UNDERSTANDING PATIENTS' AND CAREGIVERS' EXPERIENCES OF OUTPATIENT CAR T-CELL THERAPY: PRELIMINARY FINDINGS

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BACKGROUND

CAR T-cell therapy delivery is increasingly shifting to the outpatient setting, creating an evolving experience for patients, caregivers, and providers.

The benefits and challenges of an outpatient-based administration is not fully understood.

Objective

- We present the preliminary results of multi-modal ongoing investigation of the experiences of patients receiving CAR T in the outpatient setting and their caregivers.

METHODS

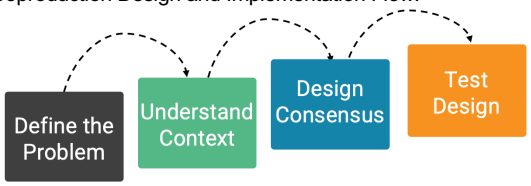
Community-engaged qualitative research methods

- Partnership Academy (n=4 participants): a facilitated community dialogue
- CAR T patient or caregiver interviews (n=5)

Co-design sessions

- Four co-design sessions with providers (n=3), patient and caregiver (n=2), medical student (n=1), and research partners (n=2)
- *This is an ongoing working group*

Coproduction Design and Implementation Flow:



RESULTS

Preparation for what's ahead

Patients' and caregivers' information preferences may differ

BARRIERS
- Unclear timeline
- Lecture-style materials

FACILITATORS
- Tailored education
- Take-home notebook
- Time for questions

"I don't want to know the details, [caregiver] can take care of it. I don't want to know too much."

PATIENT

"I liked the information, I liked it laid out scientific black and white"

CAREGIVER

Readiness for unexpected

Hard to prepare for a path with no certain timeline

BARRIERS
- Day-to-day monitoring
- Changing timelines
- Daily-life interference
- Emotional toll

FACILITATORS
- 24/7 access to the team
- Peer support community

"When do I need to tell my boss… When do I need to tell my mom she needs to take our kid for two weeks?"

CAREGIVER

Access to support resources

Non-medical demands fall on patients and caregivers

BARRIERS
- Financial hardship
- Disability paperwork delays
- Caregiver burden

FACILITATORS
- Wraparound services
- Mobilized resources
- Shared caregiving

"When you start missing like a couple weeks' paychecks… you don't have the money there to pay those bills."

PATIENT

CONCLUSIONS

Outpatient CAR T administration may create discrepancies in readiness and resource access relative to inpatient care.

Patients and caregivers report:

- Variable needs, knowledge gaps, and preferences.
- Impacted by physical, emotional, financial burdens and daily living needs

A systematic assessment of patient and caregiver needs throughout treatment, and a tailored curriculum could address these gaps.

NEXT STEPS

Develop and implement structured questions that encapsulate the patient and caregiver experience.

Examples may include:

- ***Preparation:*** *"Do you feel you have all the information you need to move forward? If not, do you know who to contact?"*
- ***Readiness:*** *"Did things go as planned?"*
- ***Access:*** *Intake questions about work leave, childcare, driving, day-to-day life*

Automate EMR-based question delivery

Ongoing investigation to assess and address caregiver-specific needs and connection to support

