

Introduction

The Department of Health and Human Services (HHS) characterizes underserved populations as communities that include members of minority populations or individuals who have experienced health disparities and includes American Indian and Alaskan Native Populations (AIAN)¹. AIAN populations have endured historical trauma, systemic racism, and a lack of funding and access to health care services. The Parkinson's Foundation established an initiative to understand the needs of AIAN individuals and to improve health education delivery to better address Parkinson's disease (PD). To our knowledge, there are no other nationwide approaches on building AIAN relationships to increase accessibility to PD resources.

Public Health Approach

Standard best practices in public health community engagement were further supported by an examination of the history of AIAN population health and specific concerns for those using IHS services and tribal health clinics.

Additionally, an ongoing process of identifying assumptions, values, beliefs, biases, culture, and how these factors impact community engagement was utilized to create collaborative and iterative approaches for engaging with AIAN people, communities, resources, and organizations.

Techniques displaying this community engagement approach included:

- Incorporating Native languages in spoken/written introductions and public service announcements.
- Collaborating with Native guest speakers and those working in tribal health to facilitate educational programs.
- Displaying only authentic photographic representation, sourcing photos from the Urban Indian Health Institute's TONL collaboration.

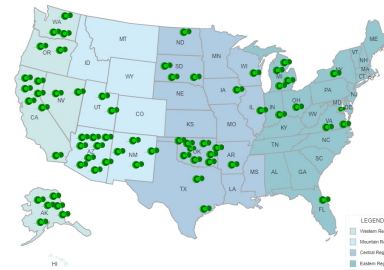


Methodology

- The Parkinson's Foundation and Strengthening Native Connections created a PSA for PD awareness in April 2022, facilitated through GoodHealth TV across Indian Health Service (IHS) facilities and tribal health clinics.
- Educational webinar programs were developed as a recurring resource on the topics of understanding PD, hospital safety & PD, and caregiving & PD.
- Participation in AIAN health conferences hosted by the National Indian Health Board was utilized to create a working relationship with health providers and representatives, increasing accessibility of Parkinson's Foundation educational tools and health care resources such as the "Aware in Care" Hospital Safety Kit.



Map of AIAN Connections

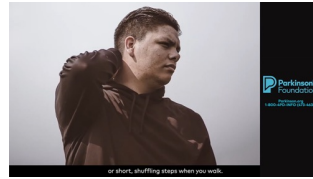


Across the 65 connections, engagement was seen with indigenous communities such as:



Results

- 56 IHS facilities broadcasted the Parkinson's awareness PSA.



- Live webinar educational programs throughout 2022-2023 yielded 81 participants who had not previously engaged with the Parkinson's Foundation.



Symptom Management: Treatments

- Medication or Surgical treatments
 - Medications for both motor and non-motor symptoms
 - Surgical options for motor symptoms for some patients
- EXERCISE, EXERCISE, EXERCISE**
- Specialized therapies
 - Physical, occupational, speech therapy
 - Counseling – individual and/or family therapy
- Social engagement and support
 - Support groups and education for people with PD, their families and caregivers

- Active participation in AIAN health conferences led to connections with 54 individuals across 32 tribes. This corresponded to the distribution shipment of 273 Aware in Care Hospital Safety Kits and 17 educational books in locations where these resources had previously not been distributed.



- Feedback in discussions with indigenous individuals with Parkinson's and care partners included new tribal health-related contacts to outreach to, requests to create a future program that differentiated Alzheimer's disease from Parkinson's disease, and tribal health organizations that could be a useful collaboration in continuing to address Parkinson's disease in Indian country.

Conclusion

The Parkinson's Foundation and Strengthening Native Connections will continue to collaborate to build a roadmap to address PD education across AIAN populations and help advance health equity for underserved populations, expanding from awareness and education into advocacy and research participation efforts.



References & QR Code

1. HHS guidance submissions. HHS Guidance Submissions | Guidance Portal. <https://www.hhs.gov/guidance/>. Accessed March 30, 2023.



Introduction

The Parkinson's Foundation conducted interviews with three Parkinson's Care Partners for the **Care Partner Program** online course "Caregiving Through the Progression." The following highlights the unique experiences of a diverse group of care partners throughout their Parkinson's journey. Self-care is an important theme across all three interviews, but as expected it looks quite different in different contexts. To see their full interviews, register for the free course at Parkinson.org/CarePartnerProgram.

Early Parkinson's Caregiving



Julia highlights the turbulent road to her husband Phil's diagnosis and the frustrations along the way. She also shares her experience of Black cultural norms around not disclosing a medical diagnosis and how this presented unique challenges, as well as the strength of their core family unit that allows for unique support

Scan the QR code to hear Julia talk about journaling as a self care tool and share the role that partnership has played in her relationship with Phil, particularly as she initiated her own journey towards a healthier life.



Mid-Stage Parkinson's Caregiving



Dick shares how he has prioritized his spiritual and emotional wellness as he cares for his wife Chris through regular support sessions through both his church and a men's group. He expresses his fears about the future as the disease progresses and how he and Chris have prioritized having conversations about advanced directives. He shares his experience as a male care partner expressing emotions in a healthy and productive way.

Scan the QR code to hear Dick share his struggle with asking for help and how he has worked towards feeling more comfortable in both paying for help when they are able and asking for help from family and friends.



Advanced Parkinson's Caregiving



Edna shares the impact of her husband Mark's PD on their daughters, who grew up with Parkinson's as an everyday part of their childhood, and her perceived mistakes along the way as a mother and wife. She walks us through a realization that based on cultural norms as a Filipino woman in her 30's at the time of his diagnosis, she did not feel that divorce was an option though now, at 60, she recognizes that she would not want her daughters to feel that same obligations.

Scan the QR code to hear Edna walk us through losing herself in the caregiving role, the moment she realized she needed help, and her "year of Edna" in her 20th year of caregiving which initiated a rare and revolutionary expression of self-care in advanced Parkinson's caregiving.



Objective

To describe the reasons for care partner contacts and to ascertain if there are gender differences in time since diagnosis and topic, using seven years of data from the Parkinson's Foundation Helpline.

Methodology

Cases from family members were reviewed for the seven-year period from 2016 through 2022. There were 21,489 cases of first-time contact with the Helpline from any family member where the gender of the person with Parkinson's was known. Of the total cases, 46% were communication with the Spouse/Partner of the person with PD and 33% were with an Adult Child. This analysis focuses on Spouse/Partner cases, as they are most likely to be the primary care partner. Case reasons were stratified by category, analyzed using frequency statistics and compared to the gender of the person with Parkinson's.

Background

The Parkinson's Foundation established its Helpline to provide the Parkinson's community with a place to find answers for general questions regarding Parkinson's disease; provide referrals to health professionals, support groups and wellness programs; provide educational materials in print and digital formats and to provide emotional support to individuals and families living with the diagnosis. Social workers, nurses and health educators staff the Helpline in English and Spanish Monday - Friday from 9am to 7pm EST.

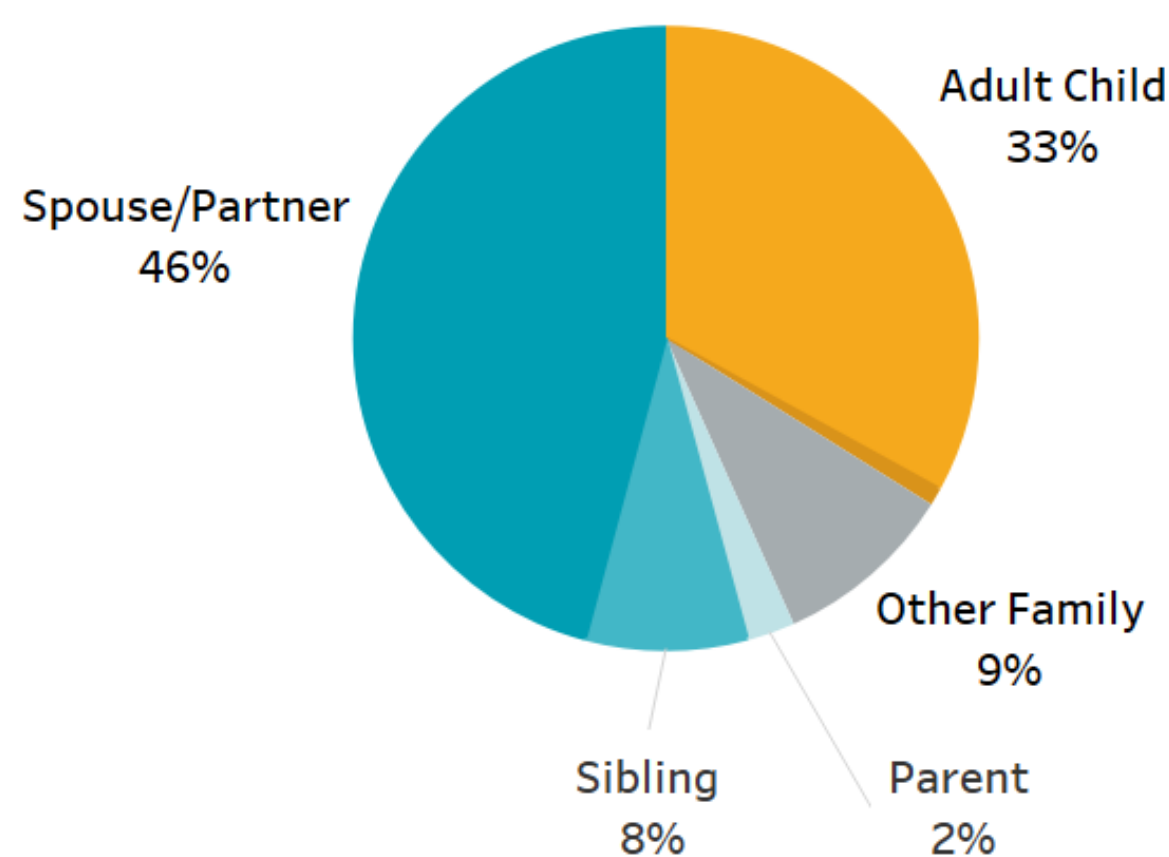
Requests range from straightforward information and/or referrals to social support that include the need to discuss complex and challenging situations with someone who really understands Parkinson's to difficult decisions about nursing home placement, hospice care and the occasional Parkinson's psychosis crisis. Family members of persons with Parkinson's – and especially the primary care partner – need as much information, referrals, and support as the individual living with the diagnosis.



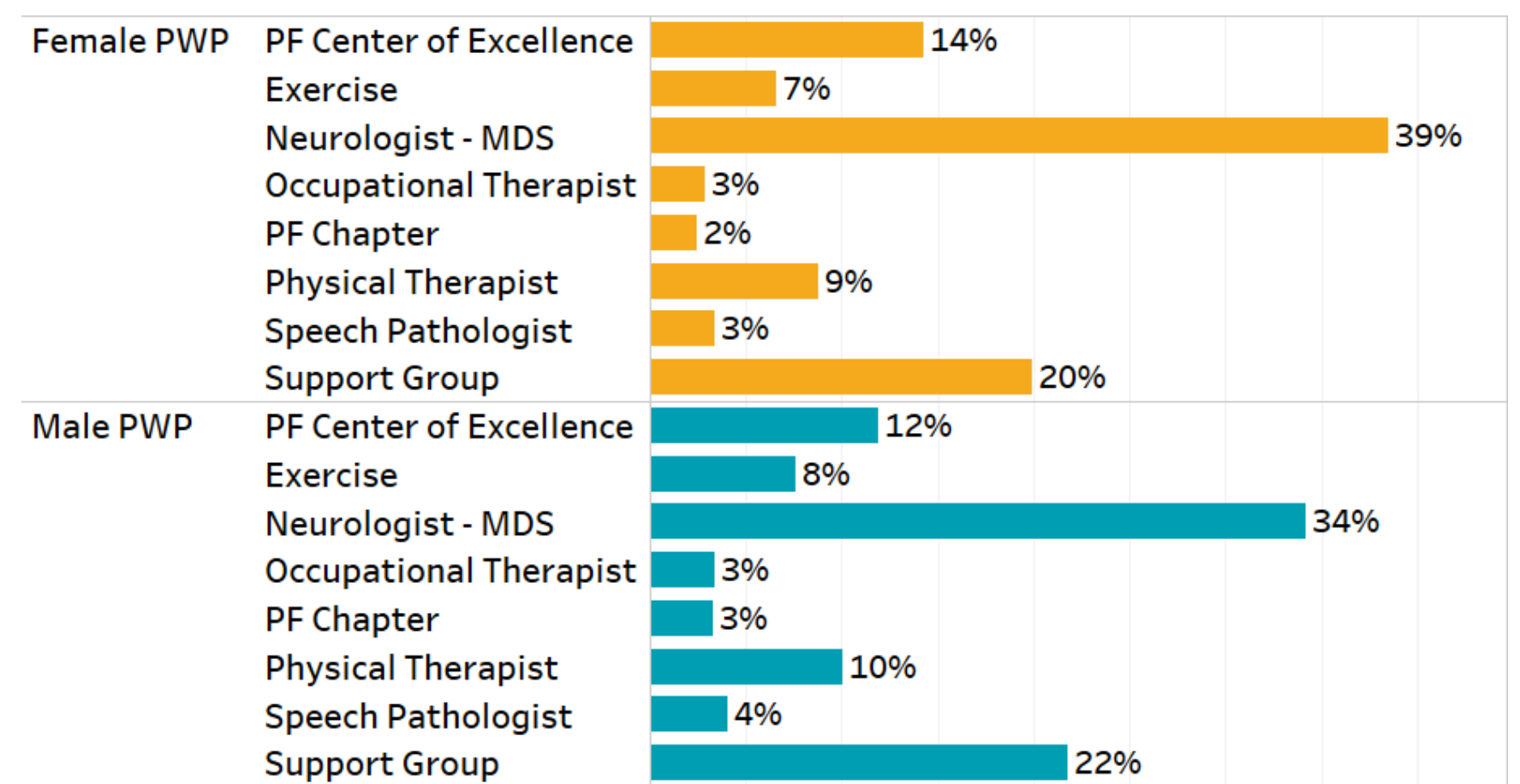
1-800-4PD-INFO (473-4636)
Helpline@parkinson.org

Results

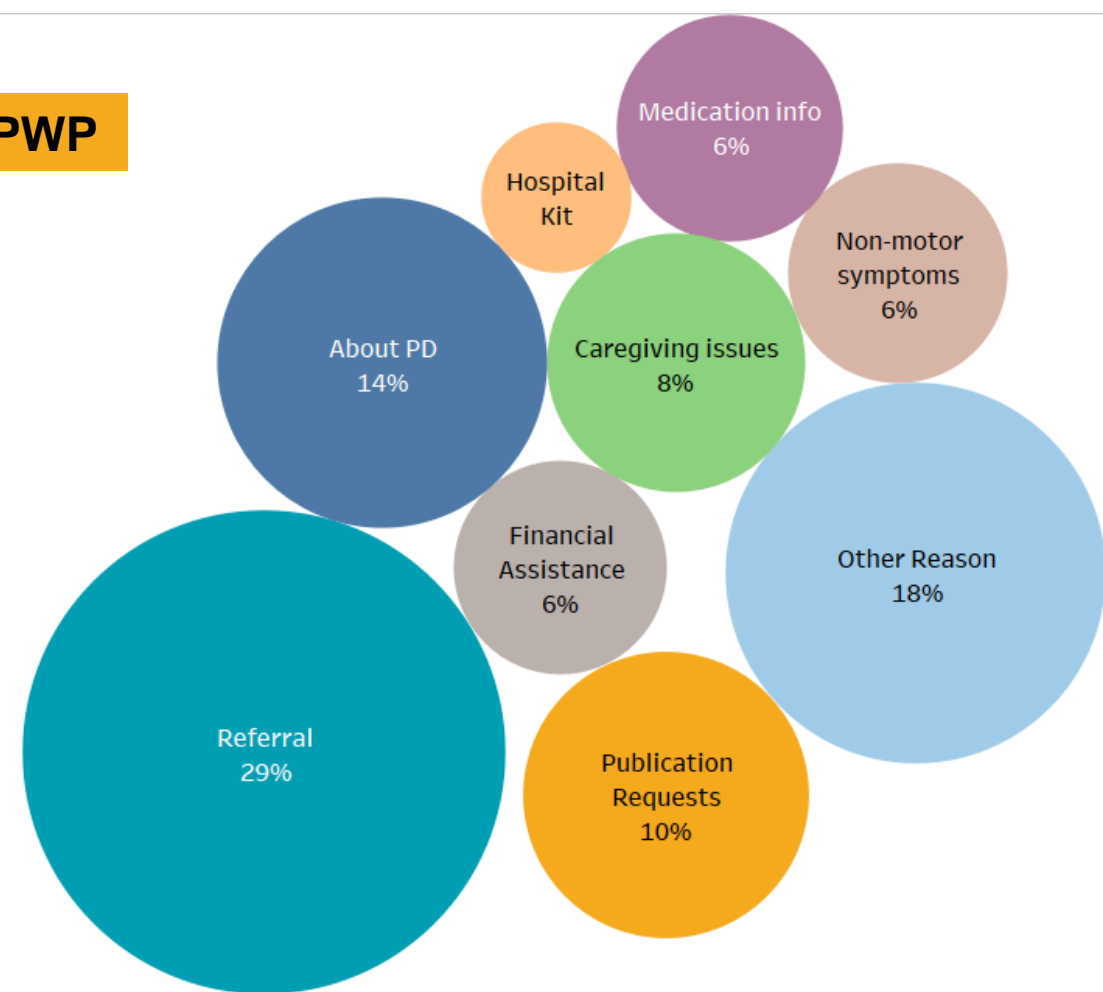
Type of Family Care Partner



Referrals Provided to Spouse/Partner



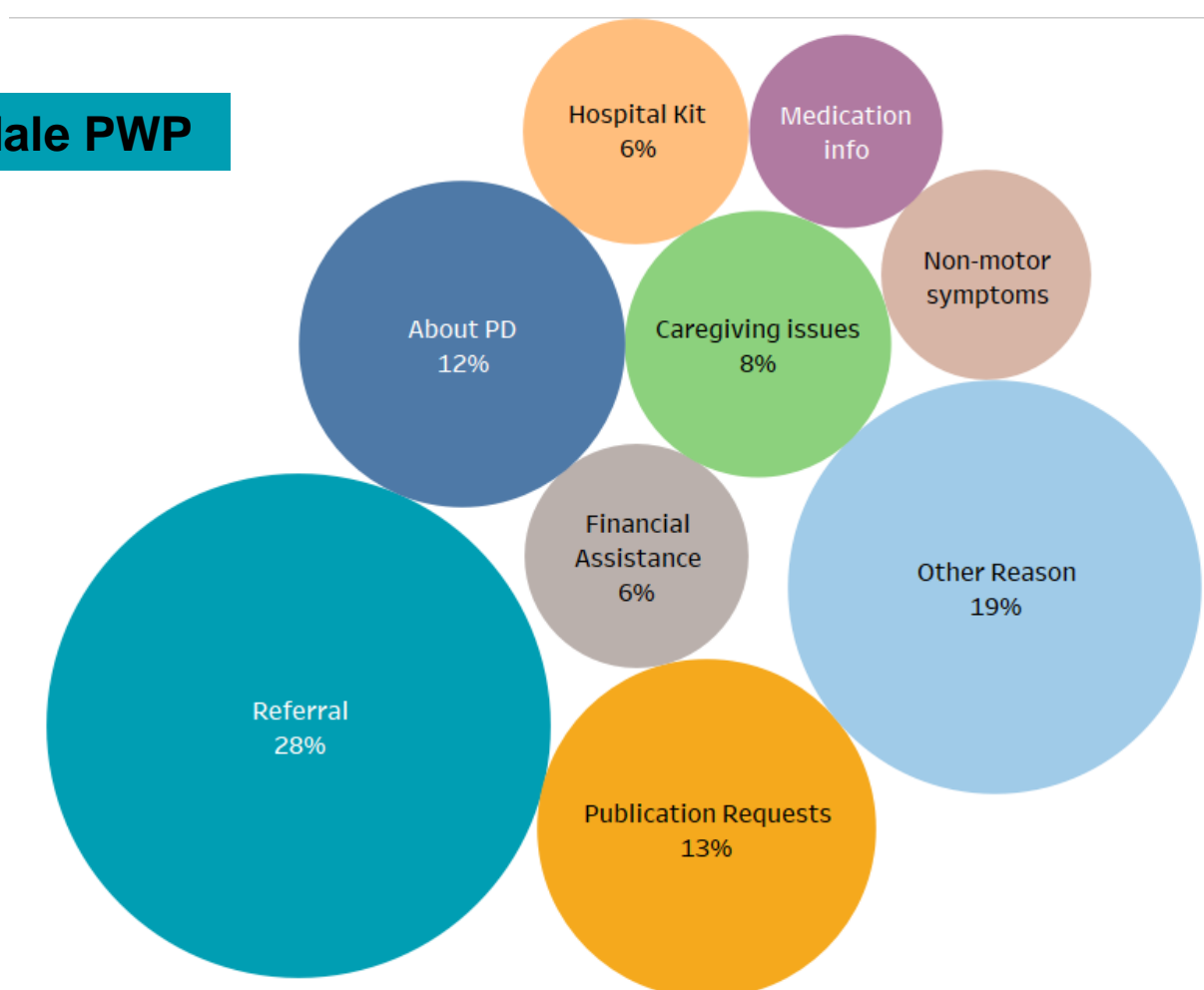
Female PWP



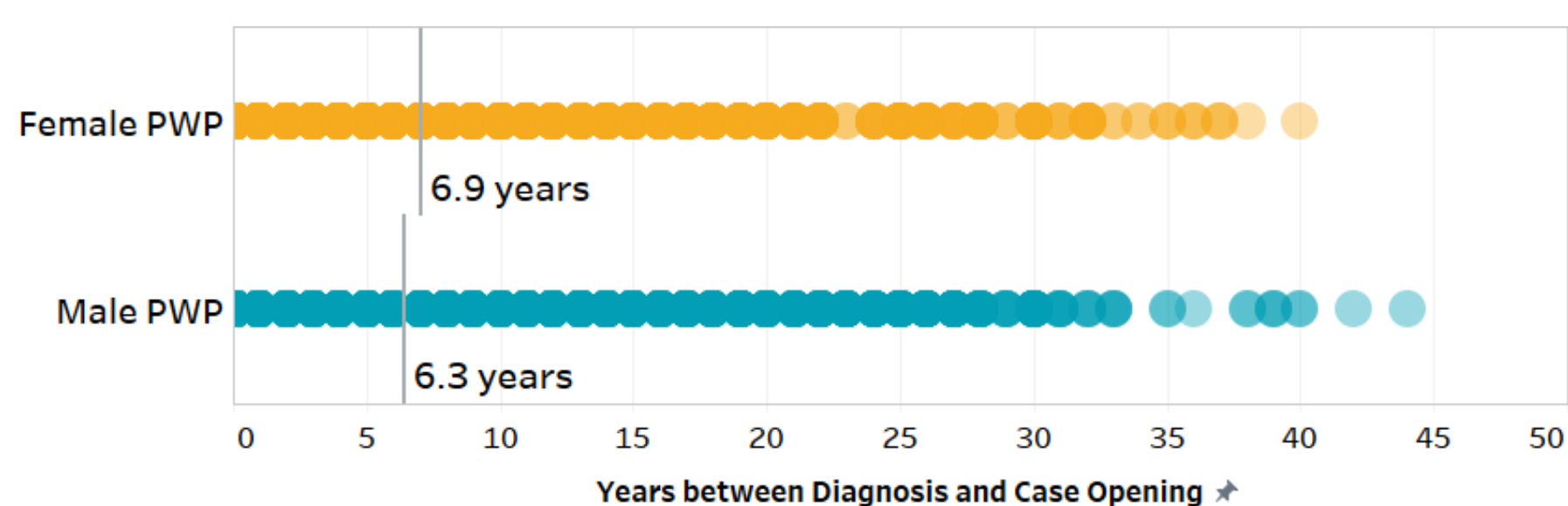
Reasons for Spouse/Partner Contact

The most common reason that Spouse/Partners (n= 9,884) contacted the Helpline, when analyzed by gender of the Person with Parkinson's (PWP), was the same, with requests for referrals the highest category for both groups. Publication requests and "About PD" were the next highest categories.

Male PWP

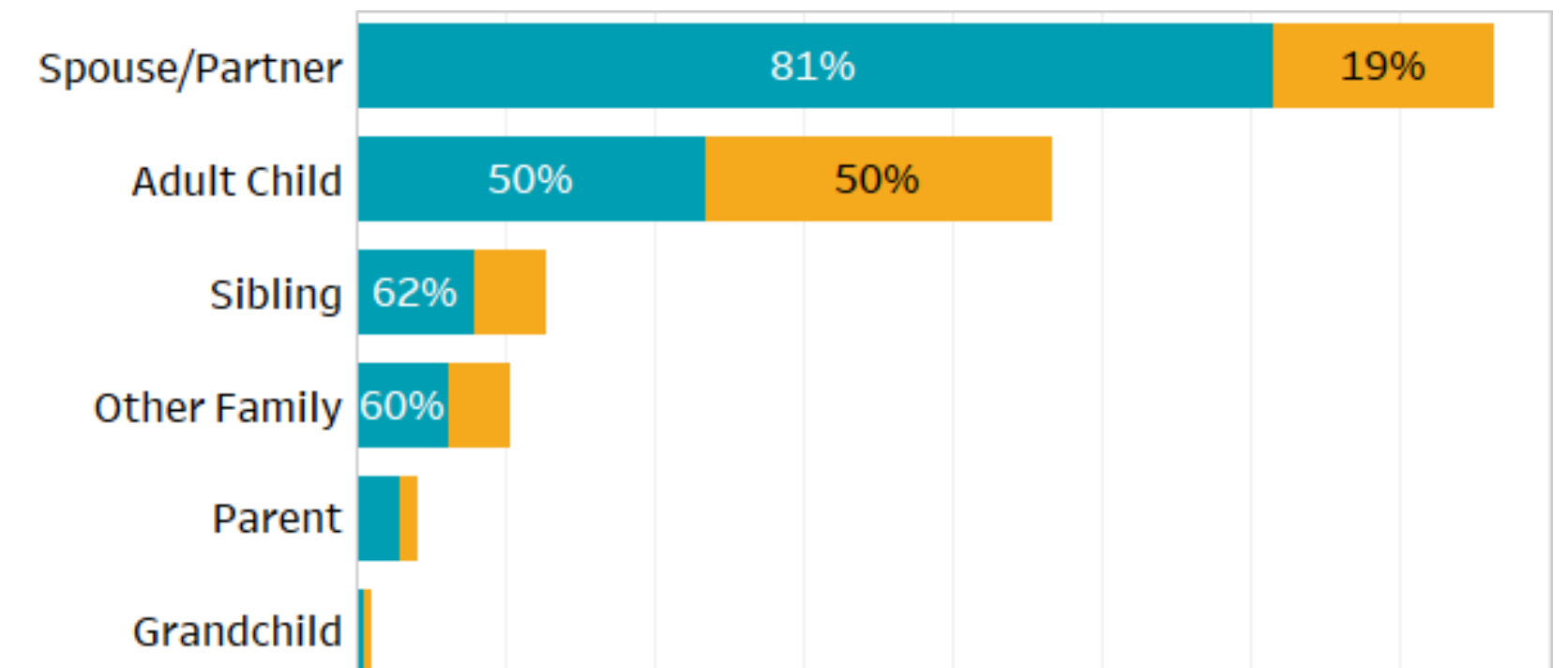


Average Disease Duration at Time of Initial Contact from Spouse/Partner



Spouse/Partners (n= 10,080) of female PWP contacted the Helpline later in the disease process. For Spouse/Partner contacts, where length of diagnosis was known, the average disease duration was 0.64 years longer for women with PD when the care partner reached out. (p value = 0.016).

Gender of PWP Differences by Type of Family Care Partner



Nearly 81% of Spouse/Partner Helpline inquiries (n= 10,080) were regarding men with Parkinson's, despite men accounting for 60% of Parkinson's cases (1).

Conclusion

Family members of persons with Parkinson's disease have a broad array of reasons for reaching out to the Parkinson's Foundation Helpline. There were no major differences in Spouse/Partner's reasons for contacting the Helpline or for the type of referrals provided. When primary care partners - typically spouses/partners - call the Helpline, they are calling about men with PD more often than about women with PD. Since most spouse/partner relationships are heterosexual, care partners of women with PD are mostly male, and they are contacting the Helpline less compared to female care partners. This disparity supports what others have seen, both in Parkinson's care specifically (2) and for chronic conditions in general (3,4). Since male care partners are calling the Helpline less often than female care partners, this suggests a need for increased targeted outreach toward male care partners. This outreach could help them access information and resources that will support their caregiving, which directly impacts the well-being of females with PD.

References

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