Measuring Unmet Need in Underserved Parkinson’s Populations
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BACKGROUND

There is a significant gap in existing research and available information about traditionally underserved people with Parkinson’s disease (PD) including information about their treatment and care, access, unmet needs, and self-reported outcomes. These populations include racial and ethnic minorities, women, residents of rural areas, individuals over 70 years of age, and those not seeing Parkinson’s specialists.

For research that is conducted, there is a lack of specificity and the focus is limited in scope. For example, studies of Hispanics with PD have focused on genetics, studies of women with PD have concentrated on disease symptoms, and studies of people with PD residing in rural areas have centered on telehealth and access to care.

The Parkinson’s Foundation is partnering with Dr. Allison Willis to carry out one of the largest ever conducted of underserved PD populations. NORC, an independent, non-partisan research institution, and one of the largest independent social research organizations in the US is providing survey and data analytics expertise. The Michael J. Fox Foundation is also providing support for the study.

OBJECTIVE

To examine health care access needs and barriers among underserved and hard-to-reach people with PD to inform strategies, programs, resources, and care practices to best serve these populations.

METHODOLOGY

Survey Instrument

Developed to gain a comprehensive understanding of all aspects of health (i.e., mental, social, and emotional) of people with PD. Combines validated tools with newly developed questions on access to care, support, and information and experiences since the start of the COVID-19 pandemic.

Survey categories and information collected on the following:

| Health status | Current functioning – UPDRS, PDQ-39, and PPMI2 | Exercise |
| Risk factors | Participation in outdoor activities | Daily tasks and daily functioning |
| PD diagnosis and onset | Support – Access to support and social network | Medications and surgical treatment |
| Decision making – QUIP-RS | Additional services – wearables, telehealth | Treatment – Access to and experience with providers |
| Information – Access to and use of PD related information | COVID-19 – Experiences, satisfaction, and preferences since start of outbreak |

Self-administered, Paper-based Survey

With $1 incentive as token of appreciation

ANALYSIS

Analysis will compare differences and examine core areas including:

- Structural Gaps in Care
- Personal Activation/Motivation
- Existing Support

RESULTS

MILESTONES

JAN-MAY 2020

Survey Instrument Development
Cognitive testing of new questions with small group of PwP; User centered design principles for formatting/layout

SEPT-OCT 2020

Data Analysis

NOV 2020

Report Development
Gaps, barriers, priorities, programmatic needs

JUNE – SEPT 2020

Survey Fielding
Round 1 (June-Aug) / Round 2 (Aug-Sept); Qualitative interviews with recipient subset

DEC 2020

Report- Public Release
Share study findings through channels (e.g., articles, webinar, conferences)

CONCLUSION

There is a significant gap in patient-reported data on health, care access, and experiential barriers among traditionally underserved and hard-to-reach people with Parkinson’s disease (PD). This study will provide a deeper understanding and inform providers, institutions, organizations, and people with PD about key issues and aid in developing targeted programs, resources, and care practices that best serve these populations.