Navigating the Diagnostic Journey: Insights From Frontotemporal Dementia Caregivers

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Introduction

- Caregivers experience significant social and economic burden while caring for an individual with FTD, a heterogeneous neurodegenerative disorder characterized by changes in behavior, language, and motor function resulting from progressive neurodegeneration of the frontal and temporal lobes[1,2]
- Caregiver burden for FTD has been shown to exceed that of Alzheimer's disease, which may be related to the earlier onset of FTD and presence of more behavioral disruption[3-5]
- It is critical to understand the perspectives and challenges of caregivers, as they play a primary role in the diagnosis and care of individuals with FTD
- We surveyed caregivers to gain a deeper understanding of their experience in the FTD diagnostic journey

Methods

- Alector developed the FTD Caregiver Survey, an online, self-administered questionnaire consisting of informed consent, eligibility screening, and questions on caregiver burden and needs that were presented in multiple choice, rating scale, or open-ended format
- The survey was conducted in collaboration with the CISCRP and was distributed with support from patient groups, individual advocates, and an FTD website community
- The study was reviewed and determined to be IRB exempt
- Eligible responders were US adults who could read and write in English and had been an unpaid primary caregiver for a person diagnosed with FTD

Results

- Of 106 total survey respondents, most caregivers were women and the spouse/partner of the individual with FTD (**Table 1**)
- The modal year of diagnosis of FTD was 2022, with the earliest diagnosis occurring in 1993 and the latest in 2024, which is the year data collection ended

Table 1. Characteristics of caregivers and individuals with FTD[a]

Demographic Characteristics of Caregivers		**N=106 (n%)**
Gender	Women	86%
	Men	14%
Age	20-39 years	6%
	40-49 years	8%
	50-59 years	24%
	60-69 years	38%
	≥70 years	25%
Race/ethnicity	White/Caucasian[b]	94%
	Hispanic/Latino[b]	3%
	African American/Black	3%
	Asian	1%
	Middle Eastern/North African	1%
	Prefer not to answer	1%
Region	Southeast	38%
	West and Southwest	20%
	Midwest	22%
	Northeast	21%
Area type	Rural	19%
	Suburban	70%
	Urban	11%
Income	Under $29,999	5%
	$30,000 to $59,999	17%
	$60,000 to $99,999	31%
	$100,000 to $149,999	21%
	$150,000 or more	12%
	Prefer not to answer	14%
Employment	Retired	47%
	Employed full-time	33%
	Employed part-time	5%
	Not working outside of home	11%
	Other	4%
Characteristics of Individuals With FTD		**N=106 (n%)**
Patient's vital status	Alive at time of survey	86%
	Deceased at time of survey	14%
FTD clinical syndrome	Behavioral variant FTD	53%
	FTD, no type specified	22%
	Primary progressive aphasia	21%
	Corticobasal syndrome	2%
	Amyotrophic lateral sclerosis	2%
	Progressive supranuclear palsy	1%
Relationship of patient with FTD to caregiver	Spouse/partner	77%
	Parent	14%
	Adult child	3%
	Sibling/aunt/uncle/cousin	4%
	Friend	1%
	Other	1%

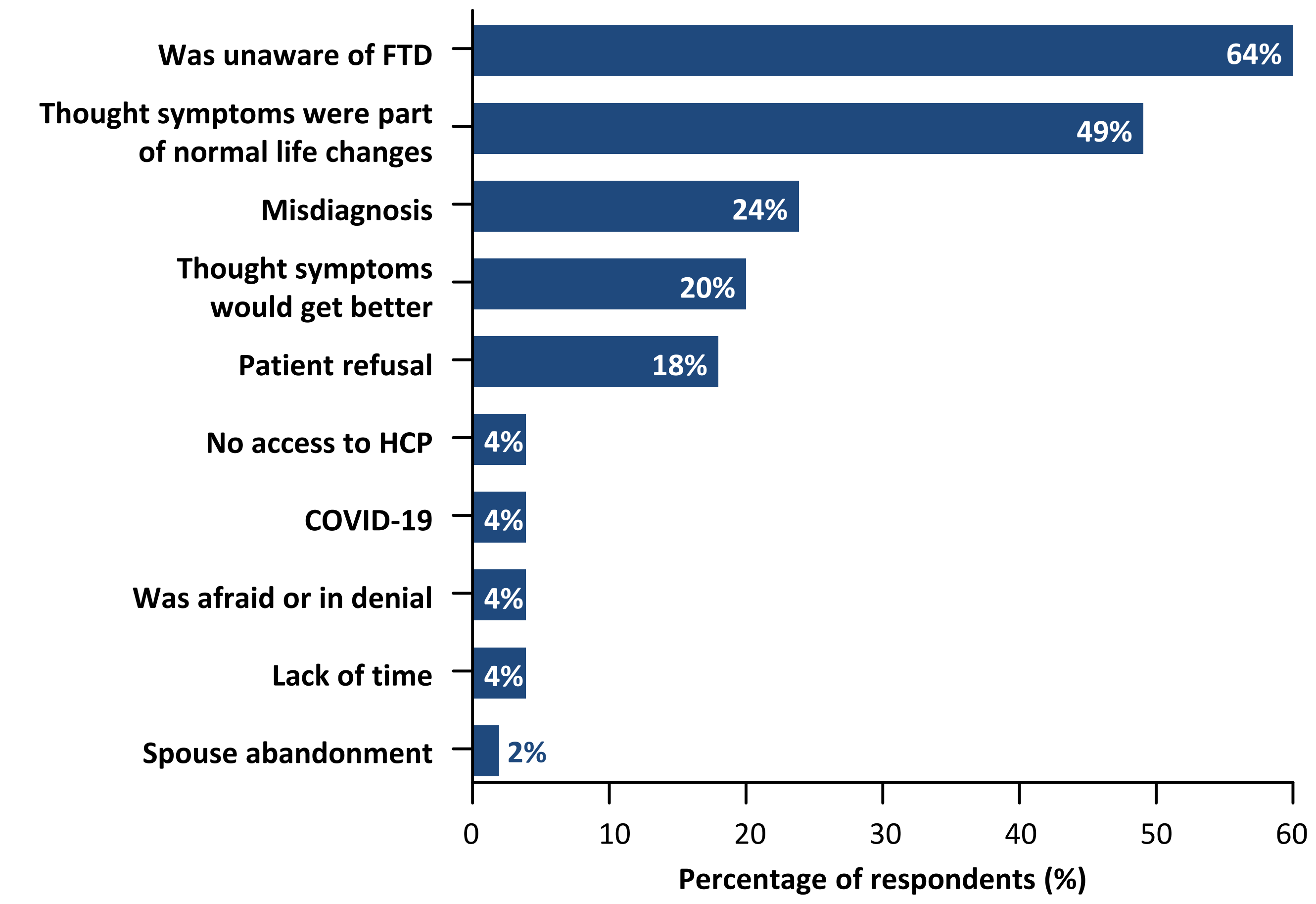
[a]Percentages may exceed 100% due to rounding.

[b]Two participants were White and Hispanic.

Results (cont.)

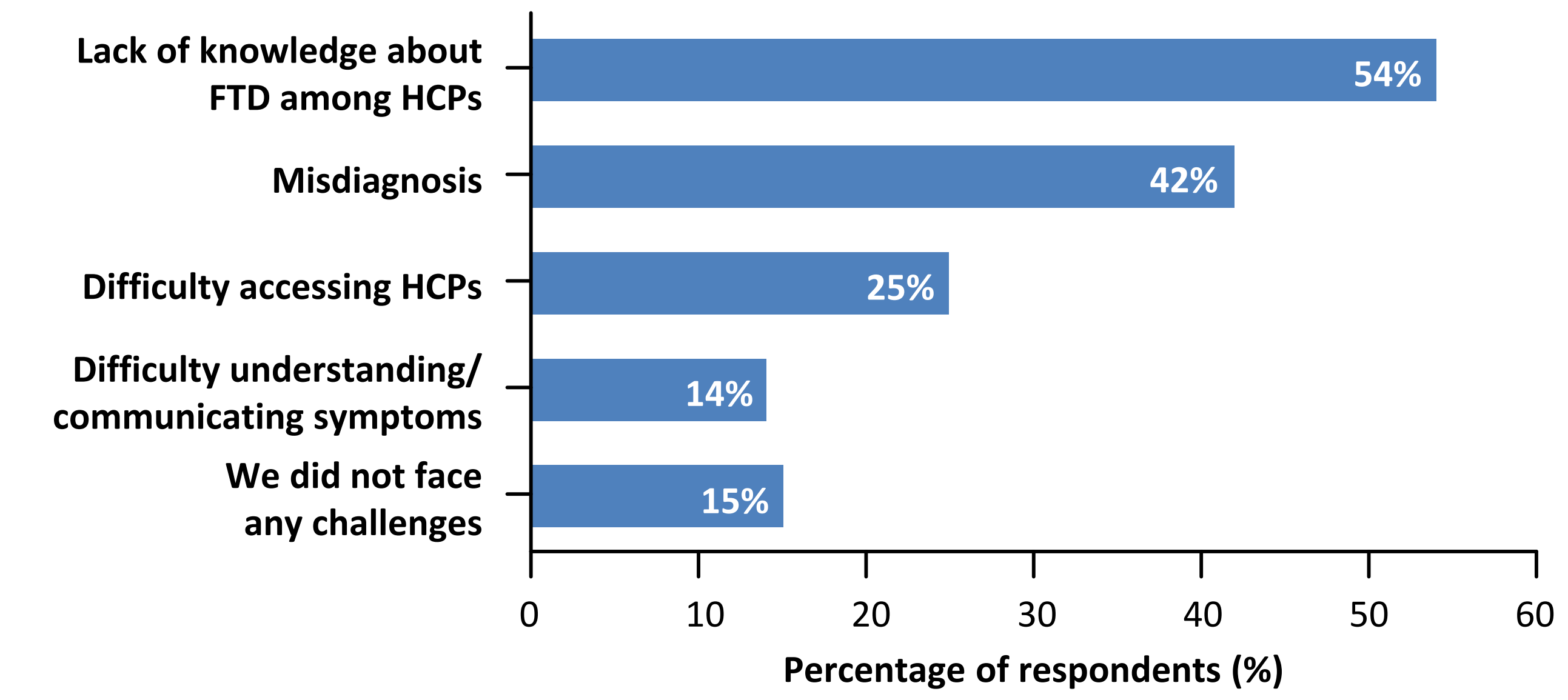
- Approximately 58% (n=61) of caregivers sought medical help within 1 year of noticing initial symptoms of FTD, while 42% (n=45) waited longer than 1 year
- Of those who reported waiting over 1 year to seek help after noticing symptoms (n=45), almost two-thirds (64%) were unaware of FTD, and almost half (49%) thought the symptoms were part of normal life changes (**Figure 1**)
- Over half of the total respondents (54%) reported that lack of knowledge about FTD was a diagnostic challenge among HCPs (**Figure 2**)

Figure 1. Which of the following factors (if any) delayed you from seeking medical advice when you first noticed these symptoms?[a]



[a]Note: This question was only asked of respondents who reported not seeking medical help within the first year (n=45). Respondents were asked to select all factors that applied.

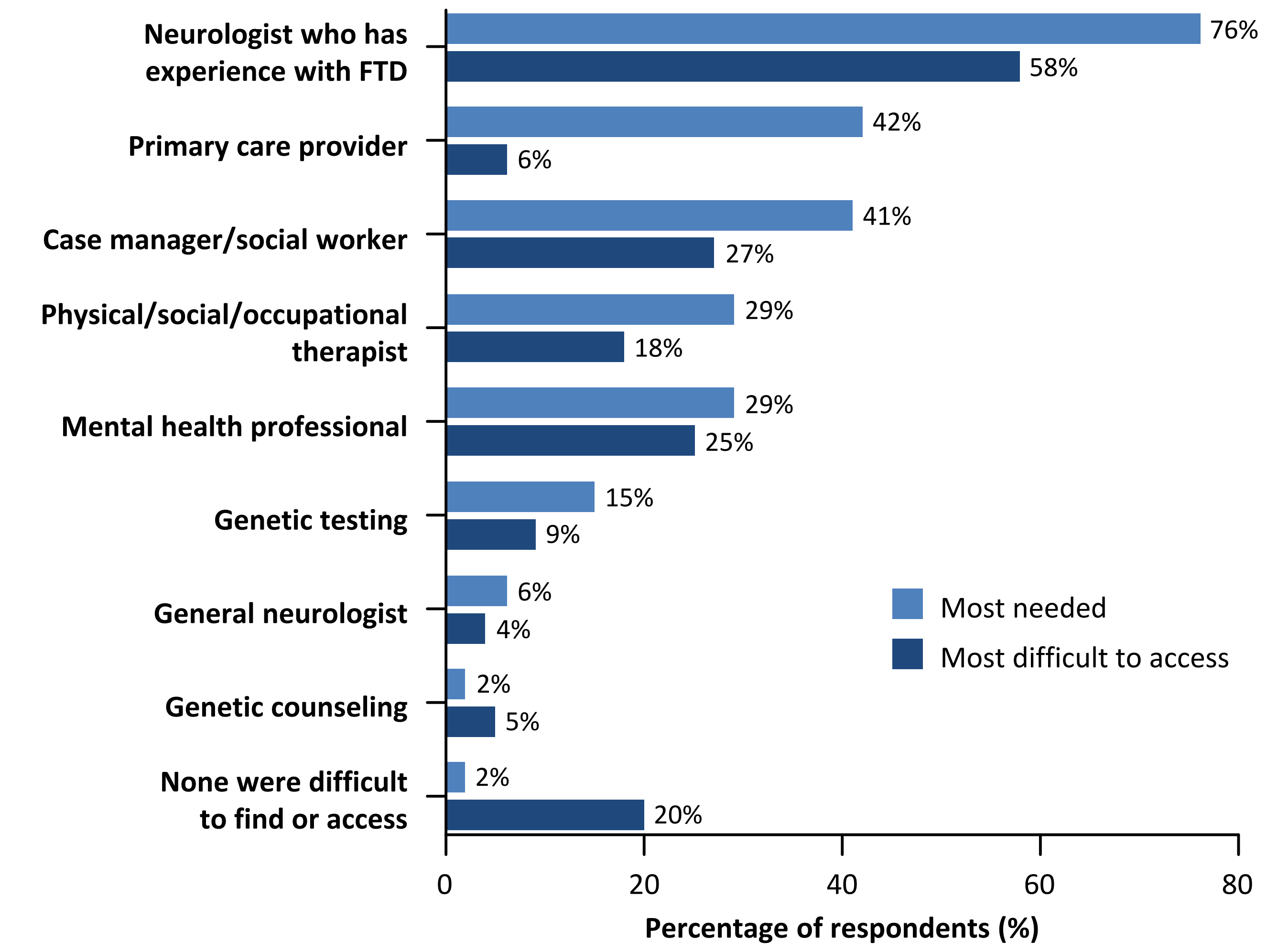
Figure 2. What challenges, if any, did you face in getting an accurate diagnosis for your loved one?[a]



[a]Note: Respondents were asked to select all factors that applied.

- Caregivers reported that neurologists with FTD experience were the most needed healthcare service and the most difficult to access (**Figure 3**)

Figure 3. Which HCPs are most needed, and which are most difficult to find and access?[a]

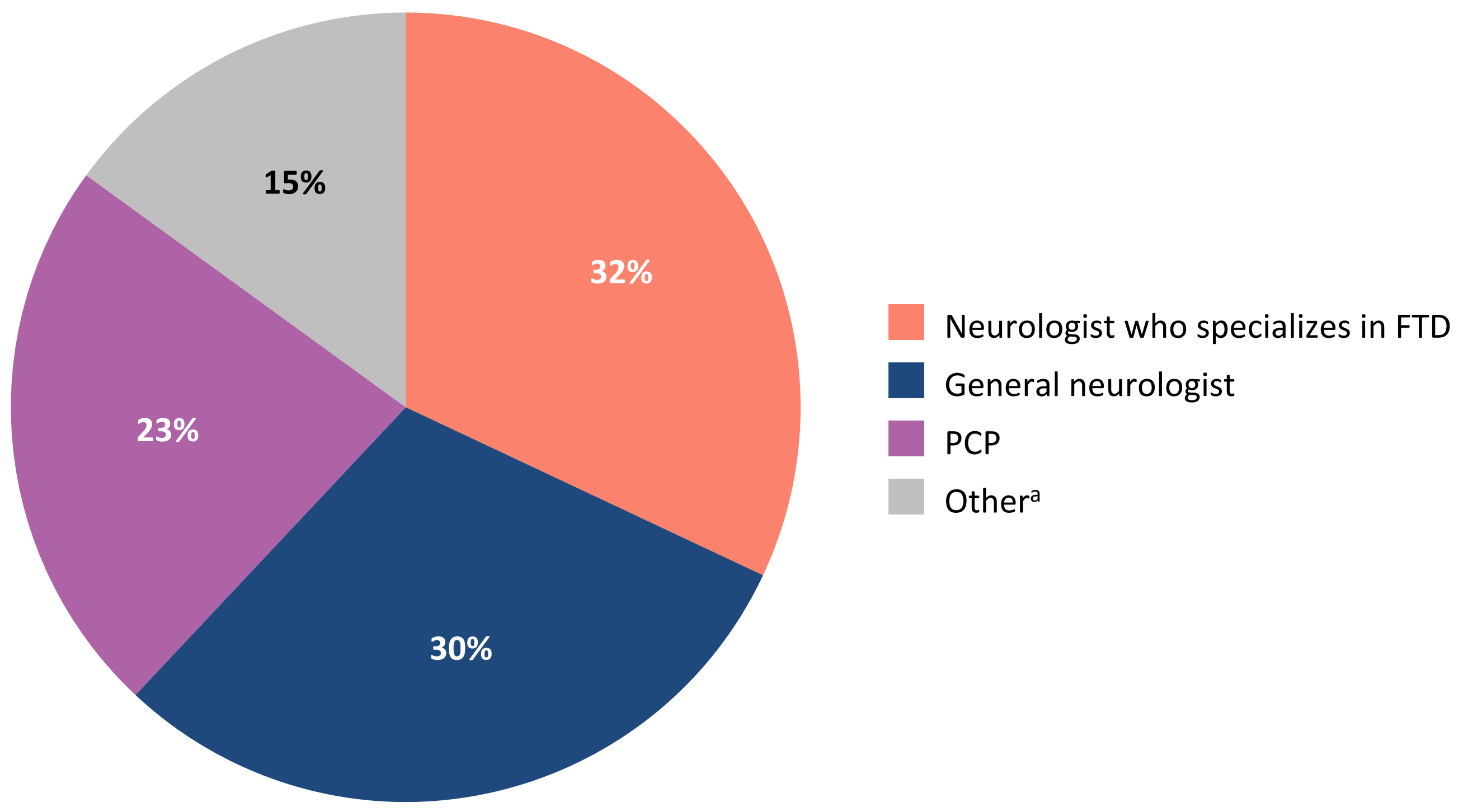


[a]The survey questions were as follows: "What healthcare-related services did you feel your loved one needs/needed most, whether or not you have been able to locate or obtain this kind of help? (Select up to 3 top choices)" and "In general, which are/were the most difficult to find and access, if any? (Select up to 3 top choices)".

Results (cont.)

- Most individuals with FTD (62%) primarily received care from a general neurologist or a neurologist specializing in FTD (**Figure 4**)

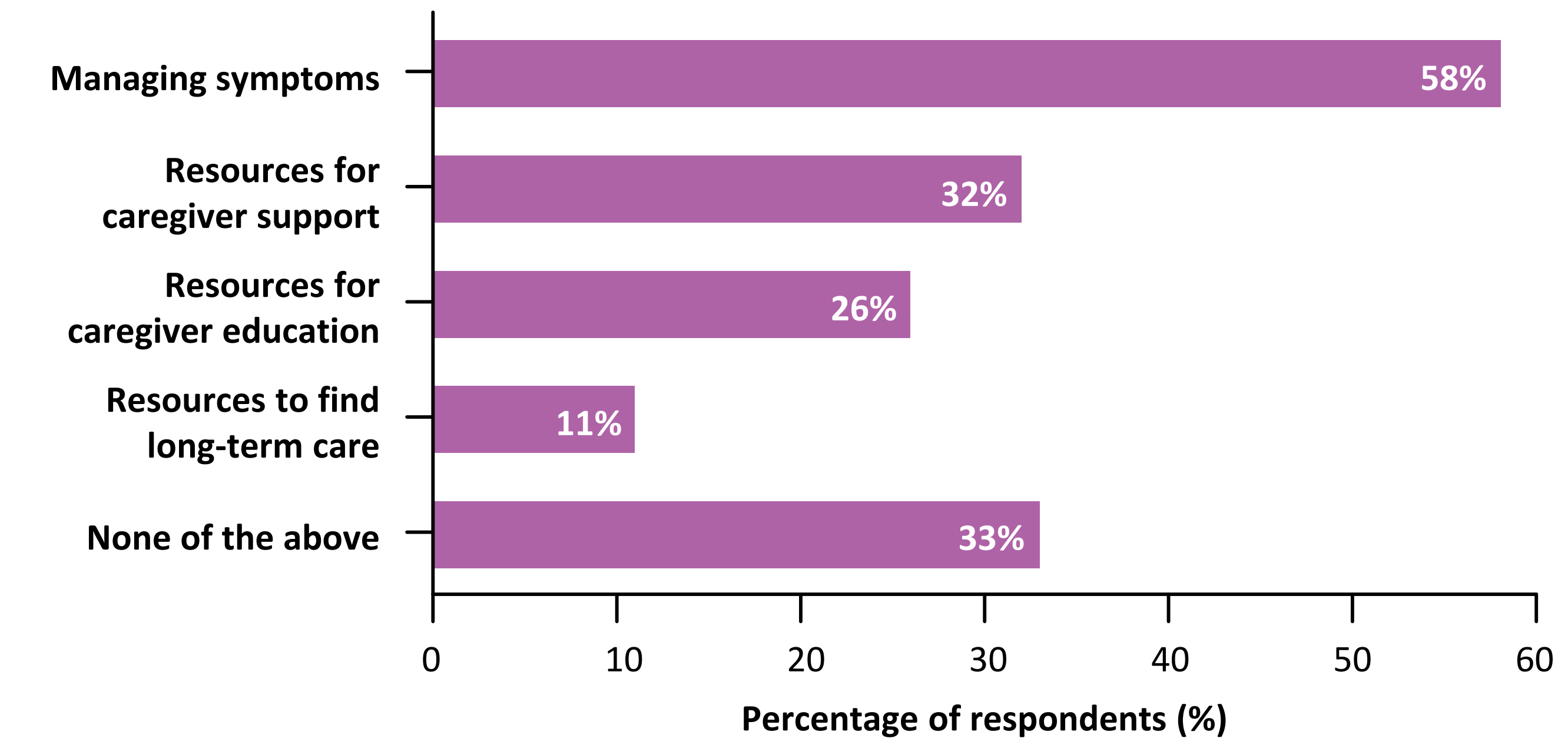
Figure 4. Which one of the following HCPs is/was primarily responsible for the ongoing care of your loved one's FTD?



[a]"Other" included but was not limited to psychiatrists, geriatricians/gerontologists, combination, and hospice healthcare professionals.

- While more than half of respondents (58%) had discussed symptom management with their doctor, one-third (33%) had not discussed any of these topics (**Figure 5**)
- 36% of caregivers reported that an HCP discussed clinical research or clinical trials with them or the individual with FTD

Figure 5. Which of the following topics, if any, has your doctor discussed with you or your loved one?[a]



[a]Note: Respondents were asked to select all factors that applied.

Conclusions

- In this caregiver survey, 42% of caregivers reported waiting over 1 year to seek medical help for their loved one's FTD after first noticing symptoms
- The primary contributors to delay were lack of awareness about FTD and/or thinking the symptoms were part of normal life changes
- Over half of respondents reported that lack of awareness about FTD among HCPs was a diagnostic challenge
- Survey limitations included the potential for self-reporting bias and responder sampling limitations
- These findings highlight the importance of raising awareness of early symptoms of FTD among both HCPs and caregivers
- Continued FTD education efforts among HCPs may help to advance the early and accurate diagnosis of FTD, as well as increase the support provided to caregivers

References

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Abbreviations

CISCRP, Center for Information and Study on Clinical Research Participation; COVID-19, coronavirus disease 2019; FTD, frontotemporal dementia; HCP, healthcare provider; IRB, Institutional Review Board; PCP, primary care provider.

Disclosures

GM, DMC, and TWC are current or former employees of Alector, Inc., and may have an equity interest in Alector, Inc. ADB is an employee of CISCRP. SG is a consultant for Alector, Inc. CISCRP received funding from Alector to support the development and conduct of this survey. This research was funded by Alector, Inc.

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