

# A Pandemic Care Partner Summit: Online Program Helps Parkinson's Care Partners Take Positive Actions

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## Introduction

The Parkinson's Foundation Care Partner Summit | Cumbre Para Cuidadores was held virtually on May 16, 2020 in the height of the COVID-19 Pandemic. For the first time, this event was offered without an in-person element, redesigning its format over the course of eight weeks. Six months after the event, a survey was sent to all registrants of the program to assess the lasting impact of the program on the lives of participating care partners.

## Background

Respondents were asked when they watched the Summit (Live vs. recorded), what positive actions they have taken since watching (based on responses to the post-event evaluation question "After attending today's summit, what are your plans to change and implement lessons learned?"), and which of their loved one's PD symptoms has been most challenging for them (the care partner).

## Methods

1136 participants joined live while an additional 1692 pre-registered but did not attend day of. The combined 3190 registrants were sent a short survey via email in November.

## Results

47 participants responded, 36 of whom watched the summit live and did not review any of the recordings. 7 participants reported watching both live and recorded content and 4 reported only watching the recorded content. An additional 9 responses were excluded because respondents reported that they did not watch the summit live or recorded or did not report when they watched the summit.

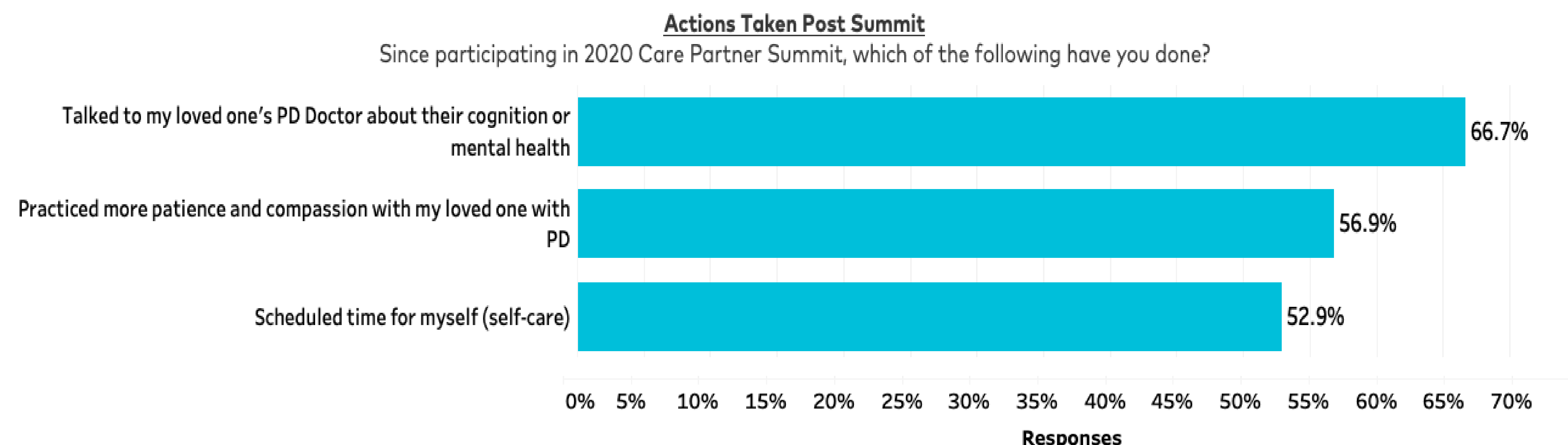
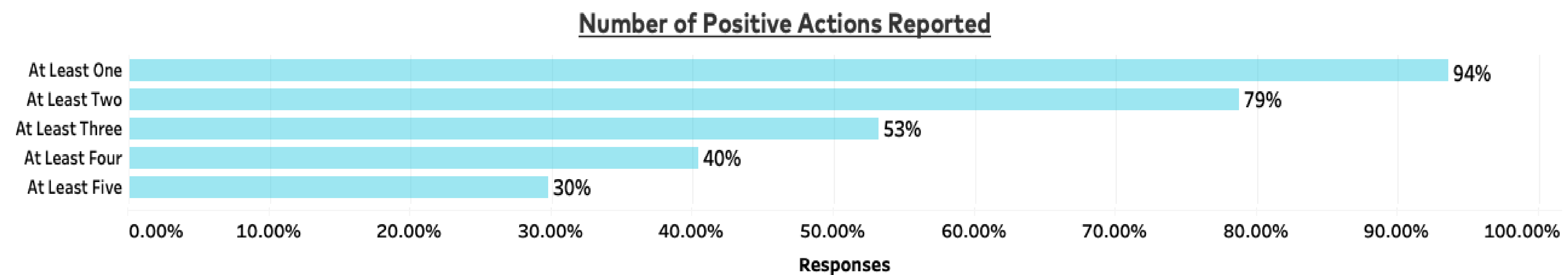
94% reported at least one positive action, 79% reported at least two, and 53% reported at least three. More than half of respondents reported talking to the PD doctor about cognition or mental health (67%), practicing more patience and compassion with their loved one (57%), and scheduling time for self-care (53%).

When asked about the most challenging symptom for the care partner, 17% reported cognitive changes, followed by Speech and Swallowing Problems at 16%. However, by grouping apathy, anxiety, and depression into "mental health" this becomes the third most challenging at 14%.

## Conclusions

While the survey response was small, we are encouraged by the impact reported by participants.

Further investigation is required into the long term impact of online psychoeducational programs directed towards those caring for loved ones with Parkinson's disease, and we hope to continue to assess how these types of programs can make life better for people with Parkinson's disease and their loved ones.



## Takeaways

### Most Challenging Symptom:

- 17% of respondents indicated that Cognitive Changes in their loved one with PD was the most difficult symptom to cope with as a care partner.
- This was followed by Speech and Swallowing Problems at 16% of responses.
- When Anxiety, Apathy and Depression are combined into the category of Mental Health, they also account for 16% of responses.

### Positive Actions:

- 66% of participants talked to their loved one's PD Doctor about their cognition or Mental Health
- 56% of respondents practiced more patience and compassion with their loved one with PD
- 52% of respondents scheduled time for self-care

## Most challenging symptom for Care Partner

