Understanding the Needs and Concerns of Newly Diagnosed People with Parkinson’s disease (PD)

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Introduction

It is estimated that 60,000 individuals in the United States are diagnosed with Parkinson’s disease (PD) every year. This number and the number of people living with PD will increase substantially in the next 20 years due to the aging of the population. Despite these prominent numbers, there has been little research to date on the needs and priorities of people who are newly diagnosed with Parkinson’s (defined as diagnosed between 0-3 years) from the patient and care partner perspective. Identification of the needs and priorities of this group are critical to determining the best approach to improve disease management, yield better health outcomes and enhance quality of life.

Objective

The primary objective was to understand the needs and priorities of individuals who are newly diagnosed with Parkinson’s through an online survey. The patient and care partner reported results from the online survey were meant to aid in the development of resources specifically targeting the newly diagnosed to help assist this population and their care teams manage their disease and enhance their quality of life.

Methodology

An online survey was administered to people with Parkinson’s and care partners who have called the Parkinson Foundation Helpline in the last three years. Both quantitative and qualitative analyses were conducted on the responses. The quantitative analysis included cross-comparisons in age, gender, area of residence, years experiencing symptoms before diagnosis, and provision of educational materials from their diagnosing physician within six months of diagnosis. The thematic analysis from the qualitative data distilled and grouped complex, detailed, open-ended responses to determine: what is of top concern; what respondents wish they knew in the first three years (non-newly diagnosed only) (Figure 1); and what is most difficult about living with PD.

Results

The online survey resulted in a 21.8% response rate (n=1,124).

<table>
<thead>
<tr>
<th>Respondents (n=1,124)</th>
<th>People with PD</th>
<th>Care Partner</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respondents</td>
<td>42.8% (n=470)</td>
<td>34.2% (n=384)</td>
</tr>
<tr>
<td>Newly Diagnosed</td>
<td>40% (n=457)</td>
<td>45% (n=320)</td>
</tr>
<tr>
<td>Respondents</td>
<td>60% of people of PD were newly diagnosed</td>
<td>55% of care partners were newly diagnosed</td>
</tr>
</tbody>
</table>

Results uncovered that within the first six months of diagnosis, 42% of people with PD (n=311) and 45% (n=173) of care partners did not receive educational materials from their diagnosing physician (Figure 2). For those who did report receiving information, online resources and forums were cited as the top source of information among both people with Parkinson’s and care partners. This was followed by movement disorder specialists, general neurologists and the Parkinson Foundation. The primary concerns among respondents within the first three years of diagnosis were as follows: what the future holds (78.4%; n=884); disease progression rate (76.6%, n=892); and how to maximize quality of life (74.6%, n=838). Our thematic analysis found that 73% of people with PD and care partners consider symptom management to be the most difficult aspect of living with Parkinson’s; followed by 23% who consider barriers to quality of life (i.e., social issues, fear of the future) to be the most difficult.

Conclusion

Through the online survey administered to the Parkinson’s Foundation Helpline callers, we identified the top needs and priorities, gaps in access to and sources of information for newly diagnosed people with Parkinson’s. These findings have helped to inform the content and strategy of the Parkinson’s Foundation newly diagnosed campaign, the first national effort specifically targeting the needs and priorities for this population (launching October 2019).

The campaign includes both a content and distribution strategy based on survey results. Content includes a newly diagnosed resource kit comprised of targeted and actionable materials that focus on top concerns; an online community forum connecting the newly diagnosed with each other as well as national, regional and local information; and a dedicated section for the newly diagnosed on www.parkinson.org. These tailored tools and resources will be leveraged through a distribution strategy that includes leveraging current programming, existing clinical and non-clinical channels, and the creation of new partnerships. Analysis of the newly diagnosed campaign will determine the optimum content and distribution channels in efforts to determine the best approach to improve disease management, yield better health outcomes and enhance quality of life for the 60,000 people diagnosed with Parkinson’s each year.

Acknowledgements

Thank you to the Parkinson’s community for insights shared to further develop programs and resources to help people affected by Parkinson’s disease.