

Objective

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

Background

The Parkinson's Foundation established its Helpline to provide the Parkinson's community with a place to find answers to general questions regarding Parkinson's disease (PD); provide referrals to health professionals, support groups, wellness programs and community resources; provide educational materials in print and digital formats and to provide emotional support. Health care professionals and educators staff the Helpline in English and Spanish, Monday through Friday from 9am to 8pm ET.



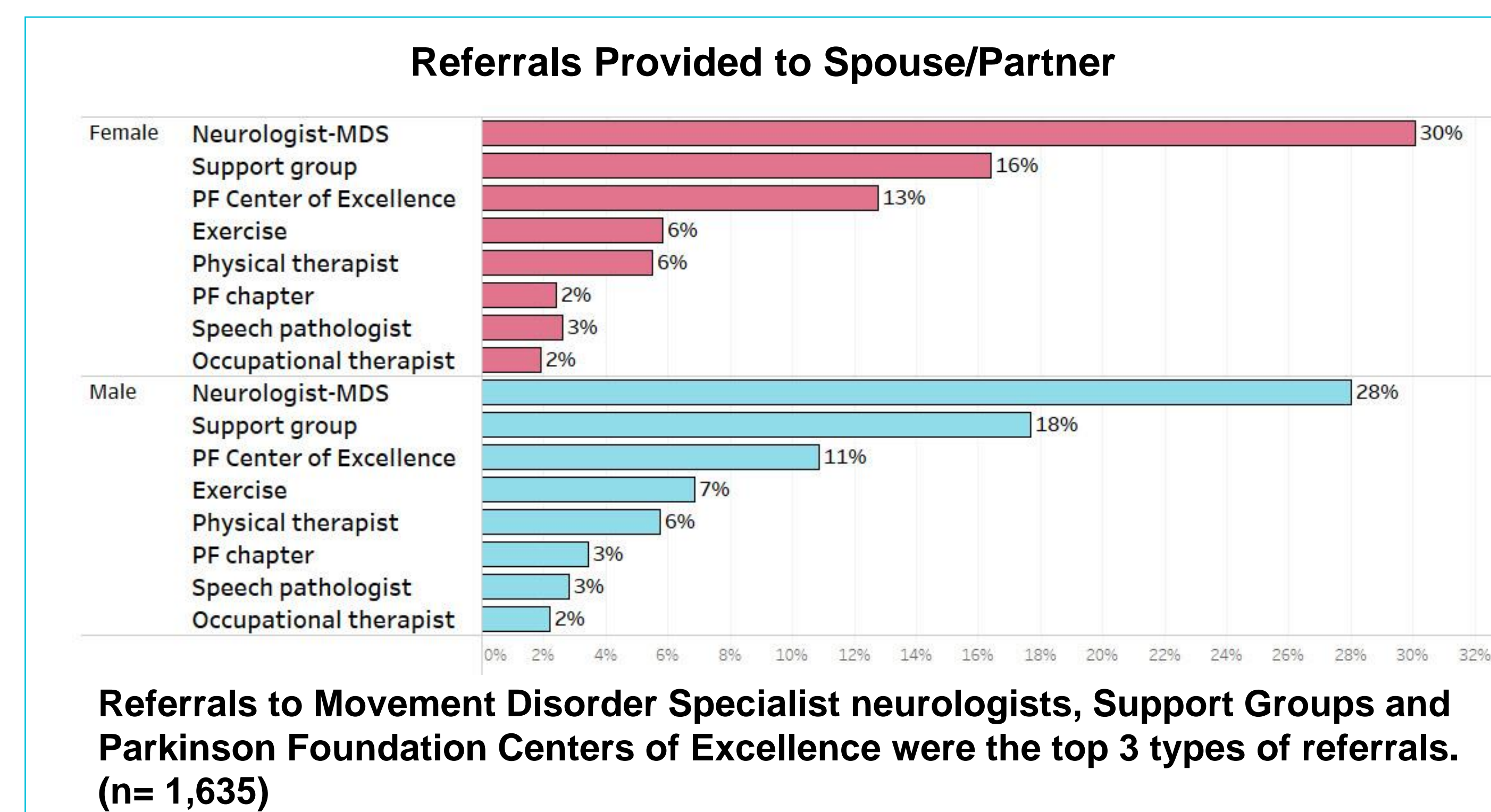
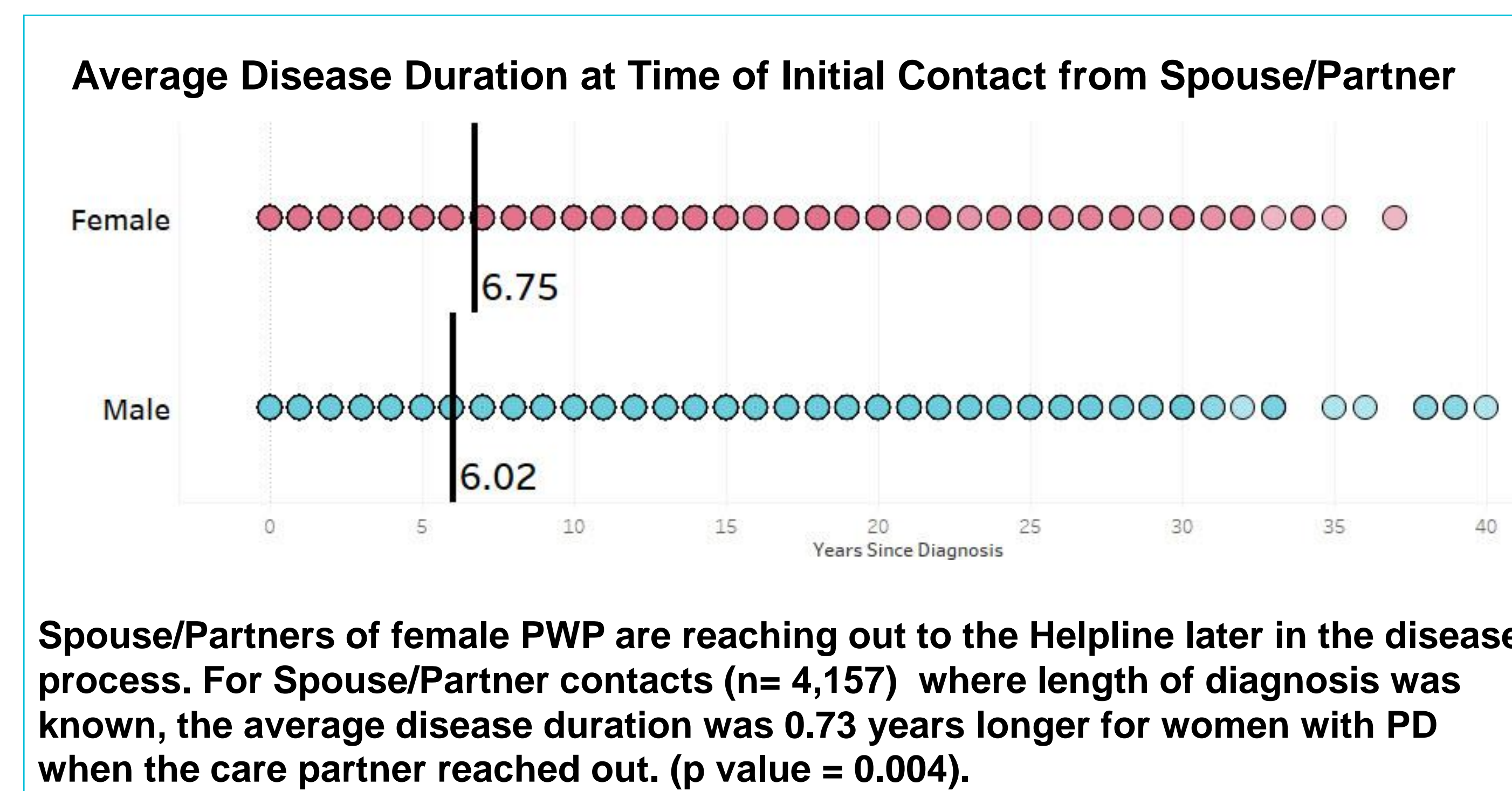
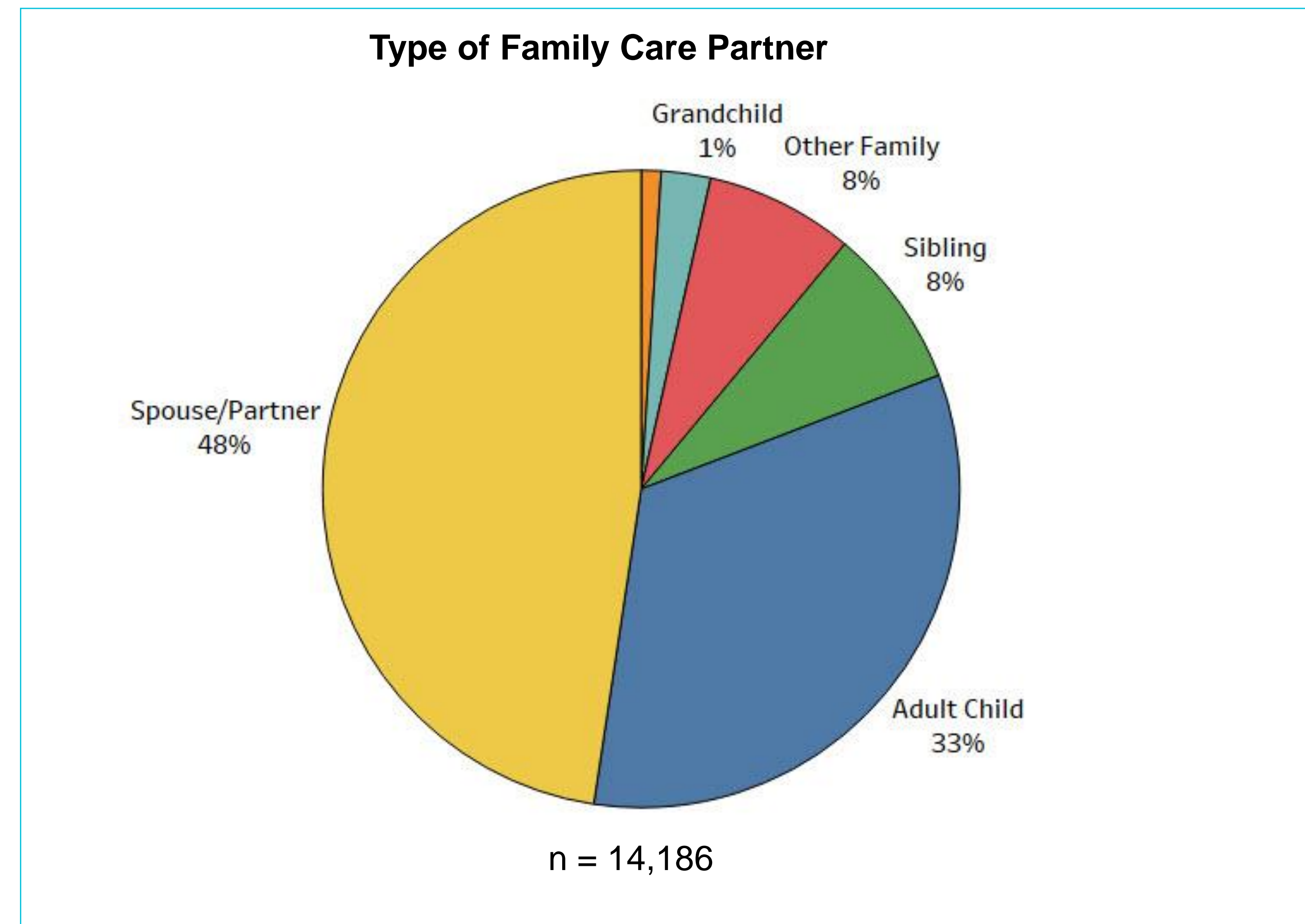
1-800-4PD-INFO(473-4636)
Helpline@parkinson.org

Communications with the Helpline range from straightforward requests for information and/or referrals to more complex and challenging situations, such as the need for guidance regarding difficult decisions about nursing home placement, hospice care and Parkinson's psychosis. Family members of persons with Parkinson's (PWP) – and especially the primary care partner – represent a significant percentage of people that contact the Helpline, along with individuals living with PD.

Methodology

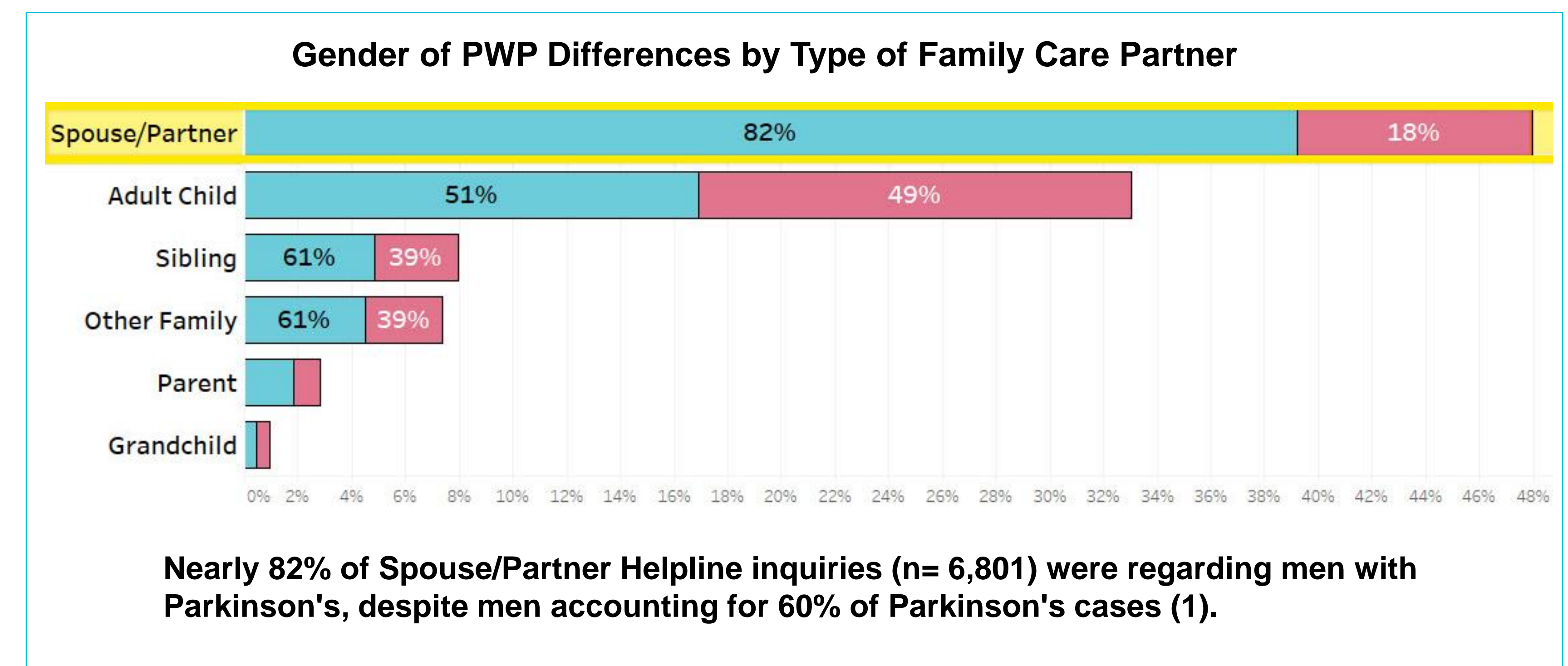
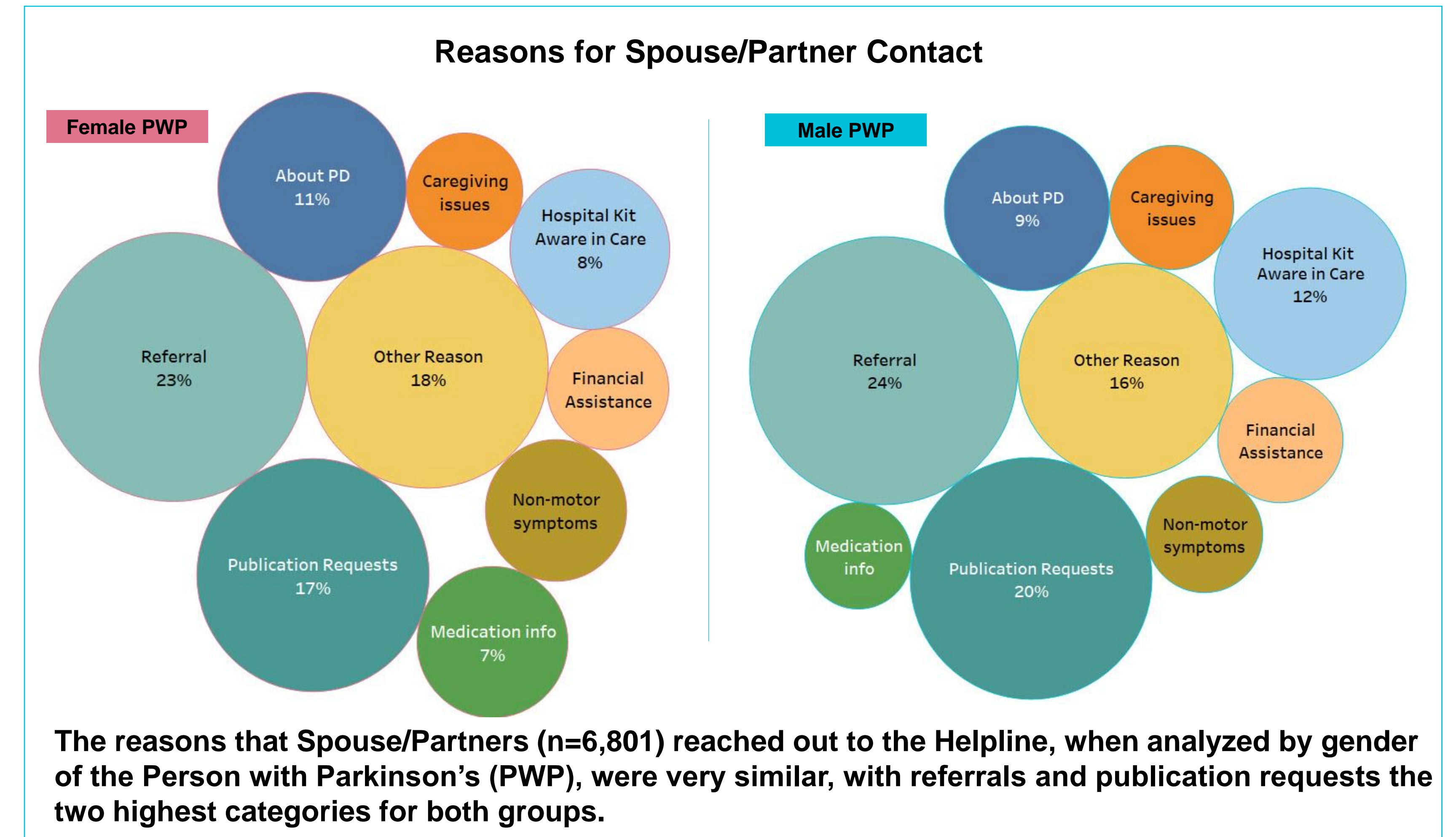
Cases from family members were reviewed and the five-year period from 2016 through 2021 was selected. There were 14,186 cases of first-time contact with the Helpline from any family member where the gender of the person with Parkinson's was known. Of the total cases, 6,801 (48%) were communication with the Spouse/Partner of the person with PD and 4,684 (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.

Results



References

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 3.Mott, J., Schmidt, B. & MacWilliams, B. (2019). Male caregivers: Shifting roles among family caregivers. (2019). *Clinical Journal of Oncology Nursing*, 23(1), E17- 24. <https://doi.org/10.1188/19.cjon.e17-e24>
 4.Lopez-Anuarbe, M. & Kohli, P. (2019). Understanding male Caregivers' emotional, financial, and physical burden in the United States. *Healthcare*, 7(2), 72. <https://www.mdpi.com/2227-9032/7/2/72>



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.