

# Personalized CAR T Navigation: Bridging Gaps in Patient and Caregiver Needs

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## BACKGROUND

The Cancer Support Helpline at Cancer Support Community (CSC) provides proactive navigation services for cancer patients and their loved ones across the US and Canada. Through telephone, chat and video communication, navigators empower patients, caregivers, and families to manage social, emotional, practical, and financial barriers to their cancer care through all phases of the cancer experience.

Built on the Expanded Chronic Disease Navigation framework, our evidence-based navigation program collaborates with centers of excellence to provide patient- and caregiver-centered evaluations and interventions focused on core navigation goals:

- Distress screening and psychosocial assessment
- Identification of barriers
- Coordination of care
- Timely education

## INTERVENTION

CSC recognized that patients and caregivers undergoing CAR T-Cell Therapy benefit from specialized 1:1 support throughout their treatment course. The Cancer Support Helpline customized the already established navigation framework to support this specific population.

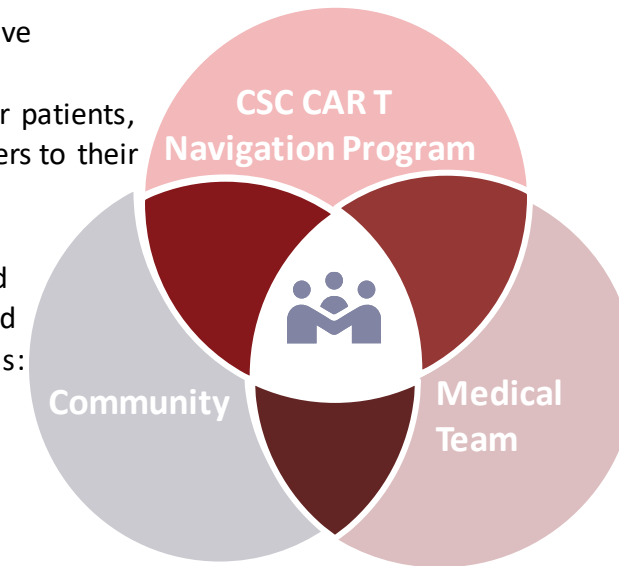
Program components include:

- Outreach to both CAR T treatment centers and community-based oncology programs creating hospital referral partnerships, eliciting timely referrals
- Proactive patient navigation provided by a licensed clinical oncology social worker at key points of their CAR T experience, ensuring connection to resources and improved outcomes
- Distress screening and assessment (using the customized, validated distress screening tool CancerSupportSource®)
- Referrals and linking to support, including referrals to 190 local CSC and Gilda's Club locations for in-person services
- Education on CAR T-related psychosocial concerns such as coping with side-effects, fear of relapse, post-treatment survivorship, and caregiver support
- Spanish speaking navigators and a 200+ language interpreter service

## SUMMARY & APPLICATION

Through 1:1 personalized navigation support, the CSC CAR T Navigation Program provided the following support:

- Practical – travel to treatment center, work concerns including FMLA and disability options, family/life balance
- Financial – affording travel and lodging, taking time off from work, copays, insurance coverage and medication costs
- Collaborated with medical teams to submit appeals as indicated and obtaining insurance coverage for CAR T treatment
- Emotional – communicating to friends and loved ones, managing ones' own and others' emotions including stress and uncertainty
- Preparing for treatment
- Coping with symptom burden
- Navigation for those seeking treatment not yet connected to CAR T Program
- Proactive follow-up to ensure ongoing resource & support needs are met during and post treatment



*"The social and emotional support of regular conversations with an extremely thoughtful, competent, caring, empathic social worker was valuable beyond words." - participant feedback*

## RESULTS

### Respondent Characteristics

Between March 1, 2022, and October 17, 2023, navigators assisted 51 unique individuals. There were over 200 calls and emails to participants.

#### Age Range (n=40)

- 30-79

#### Gender (n=50)

- Women 72% Men 28%

#### Race/Ethnicity (n=35)

- White 80%
- Black/African American 14%
- Hispanic/Latino 6%

#### Cancer Type (n= 48)

- Lymphoma 48%
- Multiple myeloma 35%
- Leukemia 8%

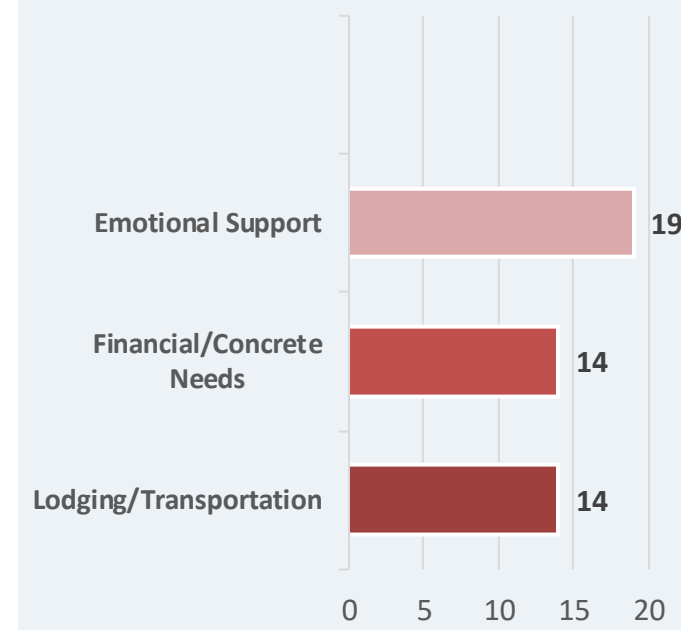
#### Participant Type (n=43)

- Patient 67%
- Caregiver 28%
- Healthcare Professional 5%

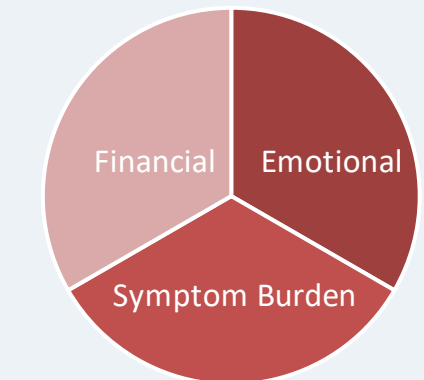


- The Frankly Speaking About Cancer (FSAC) series provides in-depth coverage of topics relevant to those affected by cancer that are often not otherwise available in a comprehensive format. There are materials available for specific cancer types, as well as pan-cancer topics such as Clinical Trials, Cost of Care, and Immunotherapy.
- FSAC: CAR T is a comprehensive psychosocial educational program that provides information about what to expect, side effect management, and social and emotional challenges of CAR T Cell treatment.

### Top 3 Contact Reasons



### Top Reported Areas of Distress/Barriers to Care



**Financial:** Rx & Co-pay assistance, Transportation & Lodging  
**Symptom Burden & Impact:** Fatigue, Pain, & Cognitive Changes  
**Emotional:** Anxiety, Isolation, & Depression

## FINDINGS & LOOKING FORWARD

**Large unmet needs exist for patients who have been referred to a CAR T center by their primary oncologist but have not yet been approved for CAR T-cell therapy**

**CSC plans to continue & expand this program to:**

- Facilitate access to CAR T consultations
- Offer ongoing support to CAR T survivors and caregivers, including assistance for thriving beyond treatment
- Increase education to identify patients not in treatment that would benefit from CAR T-Cell Therapy
- Continue to extend an extra layer of support to the medical teams providing life-saving CAR T-Cell Therapy Treatment

