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THE BURDENS ASSOCIATED WITH RECEIVING CAR T-CELL THERAPY: A QUALITATIVE STUDY OF CAR T PATIENTS & CAREGIVERS

A. Newell¹, E. E. Fortune¹, M. Gonzalo¹, and M. C. Saxton¹

¹Cancer Support Community, Washington, DC



INTRODUCTION

Chimeric antigen T-cell therapy (CAR T) offers potential progression-free survival for cancer patients, but only 2 in 10 eligible patients receive the therapy.¹

Previous studies identified insurance access, timely referrals, financial toxicity, and 24/7 caregiving requirements as barriers to CAR T, but it remains unclear what barriers are most **significant for patients and caregivers.**

OBJECTIVES

Assess patients & caregivers experiences accessing CAR T-cell therapy, including:

1. **Barriers** to accessing CAR T
2. **Psychosocial and financial burden** associated with receiving CAR T

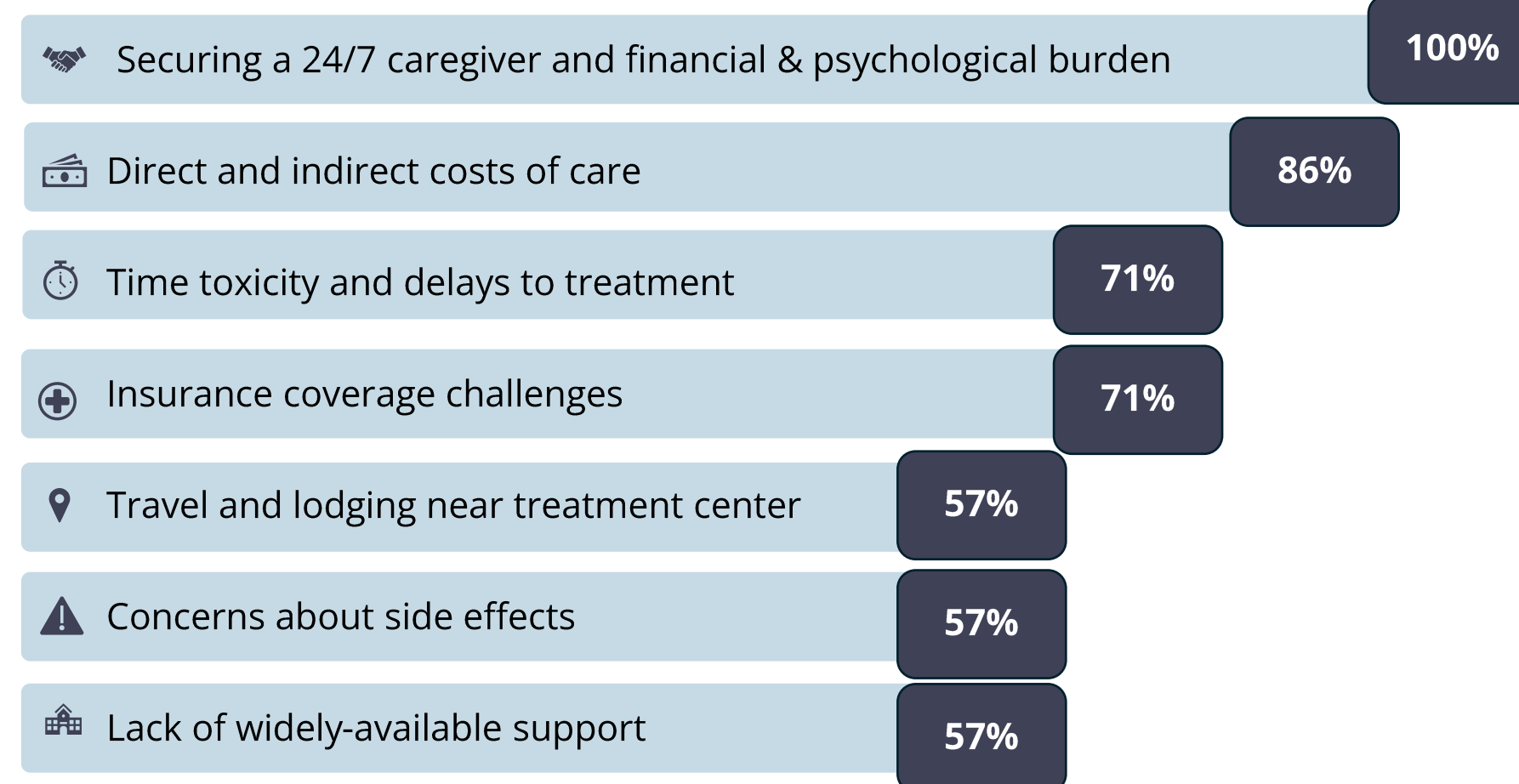
METHODS

We conducted **interviews** with CAR T experts and a **focus group** with patients and caregivers.

- We interviewed CAR T providers, advocates, and navigators (*n*=4) to design the focus group discussion guide and sampling strategy.
- Discussion topics included treatment history, CAR T timeline and experience, caregiving, follow-up care, and unmet needs.
- Participants included 5 women and 2 men, aged 35-72 years old, 5 White, 1 Latino, and 1 Black, with diverse diagnoses including DLBCL, CNS lymphoma, follicular lymphoma, and multiple myeloma. (*n*=7)

RESULTS

Patients faced multiple barriers to care



% of participants who reported theme (*n*=7).

"I had to travel to [academic cancer center] to do my CAR T-cell therapy **about a five-and-a-half-hour drive, so not an easy experience...** (Follicular lymphoma patient)

"There wasn't one person who could just come and live with me for a month... I actually had friends who were afraid to do it. More than one person just said, "I just can't handle it..." (DLBCL patient)

"We were concerned about the cost... we still had to pay \$12,000... And I was laid off from my job one-year post-CAR T... **that was a really stressful time.**" (Caregiver of DLBCL patient)

Patients and caregivers who were referred to a distant academic cancer center from their primary oncology care site incurred greater costs related to travel, lodging, and necessities, and spent more time travelling to and from care.

Academic center for prior cancer care & CAR T

"I'm about **45 minutes away from the facilities**, but they were able to accommodate me to keep me from going back and forth. That's why my hospital stay was about 4 weeks... I also get the IVIG also every 6 months, because of my immune system." (DLBCL patient)

Community site → nearby academic center for CAR T

"He [patient] had to go in **2 to 3 times a week for the first 3 weeks** after infusion once he was released. And he'd be there for like **3 to 4 hours**, so they'd like run labs monitor him, they'd wait for the labs to come back to see if he needed any like infusions of some sort. **Luckily, we only live like 15-20 minutes** from [academic cancer center]." (Caregiver of DLBCL patient)

Community site → distant academic center for CAR T

"[Academic cancer center] is **100 miles away from us and about 2 hours driving...** And he's [patient] getting pentamidine **once a month**, and that's where we travel to [academic cancer center], and **it takes all day...** He's getting IVIG once a month... which takes all day, but we can still stay local... And they're monitoring his blood count once a week here [at community cancer center]." (Caregiver of DLBCL patient)

Over half (56%) of participants valued the expertise of academic centers to manage **side effects**, which was one of their top concerns about receiving CAR T.

CONCLUSIONS

- For patients and caregivers, **travel time** and **cost**, difficulties with **care coordination**, securing a **24/7 caregiver**, and the perceived **risk of side effects** are the most significant barriers to CAR T.
- Having to travel long distances to academic cancer centers away from patients' primary care sites for CAR T-cell therapy compounded the **psychosocial** and **financial burden** associated with receiving CAR T for patients and caregivers.
- The time, financial, and social toxicity associated with CAR T-cell therapy impacts patients, caregivers, families, and **communities.**
- CAR T should be made available at **more care sites** and **supportive resources** should be made more widely available to reduce the financial, logistic, and psychosocial burden of CAR T and improve access to this innovative therapy.

REFERENCES

¹ Hoffmann MS, Hunter BD, Cobb PW, Varela JC, Munoz J. Overcoming barriers to referral for chimeric antigen receptor T cell therapy in patients with relapsed/refractory diffuse large B cell lymphoma. *Transplant Cell Ther.* 2023;29(7):440-448. doi:10.1016/j.jtct.2023.04.003

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QUESTIONS?

Abigail Newell, PhD
anewell@cancersupportcommunity.org

