

Location Matters: Expanding Advanced Practice Provider Roles to Increase Access to Specialized Adolescent and Young Adult Oncology Care

COURTNEY HENNELLY, MS, APN, FNP-BC, and
PAULETTE KELLY, MSN, NP, FNP-BC, CPN, CPON, ONC

From Memorial Sloan Kettering Cancer Center,
Basking Ridge, New Jersey

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found at the end of this article.

Correspondence to: Courtney Hennelly, 136
Mountain View Blvd, Basking Ridge, NJ 07932

E-mail: hennellc@mskcc.org

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Abstract

Adolescents and young adults (AYAs) with cancer represent a unique population requiring specialized care delivered by experienced providers. Beyond treatment challenges, AYAs face financial toxicity and limited access to expert care, both of which significantly impact outcomes. This article describes how expanding the role of advanced practice providers (APPs) from a major metropolitan cancer center to regional sites improves access, mitigates financial toxicity, and enhances the patient and family experience. The collaborative model connects regional APPs with the main center oncology team, ensuring seamless communication and alignment of care goals. Advanced practice providers, drawing on their expertise, provide high-quality, patient-centered care in the regional setting. This article presents an overview of institutional efforts to expand pediatric chemotherapy administration into outpatient regional sites, with a focus on AYA patients diagnosed with pediatric sarcomas. Case presentations highlight the unique needs of AYAs, the benefits of regionalized specialized care, and the strengths of a collaborative APP model.

In 2026, an estimated 88,120 new cancer cases will be diagnosed among adolescents and young adults (AYAs), with 8,940 deaths attributed to pediatric-driven cancers (National Cancer Institute, 2026). The AYA age group spans from 15 to 39 years,

a developmental period marked by major life transitions (National Cancer Institute, 2026). According to Erikson's Stages of Psychosocial Development, adolescents (ages 12–18) grapple with identity formation, while young adults (ages 19–40) navigate intimacy and relationships

(McLeod, n.d.). Cancer interrupts these developmental milestones, compounding distress and care needs.

Specialized outpatient oncology models have demonstrated multiple benefits, including continuity of care, clear prognostic understanding, improved goal setting, enhanced symptom management, treatment adherence, psychological support, and overall coordination (Brock et al., 2019). For over three decades, Memorial Sloan Kettering Cancer Center has prioritized ambulatory care, reserving inpatient admissions for the most complex cases. The successful implementation of outpatient pediatric care prompted discussions about expanding services to the established adult regional sites. The pediatric/AYA department reviewed catchment data on established patients and evaluated which regional sites could be utilized based on patient and caregiver interest. Since these regional sites were already operational, the expansion process involved collaboration across multiple departments, including administration, physicians, advanced practice providers (APPs), nursing, and facility management, all with a focus on the pediatric/AYA community.

This planning took several years and included the development of regional care protocols and staff education to ensure consistent, high-quality care across all locations. An expansion process was also featured in an article discussing AYA care at the Princess Margaret Cancer Centre in Toronto, Ontario (Smith et al., 2024).

Pediatric Regional Guidelines were created to facilitate the safe expansion of pediatric/AYA care to regional sites. Patient selection was determined by primary teams who assessed Lansky/Karnofsky scores, medical and psychological stability, age, and the individual needs of the patient. Staffing in the regional sites included training for nursing staff, which involved educational programs, competency assessments, and rotations through the main pediatric clinic in the city for hands-on management and chemotherapy administration training.

Experienced pediatric/AYA APPs were stationed at the regional sites to oversee chemotherapy treatments, triage medical issues, and provide ongoing support for patients/caregivers and staff. Additionally, staff were required to hold Basic Life

Support (BLS), Pediatric Advanced Life Support (PALS), and Association of Pediatric Hematology/Oncology Nurses (APHON) certifications. Collaborative relationships with local hospitals were also established to ensure access to emergency care for pediatric/AYA patients when necessary.

Expansion of pediatric and AYA outpatient services into regional sites brought care closer to home, reducing travel burdens and enhancing patient satisfaction. Onsite APPs were instrumental in guiding staff and helping patients and families adjust to care at the regional site. An informal survey sent to established patients and families regarding regional care revealed that 96% of patients and caregivers rated convenience and quality of care highly, with 100% indicating they would return for future care in the regional sites (Figures 1 and 2).

Thus far, this institution's experience has been positive; however, extensive planning and resources are required if implementing this model at other facilities.

UNIQUE CHALLENGES OF THE AYA POPULATION

Adolescents and young adults face poorer outcomes and greater quality-of-life challenges compared with pediatric or older adult patients (Avutu et al., 2022). Many are in high school or college, entering the workforce, building families, or establishing independence. This stage is a “pivotal period for educational, vocational, and social transition” (Parsons & Kumar, 2019). This is all disrupted by cancer treatment.

A qualitative study identified six key themes central to AYA cancer care: (1) social isolation and loss of independence; (2) uncertainty about the future; (3) desire for autonomy in care discussions; (4) need for caregiver and navigation support; (5) access to AYA-specific spaces; and (6) addressing LGBTQ+ concerns (Avutu et al., 2022). Access to expert care is another key concern that AYA patients report. Their medical and psychosocial needs are distinct from those of other age groups (Aime, 2024). Advanced practice providers are integral to assessing and coordinating the care that AYA patients require, which includes psychosocial support, fertility concerns, financial burdens, and end-of-life

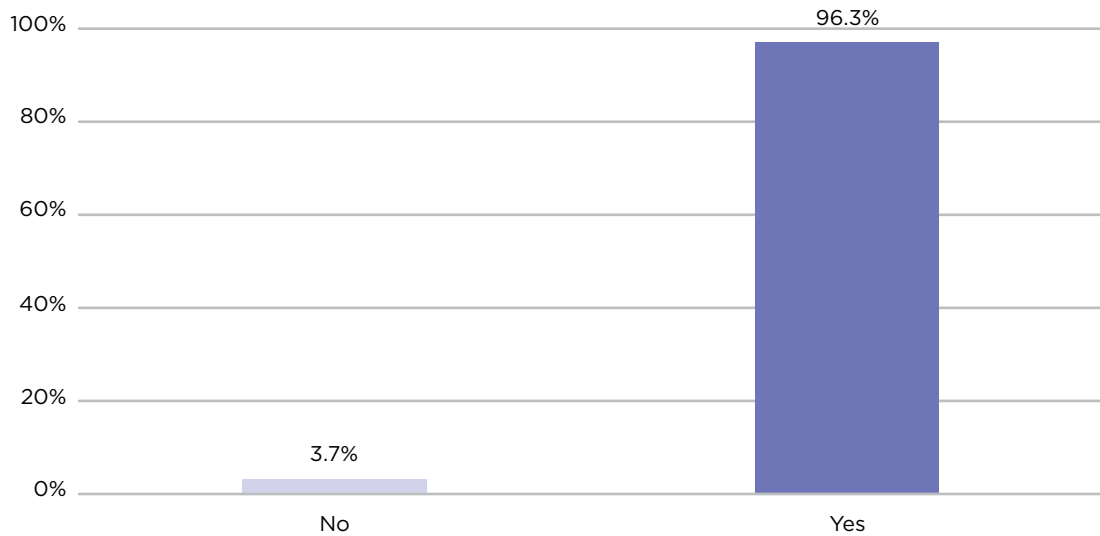
Overall, the care provided at the facility met my expectations

Figure 1. Patient/caregiver survey result regarding quality of regional care ($n = 27$).

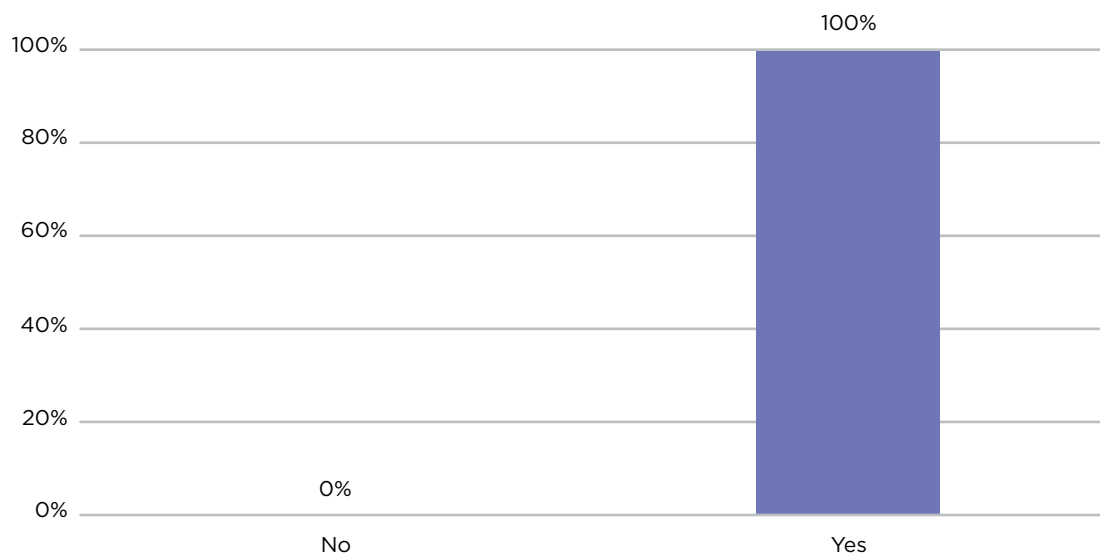
I would return to this facility for future care

Figure 2. Patient/caregiver survey result regarding plans on returning to regional site ($n = 27$).

discussions. At regional sites, this age group is open to utilizing telehealth to remain linked to their medical oncologist and to have additional consults with specialists for any identified needs (Parkes & Lee-Miller, 2022).

Financial toxicity is a significant additional burden that can reduce survival, decrease quality of life, and reduce treatment compliance (Skinner et al., 2023). Families often face income loss due to reduced work hours, unpaid leave, and out-of-pocket expenses (Ghazal et al., 2021). Travel to major cancer centers compounds these costs. For example, commuting into New York City from New Jersey or Pennsylvania averages \$65 per visit for tolls, gas, and parking, often repeated 4 to 5 times weekly. These stressors highlight the need to decentralize care and make specialized services accessible regionally.

CASE 1: 31-YEAR-OLD MALE

A 31-year-old male with metastatic Ewing sarcoma began treatment shortly after the birth of his first child. His regimen included 14 to 17 cycles of high-dose chemotherapy, with potential surgery and radiation. Although his family sought care at the metropolitan cancer center, commuting from their home in New Jersey was impractical with a newborn.

The patient's primary oncologist in New York partnered with a regional APP who provided daily in-person monitoring, symptom management, and coordination with psychiatry and pain specialists. The primary oncologist conducted telehealth visits as needed, maintaining oversight.

This model spared the patient a 3-hour daily commute, reduced financial strain, and allowed him to spend more time with his family. Services such as social work and radiation oncology consults were available through telemedicine. The patient and family reported high satisfaction with the convenience and quality of regional care while maintaining strong connections with the central oncology team.

CASE 2: 15-YEAR-OLD FEMALE

A 15-year-old female with osteosarcoma lived outside the metropolitan area. Her treatment included two complex surgeries requiring plastic reconstruction, complicating her recovery.

Her mother strongly advocated for regional care, citing the overwhelming toll of frequent travel into Manhattan: "The financial, physical, and emotional burden of commuting has been challenging. Traffic, parking, tolls, congestion pricing, and the discomfort of long car rides while nauseous created unnecessary suffering for our daughter." She also noted the strain on family dynamics, including missed time with siblings and spouse.

Receiving care at a regional site alleviated many of these challenges, improved the family's quality of life, and provided the patient with greater comfort and stability during treatment.

DISCUSSION

Expanding specialized oncology care into regional sites through a collaborative APP model offers benefits for AYA patients and their families. Reduced financial toxicity, improved access to expert care, care navigation, and greater patient satisfaction strengthen outcomes and quality of life. Families were enriched with the gift of time, as the burden of daily travel/cost to the major center was minimized.

Future opportunities include expanding clinical research within regional sites, developing dedicated AYA spaces, and increasing staff trained specifically in AYA oncology. Additionally, evaluating the benefits of AYA regional care in terms of appointment/treatment adherence and decreased hospitalizations would be valuable. Continued investment in APP roles will ensure sustained excellence, supporting both patients and local teams while maintaining integration with central cancer center expertise.

CONCLUSION

Regional expansion of AYA oncology care through APP leadership is a promising, patient-centered model. By addressing barriers of access, travel, and cost, while maintaining high-quality specialized care, this approach empowers AYAs to receive treatment closer to home without sacrificing expertise. Advanced practice providers play a critical role in advancing institutional goals, supporting families, and improving the overall oncology care experience. ●

Disclosure

The authors have no conflicts of interest to disclose.

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