Caregiver Support Programs as Core Infrastructure in Cancer Care

Overview

Lessons from CAR T-cell therapy for integrating caregiver programs into oncology delivery systems

Family caregivers are essential participants in cancer care delivery, particularly in complex, high-acuity treatments such as CAR T-cell therapy. Yet health care systems continue to rely on caregivers as an unpaid, under-assessed, and under-supported extension of the clinical workforce. The ACS–Kite Year 1 report demonstrates that CAR T programs have developed processes to identify and educate caregivers, but these processes are largely oriented toward patient safety and treatment eligibility rather than caregiver well-being. Few programs offer comprehensive caregiver-specific services, instead, expecting patient-centric services to meet the needs of caregivers. Validated caregiver assessment tools, structured documentation of caregiver interventions, and caregiver outcomes are essentially absent.

Dedicated caregiver programs should be treated as core oncology infrastructure, not optional supportive services. Health systems, payers, accrediting bodies, philanthropic partners, and policymakers should align around a minimum caregiver support standard that includes caregiver identification, structured assessment, competency-based training, navigation, financial and logistical support, psychosocial services, respite planning, electronic health record (EHR) documentation, and caregiver-level quality metrics.

This requires robust engagement from stakeholders moving forward towards a common goal of making caregiving a core infrastructure in cancer care.

Caregiver Support is a Health System Issue

Cancer care has shifted toward more complex, outpatient, home-based, and longitudinal models of treatment. This has increasingly transferred clinical and logistical work to caregivers. The expectation is that caregivers conduct symptom monitoring, medication management, coordinate transportation and navigate appointments and care coordination across a complex health care system.

According to research, caregivers provide substantial unpaid care and as a result experience financial, emotional, and health-related consequences. AARP and the National Alliance for Caregiving estimated that 63 million Americans were caregivers in 2025, underscoring the scale of caregiving as a national health system issue.[2] (AARP)

Cancer caregiving is often episodic, high-stakes, and clinically complex. The National Alliance for Caregiving's cancer caregiving report describes cancer caregiving as an "intense, episodic, and challenging care experience," emphasizing the distinctive burden associated with treatment transitions, symptom crises, and care coordination. Further, the psychological burden that caregivers face with a loved one experiencing cancer compounds the intensity of the burden.[3] (National Alliance for Caregiving)

CAR T-cell therapy illustrates the broader problem in concentrated form: treatment access and safety often depend on the availability and capacity of a caregiver. Although caregiver requirements are outlined in CAR T and other cellular therapy services, our report found

that caregiver-specific resources and support services in CAR T are underdeveloped despite caregivers being central to treatment feasibility, outpatient monitoring, and post-treatment safety.

Current Health System Models Fail Caregivers

Caregiver availability is an implicit eligibility criterion for many advanced cancer therapies. While health systems often recognize caregivers as essential to care delivery, caregiver support is not operationalized as a defined clinical function. This produces a mismatch between caregiver responsibility and caregiver support.

Requirements for 24-hour monitoring with complex cancer therapies put significant emotional and logistical burden on caregivers with little health system support to offset the cost of time off work, travel and lodging, or respite care. The financial strain experienced is not insignificant. These factors impact the willingness of caregivers to commit to care for services like CAR T-cell therapy and literally become a barrier to patient's accessing to life-saving therapies. An estimated 2 in 10 patients who are medically qualified for CAR T receive this therapy, and absence of a caregiver is a primary reason for ineligibility

When patients do have caregiver support, most health systems function with the caregiver as a peripheral consideration in the treatment plan and execution. While caregiver presence is documented, little is done to assess the caregiver as a unique individual in the treatment plan. Without routine caregiver screening, programs cannot reliably identify burden, distress, financial strain, health-related social needs, functional limitations, competing obligations, or caregiver readiness. National caregiver policy literature has long recommended that health care and human service systems identify, assess, and support

family caregivers as part of routine care, however this clinical approach is missing in most CAR T-cell therapy programs.[4] (National Academies)

A National Survey of CAR T-Cell Therapy Programs

In a recent survey of 153 CAR T-certified centers, across a range of settings, including academic medical centers, NCI-designated centers, and community oncology programs, a core finding was that caregiver support is compliance-oriented, not caregiver centered.

Most CAR T programs have processes to identify caregivers and provide education, but these processes are primarily designed around enabling patient readiness, toxicity monitoring, and safety. The report found that caregiver support systems rarely address caregiver mental health, role strain, financial toxicity, or respite needs. Further, CAR T care delivery systems are ill-equipped to provide caregiver-dedicated services with few programs exhibiting dedicated staffing or formal clinical pathways to meet caregiver needs.

An Infrastructure Gap

While 74% of programs surveyed reported having caregiver education and training materials, most lacked dedicated caregiver staffing, dedicated caregiver service lines, structured support pathways, or caregiver-specific metrics. Social workers were the most common team members supporting caregiver-related functions, but these responsibilities were usually layered onto existing roles rather than supported through dedicated staffing.

A Documentation Gap

Only 23% of systems reported using validated instruments to assess caregivers, most

using assessment tools designed to assess patient distress. No program identified a validated caregiver burden scale as part of routine caregiver screening. Most caregiver information was documented in the *patient* Electronic Health Record (EHR) rather than a dedicated caregiver record in the EHR.

Education and Training Gap

Caregiver education was widespread but variable. Most programs rely on handouts or brochures to educate caregivers, but few programs use structured teaching interventions such as group teaching or videos, and formal competency assessment of training effectiveness is nearly absent.

Gaps Lead to Shortfalls in Supportive Care

Educational materials designed to improve knowledge about the patient's treatment plan can improve awareness, but they do not provide caregivers with dedicated information about their unique role in this care continuum. Little support is provided to help caregivers manage their own unique needs, reduce burnout, address financial strain, or ensure backup coverage when a caregiver becomes unavailable. This is a failure of the health care system to provide whole person care to those facing the most complex cancer therapies.

When caregiver information is documented only in narrative notes or patient records, it is difficult to retrieve, analyze, stratify, or use for care planning. This limits care coordination, quality improvement, research, and business-case development.

The FDA eliminated REMS requirements for currently approved BCMA- and CD19-directed

autologous CAR T-cell therapies in June 2025, stating that REMS was no longer necessary and that the change would reduce burden on health care delivery systems. This makes it even more important for health systems to distinguish between regulatory compliance and durable caregiver support infrastructure. Safety monitoring may evolve, but caregiver support needs remain.[5] (U.S. Food and Drug Administration)

Durable Solutions

A clinical program that supports caregivers of patients receiving complex cancer therapies, such as CAR T, is valuable, but program implementation also serves the greater good of all cancer care service lines. A framework for comprehensive caregiver programs include;

Universal Caregiver Identification and Screening: Caregiver identification should occur at diagnosis or treatment planning and be updated at routine intervals for surveillance to identify meaningful changes in needs. Every oncology program should have a standard process to identify the primary caregiver, backup caregiver, caregiver relationship, availability, language needs, health literacy needs, and role expectations, and develop standard operating procedures to support screening intervals.

Structured Caregiver Assessment: Caregiver assessment should include validated or standardized domains that align with the greatest areas of caregiver unmet needs, this includes; caregiver burden, financial strain and employment disruption, transportation, lodging, food, utilities, and childcare needs, health literacy and language access, medication management capability, symptom monitoring and escalation readiness, availability of backup caregiver support, emotional health, burnout risk, and social isolation.

EHR-Integrated Caregiver Documentation: A minimum data set outlining caregiver identity, role, contact permissions, training completion, competency verification, burden screening results, health related social needs (HRSN), referrals placed, services used, and follow-up status should be developed and collected in structured caregiver fields in the EHR. This may be part of the patient's medical record, or a unique caregiver record, but should be developed in a way that data can be updated longitudinally and used for care planning, referrals, reporting, and quality improvement.

Dedicated Caregiver Navigation: A caregiver navigator or caregiver support specialist could coordinate assessment, education, referrals, resource connection, financial support, lodging, transportation, respite planning, and follow-up. Navigation is prevalent in cancer care delivery, but the specific roles of the navigator should be defined to specifically address caregivers, specifically in high intensity, complex therapies, such as CAR T.

Psychosocial and Behavioral Health Support: Programs should provide caregiver-specific counseling, support groups, peer support, distress screening, burnout prevention, and referral pathways to psycho-oncology, social work, chaplaincy, palliative care, and community-based supports.

Financial and Logistical support: Screening and rapid-response pathways should be developed to identify needs for transportation, lodging, food, parking, utilities, lost wages, childcare, and emergency assistance. Financial assistance programs are a compelling model for supporting caregiver unmet practical needs. A further logistical support consideration is for respite care. Understanding the limitations of caregiver availability, identifying backup caregivers, planning for caregiver illness or overload, and establishing escalation procedures when caregiving arrangements become unstable.

The Case for Sustainable Caregiver Programs

Sustainability comes from intentional design and purposeful implementation. Metrics that help track caregiver outcomes, clinical process measures, and patient-linked outcomes describe the value of the program in the health system as well as to the patient care outcomes.

Potential Measures

Domain	Example Measures
Access	Percentage of patients with identified caregiver and backup caregiver
Assessment	Percentage of caregivers screened for burden, distress, and HRSN
Training	Training completion, competency verification, teach-back documentation
Support	Referrals to financial, lodging, transportation, respite, psychosocial services
Outcomes	Caregiver burden, distress, unmet needs, satisfaction, confidence
Cancer Care Outcomes	Treatment delays, ED visits, unplanned admissions, adherence to monitoring, completion of therapy
Equity	Caregiver needs by geography, parental status, income, language, race/ethnicity, distance from center

Maturity Model for Caregiver Programs

Foundational

- Identify and document caregiver characteristics
- Provide standardized caregiver education
- Screen for caregiver burden and HRSN
- Refer to social work, navigation, financial counseling, and community resources
- Document caregiver support needs in structured EHR fields

High Risk Enhancements

For CAR T, transplant, high-dose chemotherapy, complex surgery, advanced disease, and prolonged outpatient regimens:

- Require caregiver readiness assessment
- Use competency-based training and teach-back
- Establish emergency escalation protocols
- Provide lodging, transportation, and financial navigation
- Develop backup caregiver plans
- Track caregiver-level outcomes

Intensive Programs for High-Need Dyads

For patients and caregivers with high financial strain, distance from care, low support, high distress, limited health literacy, or unstable caregiving arrangements:

- Assign caregiver navigator
- Provide proactive psychosocial support
- Offer rapid-response financial assistance
- Coordinate respite or paid caregiving resources when available
- Conduct interval reassessment across the care continuum

Policy Considerations: Advancing Opportunity

The 2022 National Strategy to Support Family Caregivers established a federal framework for improving caregiver recognition, assessment, respite, financial security, workplace supports, and integration into health care and long-term services systems. This creates a policy platform for oncology-specific caregiver program development. (NAC)

CMS has adopted Medicare payment mechanisms beginning in 2024 related to **Caregiver Training Services**, **Community Health Integration**, **Principal Illness Navigation**, and related services, signaling that caregiver training and social-needs navigation are increasingly recognized as reimbursable care delivery functions.[6] (Centers for Medicare & Medicaid Services)

CMS's Accountable Health Communities Health-Related Social Needs Screening Tool provides a standardized approach to identifying needs such as housing instability, food insecurity, transportation problems, utility needs, and interpersonal safety. However, caregiver-specific oncology programs need to go beyond patient HRSN screening to assess caregiver burden, capacity, training needs, emotional strain, financial toxicity, and backup-care planning.[6] (Centers for Medicare & Medicaid Services)

Policy Options

Audience	Description
Health Systems	Establish caregiver support as a formal oncology service line or cross-cutting supportive care function including; dedicated staffing, EHR documentation, caregiver metrics, and clear referral pathways.

Payers	Explore pilots for payment models that reimburse caregiver assessment, training, navigation, psychosocial support, and care coordination when caregiver participation is necessary for safe outpatient care. CMS's caregiver training and navigation-related payment policies create a starting point for broader oncology implementation.[6] (Centers for Medicare & Medicaid Services)
Accrediting Bodies & Quality Organizations	Consider caregiver identification, assessment, documentation, and training as quality indicators for complex oncology care. Leverage quality improvement projects to determine appropriate standards for caregiver program and consider accreditation standards.
Policymakers	Support paid leave, caregiver tax credits, respite services, transportation and lodging benefits, and protection against caregiver-related financial toxicity.[7] (NASHP)
Cancer Professional Societies	Develop oncology caregiver standards, validated caregiver assessment pathways, training competencies, and implementation toolkits tailored to high-risk treatment contexts.
Philanthropy & Industry Partners	Accelerate caregiver program development by funding demonstration projects, caregiver navigation pilots, financial assistance funds, EHR innovation, and multi-site evaluation.

High Quality Caregiver Care

Cancer care already depends heavily on caregivers, but health systems have not yet accepted full responsibility for supporting them. Patient-centered approaches to cancer care should be expanded to include caregivers. Dedicated caregiver programs are needed to protect patient safety, improve access to advanced therapies, reduce inequities, support caregiving sustainability, and recognize caregivers as essential partners in cancer care delivery. Broad stakeholder involvement is needed to create the system of care that is needed to support high quality caregiver care.

Resources

American Cancer Society

- **Developing Caregiver Clinical Services: A Toolkit for Cancer Centers and Staff:** https://www.cancer.org/content/dam/cancer-org/cancer-control/en/toolkits/caregiver-clinic-toolkit.pdf/.

National Cancer Institute

- **Financial Toxicity and Cancer Treatment (PDQ®)–Health Professional Version:** https://www.cancer.gov/about-cancer/managing-care/track-care-costs/financial-toxicity-hp-pdq?utm_source=chatgpt.com

- **Informal Caregivers in Cancer: Roles, Burden, and Support (PDQ®)–Health Professional Version:** https://www.cancer.gov/about-cancer/coping/family-friends/family-caregivers-hp-pdq?utm_source=chatgpt.com

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