Yahr stage at presentation as compared to whites with PD after controlling for education and income |
|               | Total Subjects: 1090 patient with parkinsonism at a tertiary movement disorders center |          |
|               | - 66 African American patients |          |
|               | - 1024 White patients |          |
|               | Age: |          |
|               | - mean age African American 67.1 |          |
|               | - mean age White 67 |          |
| Dahodwala N et al., 2011 [47] | Participants: Veterans with newly diagnosed PD at the Philadelphia Veterans Affairs Medical Center | African American men reported lower rates of disability even with similar exam findings to their white counterparts |
|               | Total Subjects: |          |
|               | - African Americans: 16 |          |
|               | - White: 58 |          |
|               | Age: mean age 70.1 years |          |

(Continued)
### Table 1  
(Continued)

| Author, year | Population characteristics | Findings |
|--------------|----------------------------|----------|
| Jain S et al., 2011 [29] | Participants: Adults in the Cardiovascular Health Study with PD  
Total Subjects:  
- 5,749 total participants  
- 154 with PD  
- 84.2% white  
Age: >65 years | Lower urate levels associated with lower risk of PD, numbers of African Americans diagnosed with PD too low to have significant findings |
| McGuire V et al., 2011 [33] | Participants: consortium of five North American case-control studies with DNA samples  
Total Subjects:  
- 1325 newly diagnosed PD  
- 1735 controls  
- 2.2% PD were African American  
Age: 37.2% <60 years, 62.8% >60 years | Taq1A DRD2 polymorphism was inversely associated with PD risk in African Americans studied |
| Wright Willis A et al., 2010 [14] | Participants: Retrospective cohort study of Medicare beneficiaries with incident PD from 2002–2008  
Total Subjects:  
- 138,728 with incident PD  
- 6.1% African American  
Age: >67 years old | African Americans with PD had lowest rates of survival and highest rates of dementia diagnosis |
| Tilley BC et al., 2012 [51] | Participants: Movement disorders clinics already participating in National Institute of Neurologic Disorders and Stroke Exploratory Trials in Parkinson’s disease Long Term Study 1  
Interventions to increase minority enrollment in clinical trials through education of community providers were not effective |
| Chan AK et al., 2014 [43] | Participants: National Inpatient Sample Database  
Total Subjects:  
- 18,312 PD DBS discharges from 2002 to 2009  
Age: Mean age for DBS 63.66 years | African Americans less likely to receive deep brain stimulation |
| Pan S et al., 2014 [46] | Participants: Older adult members of 20 senior centers in Philadelphia  
Total Subjects:  
- 75 adults in focus groups, 48% African Americans  
- 154 completed questionnaires, 31% African American  
Age:  
- Focus group mean age 74.1 years (SD +/- 8.0)  
- Questionnaire mean age 76.1 years (SD +/- 7.9) | African Americans cited lack of insurance and poor trust in doctors as reasons why they would not seek treatment |
| Saadi A et al., 2017 [40] | Participants: Medical Expenditure Panel Survey participants from 2006–2013  
Total Subjects:  
- 16,936 self-reported neurologic conditions  
- 3,102 African Americans  
Age: <18 years to >65 years | African Americans with neurological diagnosis less likely to see neurologists, more likely to have more hospital stays and more emergency room visits |
| Dahodwala N et al., 2017 [17] | Participants: Random sample of 5% of Medicare part A and B claims linked with Medicare Part D files from 2007–2010 including those with PD  
Total Subjects:  
- 9482 to 9626 individuals with PD yearly  
- 5.3% to 5.8% African Americans with PD yearly  
Age: <65 years to >85 years | African Americans and those of lower socioeconomic status are less likely to be prescribed PD medications |
| Fullard ME et al., 2017 [45] | Participants: Medicare beneficiaries with a diagnosis of PD in 2007 followed through 2009  
Total Subjects:  
- 174,643 PD patients  
- 4.1% African American  
Age: >65 years old, 90% over 70 years old | African Americans with PD are less likely to utilize physical or occupational therapy |

(Continued)
patients, as ascertained by examination of hospital records and the results of a community survey [7, 8]. Given the historical underrepresentation of African Americans in medical research findings, a closer inspection was necessary to determine whether the estimates were generalizable to African Americans. Since then, there have been additional studies attempting to clarify whether there is a true difference in prevalence (Table 2). Schoenberg and colleagues studied the prevalence of PD in the community of Copiah County, Mississippi in 1985 [9]. Medically naïve study staff conducted a door-to-door survey of elderly patients within the community, collecting information that would identify those at high risk of PD [9]. At that time, the community was composed of approximately the same percentage of African Americans and whites. Their results suggested that rates of PD were found to be similar in both populations. The patients who screened positive were examined by a neurologist to confirm the diagnosis. However a small percentage of both African American and white participants who met criteria based on survey answers did not consent to the neurologist’s examination. One interesting finding of this study is that there were twice as many African American patients than whites who had no prior diagnosis of PD. A limitation of this study is that the door-to-door staff were not medically trained, which may have led to an underestimation of PD prevalence rates, as they were asked to decide who would need a clinical examination based on the answers that were given to them by the participants.

### STUDIES OF PREVALENCE AND INCIDENCE

In a study conducted in Washington Heights in northern Manhattan, information was obtained from a community registry of PD diagnosis originating from multiple sources including clinical settings, health agencies, and senior centers [10]. Information was collected over a four-year period in order to determine prevalence and incidence. All patients who were identified through these sources were contacted and underwent a physical examination to confirm the diagnosis. These investigators reported a lower prevalence in African Americans compared to whites. But, the incidence rates were highest in African American men. The combination of high incidence with low prevalence could have indicated shorter survival times in African Americans diagnosed with PD. However, incidence in this study was calculated with census data, which may underestimate minority populations, so the number may have been inflated [10]. Group differences in co-morbidities between groups were also reviewed in this study, but they did appear to be related to differences in PD prevalence.

In general, African Americans have been shown to have less access to healthcare than whites in the United States [11]. Healthcare access is a complex concept that includes not only economic resources and insurance status, but also organizational and socio-cultural barriers that can limit utilization of available services [12]. In order to attempt to remove insurance status as a potential confounding factor.

### Table 1 (Continued)

| Author, year | Population characteristics | Findings |
|--------------|---------------------------|----------|
| Chen H et al., 2017 [25] | Participants: Health, Aging and Body Composition study participants | Anosmia may not correlate with PD development in African Americans |
| | Total Subjects: | |
| | - 1,510 white | |
| | - 952 African American | |
| | Age: | |
| | - Mean age white subjects 75.6 years | |
| | - Mean age African American 75.4 years | |
| Mantri S et al., 2019 [24] | Participants: Medicare beneficiaries with PD diagnosis with 12 consecutive months of inpatient, outpatient, and prescription drug coverage from Jan 1, 2014 to Dec 31, 2014 | African Americans with PD more likely to be prescribed dementia treatment than any other ethnic group |
| | Total Subjects: | |
| | - 268,407 with PD | |
| | - 5.5% African American | |
| | Age: | |
| | - Mean age 78.9 (SD +/– 7.5) | |
in calculating prevalence and incidence, all patients within the Kaiser Permanente system were screened for PD over a period of several years [13]. The medical records of patients who were diagnosed with PD were thoroughly reviewed by movement disorders neurologists in order to verify the diagnosis using established diagnostic criteria. Race was determined through surveys completed by the patients themselves, notably with a high rate of surveys completed. This study showed a similar finding of lower incidence of PD in African Americans as compared to whites; however, the difference was not statistically significant. These results are less generalizable due to the population being more highly educated with higher socioeconomic status than the general population [13].

Medicare data have also been examined. Medicare is government subsidized healthcare in the United States that is available to disabled persons and to those above the age of 65. De-identified data, including diagnosis, medications, and procedures, are publicly available. Examination of national Medicare data reported a similar finding of lower prevalence in African Americans, with prevalence rates 50% lower in African Americans compared to whites [14]. Incidence rates were also found to be lower in African Americans as compared to whites. The incidence to prevalence ratio was much higher in African American men with PD, which again suggests that there might be a shorter survival time after diagnosis of PD in African American men than white men [14]. The differences in incidence and prevalence were not explained by age, sex, income, or healthcare utilization.

Similar results were revealed in a study of Medicaid recipients. Medicaid is a federal and state program providing healthcare services for those who are of limited income and thus has a lower mean

### Table 2
Prevalence and incidence of PD in African Americans

| Study                        | Population Studied                                                                 | African American | White |
|------------------------------|-----------------------------------------------------------------------------------|------------------|-------|
|                              |                                                                                   | Men             | Women | Overall | Men             | Women | Overall |
| Kessler II, 1972 [7]         | Random sample of physicians in Baltimore identified their PD patients, diagnosis verified in person | 30.66           | 8.67  | 128.37  | 121.47          |       |         |
| Crude prevalence             |                                                                                   |                  |       |         |                 |       |         |
| Schoenberg BS et al., 1985   | All residents of Copiah County, Mississippi in January 1, 1978                     |                  |       |         | 338*            | 353*  |         |
| Per 100,000 residents        | Prevalence                                                                        |                  |       |         |                 |       |         |
| Prevalence                    |                                                                                   |                  |       |         |                 |       |         |
| Mayeux R et al., 1995 [10]   | Community registry of all cases of PD using multiple sources from Jan 1, 1988 to Dec 31, 1991 | 92*             | 54.7* | 57*     | 172*            | 86*   | 116*    |
| Per 100,000 persons,         |                                                                                   |                  |       |         |                 |       |         |
| Prevalence                    |                                                                                   |                  |       |         |                 |       |         |
| Wright Willis A et al., 2010 | Medicare beneficiaries from 1995, 2000–2005                                        | 1,264.58*        | 916.69* | 1036.41* | 2,168.18*       | 1,378* | 1,671.63* |
| [14] All Medicare beneficiaries |                                                                                   |                  |       |         |                 |       |         |
| Prevalence                    |                                                                                   |                  |       |         |                 |       |         |
| Wright Willis A et al., 2010 | Medicare beneficiaries from 2002–2005                                               | 427.17*          | 322.73* | 361.92* | 560.42*          | 379.99* | 451.87* |
| [14] Per 100,000 Medicare beneficiaries | Incidence                                                                        |                  |       |         |                 |       |         |
| Dahodwala N et al., 2009      | Pennsylvania Medicaid beneficiaries from Jan 1, 1999 to December 31, 2003           |                  |       |         | 23              | 54    |         |
| Per 100,000 person years     | Incidence                                                                         |                  |       |         |                 |       |         |
| Prevalence                    |                                                                                   |                  |       |         |                 |       |         |
| Chen H et al., 2017 [25]      | Participants in the Health, Aging, and Body Composition Study                       |                  |       |         | 135             | 197   |         |
| Per 100,000 person years     | Incidence                                                                         |                  |       |         |                 |       |         |
| Prevalence                    |                                                                                   |                  |       |         |                 |       |         |
| Mayeux R et al., 1995 [10]   | Community registry of all cases of PD using multiple sources from Jan 1, 1988 to Dec 31, 1991 | 31.9*            | 10.3*  | 14.32*** | 13.3*            | 11.8*  | 18.89*** |
| Per 100,000 person years     | Incidence                                                                         |                  |       |         |                 |       |         |

*age adjusted. **age and gender adjusted. ***calculated from the numbers in the paper.
age as compared to those who utilize Medicare. Dahodwala and colleagues analyzed Medicaid data from Pennsylvania and found that African Americans were half as likely to be diagnosed with PD as compared to whites [15]. This study showed even lower relative risk in African Americans vs whites than the Kaiser Permanente study (0.45 vs 0.75), which the authors suggested may imply that there are higher rates of racial disparities in lower income groups [15].

Another method to estimate prevalence and incidence of PD in African Americans was to identify patients with PD by examining prescriptions for medications typically used for treatment of PD. The number of PD medication prescriptions was analyzed in a large cohort of patients in the Reasons for Geographic and Racial Differences in Stroke (REGARDS) study. This was a prospective study examining risk factors for stroke that had approximately the same number of African Americans and white patients [16]. Only 0.51% of African American patients were on PD medications as compared to 0.97% of white patients. There was no association between income, education level, or geographic area of residence. Insurance status and older age were found to be associated with higher likelihood of PD medication use. Although the diagnosis for use of these medications was not included in this study, the investigators interpreted the results as an indicator of lower prevalence of PD within the African American population [16]. In a similar study, a random sample of Medicare drug claims were analyzed from the years 2007 through 2010, and patient and provider characteristics’ association with PD-drug class and choice of drug were studied. This examination of Medicare Part D prescription utilization of PD medications shows that African Americans were significantly less likely than whites to be prescribed PD medications [17]. In addition, the findings showed that patients of lower socioeconomic status were less likely to receive PD medications, and that PD patients who were not seeing a neurologist were also significantly less likely to receive more than one PD medication [17].

Overall there is high variability in incidence and prevalence among all studies (Table 2). A meta-analysis of incidence in studies including African Americans shows the highest incidence in African American men (Table 3) [10]. This may be influenced by the Mayeux et al. finding of twice as many incident cases in African American men compared to white men. Differences in incidence estimations among these studies may be due to study time period, region of the country being studied, and age of participants in the studies.

To summarize thus far, the majority of these studies suggest that there is a difference in PD prevalence and/or incidence between African Americans and white patients. However, studies using diagnostic codes within healthcare databases to generate these numbers may underestimate true prevalence by up to 52% [18]. Attempts to correct for this discrepancy have been made by using surveys to capture symptom occurrence in the entire population in a certain area. However, even this method has limitations that can lead to discrepant outcomes, including differences in diagnostic criteria and different responses from patient participant’s vs family member [19]. Thus, the possibility that ascertainment and diagnostic bias may play a role in the observed discrepancy remains. Earlier age of mortality in African Americans may also affect prevalence calculations, which was theorized in several of the above mentioned studies where incidence rate was found to be higher than prevalence in the African American population [10, 14]. Although there has been an improvement in recent years, life expectancy of African Americans overall is lower than whites, with the largest gap between white and African American males of almost four years. Hispanic Americans, in contrast, have similar life expectancy as whites [20]. In some urban communities, such as Chicago, this difference in mortality between whites and African Americans can be quite large with significantly higher early mortality in African Americans with lower income (RR = 3.27, 95% CI 2.84 to 3.77) [21]. In PD specifically, Medicare data were reviewed and it was found that African Americans had the lowest rates of survival among racial groups studied, as well as the highest rates of dementia [22]. Further investigation using this methodology may be
difficult as PD is less likely to be listed as a cause of death on the death certificate in patients with lower education and income levels, even if these patients had a verified diagnosis of PD during their lifetime [23]. These biases may disproportionately affect the population of African American patients with PD in the US, thus skewing the prevalence calculations.

**PHENOTYPIC DIFFERENCES**

Some studies suggest that there may be phenotypic differences between whites and African Americans that could explain differences in diagnostic rates. Examination of Medicare data has shown that African Americans with PD have higher rates of dementia than whites, and are more frequently prescribed dementia drug therapy than whites [22, 24]. Another study found that anosmia, or the loss of ability to detect certain smells, in older African Americans may not confer the same amount of risk of the development of PD as it does in whites [25], even though rates of anosmia have been found to be higher in African Americans than whites [26].

There are few biological mechanisms that have shown to account for differences seen between African American and white PD patients. One hypothesis is that melanin may offer some level of protection against PD, as malignant melanoma has been shown in some studies to precede PD, and those with decreased melanin are at increased risk of developing melanoma [27]. One study showed redheads were significantly more likely to develop PD as compared to individuals with black hair [28]. Another hypothesis is that uric acid levels may play a role in the decreased rate of PD in the African American population. Many studies have consistently shown that elevated uric acid levels are correlated with lower risk of PD in white men [29]. African Americans have significantly higher uric acid levels than white persons, however the relationship between uric acid levels and PD development in African Americans has not been clearly established [30].

Genetic variability within those of African descent is not as well studied as compared to those of European and Asian descent [31]. A few studies have focused on different genes in African American PD patients. However, extrapolation of any findings to a larger patient population is difficult with small sample sizes. [32, 33].

Research in PD in Africa has been limited, as there are approximately 3 neurologists per 10 million people in sub-Saharan Africa. One study conducted in Igbo-Ora, Nigeria investigating prevalence using door to door survey techniques. Survey results from 3,412 Africans over the age of 39 indicated that an age-adjusted prevalence of PD was 67/100,000, which is five times lower than what was found in the Copiah County Mississippi African American population [9]. Another more recent study done in Tanzania used a similar technique and found age-adjusted prevalence of 40/100,000. Of these patients, 78% of those identified had no prior diagnosis of PD [34]. There are limitations in comparing these numbers to those from developed nations, as the age discrepancy is large, with only 3% of the population in Tanzania over the age of 65. Despite this barrier, a few large studies have been completed in Africa. One seminal study found that delayed levodopa administration in Ghana had no impact on development of dyskinesia as compared to an Italian PD cohort who had received earlier levodopa [35].

In contrast, research in Alzheimer’s disease (AD) in African Americans has shown an increased risk for the development of AD in African Americans as compared to whites, though this is not consistent among studies [36, 37]. A post-mortem study showed that African Americans with AD were more likely than white Americans to have mixed pathology including increased Lewy Body burden [38]. Genetic studies have also shown that the mutations that are highly correlated with increased risk of development of AD in white patients may not confer similar risk to African American patients [39]. These conclusions have been derived from longitudinal studies with large sample sizes that included participants from multiple racial groups. In contrast, research in PD that includes multi-ethnic participants (including African Americans) are not longitudinal, community-based studies. These studies will be necessary to improve understanding of the disease in these groups of patients from minority ethnic groups. Community based studies that do not rely on prior diagnosis of PD are promising in that they eliminate the barrier to healthcare access that often results in lower estimates of prevalence and incidence of PD in minority populations. By modeling the work that has been done in AD, we can gain understanding not only of rates of disease, but also risk factors and any phenotypic differences that may occur between populations.
HEALTH CARE DISPARITIES

Another issue is whether healthcare disparities, specifically differences in access to specialized (neurologic) care results in fewer African Americans being diagnosed with PD, which in turn artificially lowers the estimates of incidence and prevalence [40]. There is significant evidence that African Americans have decreased access to primary healthcare, and even in those who do have healthcare access, many do not receive standard of care or specialized services [41]. In one study using data from the Medical Expenditure Panel Survey, African American patients were 30% less likely to see a neurologist than whites, even after controlling for demographics, insurance status, and health status differences. African Americans who had an identified neurologic disorder were also more likely to be seen in the emergency department, have more hospital stays, and have higher inpatient expenditures than whites [40]. Though African American patients with PD represent a very small percentage of patients at tertiary care centers, they have higher Hoehn and Yahr stages than whites and are less likely to receive dopaminergic medications [42]. African American PD patients are also less likely to receive advanced levels of care, such as deep brain stimulation [43].

Another source of publicly available healthcare data in the United States is the Veterans Administration (VA). Individuals who have served in active duty are able to access government subsidized healthcare through the VA. Analysis of PD patients in the VA system identified differences in quality of care, such as lack of treatment of depression in African Americans compared to whites [44]. African Americans with PD are also less likely to be prescribed physical therapy and occupational therapy as compared to white patients [45]. Analysis of Medicaid data also showed that newly diagnosed African American PD patients are less likely to receive physical or medical therapy at their first appointment [15].

One hypothesis that attempts to explain the disparity in care is that African Americans may not seek treatment as often as whites for symptoms that are associated with PD. In one study, African American participants with PD cited lack of insurance and lack of trust in doctors as reasons for why they would not pursue medical care for signs of PD [46]. In addition, African American participants had a higher likelihood to regard signs of PD as normal signs of aging [46]. Dahodwala and colleagues examined differences between Unified PD Rating Scale (UPDRS) part II (self-report of symptoms) and UPDRS part III (physician examination) in African Americans and whites in the VA system [47]. African American PD patients were found to have significantly lower scores on self-reported symptoms as compared to whites, even with similar physical examination findings and stage of PD. Patients who under-reported their disability were three times more likely to present at a later stage of disease than those who rated their disability appropriately, with multivariate analysis showing that this underreporting of disability accounted for the effect of race on stage of diagnosis [47].

LIMITATIONS IN RESEARCH

Generalizing research findings to African Americans is limited due to lower numbers of minorities being included in PD research studies. Many large clinical trials do not report ethnicity or race in their published studies, but those that do show a significantly lower number of African American participants than whites [3]. A review of clinical trials in PD showed that only 17% of clinical trials between 1985–2007 reported minority enrollment, and in those studies only 6% were ‘non-white’ [3]. History of research abuses within the African American population in the US were often cited as a major reason for difficulty in recruiting African Americans for research. However, more recent reports indicate that this may no longer be a primary reason for lack of minority involvement in clinical research [48]. Lack of education about research opportunities and understanding about what occurs during research participation may be a more important factor affecting minority recruitment into clinical trials [49]. Bias within the medical community may also be a barrier to recruitment. Physicians surveyed reported that the assumption that patients were not interested in participating in research was a significant factor in not referring minority patients to clinical trials [50]. However, in a large multi-center trial attempting to address physician bias with education, recruitment of minorities in PD studies did not improve [51].

CONCLUSION

With the continual rise in life expectancy in the United States, there is an expectant increase in the
number of persons experiencing neurodegenerative diseases. Although PD is a relatively well studied disease, with significant efforts aimed at understanding underlying pathophysiology and advances in therapeutics, there is a substantial amount of information that is still unknown. The impact of PD in minority populations should be emphasized in future research, as these patients are underrepresented in current research studies. In the African American community specifically, there has been speculation about differences in PD in regard to disease occurrence or possible genetic differences in this group, but these differences have not been well established.

Current research has shown that African American patients who carry the diagnosis of PD are less likely to receive standard of care as compared to white counterparts, and more likely to present to specialty clinics with severe/advanced disease, even though initial incidence and prevalence calculations suggested lower rates in African Americans vs. whites. The most accurate study of prevalence in African Americans was published in 1985 and based on community members in Copiah County, MS, though these results have never been replicated, nor has its methodology been repeated [9]. Replication of these results with similar studies would provide a much better estimate of PD prevalence and would be fundamental for the understanding of PD in African Americans. Replication of equal prevalence among whites and African Americans demonstrated by Schoenberg and colleagues would provide an even stronger impetus for further investigation of the role that healthcare access barriers play in prevalence calculations. However, if the lower prevalence in African Americans is supported by additional studies, then more work should be done to find the underlying reasons for this difference. The studies of incidence of PD in African American patients that have been performed thus far are so variable in design and methodology that meta-analyses are unrevealing.

In the very small number of studies looking at rates of PD in the Hispanic/Latino population in the US, there may be a slightly higher rate of PD in this population compared to whites [10, 13]. In part, due to these studies, the Latin American Research Consortium on the Genetics of Parkinson’s Disease (LARGE-PD) was formed in 2005 in order to elucidate the genetics of PD in Latin America and its efforts are ongoing [52]. Similar work needs to be done in patients of African descent if true differences are found in prevalence in African Americans.

Following the model of research in other disease states has potential to improve research efforts in African Americans with PD. In AD research, there have been large, longitudinal studies examining the disease burden in populations of various ethnicities and races. These studies are ongoing, but will add significant understanding to risk factors, disease presentation and progression [53]. These studies utilize community organizations such as churches, community senior centers, and assisted living facilities to reach as many participants as possible [53, 54]. The investigators of these studies understand that there is general mistrust in the African American community toward medical research and have put forth specific and concerted effort into building relationships with community members in order to build a trusting, collaborative alliance. This has been the way to increase the number of participants enrolled [53]. Similar efforts will need to be made to foster relationships between community leaders and members and those attempting to do PD research in collaboration with this community in order to obtain useful results.

**CONFLICT OF INTEREST**

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