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704. CELLULAR IMMUNOTHERAPIES: EARLY PHASE CLINICAL TRIALS AND TOXICITIES

The burdens associated with receiving CAR T-cell therapy: A qualitative study of CAR T patients and caregivers

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Abstract *Background*: Chimeric antigen receptor T-cell therapy (CAR T) offers potential progression-free survival among patients with hematologic cancer, but only 2 in 10 eligible receive the therapy. Previous studies identified access to insurance, timely referrals from primary cancer care team, financial and time toxicity, and risk evaluation, and mitigation strategies (REMS) & caregiving requirements as primary barriers to CAR T. This study aimed to assess the patient and caregiver experience accessing CAR T therapy, especially the logistic and financial challenges associated with travelling to an academic cancer center for CAR T, care coordination across treatment centers, and the resulting psychosocial burden of therapy.
Methods: We conducted an exploratory qualitative study including four interviews with CAR T providers, policy experts, and navigators, and a focus group with five patients who had received CAR T therapy and two caregivers for CAR T patients. We selected the focus group discussion topics (treatment history, patient-provider communication and decision-making, CAR T timeline and experiences, caregiving and follow-up care, and unmet needs) based on findings from interviews with experts. Focus group participants (5 women, 2 men; 35 - 72 years-old; 5 White, 1 Latino, and 1 Black/African American) represented various hematological cancers (diffuse large B-cell (4), follicular (1), and central nervous system (1) lymphomas, and multiple myeloma (1)), resided in rural (2), suburban (3), and urban (2) communities, received primary cancer treatment at academic (4) and community (3) cancer centers, and all received CAR T at academic centers). The interview and focus group transcripts were coded in *NVIVO 14* using an iterative deductive-inductive approach based on the study's aims and emergent themes in the data.
Results: Participants faced significant barriers to receiving CAR T, namely obtaining insurance approval and coverage (4/7), securing caregivers (4/7), financial and logistic issues (6/7), lack of supportive resources (6/7), and perceived risk of side effects (6/7). The financial impacts of receiving CAR T, such as time away from work and travel costs, and psychosocial impacts, such as the stress of caregiving and coordinating care, persisted for patients, caregivers, and their families in the months after treatment. Participants wanted social support before and after CAR T (6/7) and emotional support for caregivers (7/7). However, participants' experiences with CAR T varied by their site care: those referred to a distant academic center from their local community cancer center (2/7) incurred greater costs related to travel & lodging and spent more time travelling to and from care than those who received CAR T at nearby academic centers (5/7). After receiving CAR T, those who had to travel to distant academic centers struggled to coordinate care between two healthcare teams and spent over two hours round-trip travelling to follow-up appointments, which exacerbated the psychological and financial distress of initially receiving CAR T. All participants agreed that receiving CAR T at their primary care site, including community cancer centers, would reduce the financial and psychosocial burden of CAR T. However, some participants (4/7) expressed concern about the capacity of community cancer centers to provide specialized follow-up care for side effects, which participants perceived as common and severe.
Conclusions: Patients and caregivers face significant challenges accessing CAR T, including travel and lodging costs, care team coordination, caregiving requirements, and perceived risk of side effects. Having to travel long distances to academic cancer centers away from patients' primary care sites for CAR T compounded the financial and time toxicity associated with receiving treatment for patients, caregivers, and their families. Given the potential community-wide burden of receiving CAR T therapy, treatment should be made available at more care sites, including community-based sites, to reduce the financial, logistic, and psychosocial burden of CAR T. Given the study's limited sample size and diversity, future studies should investigate the barriers to accessing CAR T among generalizable samples, including those who are eligible but did not receive CAR T. The

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next phase of this study will examine patients' experiences receiving therapy at community centers to inform policy campaigns to expand access to CAR T.

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