



PMD Alliance

Parkinson & Movement Disorder Alliance

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PARKINSON & MOVEMENT DISORDER ALLIANCE SURVEY

SELECTION OF DATA:

For Full Survey Results Contact PMD Alliance



OBJECTIVE & METHODOLOGY

- **Objective:** Raise awareness of non-movement symptoms, such as hallucinations and delusions, associated with Parkinson's disease (PD) among care partners and patients.
- **Strategy:** Partnered with PMDAlliance, based out of Arizona, and conducted a survey with their members to understand their perceptions and experiences with non-movement symptoms of PD. Results of the survey will be shared with PMDAlliance members and leveraged across media to drive awareness of non-movement symptoms.
- **Methodology:** The survey was conducted using Survey Monkey, an online survey platform. Respondents mainly consisted of PD patients and care partners of persons with PD, who either did OR did not suffer from movement related symptoms. A separate set of questions was asked to respondents who themselves or had a loved one who experienced non-movement symptoms vs. those who did not experience non movement symptoms.
- **Target Audience:** The survey was fielded only to PMDAlliance members which included patients, care partners and others.
- **Sample Size:** A total of 700* respondents took the survey. Not all respondents completed the entire questionnaire, hence sample size may vary for each question.
- **Field dates:** March 19, 2018 – March 31, 2018

*PLEASE NOTE: This includes partially completed responses.

ALLISON: We did not filter out the partially completed surveys as PMDAlliance was keen to have its members' voice heard.

SUMMARY OF FINDINGS:

Non-movement symptoms of Parkinson Disease (PD)

❖ *Parkinson's Disease:*

- ❑ 3 of 4 respondents, across patients and care partners, felt that there was very little to some understanding of the impact of Parkinson's Disease (PD) on daily living among family, friends and acquaintances.
- ❑ Movement disorder specialists (70%) played a dominant role in the management of PD, followed by neurologists (39%).
- ❑ There was interest in learning more about non-movement symptoms of PD, particularly cognitive challenges and sleep problems.
 - Interest among a smaller group of respondents on topics like hallucinations (36%) and delusions (28%)

❖ *Non-Movement Disorders of Parkinson's Disease:*

- ❑ Majority of the respondents (90%) reported experiencing non-movement symptoms (NMS) of PD.
 - A significantly higher percentage of care partners (97%) reported loved ones experiencing NMS compared to PD patients (80%) themselves.
- ❑ 53% respondents who experienced NMS themselves or had a loved one who did, reported an onset of non-movement symptoms within the first 3 years and 72% within the first 5 years, post-diagnosis of PD.
- ❑ Sleep problems, cognitive challenges, anxiety and depression were the top issues reported by PD patients/ care partners with loved ones, who experienced NMS of PD.
 - Care partners with loved ones with NMS of PD reported significantly higher instances of cognitive challenges, anxiety, depression, hallucinations and delusions than PD patients themselves.

SUMMARY OF FINDINGS:

Impact of non-movement symptoms of PD

- ❑ **More than half the respondents who experienced NMS themselves or had a loved one who did, reported a high negative impact of NMS on sleeping (60%), planning for future events (55%) and partner intimacy (53%).**
- ❑ **Nearly half the respondents who experienced NMS themselves or had a loved one who did, rated them as more to much more challenging to live with than movement symptoms.**
 - Significantly more care partners (58%) than patients (32%) who experienced NMS, rated NMS more to much more challenging than movement symptoms of PD.
 - Significantly more patients (60%) than care partners (37%) who experienced NMS, rated NMS less or as challenging as movement symptoms of PD.
- ❑ **Nearly half the respondents who experienced NMS themselves or had a loved one who did, felt that NMS had a high negative impact on quality of life.**
 - Significantly more care partners (66%) than patients (33%) who experienced NMS, rated a higher negative impact of NMS on quality of life.
 - Significantly more patients (64%) who experienced NMS than care partners (33%), rated very little to some negative impact of NMS on quality of life.
- ❑ **Respondents who experienced NMS themselves or had a loved one who did, wished people knew more about the PD symptoms (latent and overt) and the life changing impact of the disease [OPEN ENDED Q].**
 - A higher proportion of care partners whose loved ones experienced NMS of PD than patients, wished people knew more about the latent symptoms and the life changing impact of PD (difference between groups was not statistically significant).
- ❑ **Respondents who experienced NMS themselves or had a loved one who did, wished friends (55%), adult children (53%) and other immediate family like parents and siblings (41%) knew about their experience.**
 - Significantly more patients (44%) than care partners (17%) wished their spouse/partner knew about their experience.
 - Significantly more care partners (61%) than patients (44%) wished their friends knew about their experience.

SUMMARY OF FINDINGS:

Insights from respondents with loved one haven't experienced non-movement symptoms of PD

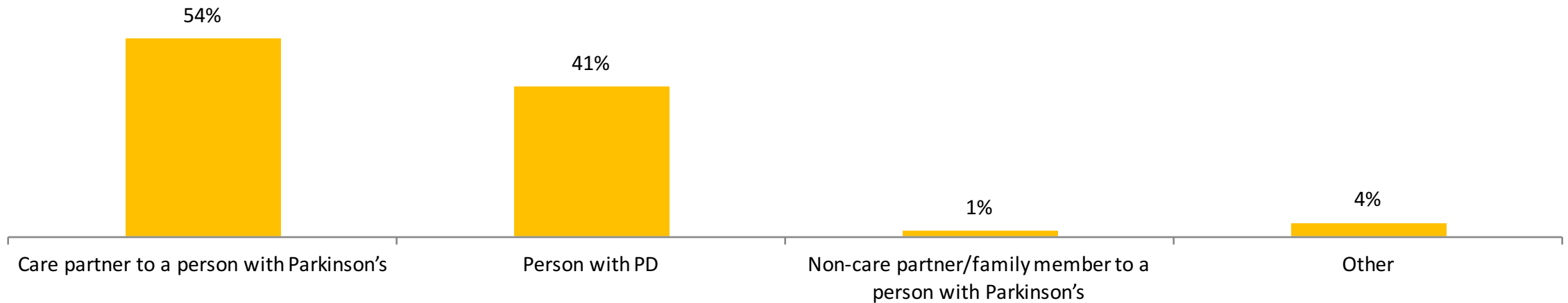
❖ *PD patients and care partners with loved ones who did not experience non-movement symptoms:*

- ❑ Nearly half of the respondents who did not experience NMS themselves or had a loved one who didn't, were educated about NMS by their movement disorder specialist or neurologist.
- ❑ 46% respondents who did not experience NMS themselves or had a loved one who didn't, felt they should be informed about NMS at the very beginning.
 - Care partners whose loved ones have not experienced NMS were either not sure (33%) or preferred to wait (34%) to learn more about NMS of PD.
- ❑ 13% respondents who did not experience NMS themselves or had a loved one who didn't, wished to know specifically about non-motor symptoms.

DETAILED ANALYSIS

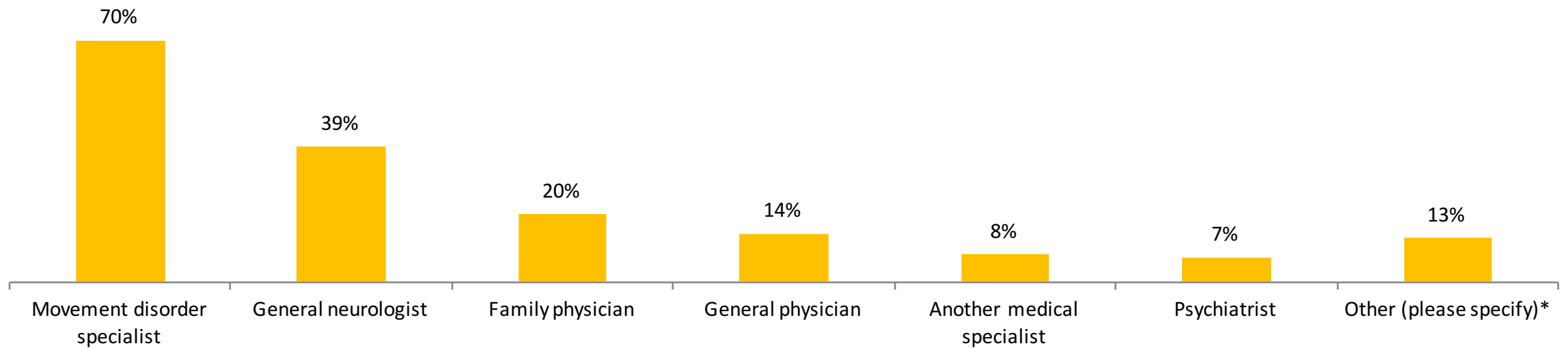
Survey respondents consisted of a good mix of care partners and PwP

Breakout of Respondents
n=700



Movement Disorder Specialists played a dominant role in the management of PD followed by Neurologists

Healthcare Provider(s) Seen for Parkinson's Disease
n=656



*Other specified responses included therapists, neurologists, acupuncturists
Q2. Who do you or your loved one see about Parkinson's? Please select all that apply.

Majority of respondents and their loved ones reported non-movement symptoms

PD Patient/Loved One Experienced Non-Movement Symptoms

n=584

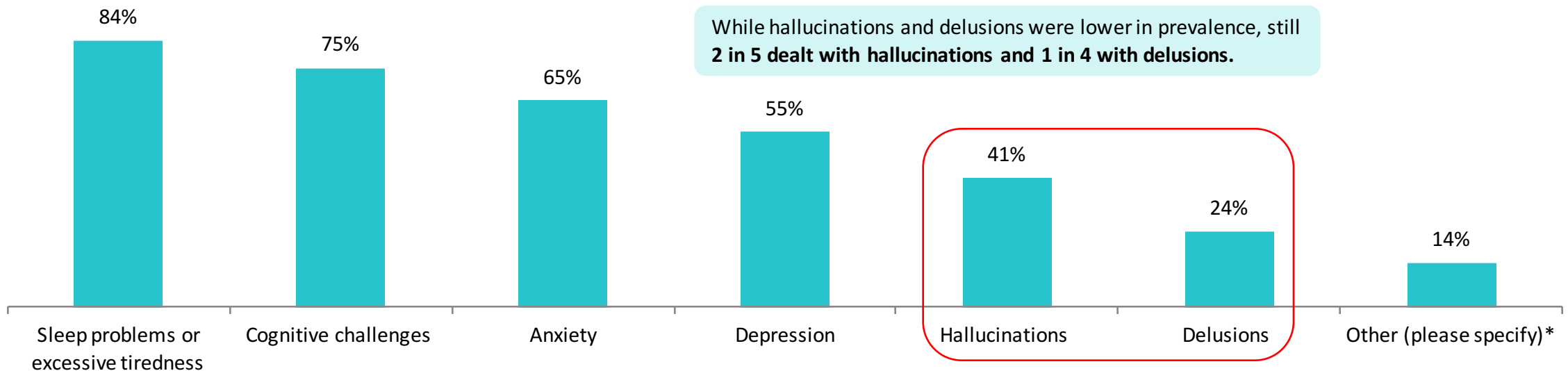


PD PATIENTS/LOVED ONES WHO EXPERIENCED NON-MOVEMENT SYMPTOMS

Sleep problems, cognitive challenges, anxiety and depression were top issues

Non-Movement Symptoms Experienced by PD Patient/Loved One

■ PD Patient/Loved one who Experienced Non-Movement Symptoms (n=581)



*Other specified responses include constipation, apathy, nightmares, anger, and mood swings.

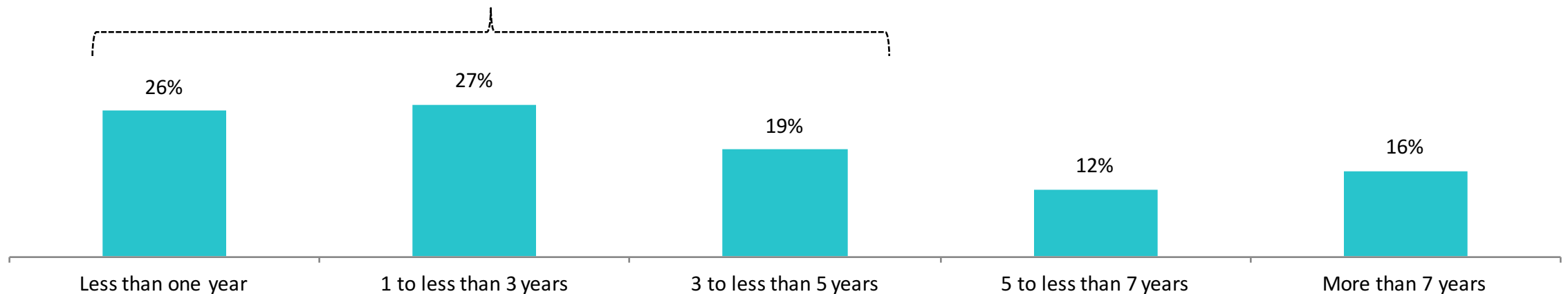
Q4. Which of the following non-movement related symptoms have you or your loved one with Parkinson's ever experienced? Please select all that apply.

53% of the respondents reported an onset of non-movement symptoms within the first 3 years post-diagnosis of PD

Number of Years After Diagnosis that PD Patient/Loved One Experienced Non-Movement Symptoms

■ PD Patient/Loved one who Experienced Non-Movement Symptoms (n=579)

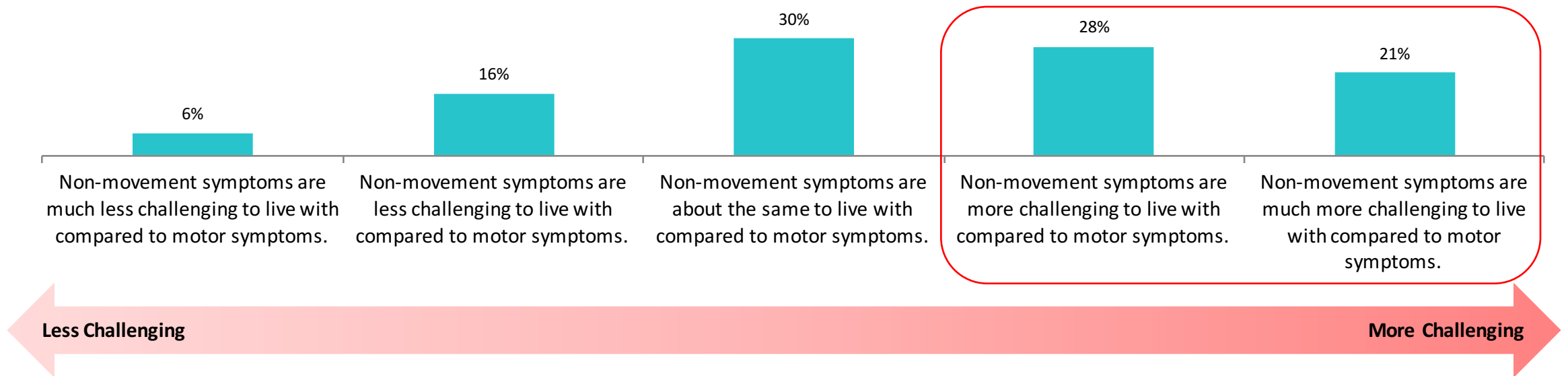
72% experienced non-movement symptoms within the first 5 years post diagnosis of PD.



Nearly half felt non-movement symptoms were more/much more challenging to live with than movement symptoms

How Challenging Is It for PD Patient/Loved One Living With Non-Movement Symptoms

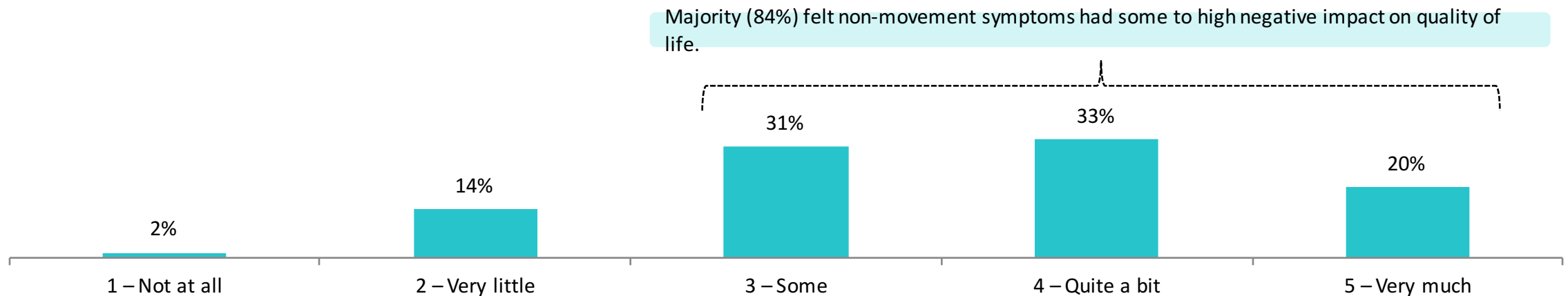
■ PD Patient/Loved one who Experienced Non-Movement Symptoms (n=573)



About half felt non-movement symptoms had a high negative impact on the quality of life

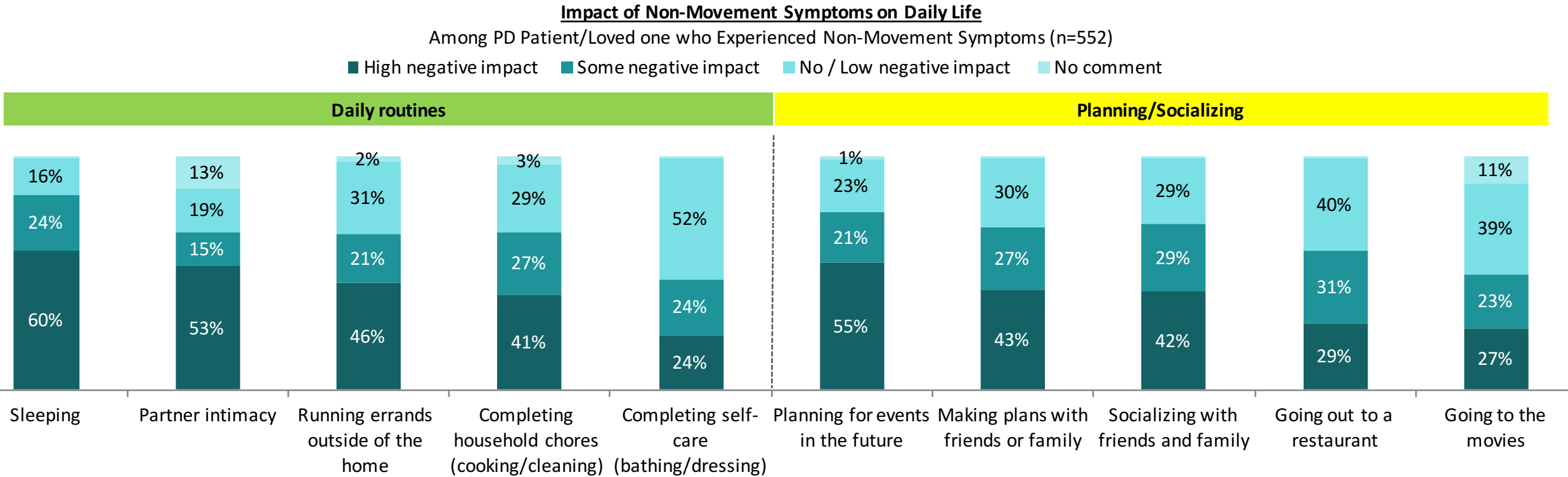
How Much Do Non-Movement Symptoms Impact/Disrupt the Quality of Life

■ PD Patient/Loved one who Experienced Non-Movement Symptoms (n=570)



Sleeping, planning for future events and partner intimacy had the highest negative impact

Of the activities listed, only 24% respondents rated non-movement symptoms as having a high negative impact on completing self-care.



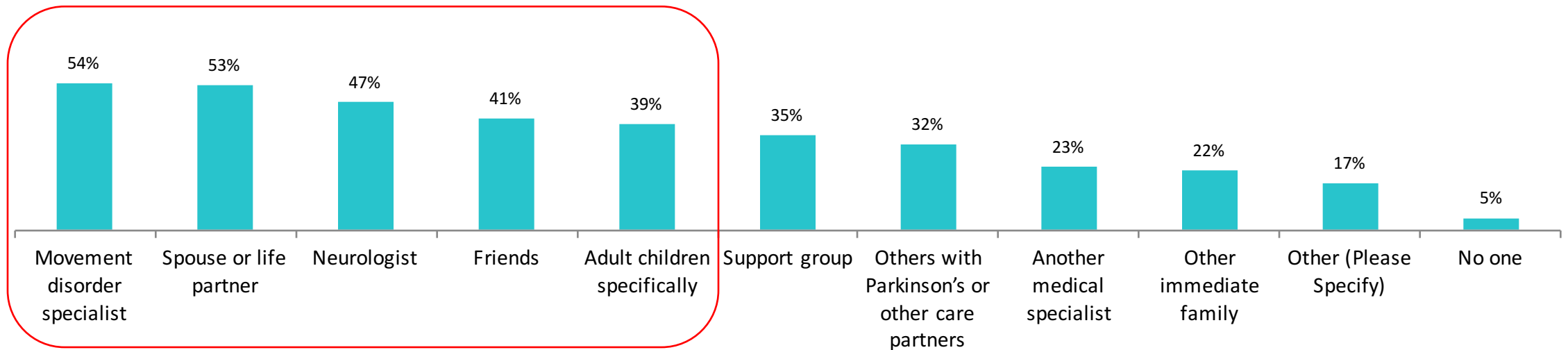
Q8. On a scale of 1-5, fill out the below table to indicate how the onset of non-movement symptoms (e.g., hallucinations, delusions, sleep, cognitive problems, anxiety, depression) associated with Parkinson's disease impact or disrupt activities in you or your loved one's daily life. Please select one response in each row.

Respondents primarily talked to HCP's, immediate family (spouse, partner, adult children) and friends about non-movement symptoms

10% respondents listed Facebook group Parkinson's Better Half among "other" options.

Who Do You Discuss Non-Movement Symptoms With

■ PD Patient/Loved one who Experienced Non-Movement Symptoms (n=550)



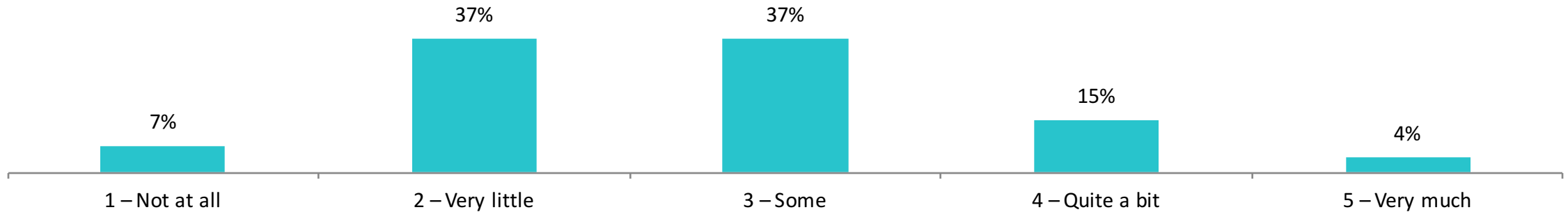
*Other specified responses include neuropsychologist, Parkinson's Better Half (Facebook group), acupuncturist, physical therapist for PD, gerontologist, family doctor, hospice, naturopathic doctor

Q9. Who did you talk to about non-movement symptoms (e.g., hallucinations, delusions, sleep, cognitive problems, anxiety, depression) related to Parkinson's disease and their impact on daily life? Please select all that apply.

74% of the respondents felt there was very little to some understanding of the impact of pd on daily living among family, friends and acquaintances

How Much Do Friends/Family Understand the Impact of Parkinson's Disease on Daily Living

■ PD Patient/Loved one who Experienced Non-Movement Symptoms (n=545)



RESPONDENTS wished people knew more about the symptoms of pd (latent/overt) and its life changing impact

"The variability in symptoms, and that it has **non-motor symptoms that are not always visible to others.**"

Care Partner

"I wish they knew the hard work we each do **everyday to just get out of bed.** I'm tired of people saying, "just do this or just do that". They have **no idea the effort it takes.**"

Patient

It is very difficult living with a person with Parkinson's with **non-motor symptoms because you never know what is going to happen next.**"

Care Partner

"I can fall on a level surface and wife gets upset with me, and it takes me several minutes to get myself up. its like **my muscles forget how to function.**"

Patient

"That the **non-motor symptoms are just as debilitating or even more so than the motor symptoms.** That Parkinson's can be a very isolating disease."

Care Partner

"A better understanding of all the symptoms of the disease and the huge fluctuations from hour to hour, day to day, month to month."

Care Partner

**Latent symptoms include cognitive changes, personality changes, lack of interest/apathetic, and general references to invisible symptoms.

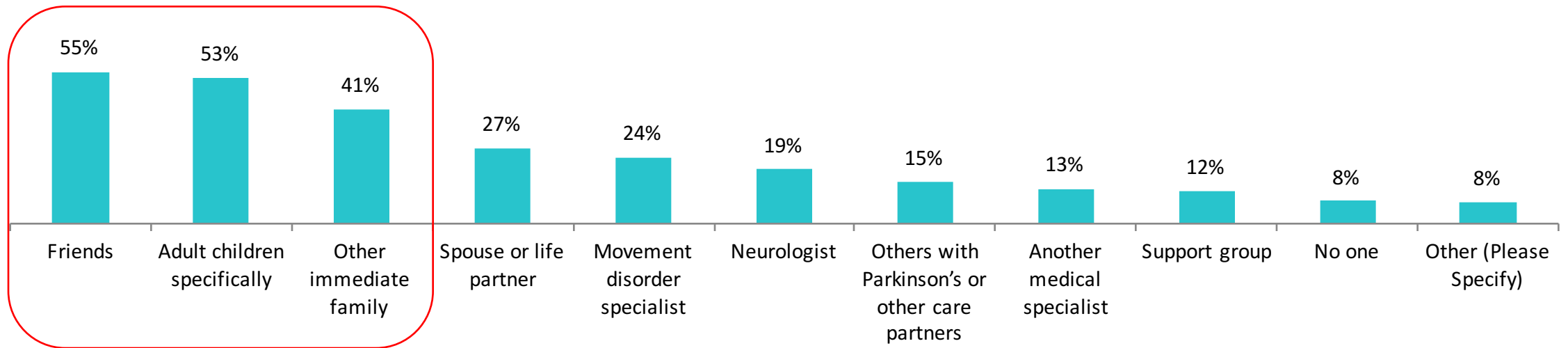
##Overt symptoms include tremors, exhaustion, gastro/heart issues, lack of energy, and slowed speech.

Q11. What, if anything, do you wish people knew about your experience with Parkinson's/being a care partner for someone with Parkinson's?

Respondents wished friends, adults children and other immediate family members knew more about their experience

Who Do You Wish Knew About Your Experience With PD/Being a Care Partner for Someone With PD

■ PD Patient/Loved one who Experienced Non-Movement Symptoms (n=530)



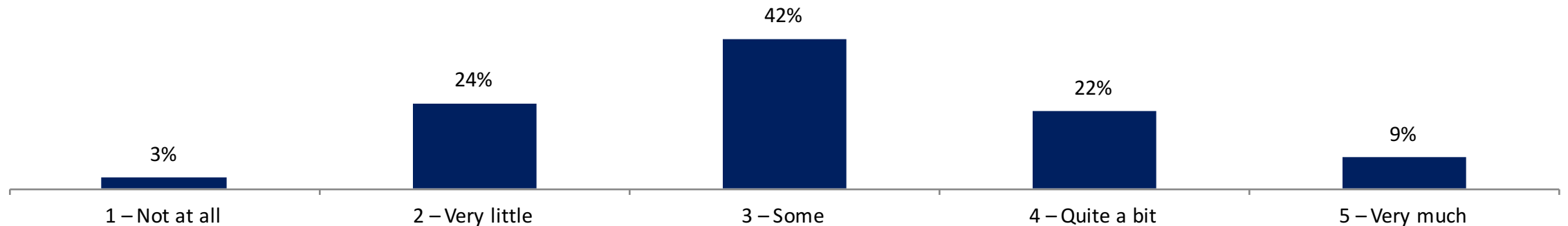
PwP/ONES WHO DID NOT
EXPERIENCE NON-MOVEMENT
SYMPTOMS

Two-thirds felt there was very little to some understanding of the impact of PD on daily living among family and friends

How Much Family/Friends Understand Impact of PD on Daily Living

■ PD Patients/Loved Ones who did NOT Experience Non-Movement Symptoms (n=69)

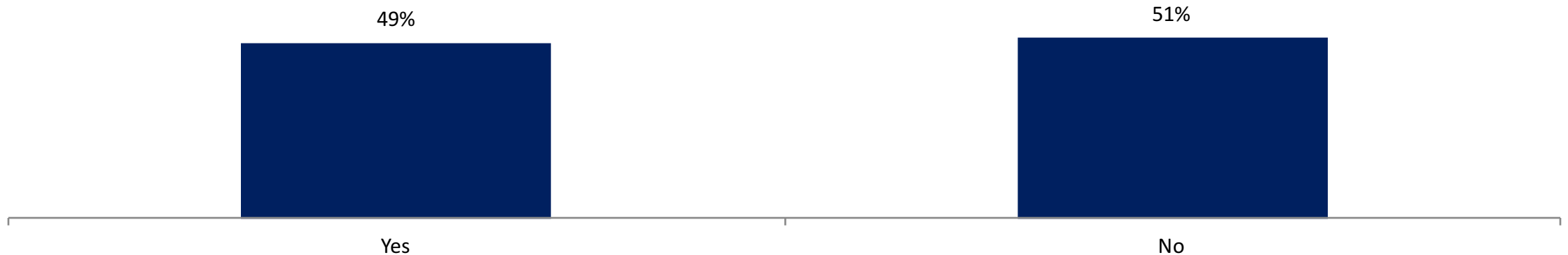
Findings are consistent across patient and their care partners who have experienced both movement and non-movement symptoms.



Nearly half the respondents were educated about non-movement symptoms by their Neurologist/Movement Disorder Specialist

Did the Neurologist/Movement Disorder Specialist Educate You/Loved One on Non-Movement Symptoms

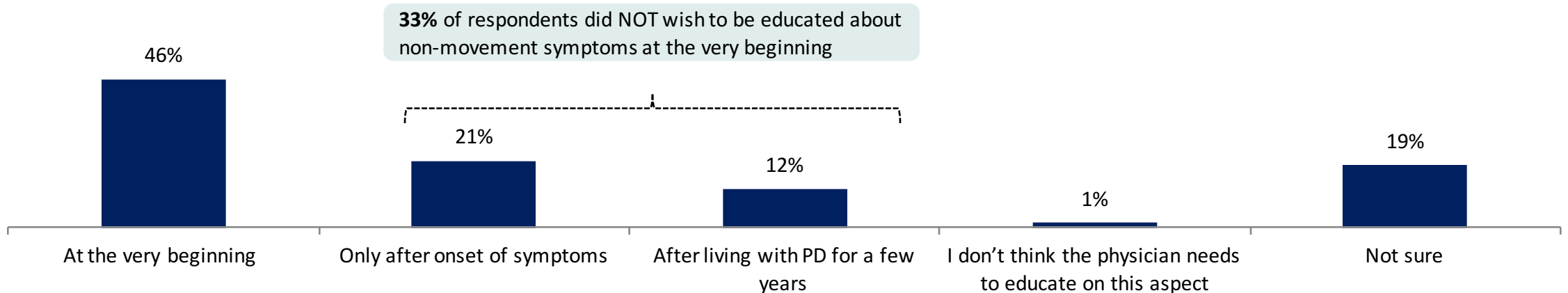
■ PD Patients/Loved Ones who did NOT Experience Non-Movement Symptoms (n=67)



46% of the respondents felt they should be informed about non-movement symptoms at the very beginning

When Should Physician Provide More Information About Non-Movement Symptoms

■ PD Patients/Loved Ones who did NOT Experience Non-Movement Symptoms (n=67)

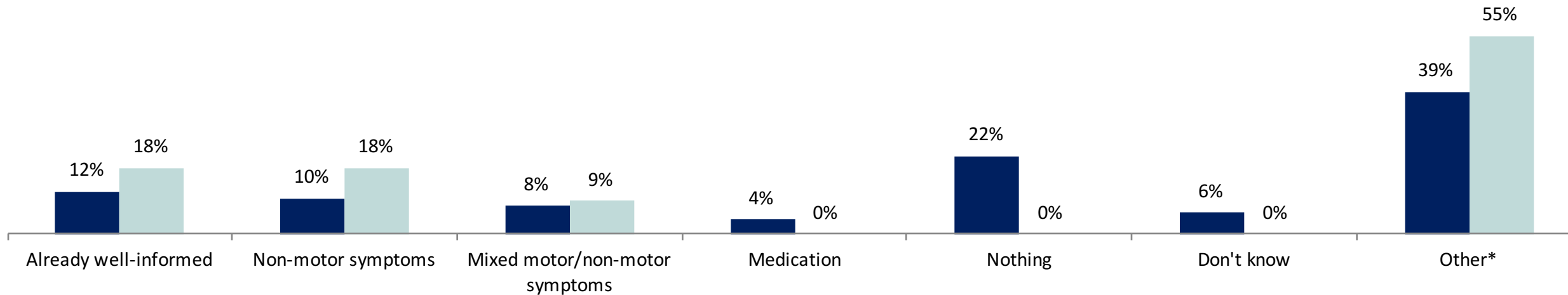


Both PwP and Care Partners knew about non-motor and mixed motor/non-motor PD symptoms

Information the PD Community Wish to be Informed Sooner (OPEN ENDS)

■ PD Patients who did NOT Experience Non-Movement Symptoms (n=51)

■ Care Partners/Loved ones who did NOT Experience Non-Movement Symptoms (n=11*)



*Other specified responses primarily included no comment or N/A.

Q16. What, if anything, do you wish your physician would have told you sooner about non-movement symptoms (e.g., hallucinations, delusions, sleep, cognitive problems, anxiety, depression) of Parkinson's disease?

*Low base sizes, please consider directional

The top 2 non-movement symptoms that respondents wished to learn more about were cognitive challenges and sleep problems

Which Non-Movement Symptoms you Would Like to Learn About
n=585

