



# Does gender influence the types of questions asked by people living with Parkinson's?

Christiana Evers<sup>1</sup>, Linda Pituch<sup>1</sup>, Jill McClure<sup>1</sup>, Jeanne Kirby<sup>1</sup>, Casey Gallagher<sup>1</sup>, Nancy Ralph<sup>2</sup>

<sup>1</sup>Parkinson's Disease Foundation, a division of the Parkinson's Foundation, New York, NY USA <sup>2</sup>New York, NY USA

## Introduction

Parkinson's disease (PD) is a complex disease and people living with the disease and their families and care partners have a variety of needs over the course of their lifetime. Research shows that Parkinson's affects more men than women at approximately a 2:1 ratio. The Parkinson's Disease Foundation (PDF) offers a national, toll-free HelpLine which is available Monday through Friday 9:00 AM to 5:00 PM ET. PDF examined whether gender may play a role in who uses the HelpLine, how it is accessed and the topics discussed. This gender-specific data may help provide a better understanding of how to provide support, information and advocacy programs.

## Methods

- 22,521 individuals contacted the PDF HelpLine over the 66 month period between August 1, 2010 and January 1, 2016.
- PDF's Information Specialists recorded data from each call in a call database, without identifying information.
- Calls were analyzed according to gender, the caller's relationship to Parkinson's, topic(s) discussed, referral source and time from diagnosis.

## Results

- The PDF HelpLine is accessed by more women than men (63% versus 32%) [Figure 1: Number of Calls by Gender]. However, 76% of men had PD while only 49% of women had PD [Figure 2: Type of Caller].
- Care partners were the most common type of female caller [Figure 3: Gender Distribution for Calls from PWP vs. Care Partners] and more women callers raise the topic of care partnering concerns (8.5% of women versus 4.2% of men).
- Slightly more male callers discussed treatment or disease specific topics: motor symptoms (11.5% of men versus 10.1% of women) and non-motor symptoms (16.3% of men versus 5.2% of women). In addition, more men discussed specific medications (22% of men versus 19.1% of women) and more men requested doctor referrals (47% of men versus 42% of women).
- Financial assistance was discussed slightly more by women than men (5.7% of women versus 4.3% of men).
- 39% of women found the HelpLine online compared to 35% of men. 37% of men found the HelpLine from publications versus 32% of women.

Figure 1: Number of Calls by Gender

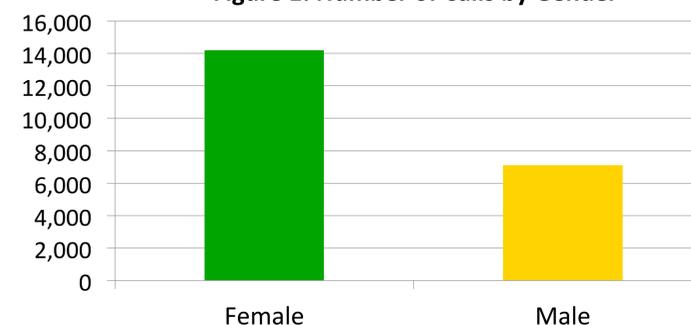


Figure 2: Type of Caller

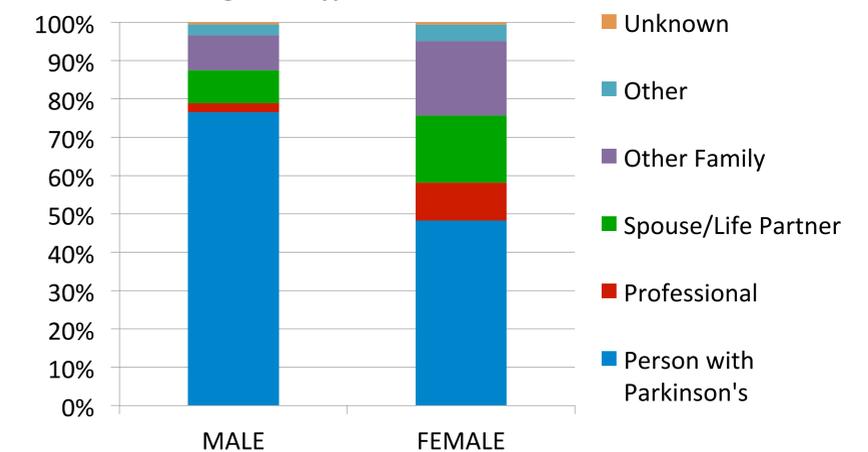
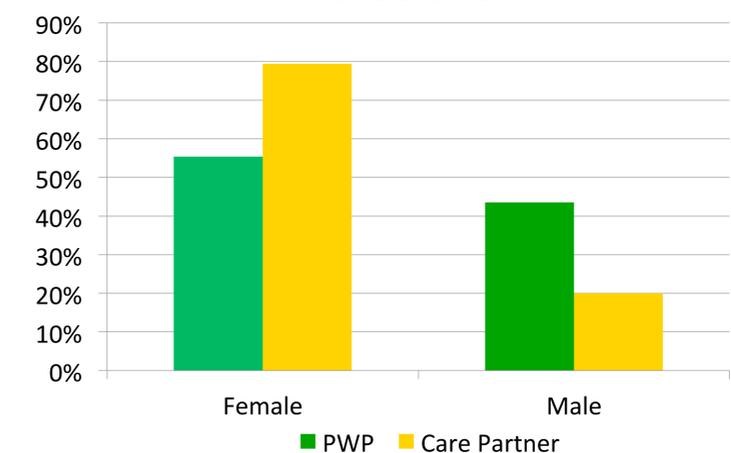


Figure 3: Gender Distribution for Calls from PWP vs. Care Partners



## Conclusions

- Gender appears to affect HelpLine use. It may also influence how people find assistance and the information they seek.
- Men and women use different sources for finding resources. Although the Internet is overall the most common referral source, the value of print materials remains for some subsets and our data shows this to be more true in men. Different communication channels must continue to be used to serve the larger PD community.
- The motivation for calls may vary based on gender as differences exist in whether a caller is calling about themselves or as a care partner.
- PDF's conclusions from this analysis may only be applicable to the limited group who contacts PDF and may not be representative of the larger PD community.