

*PARTNERSHIP.  
OUTCOMES.  
IMPACT.*

# PARKINSON & MOVEMENT DISORDER ALLIANCE SURVEY



[WWW.PMDALLIANCE.ORG](http://WWW.PMDALLIANCE.ORG)

# 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 PMDAAlliance, 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 PMDAAlliance 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 PMDAAlliance 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.

# SUMMARY OF FINDINGS: NON-MOVEMENT SYMPTOMS OF PARKINSON'S DISEASE

## ❖ ***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 WHO/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.**

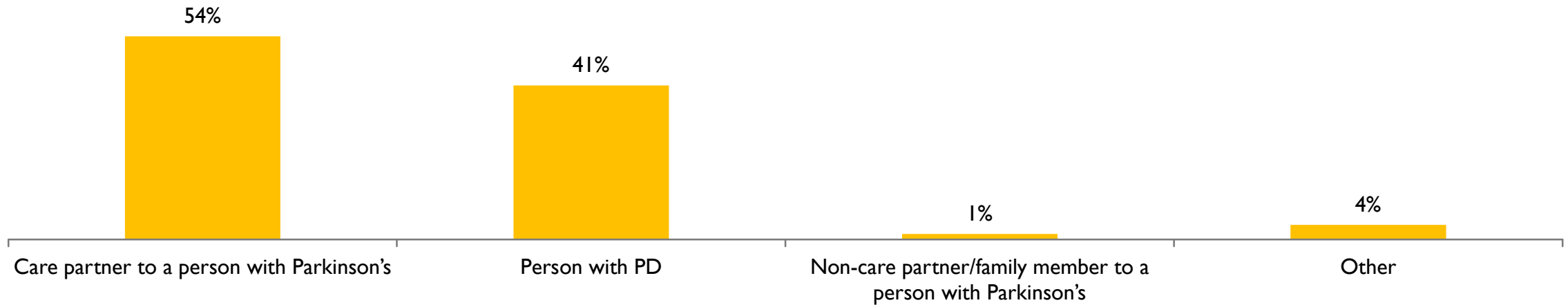


# DETAILED ANALYSIS



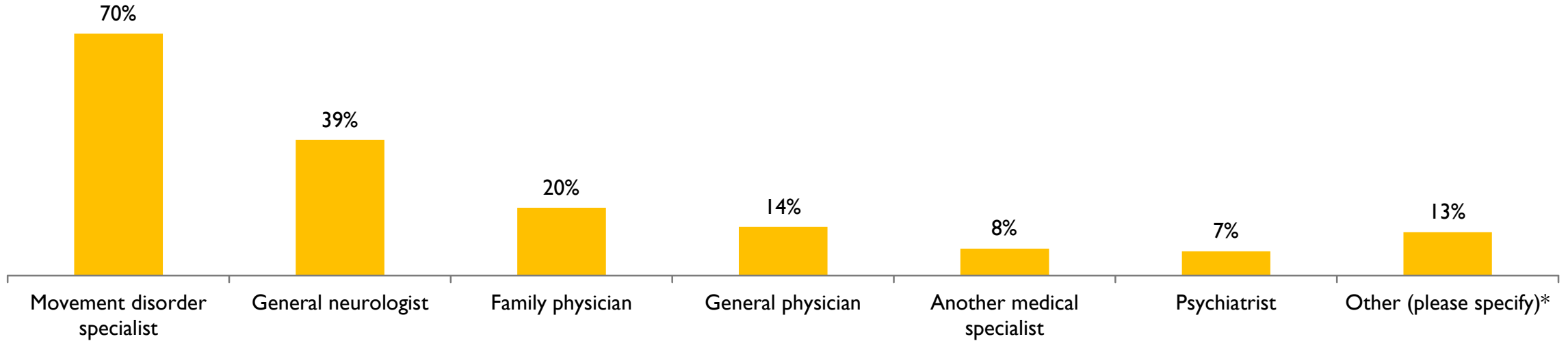
# SURVEY RESPONDENTS CONSISTED OF A GOOD MIX OF CARE PARTNERS AND PD PATIENTS

**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



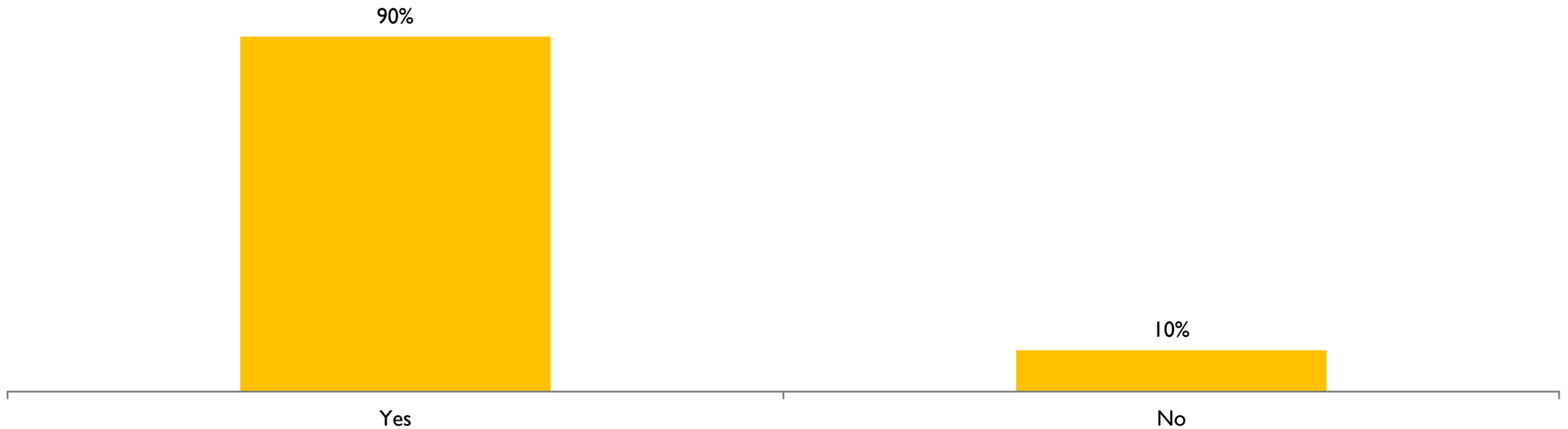
\*Other specified responses included therapists, neurologists, acupuncturists

**Q2. Who do you or your loved one see about Parkinson's? Please select all that apply.**



# MAJORITY OF RESPONDENTS/THEIR LOVED ONES EXPERIENCED NON-MOVEMENT SYMPTOMS

PD Patient/Loved One Experienced Non-Movement Symptoms  
n=584



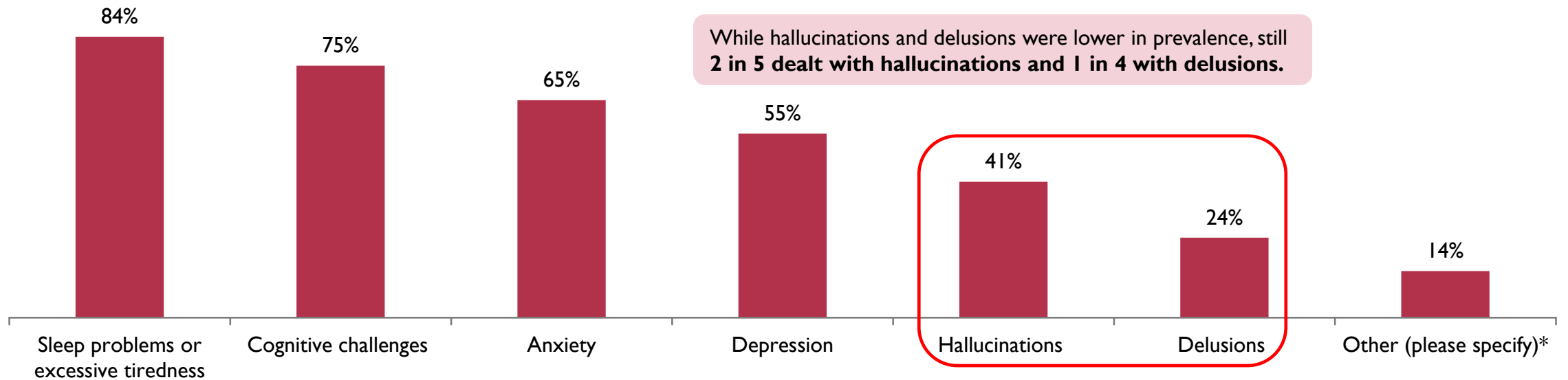


# PD PATIENTS/LOVED ONES WHO EXPERIENCED NON-MOVEMENT SYMPTOMS

# 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.

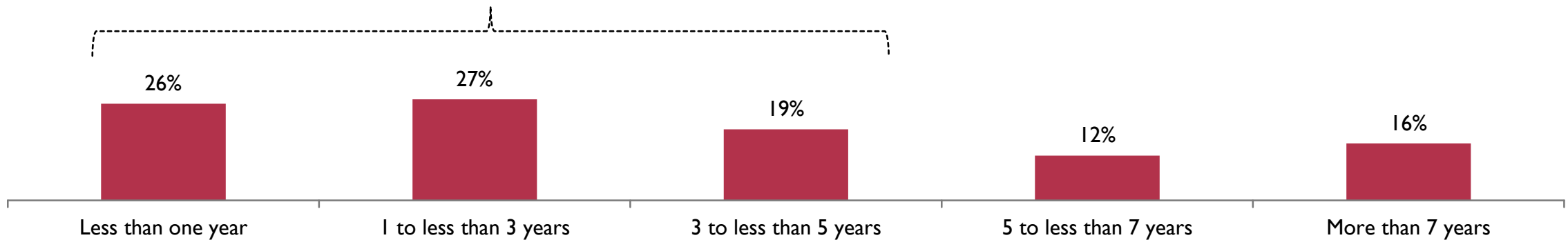
**Q4. Which of the following non-movement related symptoms have you or your loved one with Parkinson's ever experienced? Please select all that apply.**

# 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)

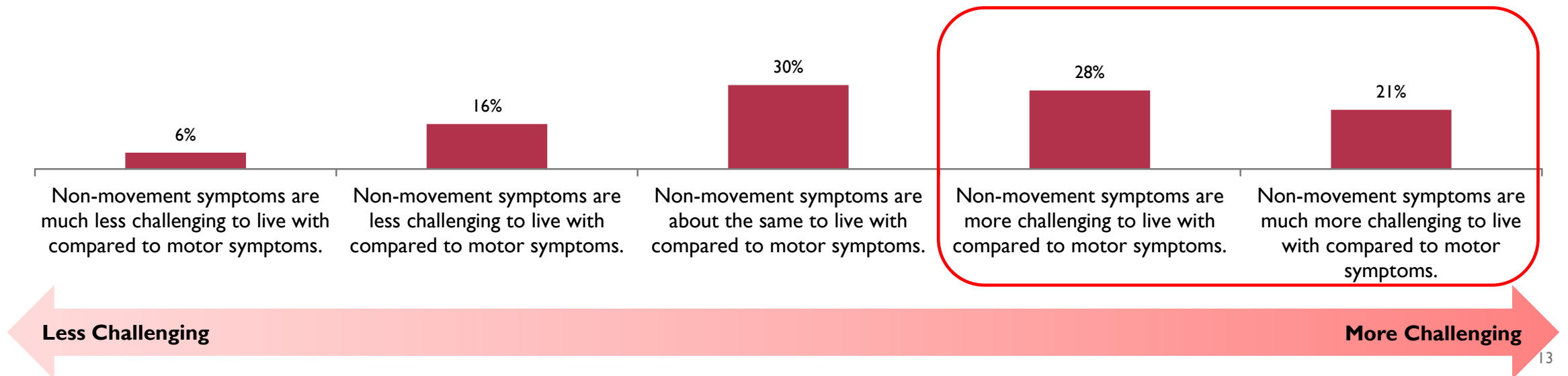
72% experienced non-movement symptoms **within the first 5 years** post diagnosis of PD.



# 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

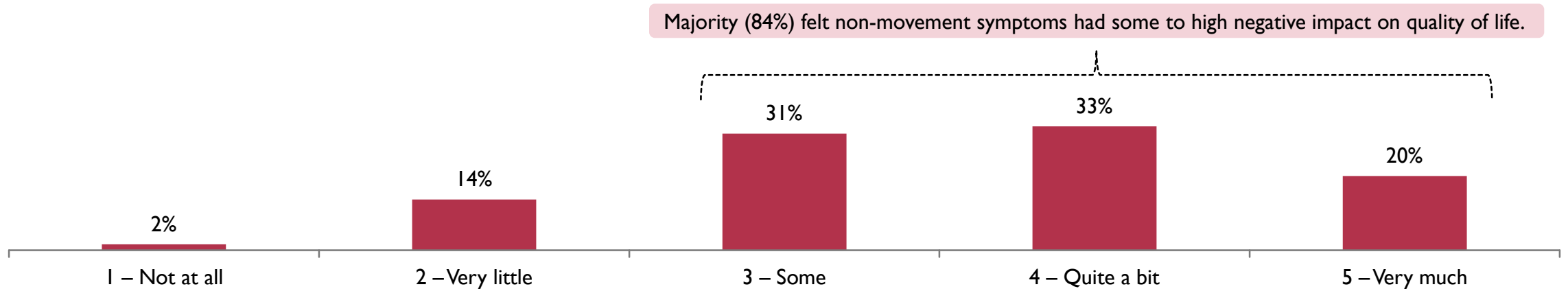
■ PD Patient/Loved one who Experienced Non-Movement Symptoms (n=573)



# 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.

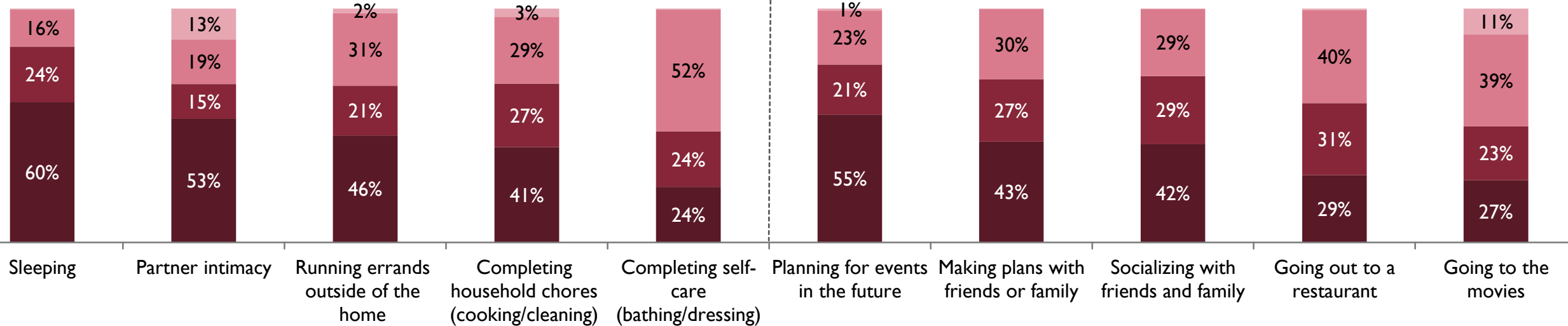
## Impact of Non-Movement Symptoms on Daily Life

Among PD Patient/Loved one who Experienced Non-Movement Symptoms (n=552)

■ High negative impact ■ Some negative impact ■ No / Low negative impact ■ No comment

### Daily routines

### Planning/Socializing



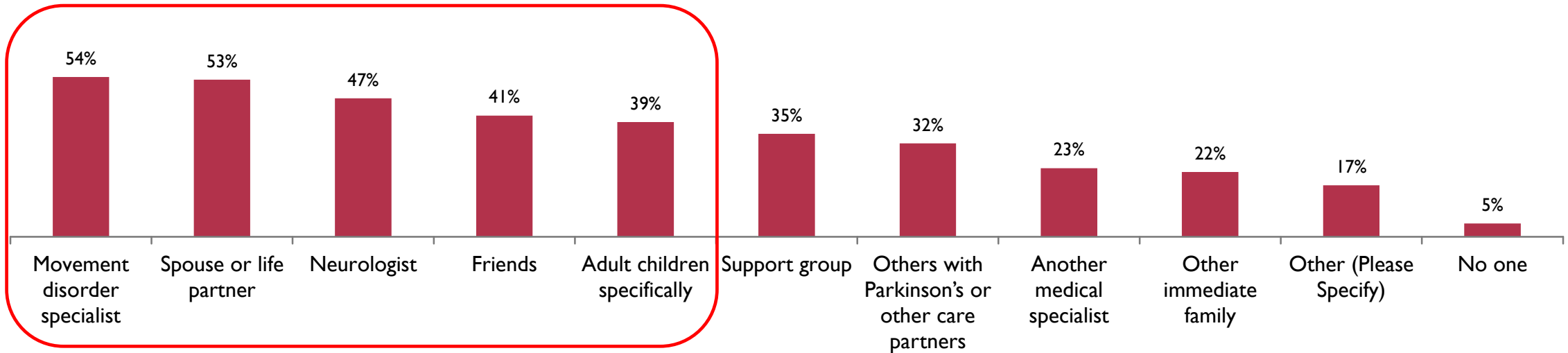
Q8. On a scale of 1-5, fill out the below table to indicate how the onset of non-movement symptoms (e.g., hallucinations, delusions, sleep, cognitive problems, anxiety, depression) associated with Parkinson's disease impact or disrupt activities in you or your loved one's daily life. Please select one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

# RESPONDENTS PRIMARILY TALKED TO HCPS, 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

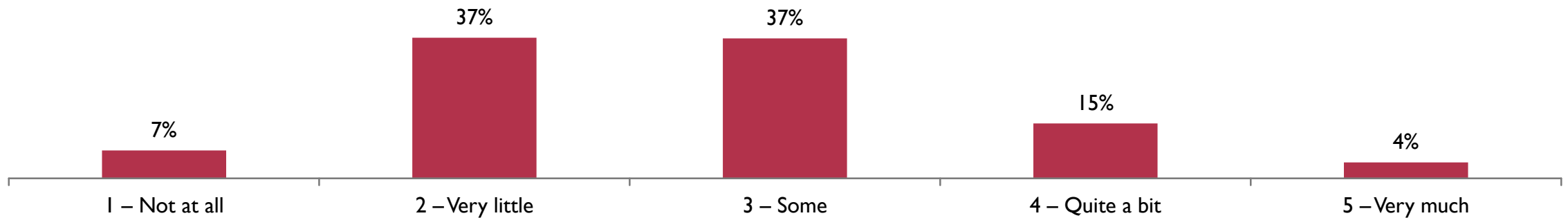
**Q9. Who did you talk to about non-movement symptoms (e.g., hallucinations, delusions, sleep, cognitive problems, anxiety, depression) related to Parkinson's disease and their impact on daily life? Please select all that apply.**



# 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

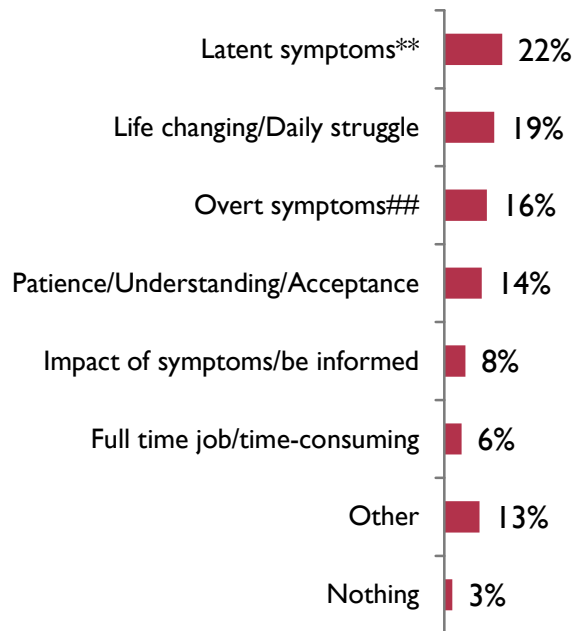
■ PD Patient/Loved one who Experienced Non-Movement Symptoms (n=545)



# RESPONDENTS WISHED PEOPLE KNEW MORE ABOUT THE SYMPTOMS OF PD (LATENT/OVERT) AND ITS LIFE CHANGING IMPACT

## What People Should Know About PD (OPEN ENDED)

■ PD Patient/Loved one who Experienced Non-Movement Symptoms (n=534)



“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?

# WHAT RESPONDENTS WISHED PEOPLE KNEW MORE ABOUT THEIR EXPERIENCE – PATIENT/CARE PARTNER QUOTES

“I want people to realize I’m still ‘me.’”

**Patient**

“I wish they understood the struggle to even walk or do simple things normally that they take for granted.”

**Patient**

“The feeling of being helpless.”

**Patient**

“I put on a good front, don’t understand the impact worrying about future. Best friend just equates it to her routine aches and pains of a senior. It makes me angry.”

**Patient**

“I wish they could really “walk in my moccasins” for a few hours to understand my frustration at times.”

**Patient**

“It affects every moment of our lives, even when meds are helping, you’re planning for the next off period or timing meals/meds or packing everything in the bathroom for a quick trip out to the store...”

**Care Partner**

“I wish they knew that Parkinson's looks different in different people. My spouse's motor symptoms are fairly well controlled, but his REM sleep disorder and dementia have made our lives incredibly challenging and exhausting.”

**Care Partner**

“It's sad. Exhausting physically and emotionally.”

**Care Partner**

“The loneliness of losing your partner even though he is still alive.”

**Care Partner**

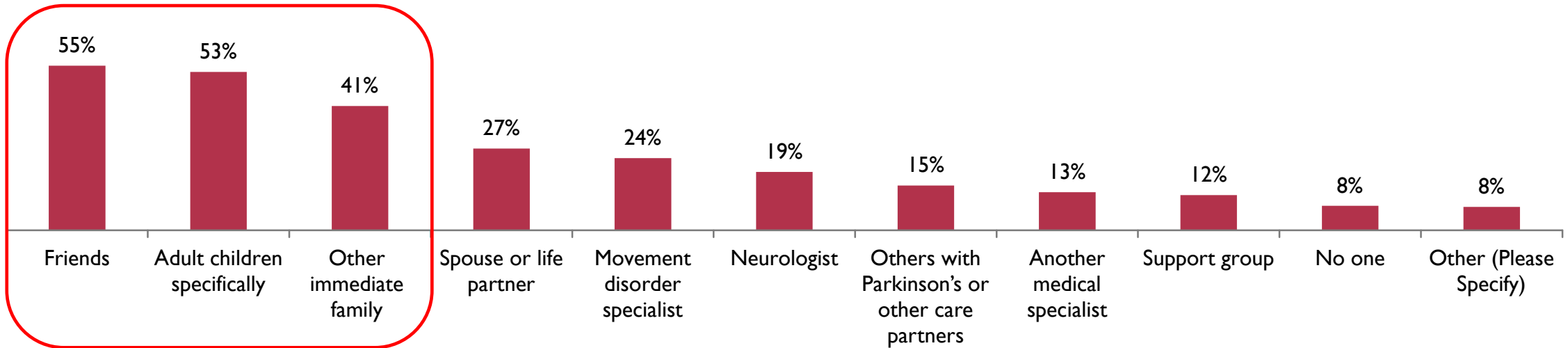
“I wish they knew what a tightrope I walk between letting my husband do what he can, and stepping in to prevent calamities. The stress on the marriage is higher on me, because I know how much he forgets and he, obviously, doesn't. I avoid upsetting him as much as possible, by not telling him when he has forgotten or made a mistake, but sometimes those mistakes are significant; e.g. forgetting to pay a large credit card bill on time.”

**Care Partner**

# 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)



Other specified responses included employers, co-workers, GPs, dieticians, pain specialist, medical staff at assisted living facilities, health advocates, policy makers.

**Q12. Who specifically do you wish knew about your experience with Parkinson's/being a care partner for someone with Parkinson's? Please select all that apply.**



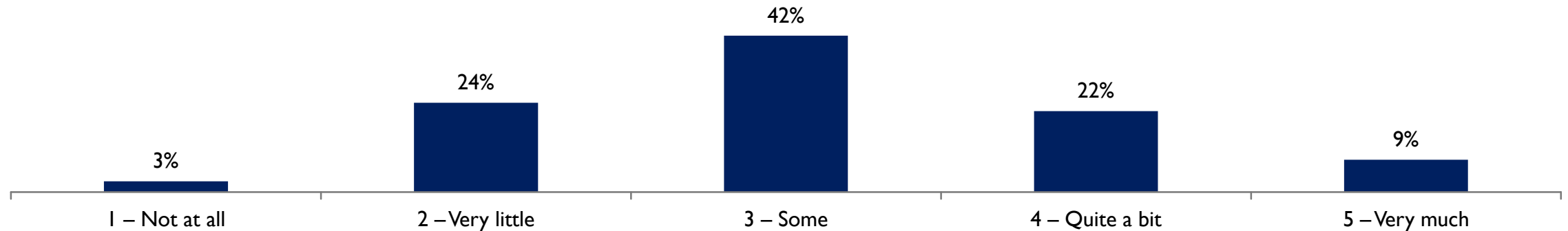
PD PATIENTS/LOVED ONES WHO DID NOT  
EXPERIENCE NON-MOVEMENT SYMPTOMS

# 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)

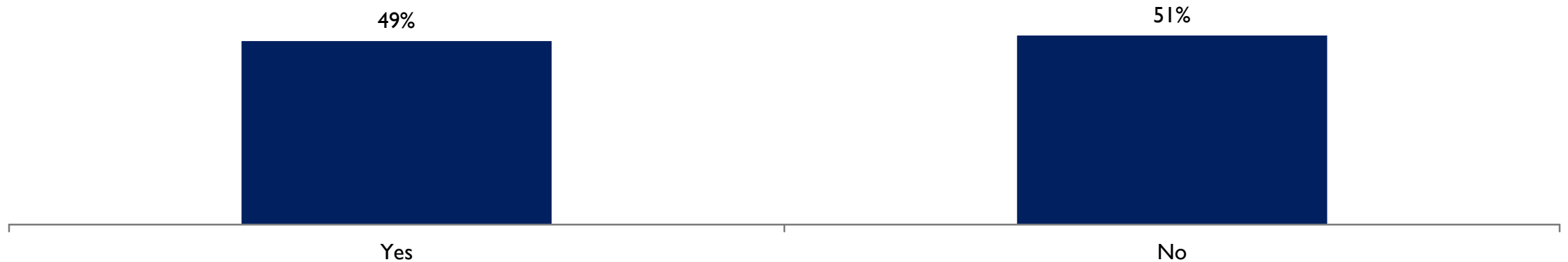
Findings are consistent across patient and their care partners who have experienced both movement and non-movement symptoms.



# 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

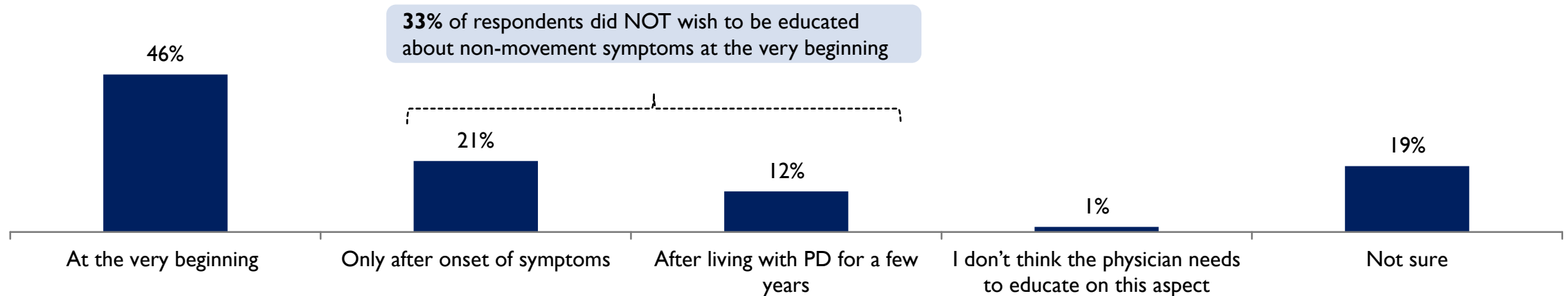
■ PD Patients/Loved Ones who did NOT Experience Non-Movement Symptoms (n=67)



# 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)

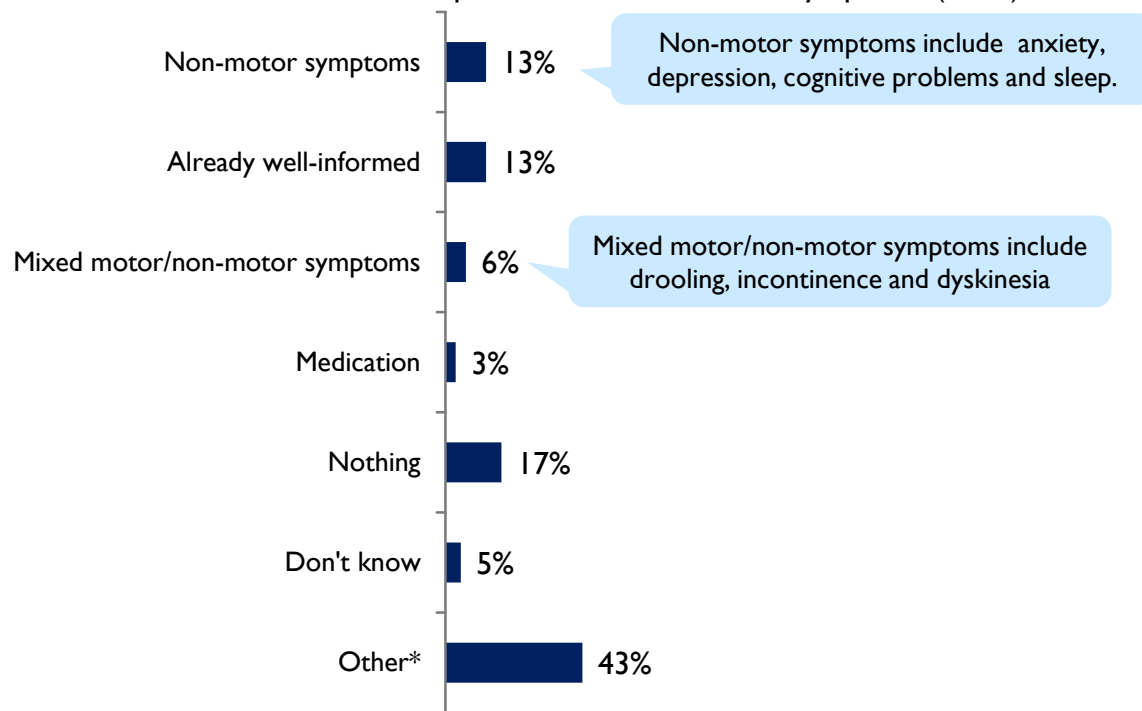




# 13% OF RESPONDENTS SPECIFICALLY SOUGHT ADDITIONAL INFORMATION ON NON-MOVEMENT SYMPTOMS

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

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



“The non-movement symptoms are hard to explain to family members, and friends.”

“Heightened anxiety/urge to resolve supposed problems NOW.”

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

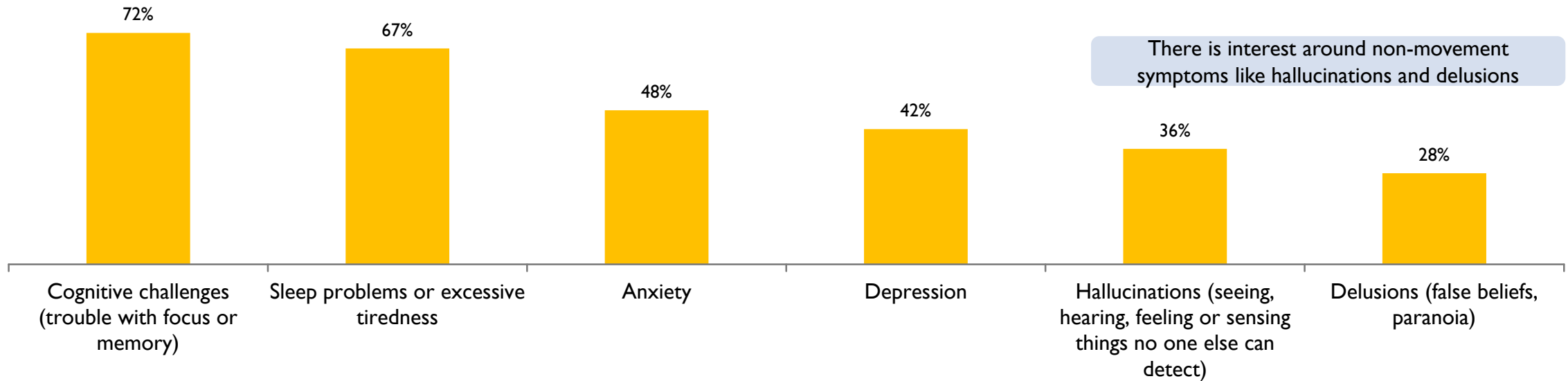


ALL RESPONDENTS:  
NON-MOVEMENT SYMPTOMS THEY WOULD LIKE TO  
LEARN MORE ABOUT

# 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





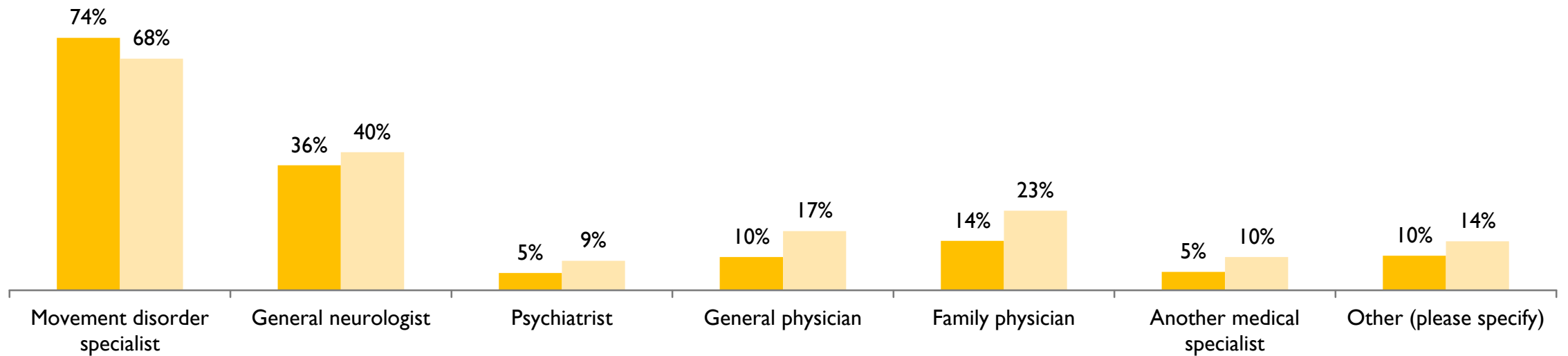
## SUB-GROUP ANALYSIS: PD PATIENTS VS. CARE PARTNERS

**NOTE: DIFFERENCES IN SUB-GROUPS ARE NOT STATISTICALLY SIGNIFICANT UNLESS SPECIFICALLY INDICATED**

# MOVEMENT DISORDER SPECIALISTS AND NEUROLOGISTS ARE THE TOP HCPS SEEN BY BOTH PATIENTS AND CARE PARTNERS FOR PD

## Healthcare Provider(s) Seen for Parkinson's Disease

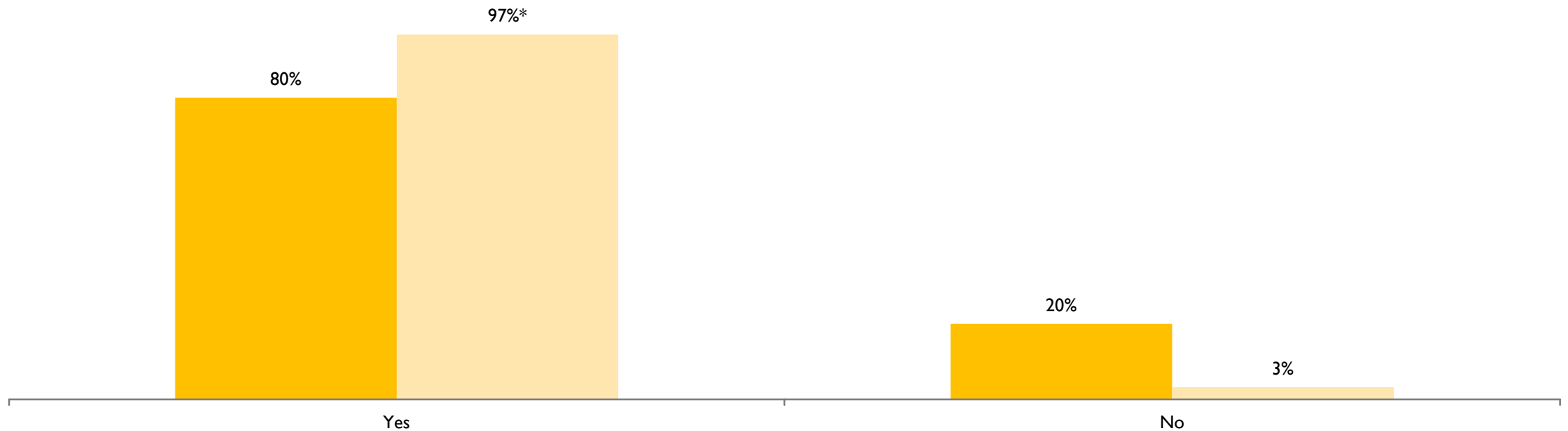
■ PD Patients who Experienced Non-Movement Symptoms (n=277) ■ Care Partners/Loved one who Experienced Non-Movement Symptoms (n=370)



# A SIGNIFICANTLY HIGHER PERCENTAGE OF CARE PARTNERS REPORTED A LOVED ONE EXPERIENCING NON-MOTOR SYMPTOMS COMPARED TO PATIENTS THEMSELVES

## PD Patient/Loved One Experienced Non-Movement Symptoms

■ PD Patients who Experienced Non-Movement Symptoms (n=274) ■ Care Partners/Loved one who Experienced Non-Movement Symptoms (n=369)



\*Differences in groups (PD patients vs. care partners) are statistically significant at the 95% confidence interval.



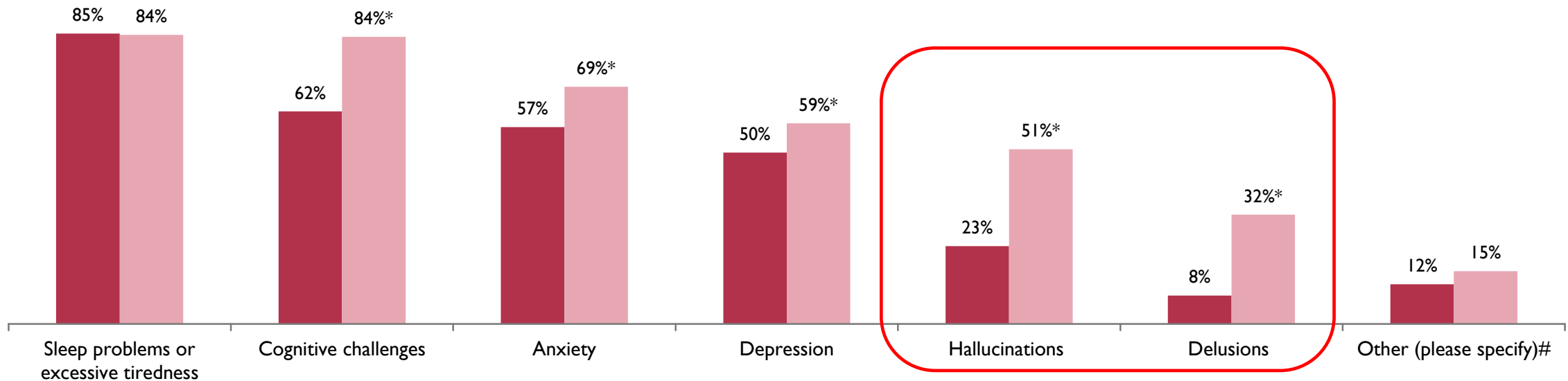
SUB-GROUP ANALYSIS:  
PD PATIENTS VS. CARE PARTNERS  
*RESPONDENTS WHO/LOVED ONE EXPERIENCED NON-MOVEMENT  
SYMPTOMS*

**NOTE: DIFFERENCES IN SUB-GROUPS ARE NOT STATISTICALLY SIGNIFICANT UNLESS SPECIFICALLY INDICATED**

# PD PATIENTS REPORTED SIGNIFICANTLY FEWER HALLUCINATIONS, DELUSIONS, ANXIETY, DEPRESSION AND COGNITIVE CHALLENGES COMPARED TO CARE PARTNERS

## Non-Movement Symptoms Experienced by PD Patient/Loved One

■ PD Patients who Experienced Non-Movement Symptoms (n=216)   ■ Care Partners/Loved one who Experienced Non-Movement Symptoms (n=357)



\*Differences in groups (PD patients vs. care partners) are statistically significant at the 95% confidence interval.

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

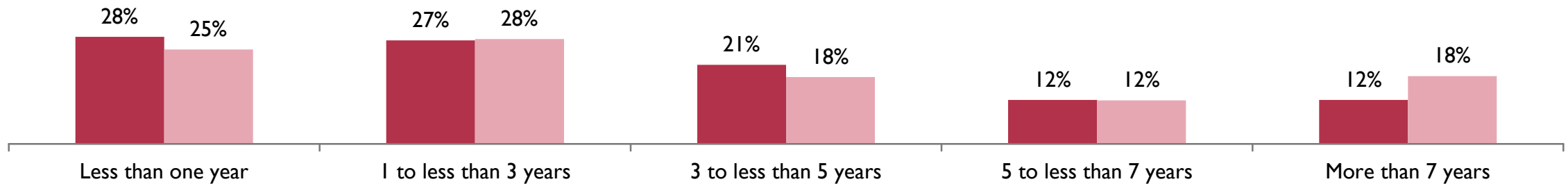
**Q4. Which of the following non-movement related symptoms have you or your loved one with Parkinson's ever experienced? Please select all that apply.**



# NO SIGNIFICANT DIFFERENCES BETWEEN PATIENTS AND CARE PARTNERS REGARDING THE ONSET OF NON-MOVEMENT SYMPTOMS

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

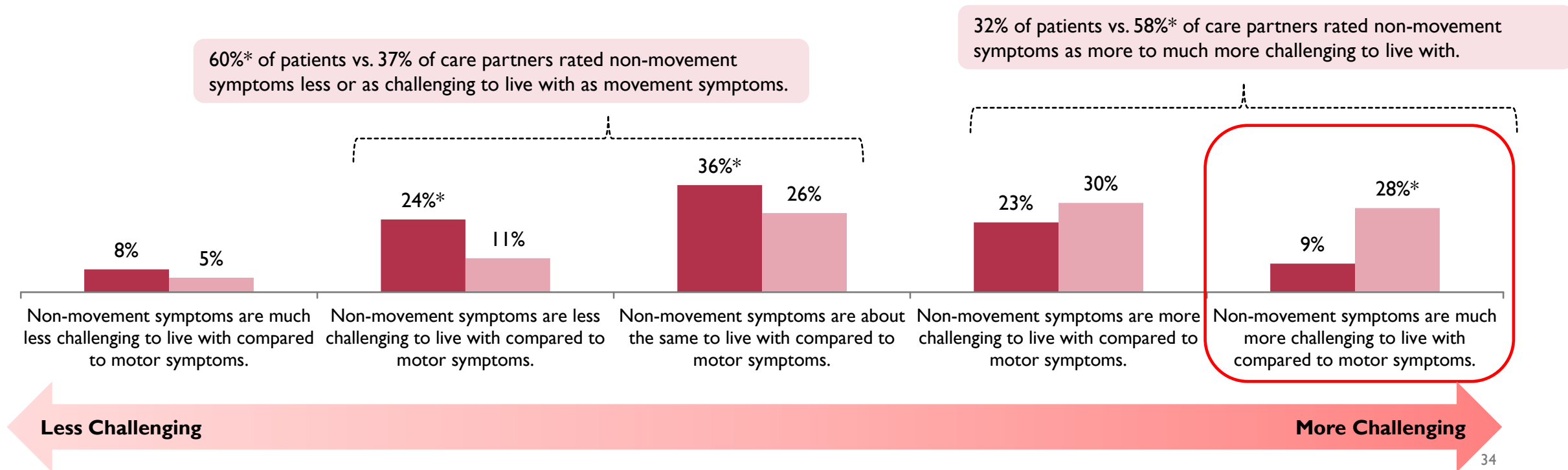
■ PD Patients who Experienced Non-Movement Symptoms (n=215) ■ Care Partners/Loved one who Experienced Non-Movement Symptoms (n=356)



# SIGNIFICANTLY MORE CARE PARTNERS RATED NON-MOVEMENT SYMPTOMS AS MORE TO MUCH MORE CHALLENGING COMPARED TO PATIENTS

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

■ PD Patients who Experienced Non-Movement Symptoms (n=211) ■ Care Partners/Loved one who Experienced Non-Movement Symptoms (n=354)



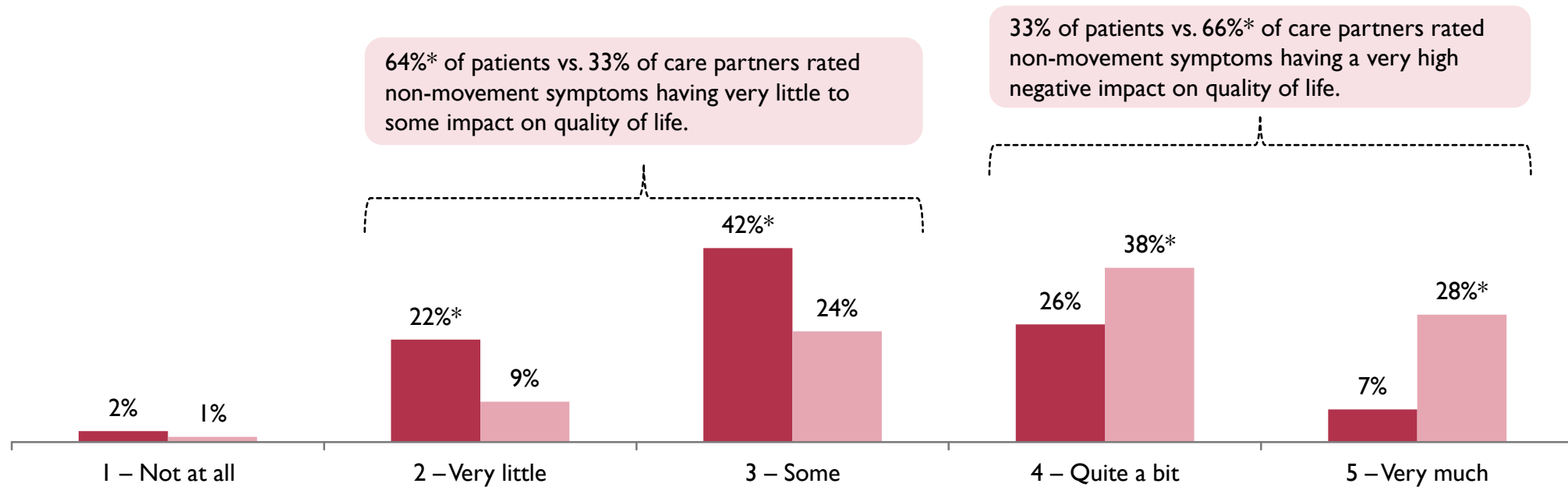
\*Differences in groups (PD patients vs. care partners) are statistically significant at the 95% confidence interval.

Q6. How challenging is it living with non-movement symptoms related to Parkinson's disease (e.g., hallucinations, delusions, sleep, cognitive problems, anxiety, depression) compared to motor symptoms (e.g., tremor, stiffness, slow movement, falls)?

# NON-MOVEMENT SYMPTOMS HAD A SIGNIFICANTLY GREATER IMPACT ON THE QUALITY OF LIFE OF CARE PARTNERS THAN PATIENTS THEMSELVES

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

■ PD Patients who Experienced Non-Movement Symptoms (n=210) ■ Care Partners/Loved one who Experienced Non-Movement Symptoms (n=352)

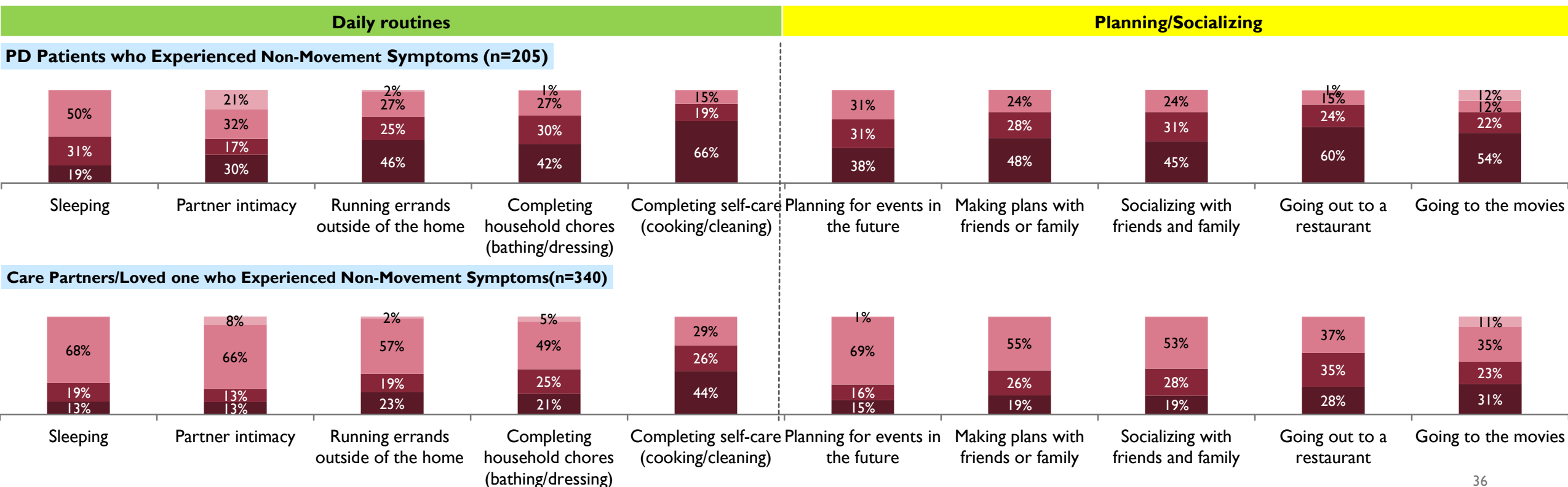


\*Differences in groups (PD patients vs. care partners) are statistically significant at the 95% confidence interval.

# ACROSS THE BOARD, PATIENTS PERCEIVED HIGHER NEGATIVE IMPACT OF NON-MOVEMENT SYMPTOMS ON DAILY LIFE COMPARED TO CARE PARTNER

## Impact of Non-Movement Symptoms on Daily Life

■ High negative impact ■ Some negative impact ■ No negative impact ■ No comment



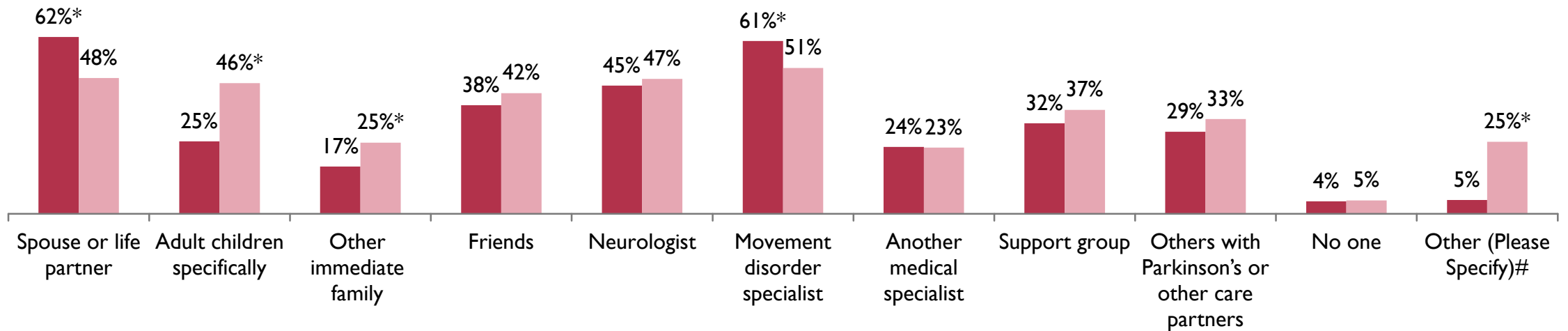
Q8. On a scale of 1-5, fill out the below table to indicate how the onset of non-movement symptoms (e.g., hallucinations, delusions, sleep, cognitive problems, anxiety, depression) associated with Parkinson's disease impact or disrupt activities in you or your loved one's daily life. Please select one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

# SIGNIFICANTLY MORE PD PATIENTS PRIMARILY DISCUSSED THEIR NON-MOVEMENT SYMPTOMS WITH THEIR SPOUSE/PARTNER OR MOVEMENT DISORDER SPECIALIST

## Who Do You Discuss Non-Movement Symptoms With

■ PD Patients who Experienced Non-Movement Symptoms (n=204) ■ Care Partners/Loved one who Experienced Non-Movement Symptoms (n=339)

Significantly more care partners than patients discussed non-movement symptoms with their adult children and other immediate family.



\*Differences in groups (PD patients vs. care partners) are statistically significant at the 95% confidence interval.

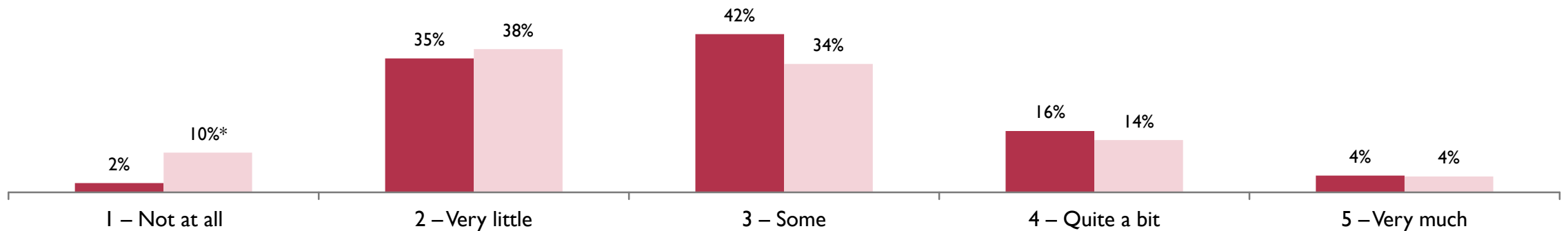
#Other specified among care partners include Parkinson's Better Halves (Facebook group), therapists, psychologists, psychiatrists, primary care provider, and neuropsychologists.

**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.**

# MAJORITY OF PATIENTS AND CARE PARTNERS FELT THERE WAS VERY LITTLE TO SOME UNDERSTANDING OF THE IMPACT OF PD AMONG FAMILY, FRIENDS AND ACQUAINTANCES

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

■ PD Patients who Experienced Non-Movement Symptoms (n=204)   ■ Care Partners/Loved one who Experienced Non-Movement Symptoms (n=339)

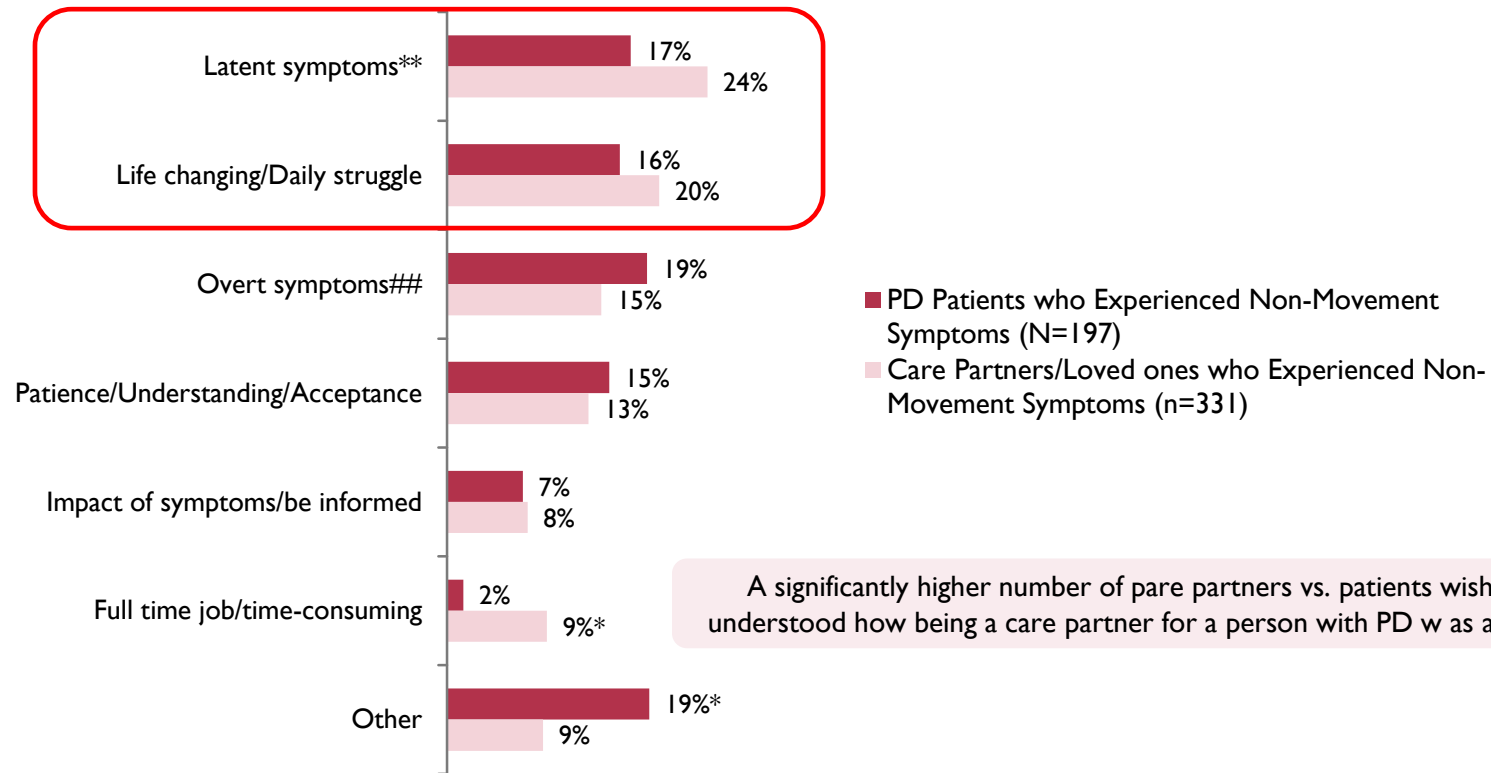


\*Differences in groups (PD patients vs. care partners) are statistically significant at the 95% confidence interval.

Q10. On a scale of 1-5 below, how much do you think family, friends or others in your acquaintance understand the impact of Parkinson's disease on daily living?

# A HIGHER PROPORTION OF CARE PARTNERS WISHED PEOPLE KNEW ABOUT THE LATENT SYMPTOMS AND LIFE CHANGING IMPACT OF PD

**What People Should Know About PD (OPEN ENDED)**



\*Differences in groups (PD patients vs. care partners) are statistically significant at the 95% confidence interval.

\*\*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.

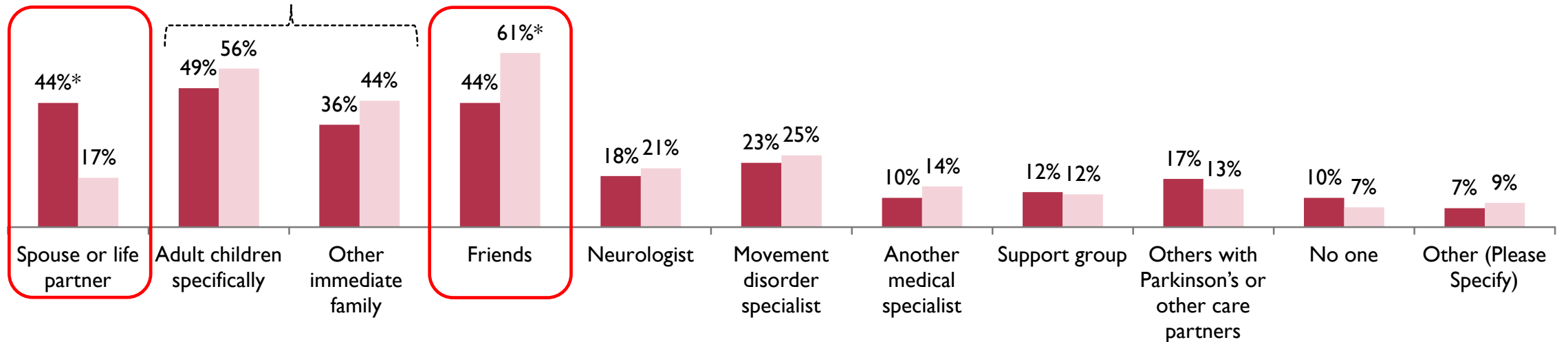
Q11. What, if anything, do you wish people knew about your experience with Parkinson's/being a care partner for someone with Parkinson's?

# SIGNIFICANTLY MORE CARE PARTNERS WERE CONCERNED ABOUT THEIR FRIENDS, WHILE SIGNIFICANTLY MORE PATIENTS WERE CONCERNED ABOUT THEIR SPOUSE/PARTNER

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

■ PD Patients who Experienced Non-Movement Symptoms (n=195) ■ Care Partners/Loved one who Experienced Non-Movement Symptoms (n=329)

Both patients and care partners wished adult children and other family knew about their experience.



\*Differences in groups (PD patients vs. care partners) are statistically significant at the 95% confidence interval.

Q12. Who specifically do you wish knew about your experience with Parkinson's/being a care partner for someone with Parkinson's? Please select all that apply.





SUB-GROUP ANALYSIS:

PD PATIENTS VS. CARE PARTNERS

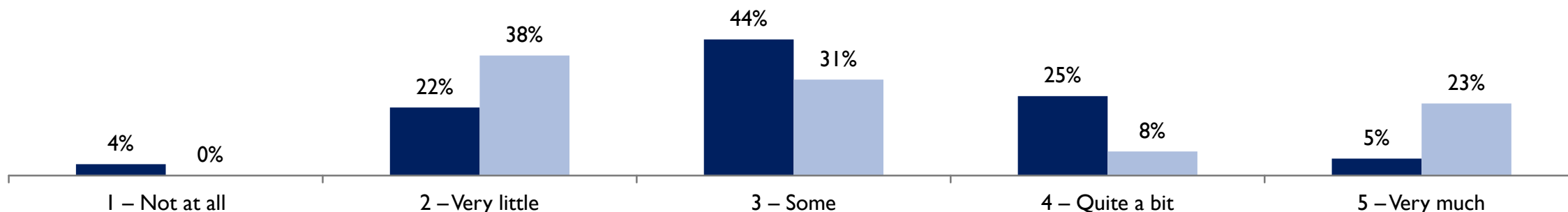
**RESPONDENTS WHO/LOVED ONE DID NOT EXPERIENCE NON-MOVEMENT SYMPTOMS**

**NOTE: DIFFERENCES IN SUB-GROUPS ARE NOT STATISTICALLY SIGNIFICANT UNLESS SPECIFICALLY INDICATED**

# MAJORITY OF PATIENTS AND CARE PARTNERS FELT THERE WAS VERY LITTLE TO SOME UNDERSTAND OF THE IMPACT OF PD AMONG FAMILY, FRIENDS AND ACQUAINTANCES

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

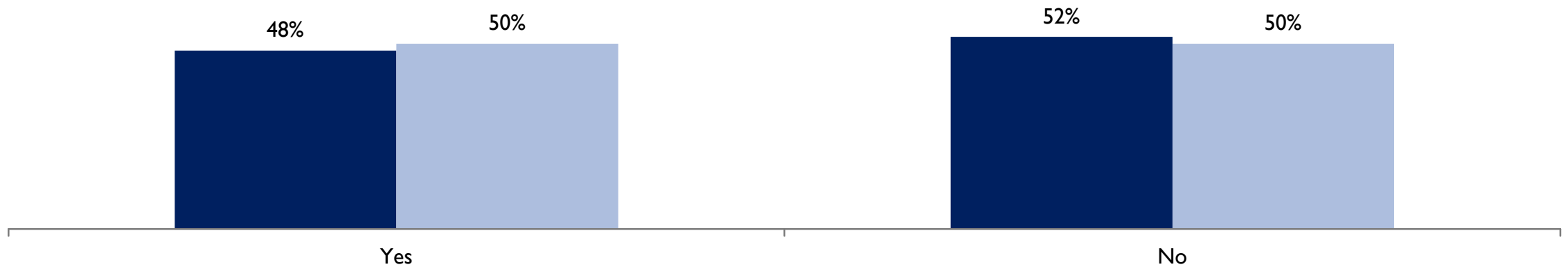
■ PD Patients who did NOT Experience Non-Movement Symptoms (n=55) ■ Care Partners/who did NOT Experience Non-Movement Symptoms (n=13\*)



# NEARLY HALF OF BOTH PATIENTS AND CARE PARTNERS WERE EDUCATED ABOUT NON-MOVEMENT SYMPTOMS BY THEIR NEUROLOGISTS OR NON-MOVEMENT SYMPTOMS

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

■ PD Patients who did NOT Experience Non-Movement Symptoms (n=54) ■ Care Partners/who did NOT Experience Non-Movement Symptoms (n=12\*)



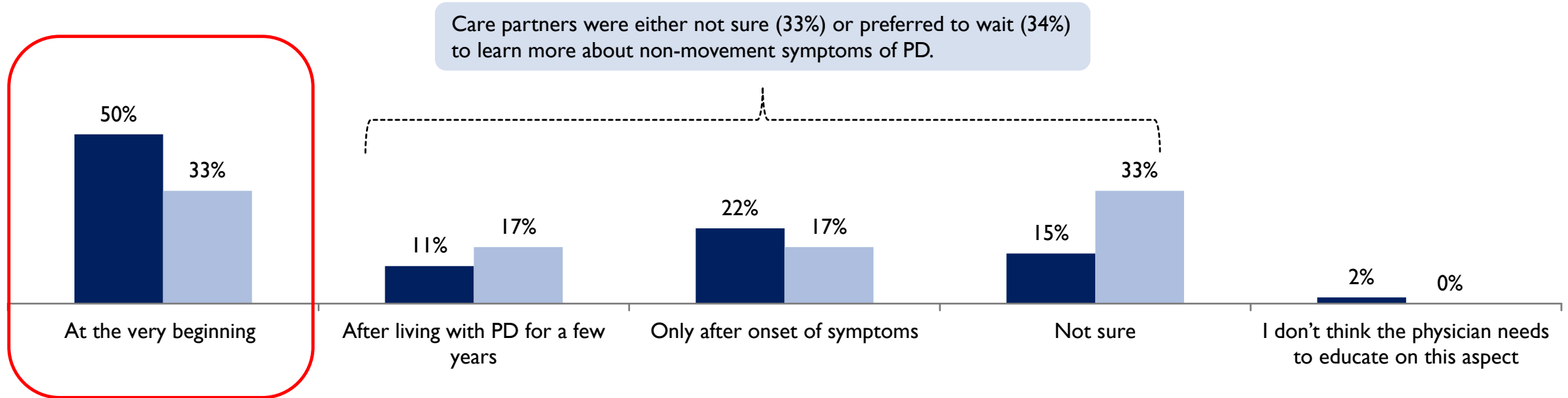
**Q14. Did your neurologist or movement disorder specialist educate you or your loved one about non-movement symptoms (e.g., hallucinations, delusions, sleep, cognitive problems, anxiety, depression) of Parkinson's disease?**

\*Low base size, please consider directional

# HALF OF THE PD PATIENTS AND A THIRD OF THE CARE PARTNERS 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 who did NOT Experience Non-Movement Symptoms (n=54) ■ Care Partners/who did NOT Experience Non-Movement Symptoms (n=12\*)

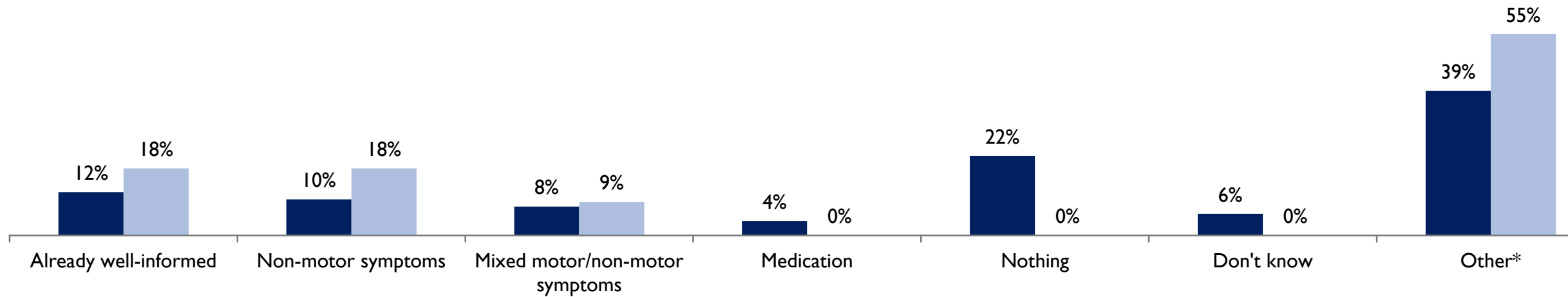


# BOTH PATIENTS AND CARE PARTNERS KNEW ABOUT NON-MOTOR AND MIXED MOTOR/NON-MOTOR PD SYMPTOMS

## 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

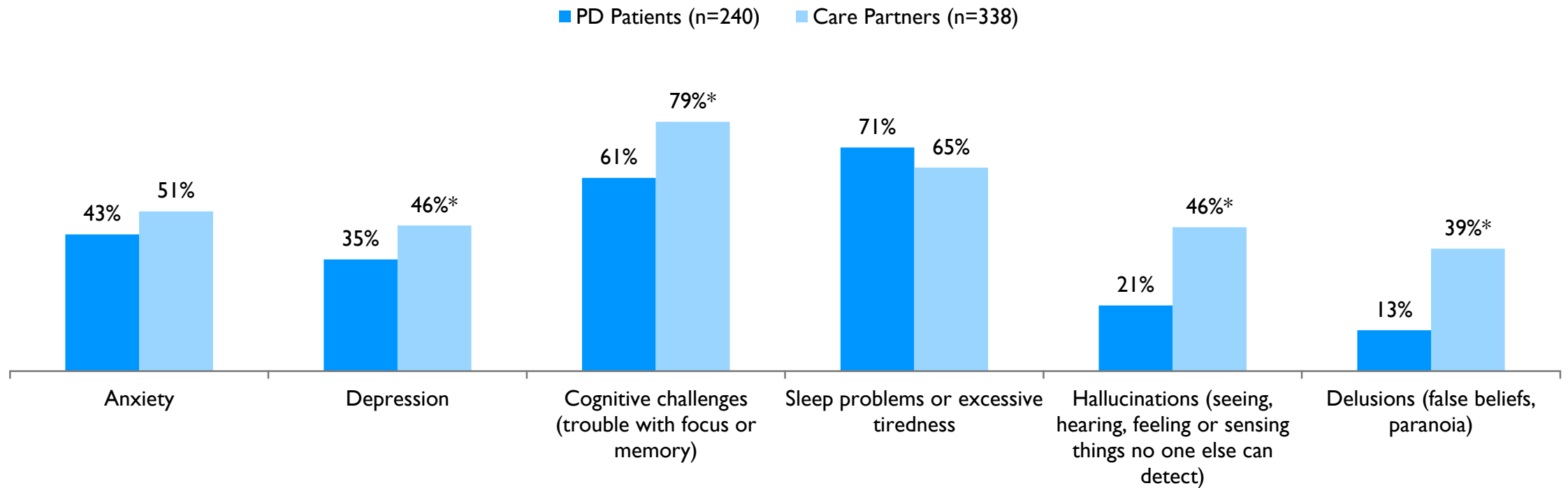


**SUBGROUP ANALYSIS:  
PD PATIENTS VS. CARE PARTNERS  
*ALL RESPONDENTS***

**NOTE: DIFFERENCES IN SUB GROUPS ARE NOT STATISTICALLY SIGNIFICANT UNLESS SPECIFICALLY INDICATED**

# NO MAJOR DIFFERENCES BETWEEN PD

**Which Non-Movement Symptoms You Would Like to Learn About**





# ADDITONAL ANALYSIS

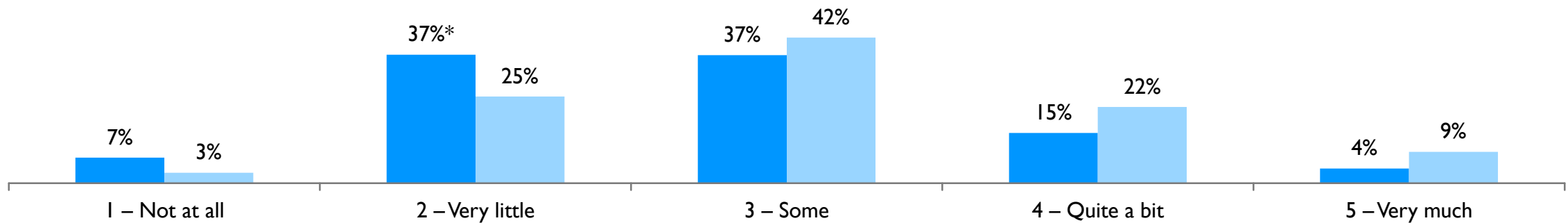




# PD PATIENTS AND CARE PARTNERS FELT THAT THERE WAS VERY LITTLE TO SOME UNDERSTANDING AMONG FAMILY, FRIENDS AND ACQUAINTANCES ABOUT THE IMPACT OF PD ON DAILY LIVING – IRRESPECTIVE OF WHETHER THEY/LOVED ONE EXPERIENCED NON MOVEMENT SYMPTOMS OR NOT

## How Much Friends/Family Understand the Impact of Parkinson’s Disease on Daily Living

- PD Patient/Loved one who Experienced Non-Movement Symptoms (n=545)
- PD Patients/Loved Ones who did NOT Experience Non-Movement Symptoms (n=69)



# RESPONDENTS WHO EXPERIENCE NON-MOVEMENT SYMPTOMS ARE MORE CURIOUS TO LEARN ABOUT THE SYMPTOMS

## Which Non-Movement Symptoms You Would Like to Learn About

