



The Parkinson's Disease Foundation Women and PD Initiative: identifying and addressing unmet needs

Megan Feeney, Susan Foster, Lori Katz, Robin Morgan, Karen Smith and Veronica Todaro
Parkinson's Disease Foundation, a division of the Parkinson's Foundation, New York, NY U.S.A.

Introduction

There are significant unanswered questions and unmet needs when it comes to women living with Parkinson's and their disease experience, participation in research, medical care and support services, yet there has been no coordinated national effort to identify and address these needs.

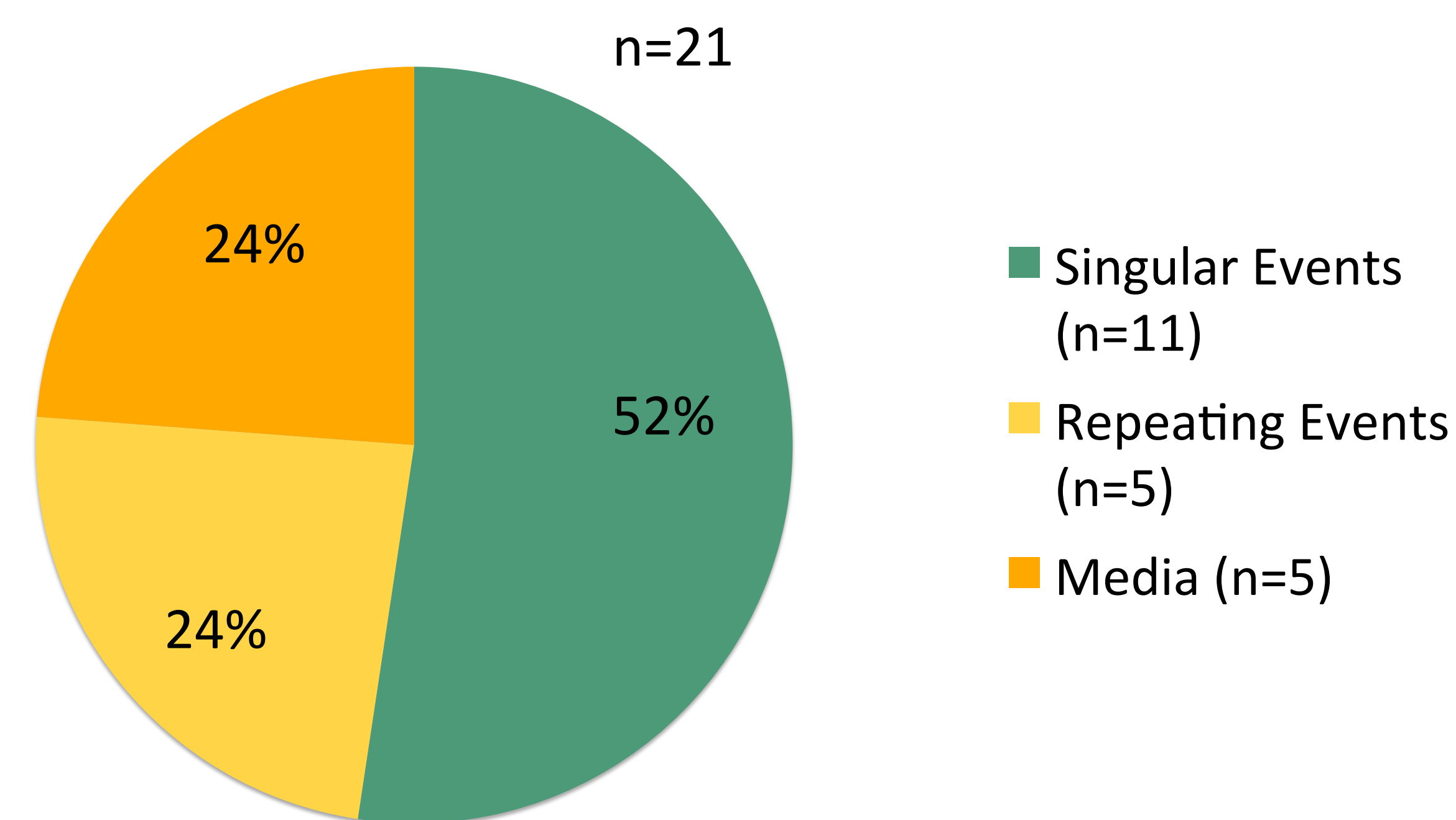
- Women with PD may be more prone to depression and medication-associated dyskinesia and tend to have more difficulty than men with daily activities, but show less cognitive impairment and are less likely to show behavioral problems (Fernandez et al. 2000).
- Women with PD are 22 percent less likely than men with PD to see a neurologist (Willis et al. 2011).
- Women are underrepresented in clinical trials.
- 72 percent of women living with PD say that there are issues specific to women with Parkinson's that they feel are not anywhere addressed (PDF Poll, 2015).

In September 2015, the Parkinson's Disease Foundation (PDF) held a three-day conference launching the PDF Women and PD Initiative. The conference brought together 26 women leaders to learn about gender differences in PD and to gain the tools and leadership skills necessary to advocate for the specific needs of women with Parkinson's disease in their communities. Women were charged with organizing at least one Women and PD event or a series of events in their communities to help other women live well and better manage their disease, and to be advocates for the needs of women with PD.

Methods

Recording outputs of the 26 women who participated in the September 2015 Women and PD Conference through tracking media, email communication, online portal exchanges, monthly group phone calls and individual phone calls.

Women and PD Initiative Awareness and Education Outputs



Results

Sixty-nine percent (18 of 26) of Women and PD Advocates have planned or completed their awareness and education commitment. Sixty-one percent (16 of 26) organized a singular or repeating event. Singular events included two state-wide conferences, three local conferences, two keynote speaking appearances, three break-out sessions, and a focus group for total of 11 events in 10 states. Repeating events included Women and PD support groups, a newly diagnosed, young onset Women and PD support group (with women video conferencing remotely) and a Women and PD book club. Fifteen percent (4 of 26) were featured in a media piece. These included *Neurology Now*, *EverydayHealth.com Women's Media Center* and *Self.com* reaching more than 8.5 million viewers (online and print) with a combined total of more than 1400 people sharing them on their online social media networks.

Conclusion

PDF Women and PD Advocates are engaged and prepared to initiate awareness and education programming on the local, state and national levels. Most women have launched events or a series of events in their own communities. Both the PDF Women and PD Initiative and the stories of individual Advocates have been picked up by the national media. This unexpected and welcome media response illustrates the lack of awareness and education about the unmet needs of women with PD and the potential impact of this program.

PDF Women and PD Advocates: Awareness and Education Commitment Completion

