Care Partners in Parkinson’s: Who calls the Parkinson’s Foundation Helpline and Why?

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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.

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

Type of Family Care Partner

<table>
<thead>
<tr>
<th>Spouse/Partner</th>
<th>40%</th>
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<tbody>
<tr>
<td>Grandchild</td>
<td>8%</td>
</tr>
<tr>
<td>Adult Child</td>
<td>1%</td>
</tr>
<tr>
<td>Other Family</td>
<td>8%</td>
</tr>
<tr>
<td>Sibling</td>
<td>8%</td>
</tr>
<tr>
<td>Female</td>
<td>6.75</td>
</tr>
<tr>
<td>Male</td>
<td>6.02</td>
</tr>
</tbody>
</table>

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

Female

Male

Spouse/Partners of female PWP are reaching out to the Helpline later in the disease process. For Spouse/Partner contacts (n= 4,157) where length of diagnosis was known, the average disease duration was 0.73 years longer for women with PD when the care partner reached out. (p value = 0.004).

Reasons for Spouse/Partner Contact

The reasons that Spouse/Partners (n=6,801) reached out to the Helpline, when analyzed by gender of the Person with Parkinson’s (PWP), were very similar, with referrals and publication requests the two highest categories for both groups.

Gender of PWP Differences by Type of Family Care Partner

Nearly 82% of Spouse/Partner Helpline inquiries (n= 6,801) 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