original contributions

Guidance to Support the Implementation of Specialized Adolescent and Young Adult Cancer Care: A Qualitative Analysis of Cancer Programs

Emily Haines, PhD[1]; Sarah Asad, MSc[2]; Lauren Lux, MSW, LCSW[3,4]; Hilary Gan, MA[5]; Kara Noskoff, BS[5]; Bindu Kumar, MScN[5]; Betty Roggenkamp, MSHC[6]; John M. Salsman, PhD[7]; and Sarah Birken, PhD[1]

QUESTION ASKED: What are the barriers to implementing specialized care for adolescents and young adults (AYAs) with cancer and what strategies have been used to overcome these barriers?

SUMMARY ANSWER: Cancer care programs face multilevel barriers to implementing specialized cancer care for AYAs including costs, difficulties in coordinating across pediatric and adult oncology, the multiple disease groups providers caring for AYA patients, and a lack of metrics for program evaluation. Programs interviewed used creative strategies to address these barriers and facilitate the integration of AYA-specific services in their setting.

WHAT WE DID: We interviewed cancer care programs around the country about their experiences implementing specialized AYA cancer care. We used the Consolidated Framework for Implementation Research, a metatheoretical implementation framework that identifies implementation determinants across five domains, to guide qualitative data collection and analysis efforts. We collaborated with a multidisciplinary research team to synthesize findings and generate guidance to inform the implementation of specialized AYA cancer care.

WHAT WE FOUND: Participants reported barriers to implementing specialized AYA cancer care across all five domains of the Consolidated Framework for Implementation Research: (1) intervention characteristics (eg, costs), (2) inner setting (eg, difficulties in collaborating between pediatric and medical oncology), (3) outer setting (eg, patient-level barriers to participating in AYA services), (4) individual characteristics (eg, provider attitudes about AYA oncology), and (5) process (eg, lack of metrics for program evaluation). They also shared practical guidance for addressing these barriers (Fig).

BIAS, CONFOUNDING FACTORS: Cancer care programs interviewed likely had AYA champions given their involvement with community partners at Teen Cancer America and, thus, might have been a step ahead of cancer care programs without this kind of AYA interest/expertise. As such, the findings of this study may represent a rosier picture than reality in terms of the availability of specialized AYA care nationally.

REAL-LIFE IMPLICATIONS: When implementing specialized AYA cancer care, cancer care programs can learn from the implementation experiences of other institutions. This study is novel in its application of an implementation science lens to systematically study the implementation experiences of diverse cancer care programs and generate guidance to inform future implementation efforts. In this sense, this study contributes to the body of evidence available to inform the implementation of specialized AYA cancer care.

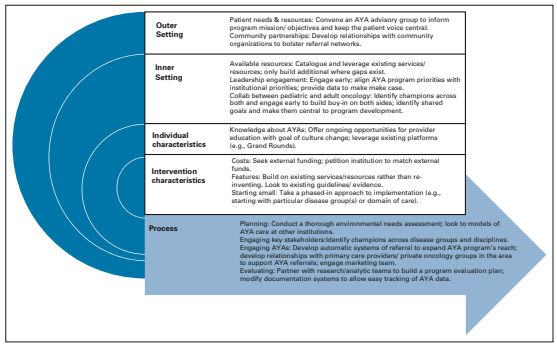

FIG. Strategies for implementing specialized AYA care.

ASSOCIATED CONTENT

Data Supplement

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CARE DELIVERY

original contributions

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abstract

PURPOSE The nearly 90,000 adolescents and young adults (AYAs) diagnosed with cancer in the United States yearly have tended to occupy a no-man's land between medical and pediatric oncology, often reporting that existing models of care are misaligned with their needs and preferences. Although guidelines for optimal AYA cancer care are increasingly available, the implementation of such standards has been varied. This may be in part due to a lack of guidance for implementing specialized AYA care. In this study, we leveraged an implementation science framework to identify barriers and generate practical guidance to inform the implementation of specialized AYA cancer care.

METHODS We conducted semistructured qualitative interviews, guided by the Consolidated Framework for Implementation Research, with AYA care stakeholders (N = 32 from 14 cancer programs). Our multidisciplinary research team analyzed interview transcriptions using a template analysis approach and gleaned from interviews practical guidance for implementing specialized AYA care.

RESULTS Participants reported barriers to implementing specialized AYA care across all five Consolidated Framework for Implementation Research domains: (1) intervention characteristics (eg, costs), (2) inner setting (eg, difficulties in collaborating between pediatric and medical oncology), (3) outer setting (eg, patient-level barriers to participating in AYA services), (4) individual characteristics (eg, attitudes about AYA oncology), and (5) process (eg, lack of metrics for program evaluation). They also shared practical guidance for addressing these barriers.

CONCLUSION Emerging guidance on the core elements of AYA cancer care must be matched with guidance to support the implementation of specialized AYA care. This study contributes to the body of evidence available to inform future implementation efforts.

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BACKGROUND

The nearly 90,000 adolescents and young adults (AYAs) diagnosed with cancer in the United States yearly[1] have tended to occupy a no-man's land between medical and pediatric oncology,[2] often reporting that existing models of care are misaligned with their needs and preferences.[3-5] In response to demands for improvements in care for this population from patients, providers, and researchers,[6-9] models of specialized (ie, AYA-specific) care have emerged within cancer centers across the country to better meet AYAs' unique needs.[10] To provide specialized AYA care, some cancer programs have formally established AYA programs, which include staff or services dedicated to AYAs. Although the scope, composition, and functions of these programs vary greatly, common components include provider expertise, coordination between pediatric and medical oncology, age-appropriate supportive services, efforts to increase clinical trial participation, and patient/family advocacy. The provision of specialized AYA care has been associated with improved outcomes for AYAs including reduced unmet needs,[11] increased clinical trial enrollment,[12] and the provision of guideline-concordant care.[13]

Although guidelines for optimal AYA cancer care are increasingly available,[8,14,15] the implementation of such standards has been varied. In preliminary studies, half of cancer programs reported having an established AYA program; even among these programs, the availability of key elements of specialized

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AYA care varied. Such variation may be in large part due to a lack of guidance for implementing specialized AYA care in the context of complex cancer programs, which face multilevel barriers to change.

Although some guidance for implementing specialized AYA care exists in the literature,[10,16-18] much of it is constrained to single case studies and, to our knowledge, none of it has been developed through an implementation science lens.[19] In this study, we leveraged an implementation science framework[20] to identify key barriers and generate practical guidance to inform the implementation of specialized AYA cancer care.

METHODS

We conducted semistructured qualitative interviews with AYA care stakeholders to identify the provider- and organizational-level barriers to implementing specialized AYA care and generate guidance to facilitate implementation. This study was approved by the Wake Forest Institutional Review Board (IRB00074316) before the completion of all data collection activities, and informed consent was obtained from each participant. The Data Supplement (online only) includes the Standards for Reporting Qualitative Research checklist adhered to for these data collection activities.

Sample

In preliminary studies, we surveyed AYA advocates directly involved with AYA care in cancer programs across the country (N = 90). For this study, using survey data, we purposefully sampled cancer programs to maximize variation in (1) having a formalized AYA program (self-reported, yes/no), (2) type of institution (eg, academic medical center *v* community hospital), (3) geographic location, and (4) AYA patient volume. Within each cancer program, we sought to interview individuals with robust involvement in AYA care (eg, oncology providers, nurses, social workers, patient navigators, etc). The goal was to triangulate across multiple perspectives at each institution, capturing a comprehensive picture of AYA care across diverse health systems.

Recruitment

We recruited interview participants through Teen Cancer America (TCA), an advocacy and consulting organization that works with cancer programs around the country to facilitate the implementation of specialized AYA cancer care. Our TCA partners (H.G. and K.N.) reached out to the AYA advocate who responded to the preliminary survey at each identified cancer program via e-mail using Dillman's[21] approach for maximizing response rates. Those who expressed interest in participating were connected to E.H. to schedule interviews and to identify additional relevant interview participants from their institution who were directly involved with AYA care. We recruited until thematic saturation was reached, that is, when subsequent interviews did not generate new information on implementation barriers.

Instrument

We developed a semistructured interview guide (Data Supplement) using constructs from the Consolidated Framework for Implementation Research (CFIR), which identifies implementation determinants across five domains: *inner setting* (eg, the structural, political, and cultural context within a cancer program), *outer setting* (eg, a cancer program's broader social, political, and economic context), *individual characteristics* (eg, characteristics of those involved with AYA care or its implementation), *intervention characteristics* (eg, features of specialized AYA care), and *process* (eg, activities related to implementing specialized AYA care).[20] Interview guide questions, adapted from those available in the Consolidated Framework for Implementation Research online resources,[22] asked interviewees to reflect on the implementation of specialized AYA care at their institution including the barriers that they have faced and the strategies that they have deployed.

Procedure

E.H. conducted 45-minute semistructured interviews via Zoom. We recorded and transcribed interviews for analysis.

Analysis

We analyzed interview transcriptions using template analysis[23] based on a priori themes (Data Supplement; ie, CFIR constructs) but allowing for additional themes to emerge. To calibrate our coding schema, E.H. and S.A. independently coded excerpts from one interview transcript. After they met to resolve any discrepancies, E.H. coded the remaining transcripts. This commonly used approach to qualitative analysis[24] ensured codebook quality.[25] Findings were then summarized by CFIR domain and distilled into guidance for implementing specialized AYA care through collaborative discussion with the study team including experts in implementation science (E.H. and S.A.), AYA research (E.H., L.L., and J.M.S.), and AYA clinical care and program development (L.L., H.G., K.N., B.R., and B.K.).

RESULTS

Participants included 32 AYA care stakeholders from 14 cancer programs (1-5 stakeholders per program; Table 1).

Participants reported barriers to implementing specialized AYA care across all CFIR domains and shared practical guidance for addressing these barriers (Fig 1 and Data Supplement).

Intervention Characteristics

The Data Supplement contains a brief description of the characteristics of AYA care at each institution interviewed.

TABLE 1. Summary of Participants

Characteristics	n
Institution type	
Academic medical center	9
Community hospital	4
Community hospital affiliated with an academic medical center	1
Formalized AYA program at institution?	
Yes	10
No	4
No. of new AYA diagnoses/year at institution	
0-25	6
25-50	1
50-100	2
100-200	2
200-300	1
300-500	1
500+	1
Location of the institution	
Texas	3
California	2
Florida	2
Ohio	1
North Carolina	1
Illinois	1
Tennessee	1
Pennsylvania	1
South Carolina	1
Missouri	1
Total	14
Interviewees	
Oncologists	10
Navigators	6
Social workers	6
Nurse practitioners	2
AYA program managers	4
Psychologists	2
Supportive oncology director	1
AYA research coordinator	1
Total	32

Abbreviation: AYA, adolescent and young adult.

Features of specialized AYA care. Programs interviewed varied tremendously in terms of the structure and functions of AYA care at their institution. AYA services included psychosocial support, educational/vocational support, fertility preservation, support groups or patient events, and efforts to increase clinical trial enrollment. Programs made decisions about where to focus their activities based on patient engagement, clinical practice guidelines (eg, National Comprehensive Cancer Network guidelines), frameworks for AYA care, or other existing evidence. Although most programs focused initial efforts on medical or psychosocial care, more established AYA programs articulated additional goals related to AYA research and education.

Decisions about a program's structure, functions, and model of care often hinged on the services and resources already available at a given institution. Interviewees noted that demonstrating the value-add of specialized AYA care can be challenging; they faced pushback from other providers who felt that the AYA team was stepping on [their] toes. They emphasized the importance of adding value rather than competing with existing provider teams. This was the impetus behind several programs opting for a consultation-based model.

Staffing. For programs that had AYA-specific staff, their multidisciplinary AYA team was often built over time. One program started with a program director funded through foundational funds and has since expanded to include a multidisciplinary AYA team as their institution recognized the value-add of the AYA program. Here again, interviewees emphasized the importance of capitalizing on existing staff at an institution to avoid reinventing services. Another commonly expressed theme was the importance of having administrative staff to spearhead AYA program development.

Costs. All programs noted cost as a key barrier. Although some programs benefitted from robust institutional support, most sought external funding from philanthropic donors, foundations, or other groups. Two programs noted that obtaining external funding helped them to galvanize leadership willingness to provide institutional support. One program mentioned that adult providers are judged more closely on their patient billable hours than pediatric providers, resulting in more pushback for nonbillable activities in an adult setting.

Starting small. Interviewees often discussed the importance of phasing in implementation; they focused initial efforts on specific standards of care or subpopulations before rolling out their program more broadly. Several programs launched their AYA program with a focus on one specific gap in AYA care around which they felt that they could rally broad support (eg, supportive oncology, clinical trial enrollment, and fertility preservation). Three programs started with specific disease groups. For example, one program started with the disease groups for which there was the most overlap between pediatric and adult oncology (eg, leukemia, lymphoma, and sarcoma). This approach allowed them to solidify the collaboration between pediatric and medical oncology. Two programs spoke to the importance of an AYA's program adaptability: they established a program mission and goals upfront but knew that their

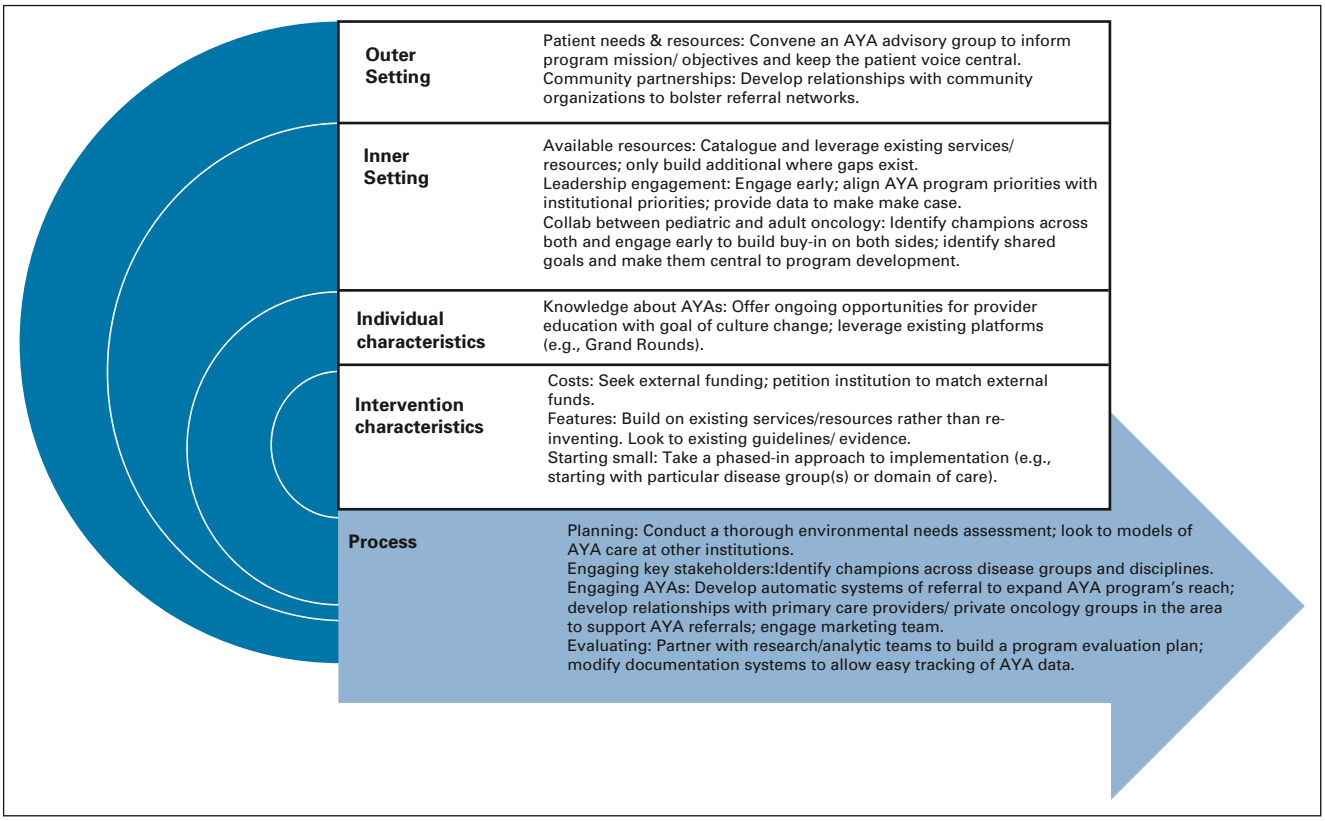

FIG 1. Strategies for implementing specialized AYA care. AYA, adolescents and young adult.

objectives would have to be flexible and responsive to the dynamic needs of their patients and their institution.

Inner Setting

Leadership engagement. Leadership buy-in was among the most frequently discussed barriers to implementing specialized AYA care. Programs described changes in leadership as both catalysts for and disruptors of AYA program growth. To garner leadership support, interviewees noted the importance of aligning AYA program goals with institutional priorities and showing administrators the hard numbers to illuminate a few key problems or challenges in AYA care at their cancer center; by approaching leadership with proposed solutions to these challenges, they were able to garner administrative support.

Available resources. All programs interviewed voiced resource constraints, particularly staffing availability, as a primary barrier to launching or expanding AYA services at their institution. Interviewees often reported that pediatric oncology had more staffing and support resources than adult oncology, making it easier for existing resources to be leveraged for their AYA population.

Provider education. Interviewees described a variety of methods that they used to educate providers on AYA care and AYA program activities including Grand Rounds, division and team meetings, guest lectures, nursing forums, etc. Three programs emphasized that efforts to educate providers must occur on an ongoing basis to account for provider turnover. Through ongoing education, interviewees hoped to build a culture that was supportive of AYA oncology as its own subspecialty and thus receptive to the implementation of specialized AYA care.

Structural characteristics. Many interviewees emphasized the importance of the geography of an institution. For example, when pediatric and adult hospitals were colocated, this facilitated greater collaboration. Other programs faced challenges in caring for AYAs across disparate locations. One program addressed these challenges by specifying set days in which their AYA navigator would be at various locations and scheduling patient visits accordingly. Two programs mentioned that telehealth helped to alleviate the challenge of serving patients across disparate locations. Some programs sought to build AYA-specific spaces (eg, lounges and infusion rooms) to address these challenges. However, institutional space limitations hindered some of these efforts.

Collaboration between pediatric and medical oncology. Interviewees discussed the collaboration between pediatric and medical oncology at length. Programs varied in the extent to which providers and resources from both sides were engaged, with five programs confined completely to one or the other with little collaboration between the two.

Programs with more of a shared model emphasized the importance of identifying champions in both pediatric and medical oncology, articulating shared goals, and establishing clear channels of communication. Three programs housed their AYA program in a supportive care department, where there was infrastructure and precedent for offering services across pediatric and adult oncology.

Outer Setting

Patient needs and resources. In general, interviewees displayed a robust knowledge of the needs and constraints of AYAs. They reported patient-level barriers to participating in AYA services including awareness, insurance, and bandwidth in the face of many competing demands. Two programs discussed their difficulties in engaging minority patients, pointing to the need for a health equity focus in implementing specialized AYA care.

Community partnerships. Programs partnered with a range of community organizations to launch and grow their AYA program. Interviewees recommended that social workers and other AYA providers develop a robust knowledge of resources available in the community and foster relationships with community organizations to strengthen referral networks.

External pressures. For some programs, the implementation of specialized AYA care was influenced by existing guidelines or external incentives. Two programs mentioned that the National Comprehensive Cancer Network guidelines for AYA care offered a template for identifying gaps in existing services and resources and building services to address those gaps.

Interviewees disagreed about whether having a formalized AYA program offers or would offer them a competitive advantage over other hospitals in the area. Four programs felt that having an AYA program was a feather in their cap, potentially promoting referrals. Others disagreed, noting that AYAs select their location of care on the basis of geographical convenience, availability of disease-group specialists, and where their primary care provider refers them.

Individual Characteristics

Interviewees discussed the extent to which other providers in their institution were bought into the notion of AYA oncology as its own subspecialty. Although most interviewees reported that providers in their institution were receptive to AYA-specific care, some reported pushback. Interviewees mentioned inertia as a barrier, noting hesitance from other providers to disrupt systems that are already in place.

Implementation Process

Planning. Interviewees tended to agree that the first critical step to implementing specialized AYA care is conducting a thorough environmental needs assessment, which includes identifying (1) characteristics of the AYA population served by the institution (eg, patient volume, demographics, and clinical characteristics); (2) services and resources available through the institution or community partnerships; (3) attitudes and knowledge on AYA care among leadership, providers, and staff; and (4) organizational capacity or readiness to implement specialized AYA care. In addition to informing the objectives, structure, and functions of the AYA program, this provided an opportunity to collect data to build a case for the value-add of the program. By understanding the needs and resources at their institution, they were able to identify service gaps to focus on. Often, this involved conducting informal interviews with key stakeholders. Many programs convened an advisory board composed of key stakeholders to guide implementation planning or solicited input directly from AYAs about their needs and preferences for care delivery. Two programs mentioned connecting with existing AYA programs to inform their model of care.

Engaging providers and staff. A critical aspect of conducting an environmental needs assessment was engaging providers and staff from across an institution. This allowed programs to gather information about existing attitudes and processes and build buy-in across departments. The majority of programs relied on referrals from disease group providers to reach AYA patients; they noted the importance of identifying champions across disease groups and disciplines to promote referrals. One program emphasized the importance of engaging nursing staff, including mid-level managers, to promote referrals. Interviewees also discussed the importance of engaging providers in the community to influence referral patterns.

Engaging AYAs. Interviewees expressed that getting disease group providers to add a step to their workflow was challenging, even when those providers bought into the value-add of AYA-specific care. They noted that, to the extent that referrals can be automated, this will expand the reach of AYA services.

In some cases, programs targeted outreach efforts directly to AYAs. They deployed a range of marketing strategies including developing AYA program brochures/pamphlets across disease group clinics, developing a social media presence, and sending out periodic newsletters.

Program evaluation. Interview participants used a range of metrics to track the performance of their AYA services and to inform program growth and changes (eg, patient volume and demographics, relative value units, patient satisfaction, etc). Two programs partnered with researchers or other groups within their institution to articulate a plan for program evaluation. Most programs, although, were in the early phases of thinking through program evaluation, pointing to a lack of consensus or guidance on key metrics to track.

DISCUSSION

The provision of specialized AYA care has been associated with improved outcomes for AYAs including reduced unmet needs,[11] increased clinical trial enrollment,[12] and the provision of guideline-concordant care.[13] However, implementing specialized AYA care requires multilevel change, including changes to organizational workflow, interorganizational networks, communication and documentation systems, and culture. In light of these complexities, cancer programs need practical guidance to support decisions about adopting and implementing AYA-specific models of care at their institution. In this study, we synthesized the experiences of 14 cancer programs to provide such guidance.

This study is not without its limitations. As evidenced by their engagement with TCA, programs interviewed had AYA champions; in this sense, they may be ahead of programs without this kind of AYA interest/expertise. Thus, our findings may paint a rosier picture than reality in terms of the availability of specialized AYA care. In many cancer programs around the country, efforts to provide specialized AYA care may be nonexistent or in their infancy. This may be especially true in community-based cancer programs where the majority of AYAs receive care. Indeed, the community hospitals that we interviewed who reported having robust AYA services may be outliers; future research diving deeper into the development of AYA-specific care at these institutions could inform efforts to expand AYA care in other community-based settings. In addition, although interviewees discussed some barriers that AYAs face in participating in AYA services, the focus of this study was on the provider- and organizational-level determinants of implementation; future research exploring AYA-level barriers should include robust engagement of AYAs. AYA care is inherently multidisciplinary, including providers and staff from across many disease groups and disciplines. Although we interviewed a range of AYA stakeholders, there are likely additional perspectives that we did not capture. We aimed to interview cancer programs with and without formalized AYA programs. In the absence of a standardized definition of an AYA program, we relied on self-reported data to make this distinction. Interestingly, during interviews, we discovered that this distinction was not always straightforward. Among the programs that we interviewed, the structure and functions of AYA care varied tremendously. Although guidelines and criteria for optimal AYA cancer care have become increasingly available,[8,14,15] more work is needed to define the core components of a comprehensive AYA program. Our interviews suggested that a one-size-fits-all approach to AYA care may not be possible or appropriate; however, interviewees shared elements of their implementation process, which may be generalizable across diverse health systems.

Before implementation planning, cancer programs should conduct a thorough environmental scan of services and resources to identify existing gaps in service availability or capacity. Where gaps exist, additional services may be developed or partnerships with community-based programs may be established to bolster referral networks. Our interview findings highlight the importance of building noncompetitive services for AYAs rather than duplicating existing services or resources. To address concerns about institutional service capacity, many cancer programs took a phased-in approach to implementing specialized AYA care (eg, starting with one disease group and expanding over time). This approach allowed for programs to identify gaps and troubleshoot as they expanded. AYA-specific staffing may also be built over time, but appointing a program manager who is more focused on program development than clinical tasks may be critical to implementation and sustainment.

In addition to leadership buy-in, implementing specialized AYA care requires buy-in from providers beyond just the AYA team, who may not be familiar with AYA-specific services or may view them as redundant with those already provided by the primary oncology team. Educating providers on the added value of AYA-specific care can help build awareness and buy-in. In the early phases of implementation, providers from both pediatric and medical oncology should be engaged to foster a shared ownership of AYA care. Effective collaboration between pediatric and medical oncology may be key to AYA program reach and success.[26] Involving AYAs and diverse providers in implementation planning can ensure that AYA program objectives are aligned with stakeholder needs and constraints and help to build a culture that is supportive of AYA oncology as its own subspecialty. Tracking data on AYA experiences and outcomes can inform AYA program growth; although some guidance exists in the literature,[27] more consensus and guidance are needed on key structural, process, and outcome measures to track.

In conclusion, emerging guidance on the core elements of AYA cancer care must be matched with guidance to support the implementation of specialized AYA care. This study contributes to the body of evidence available to inform future implementation efforts. Efforts to empirically test the effectiveness of particular strategies in optimizing the implementation of specialized AYA care will only enhance that knowledge base and advance the fledgling field of AYA oncology.

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DISCLAIMER

The content of this article is solely the responsibility of the authors and does not necessarily represent the official view of NCATS or NIH.

EQUAL CONTRIBUTION

J.M.S. and S.B. contributed equally as cosenior authors to this work.

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Guidance to Support the Implementation of Specialized Adolescent and Young Adult Cancer Care: A Qualitative Analysis of Cancer Programs

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