



Challenges Facing Caregivers of Individuals Diagnosed With Frontotemporal Dementia in the United States

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Background & Objectives

- Caregivers, also known as care partners, experience unique challenges while caring for an individual diagnosed with Frontotemporal Dementia (FTD), which is typically earlier in onset by 1-2 decades and presents predominant behavioral and language challenges compared to Alzheimer's Disease (AD).^{1,2,3}
- FTD often develops while individuals are still working or raising children^{4,5} and results in a decline in overall household income due to lost workdays and early departure from the workforce.⁴
- Studies have found higher caregiver burden levels, psychological distress, and financial difficulties in FTD caregivers than in AD.^{4,6,7}
- The aim of this study was to better understand the caregiver experience and identify specific needs for support.

Methods

- Alector developed the FTD Caregiver Survey, an online self-administered questionnaire consisting of informed consent, eligibility screening, and questions regarding caregiver burden and needs that were presented in multiple choice, rating scale, or open-ended format.
- The survey was conducted in collaboration with the Center For Information and Study for Clinical Research Participation (CISCRP) and was developed and distributed with the support from patient advocacy groups, independent advocates, and an FTD website community.
- Expressed consent was obtained from respondents who were also informed of the survey's objectives and anonymity. The study was reviewed and determined to be exempt by the WCG Institutional Review Board.
- Eligible respondents were adults who could read and write in English, reside in the United States, and who have been a primary caregiver for a person diagnosed with FTD. Professional caregivers were excluded.
- Survey responses related to caregiver responsibilities, needs, and assessment of existing resources are descriptively reported from the first 90 surveys, completed from May to June 2024.

Results

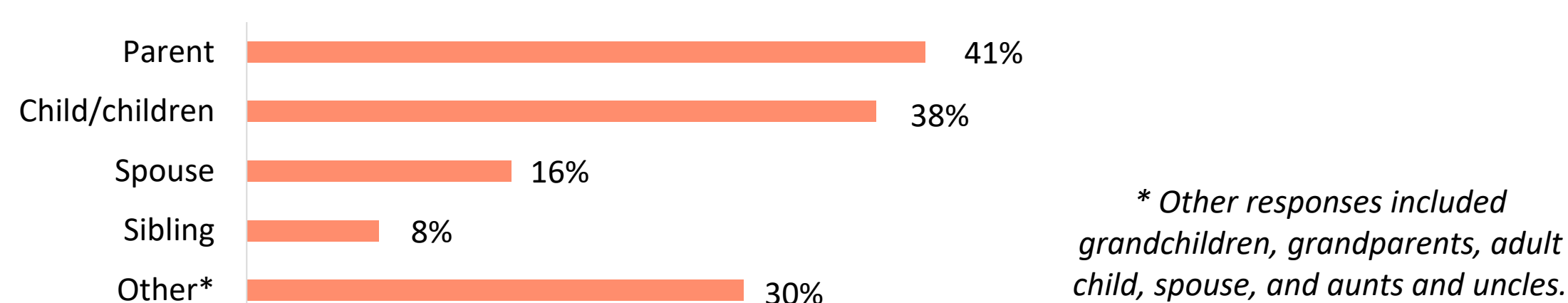
Table 1. Respondent Demographics and Care Recipient Characteristics. Of all respondents, 87% were women. 86% of care recipients were still alive at the time of survey, and 45% of care recipients were 70 or older. Column totals may exceed 100 percent due to rounding.

Age (one invalid response excluded)	Under 50	12%	50-59	26%	60-69	35%	70 and above	27%	Region	Southeast	39%	West and Southwest	24%	Midwest	19%	Northeast	18%											
Race/Ethnicity (more than one choice allowed)	White or Caucasian	93%	Hispanic or Latino	3%	African American or Black	3%	Asian	1%	Community Setting	Rural	18%	Suburban	71%	Urban	11%	Relationship to Individual with FTD	Spouse	80%	Parent	12%	Adult Child	3%	Sibling	2%	Aunt, Uncle, Cousin	1%	Friend	1%
	Middle Eastern or North African	1%	Prefer not to answer	1%	Education Level	High school or GED	14%	Technical school/Associates Degree		17%	Bachelor's degree	37%	Graduate school/professional degree	32%	Age of Living Individuals with FTD (n=76)		Under 50	7%	50-59	17%	60-69	32%	70 and above	45%				
	Income	Under \$29,999	6%	\$30,000 to \$59,999		18%	\$60,000 to \$99,999	32%		\$100,000 to \$149,999	16%	\$150,000 or more	13%	Prefer not to answer			16%	Diagnosis Type of Individual with FTD	General FTD, no specific type	22%	Behavioral variant FTD (bvFTD)	52%	Primary Progressive Aphasia (PPA)	21%	Amyotrophic Lateral Sclerosis (ALS) with FTD	2%	Corticobasal Syndrome (CBS)	2%
	Current Employment Status	Retired	51%	Employed full-time		30%	Employed part-time	4%		Not working outside of the home	11%	Other	3%															

Care Provided

- Over a third of caregivers spend more than 40 hours per week providing direct care. Over a quarter spend more than 20 hours managing health care needs.
- Nearly half of respondents were the sole caregiver.
- 41% of those surveyed had additional caregiving responsibilities, besides caring for the person with FTD.

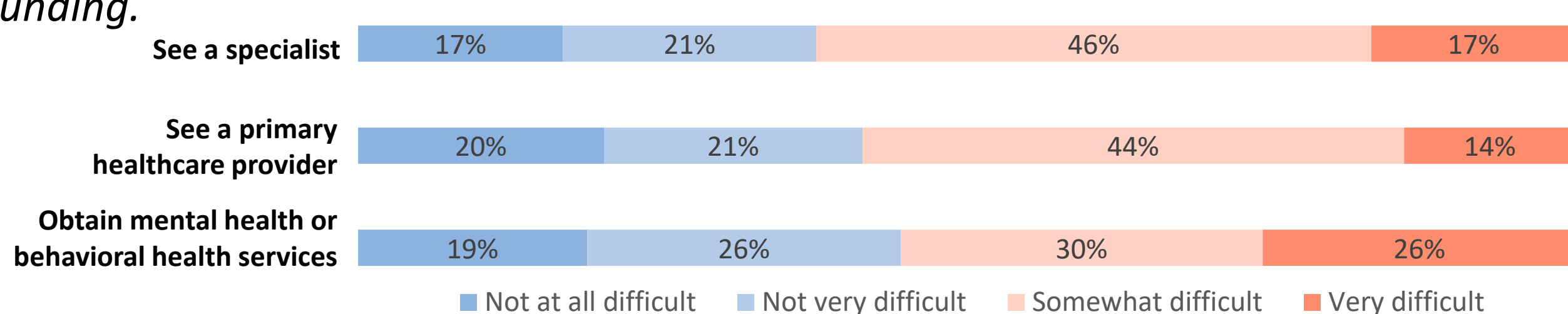
Figure 1. Those with additional caregiving responsibilities often also cared for a parent and/or child(ren). Based on respondents who indicated they have additional caregiving responsibilities, to the Question: Who else do/did you provide care for? Select all that apply, (n=37).



- A majority (92%) of caregivers found it somewhat difficult or very difficult to manage these additional caregiving responsibilities.

Caregiver Needs

Figure 2. More than half of the respondents expressed difficulty attending to their own personal healthcare. Based on all respondents, (n=90). Percentages may not add to 100 due to rounding.



Results (Continued)

Caregiver Needs

Figure 3. Respite services, in-home care, adult day care were the most needed and the most difficult support service to find and access. Based on all respondents, (n=90).

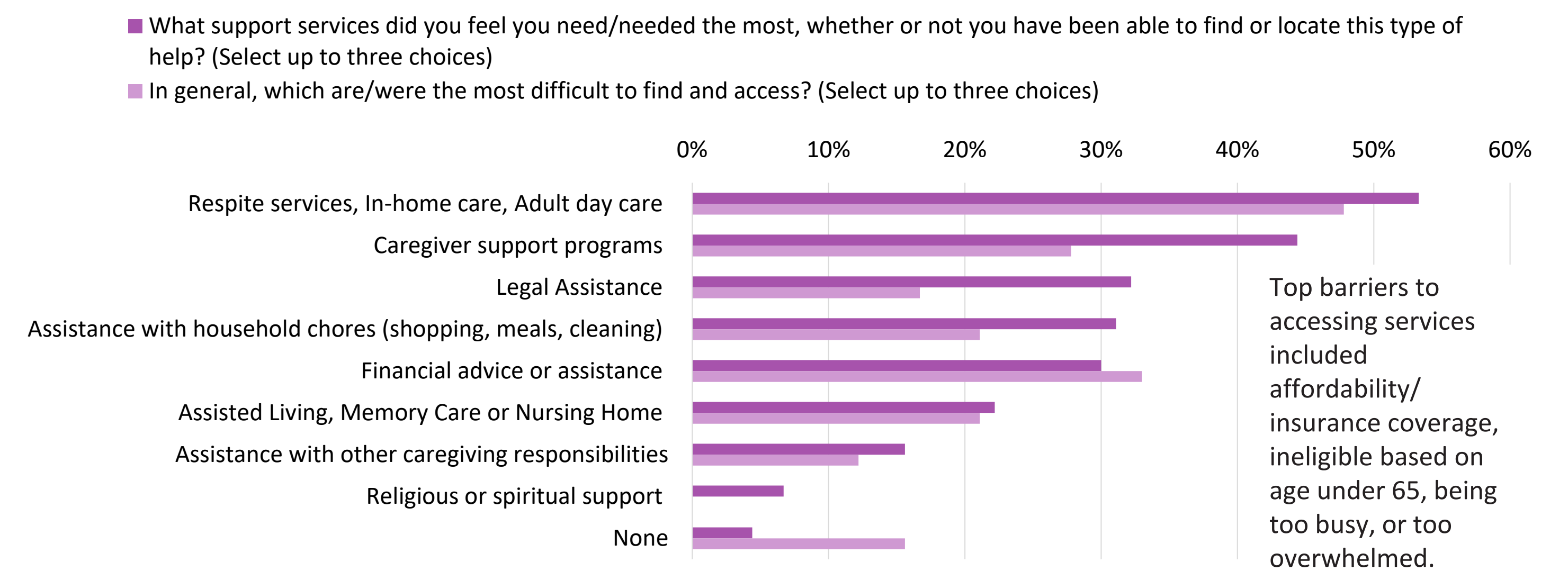
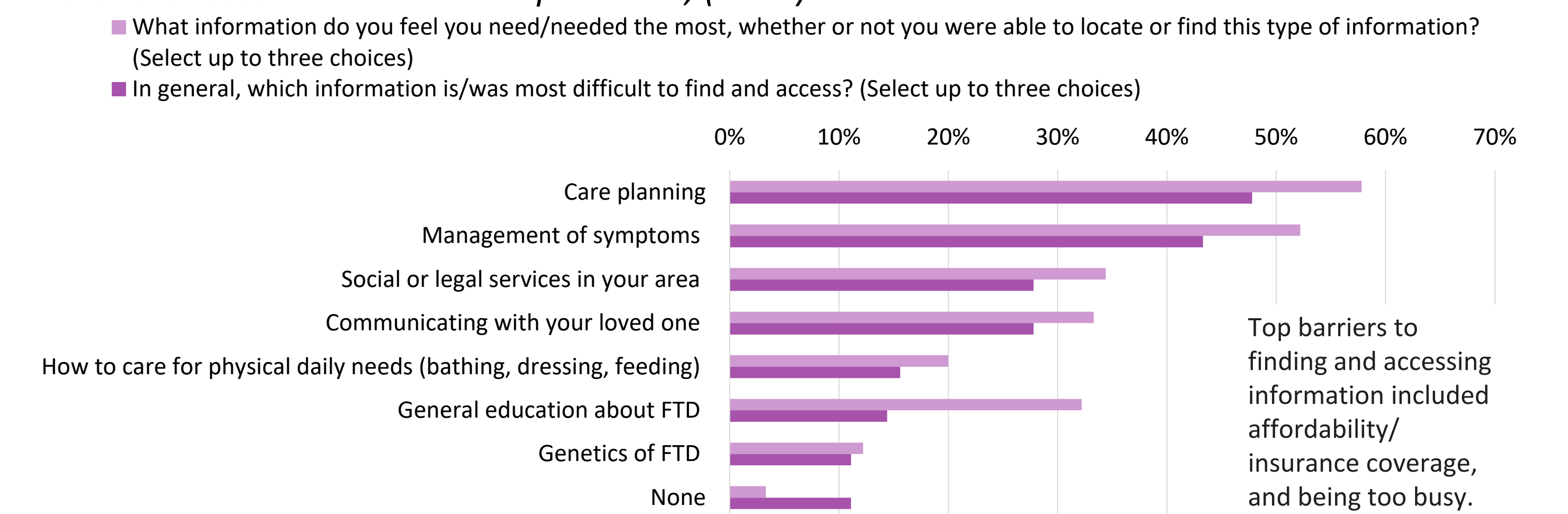
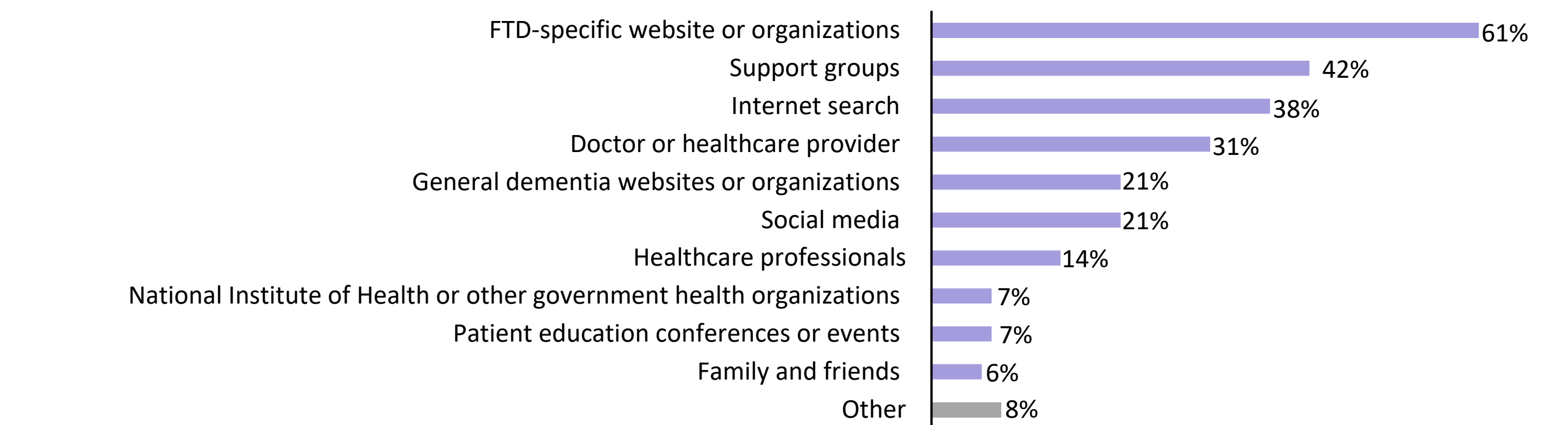


Figure 4. Care planning was the most needed and the most difficult type of information to find and access. Based on all respondents, (n=90).



Caregiver Assessment and Awareness of Existing Resources

Figure 5. FTD-specific sources and support groups were most often reported as helpful. Based on all respondents to Question: If you sought out help or information about caring for someone with FTD, which were the most helpful? Select top three choices, (n=90).



- FTD-specific websites and organizations (61%) were reported as the most helpful source much more frequently than general dementia websites and organizations (21%).
- Between 24-26% of respondents were not at all or not very aware of educational programs or supportive resources for FTD caregivers.

Discussion & Conclusion

- This survey identified opportunities to advocate for improved access, as the most needed caregiver support services and information were also generally the most difficult for FTD caregivers to access. The financial and legal assistance required in the context of FTD, particularly among younger families, differ from those needed by families who are caring for someone with AD, contributing to these unmet needs and challenges.^{4,8}
- Limitations include a small sample size and potential selection bias, as our distribution mainly relied on advocacy groups. The online medium of the survey may reduce the number of supports chosen that are not available online or virtually. Additionally, responses from the United States may not reflect caregiver experiences in other countries.
- Future expansion of the research would adapt the survey as relevant to culture and language for other global regions, explore the impact of socioeconomic status on unmet need and barriers to support, and engage a larger diverse population of caregivers through various survey mediums.
- Patient organizations and healthcare professionals can help address the need for strategies to overcome barriers and expand on FTD-specific support, ranging from caregiver support groups to financial assistance and additional support in the day-to-day caregiving at home.

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Abbreviations

AD, Alzheimer's Disease; ALS, Amyotrophic Lateral Sclerosis; bvFTD, behavioral variant Frontotemporal Dementia; CBS, Corticobasal Syndrome; CISCRP, Center for Information and Study on Clinical Research Participation; FTD, Frontotemporal Dementia; GED, General Educational Development; PPA, Primary Progressive Aphasia

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