

Mapping Caregiving Support: A Landscape Study of CAR T Authorized Treatment Center’s Policies around Caregiving in the U.S.

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BACKGROUND

- Chimeric antigen receptor (CAR) T-cell therapy has been shown to offer durable response and improved survival rates for patients with blood cancer.¹
- Only 20% of eligible cancer patients receive access to CAR T.²
- One of the primary barriers to CAR T is lack of access to caregiving support to monitor symptoms, as most authorized treatment centers (ATCs) require that patients be monitored for adverse reactions for up to 6 weeks after infusion.³

This study characterized the variation in ATCs policies and procedures around caregiving to improve navigation and support for patients and caregivers.

METHODS

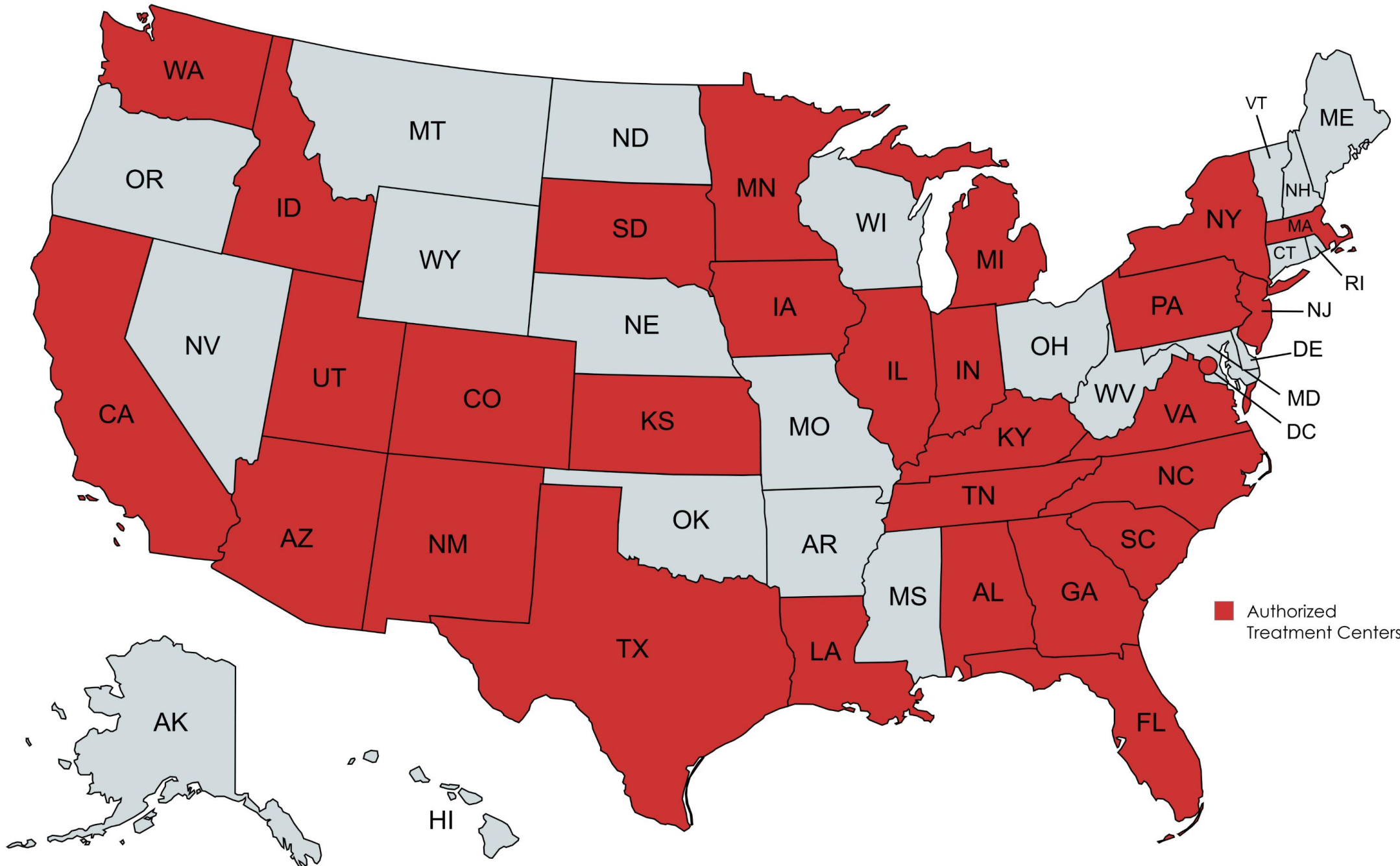
- We fielded a survey with **94 healthcare providers** representing **55 CAR T ATCs** between Nov 2025 – May 2026.
- Participants were recruited via direct email outreach through **CSC’s CAR T Concierge** navigation program and the **Association of Cancer Care Centers (ACCC)** membership
- Survey participants reported:
 - Professional background and sociodemographics
 - ATC characteristics and geography
 - Risk evaluation and mitigation strategy (REMS) policies
 - Policies around caregiving for CAR T-cell therapy patients
 - Supportive resources offered to patients and caregivers
 - Barriers to accessing care
- Descriptive statistics and chi-square tests were employed to assess variation in caregiving policies and procedures

Table 1. Sample Characteristics

	Mean/n	SD/%
Age, years (range 13-78)	M=49	SD=10.8
Gender		
Man	80	85%
Woman	10	11%
Non-binary/gender fluid	1	1%
Prefer not to share	3	3%
Race & Ethnicity		
Non-Hispanic White	62	66%
Non-Hispanic Black	3	3%
Hispanic/Latino	3	3%
Asian American	14	15%
Multi-racial/ethnic	4	4%
Prefer not to share/Other	8	9%
Profession		
Social worker	40	43%
Nurse coordinator	18	19%
Nurse practitioner	15	16%
Nurse navigator	6	6%
Physician/doctor	3	3%
Nurse Manager	2	2%
Other (clinical coordinator, program manager)	10	11%
Site type		
Academic	75	80%
Community	19	20%
Professional experience in CAR T		
<1 year	5	5%
1-5 years	34	36%
5-10 years	41	44%
>10 years	14	15%

N=94 healthcare providers

Figure 1. Geographic distribution of ATCs surveyed



RESULTS

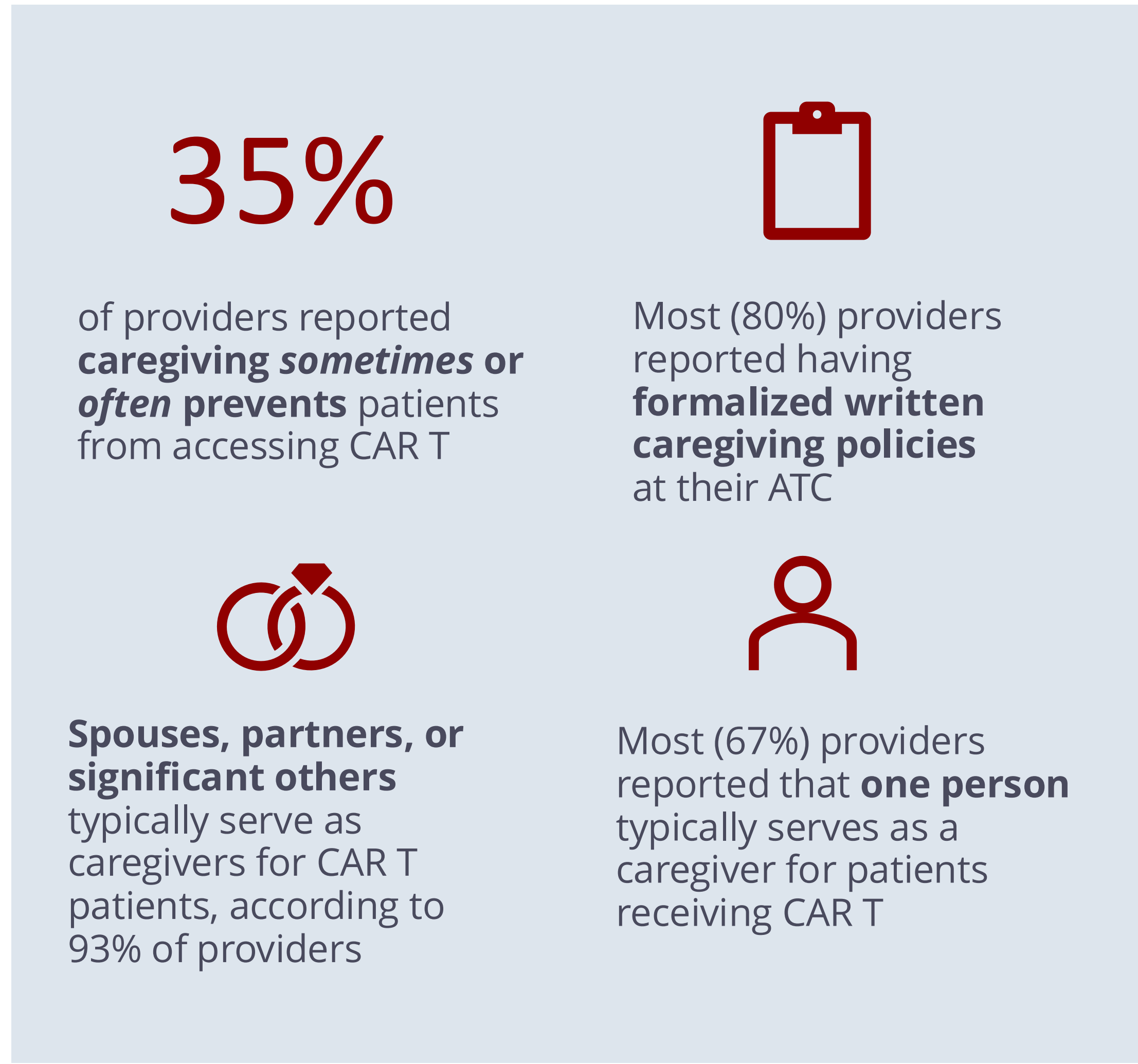
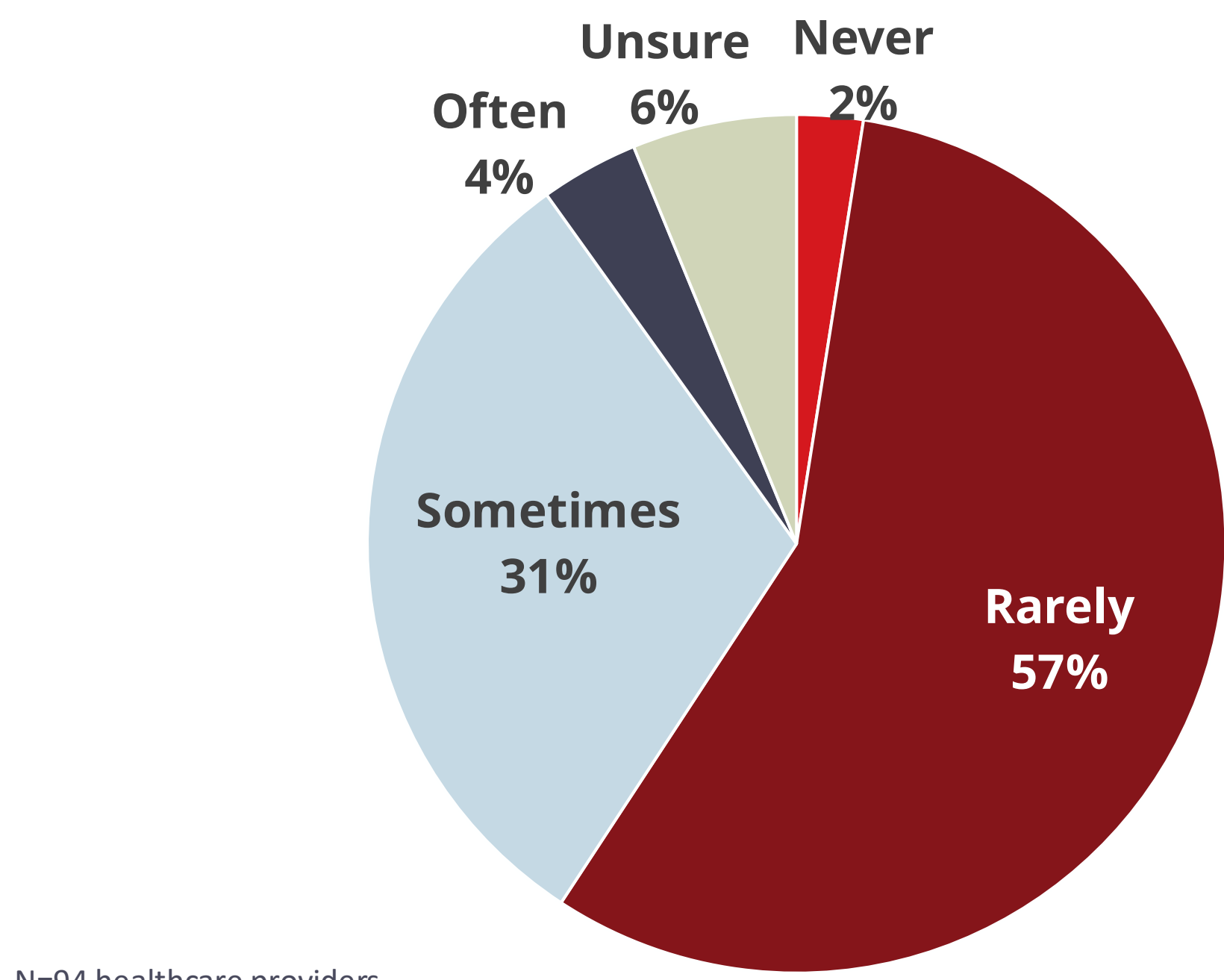


Figure 2. How often does securing a caregiver prevent patients from receiving CAR T?



N=94 healthcare providers



Figure 3. Would your ATC allow patients to hire a paid caregiver for CAR T?

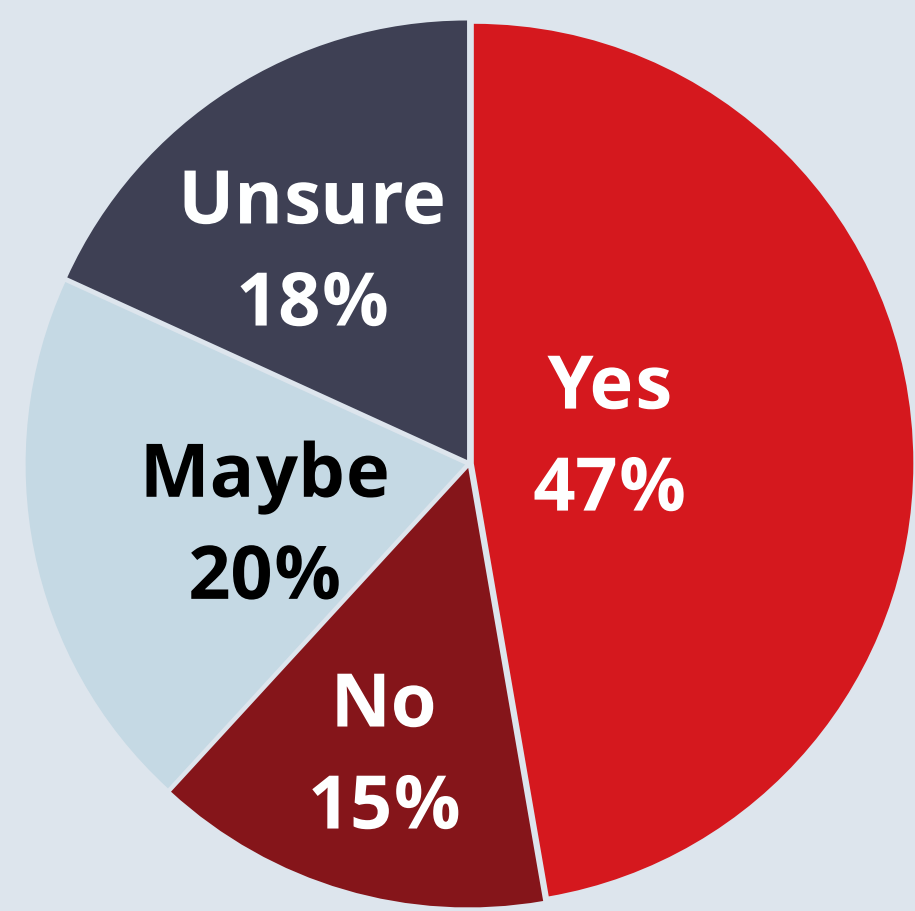
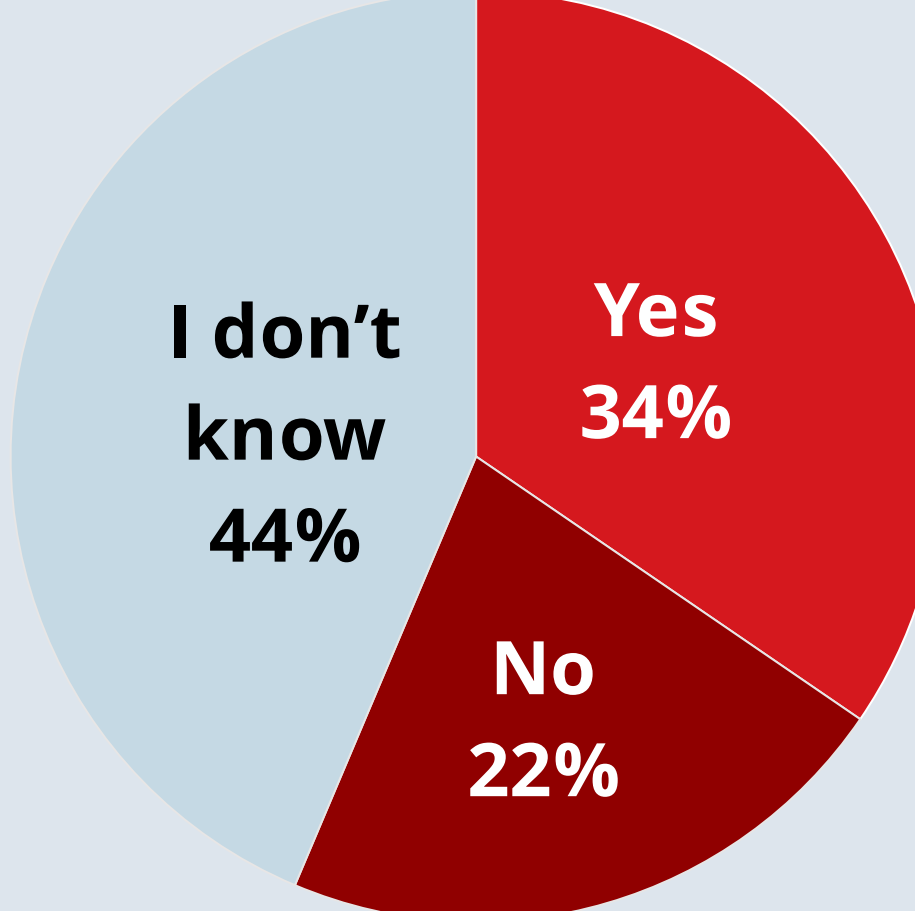
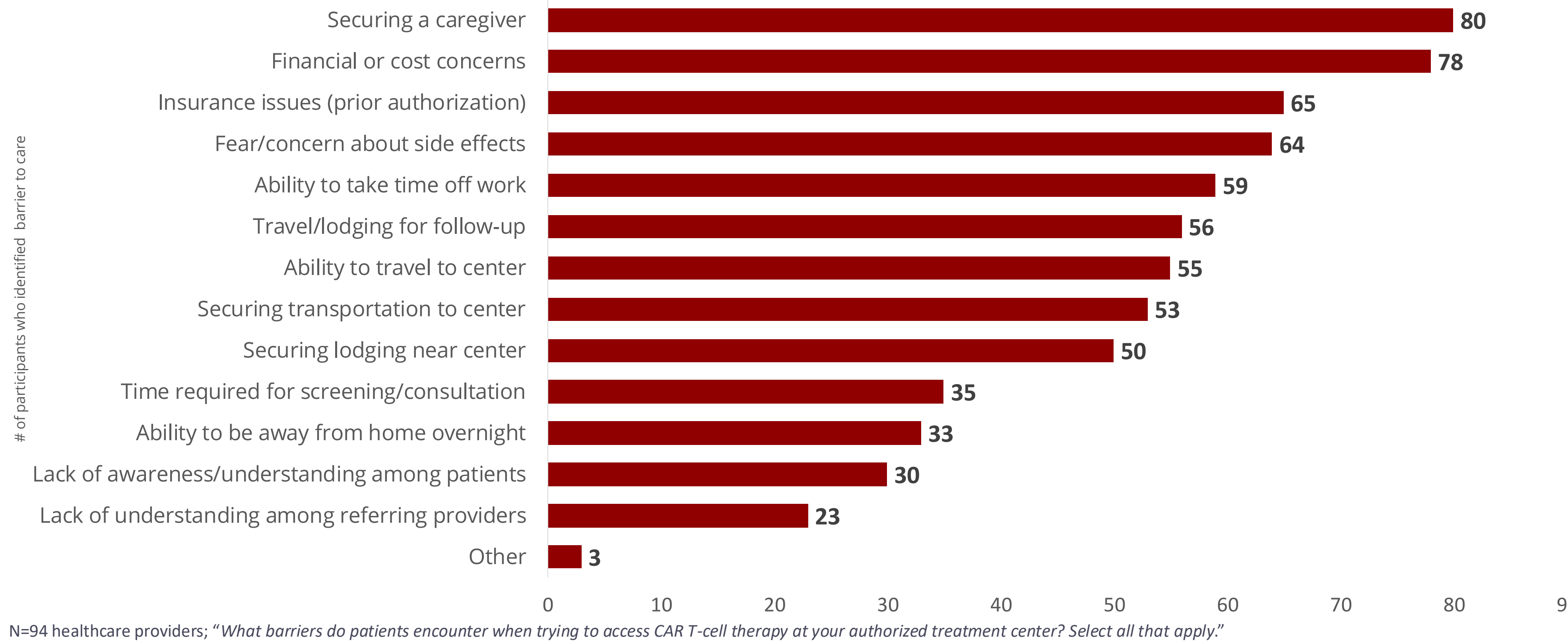


Figure 4. Have you ever had a patient at your ATC hire a paid caregiver?



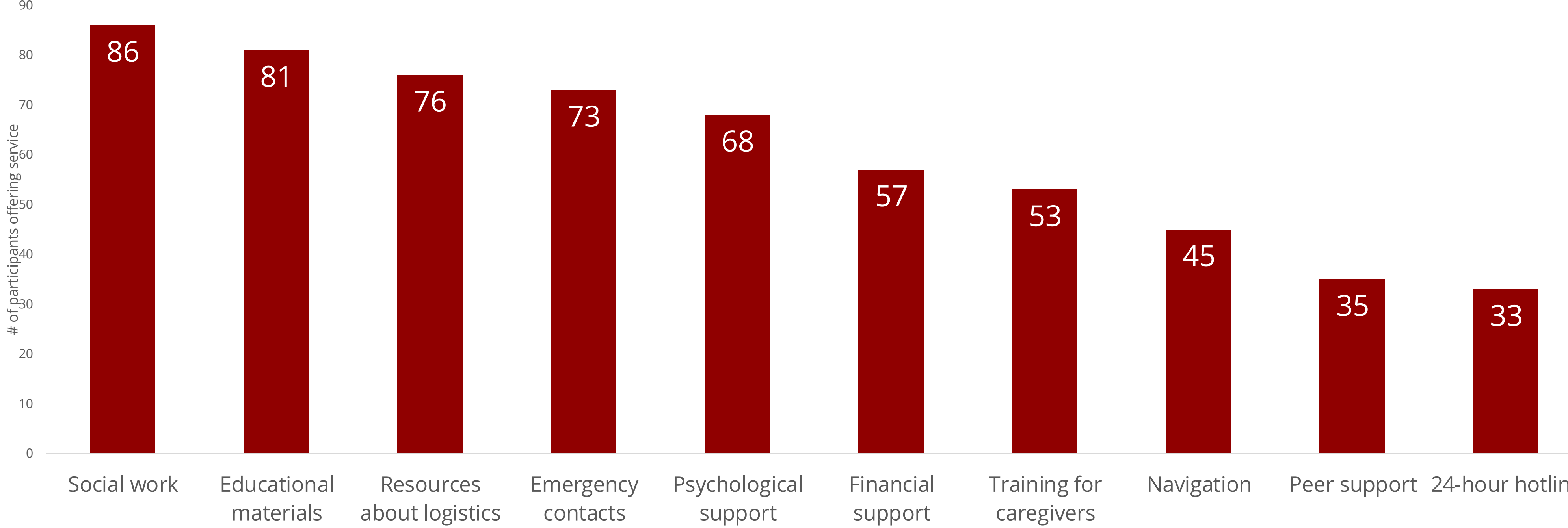
N=55 ATCs

Figure 5: Barriers to CAR T reported by HCPs at U.S. ATCs



N=94 healthcare providers; "What barriers do patients encounter when trying to access CAR T-cell therapy at your authorized treatment center? Select all that apply."

Figure 6: Resources provided to caregivers by HCPs at U.S. ATCs



N=94 healthcare providers; "What barriers do patients encounter when trying to access CAR T-cell therapy at your authorized treatment center? Select all that apply."

CONCLUSIONS & FUTURE DIRECTIONS

- Although most CAR T ATCs required that patients have a caregiver to monitor symptoms, specific requirements and supportive resources for caregivers varied widely across the U.S.
- Given that securing a caregiver was perceived as a significant barrier to care, patients may face disparate challenges accessing CAR T at different ATCs as they encounter different policies and access to support.
- Findings illustrate the need for more caregiving support, in addition to resources to help patients secure caregiving assistance.
- Peer-to-peer education among advanced practitioners in CAR T may help strengthen caregiving resources provided across ATCs and strategize how to facilitate caregiving support for patients with limited social support.
- Investing in supportive resources for caregivers and helping patients find caregiving support may help expand access to CAR T.

References:
1. Khan, S. H., Choi, Y., Veena, M., Lee, J. K., & Shin, D. S. (2024). Advances in CAR T cell therapy: antigen selection, modifications, and current trials for solid tumors. *Front Immunol*, 15, 1489827. <https://doi.org/10.3389/fimmu.2024.1489827>
2. Mikhael, J., Fowler, J., Shah, N. 2022. Chimeric antigen receptor T-cell therapies: Barriers and solutions to access. *JCO Oncology Practice*, 18(12): 800-807. DOI: 1200/OP.22.00315.
3. Andersen, L. P., Quinn, R.J., Difilippo, H., Garfall, A. L., Porter, D. L., Meghani, S. H., & Deng, J. (2025). Factors Related to Long-Term Caregiving Burden Among Chimeric Antigen Receptor (CAR) T-Cell Recipients and Their Informal Caregivers. *Seminars in Oncology Nursing*, 41(5): 1519999. Doi: 10.1016/j.soncn.2025.151999.

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