

Starting an Adolescent and Young Adult Program: Some Success Stories and Some Obstacles to Overcome

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ABSTRACT

Adolescent and young adult (AYA) patients seem to be in a sort of no-man's land, halfway between the two different worlds of pediatric and adult medical oncology and bearing the brunt, in terms of inclusion in clinical trials and quality of professional care, of the lack of integration between these two worlds. This article discusses the different organization models of care used in pediatric oncology (mainly family-focused) and in adult medical oncology (disease-focused). There is a growing awareness that these models are not ideally suited to the complex needs of AYA patients, which require a different, new, patient-focused multidisciplinary approach. A comprehensive, multipronged effort is required to bridge the gap in the care of AYA patients, with the ultimate challenge of creating a new discipline, AYA oncology. In this article, we review the experiences of AYA oncology programs in Europe, North America, and Australia, focusing on similarities and differences in strategy, as well as the major challenges and opportunities faced by these programs. Among the most important factors for the successful establishment of an AYA oncology service are the degree of engagement of both pediatric and adult medical oncologists, the philanthropic support of powerful charities, and the role of dedicated professionals across a range of disciplines in driving the development of services for AYA patients.

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INTRODUCTION

The start of the new millennium seems to be a key time for adolescent and young adult (AYA) oncology. The larger oncology community has become aware that there is a peculiar gap in our recognition of the needs of patients with cancer from 15 to 29 (or 39) years of age in the treatment and support measures that we provide and in their outcomes.¹⁻⁴ Several studies and publications have emphasized, for instance, that AYA patients have been underrepresented in clinical trials and that this has been associated with a corresponding lack of improvement in their survival rates over the last few years.⁵⁻¹³ It has also been emphasized that this age group includes individuals who may be particularly complicated to care for, with very different levels of maturity, specific sociopsychological problems, and needs.¹⁴ In terms of health care delivery, it has become apparent that AYA patients tend to occupy a sort of no-man's land, at home in neither of the two different worlds of pediatric and adult medical oncology. It is concerning that the AYA population may be paying the price, in terms of quality professional care and shortcomings in communications and collaborations between these two worlds (even when they are dealing with the same diseases).¹⁵

AYA oncology "programs" are being formed in an attempt to bridge this gap and address the unmet needs of this age group. These programs must navigate the obstacles of ingrained cultures, physical space constraints, and provider expertise in the attempt to achieve a desired change in outcomes for the AYA patient with cancer.

CURRENT HEALTH CARE DELIVERY MODELS: MEDICAL ONCOLOGY VERSUS PEDIATRIC ONCOLOGY

Pediatric oncology and medical oncology cultures are driven by slightly different organization models, particularly regarding interaction with the patient.¹⁶ The pediatric oncology delivery system has been built to serve its average patient: A typical example might be a 4- to 5-year-old with acute leukemia, whose parents are making the decisions, and who will be quite ill and dependent on the health care system to provide multitiered levels of support. Pediatric-type cancers themselves are often relatively responsive to treatment, with a high expectation of cure. As for other complex or chronic diseases of childhood, the model of care is based on a complex, sometimes dualistic, relationship between

three leading actors: the child, the parents, and the professional.¹⁷ However, the interactions are on different levels: For instance, parents are fully informed about the child's condition and prognosis and involved in the decision-making process, whereas the child himself or herself is often not. Another distinction in pediatric oncology units is that rather than assembling consultants piecemeal, the young patients are routinely managed by an integrated multidisciplinary staff of surgeons, radiotherapists, and nutritionists, as well as teachers, psychologists, and social workers; sometimes subspecialists in infectious disease, neurology, and endocrinology are also required. Care is often given on or according to standardized protocols or clinical trials. Although pediatric cancers account for less than 1% of the total cancer burden,¹⁸ society and the health care system have accepted a disproportionate allocation of resources to children and their families (benefiting from much higher staff/patient ratios) and greater amounts of time given in support and interaction with patients and families. One reason for this is the differential societal burden of years-of-life lost, which is estimated to be 69.3 years for childhood cancers compared with 15 to 20 years for the most common adult malignancies.¹⁹

The medical oncology delivery system is built to serve its average patient: for example, a 60-year-old with carcinoma who will mainly be treated as an outpatient and will be capable of making most of his decisions, taking actions independently throughout treatment. In many cases, adult cancers are relatively resistant to chemotherapies, and the cost-benefit ratio in treatment is more equivocal than that seen in pediatric oncology. There is more variability of care models in adult oncology. Compared with the centralization of pediatric oncology at major, usually academic centers, much of medical oncology care is provided in community private practice settings by individual oncologists who refer to specialists as needed. Although a multidisciplinary approach has also been increasingly implemented in adult units, particularly at referral centers, this often refers to the involvement of the surgery and radiation disciplines within a clinic program dealing with a specific type of tumor. Therefore, it is rare for psychosocial, nutritional, or educational support to be universally provided without triage or request. In the adult model of care, treatment still tends to focus on direct interaction between a lead doctor and the patient, and patient autonomy is assumed in the therapeutic relationship. Hence the patient is expected to capably navigate the medical system, request supportive care consults as desired, and be responsible for appointments, medications, and so on.

THE IDEAL MODEL OF CARE FOR AYA

Being neither children nor adults and yet sharing many characteristics of both, it is not surprising that neither of the above-described models of care is ideally suited to meet the needs of AYA patients.^{11,20-22} It is important to consider whether a single, ideal, new model of care should exist for AYA patients and whether it could feasibly be implemented. Alternatively, should adjustments be made to one or both systems to better meet the needs of the AYA patient? A helpful exercise is to consider the components of an ideal model of care for the AYA patient and then examine some international attempts in establishing just such AYA programs. In the process, we can also elucidate the barriers to the realization of such a model.

Culture of Care

As the AYA is cognitively and (for the most part) legally mature, an AYA model of care would have to be patient-focused: The doctor needs to interact directly with the patient, with sufficient sensitivity to acknowledge each patient's level of maturity and independence and unique needs. Yet a patient's parents and/or other figures, such as a partner or friends, often play extremely important roles, given the wide range of independence seen across AYA stages of development. As a result of the frequent complexity of their care, their lack of experience navigating the medical system, and the variety of their psychosocial issues, the AYA benefits from an AYA multidisciplinary team approach. In addition to the routine plethora of specialties, this may well include nurse educators, navigators, fertility experts, social workers (especially skilled in employment and insurance counseling), teachers, psychologists, sexual consultants, or even cosmetics expert.^{16,20,22,23} Clinical trial enrollment should be encouraged, both for establishment of standards of care for the age group and for access to investigational agents.⁹

Physical Space

One of the most common sentiments expressed by AYA patients is the feeling that they do not belong. The physical space that they go to (waiting rooms, clinics, inpatient wards) can accentuate this feeling of homelessness. Although juvenile themes (cartoons, stuffed animals, or clowns) are inappropriate, AYAs report finding the environment of certain adult clinics bare and often depressing. Ideally, AYA patients should have dedicated, multifunctional spaces to suit their requirements. These would be variously equipped with the gadgets of their daily life outside the hospital: TVs, computers, musical instruments, books, magazines, and DVDs appealing to the age group concerned, but also a quiet place where they can take some time off and not be disturbed and an area where patients themselves can interact with peers and organize their own activities. Of course, this is more easily (and cheaply) said than done, but just such a facility was created at the first adolescent oncology unit established in 1978 at the Roswell Park Memorial Institute in Buffalo, NY. Though initially welcomed, the unit was unfortunately closed 10 years later, probably due to cost-cutting measures.²⁴

Provider Expertise

Current training for either pediatric or medical oncologists does not provide all the skills needed to manage a multidisciplinary AYA treatment strategy (preferably involving current pediatric AND adult trials as well as the creation of AYA-focused cooperative trials) and cope, at the same time, with the psychosocial issues of young adulthood, including, for example, sexuality and fertility. A new health care provider would be needed: the AYA oncologist.^{16,20,23} A discussion of the training and certification of such a provider is beyond the scope of this article, but it could be achieved via modification or combination of current fellowships in pediatric and medical oncology or a free-standing clinical fellowship (such as done for geriatric oncology, neurooncology, or palliative care). However, a key unresolved issue is whether, in practice, the AYA oncologist ought to cross all disease boundaries, treating breast cancer, rhabdomyosarcoma, and leukemias with equal competence. Given the complexity and multidisciplinary nature of disease-focused teams in modern oncology, this seems unlikely. The role of the AYA oncologist seems more likely to be complementary to these existing services, although exactly how this

may be achieved remains unclear, and many possible variations exist. Likewise, the AYA patient will benefit from providers such as psychologists, social workers, nurses, and recreational (“child” life) therapists, who have extra training and clinical focus on the AYA population.^{14,18,25,26}

Ideally then, the AYA would be cared for in a unique space (inpatient and outpatient) with specially trained providers (medical and supportive care) within a culture that recognizes varying levels of developmental maturity and independent decision making, but acknowledges the need for navigation and support, especially around the psychosocial issues of emerging adulthood. The disease-specific clinical care provided would draw on evidence-based knowledge of best practice specifically for the age group and broad access to clinical trials, including standard of care registry trials and novel therapies.

However, most AYA units have not been, and will not be, formed instantly or in isolation, but rather have typically evolved as AYA focused programs through gradual changes in care. Consequently, in practice AYA units reflect not only an ideal, but also local issues, variations in funding, medical culture, and resources, which have generated and will continue to generate an interesting heterogeneity of solutions. An important reminder is that the bulk of young adults are treated outside of major oncology centers, so creating AYA unit “centers of excellence” without a strategic plan for outreach will not serve a large proportion of the AYA population. We next examine several international programs that have attempted to start AYA Oncology programs to learn from their successes and failures.

SEVERAL APPROACHES TO ESTABLISHING AYA PROGRAMS

Several attempts at AYA comprehensive programs are in development all over the world. The United Kingdom philanthropists kindled the movement in the 1990s by founding a national charity, the Teenage Cancer Trust (TCT), followed by successful opening of the first adolescent cancer unit at the Middlesex Hospital in London in 1990 (dedicated mainly to caring for youth with osteosarcoma). There are now eight comprehensive AYA units operating in the United Kingdom, whereas others are at various stages of development, with a view to building such a unit at every regional center. Some of these units were born as an adjunct to adult oncology departments, others under the guidance of pediatric units.^{2,3,27,28} The TCT-related experience has strongly influenced other nations, in particular Australia and Canada, given their similar government-funded health system.

Their success was also recognized and supported by the United Kingdom government when the National Institute for Health and Clinical Excellence wrote the Improving Outcomes in Children and Young People with Cancer guidelines,²⁹ which outlined recommended specific age-appropriate services and facilities for AYAs and established its Teenage and Young Adult Clinical Studies Group.

In North America, much of the efforts in AYA oncology started not at a local but at a national level by concerned professionals within pediatric oncology. The National Cancer Institute (NCI) –funded Children’s Oncology Group formed an AYA Committee in 2000, whose focus was more on improving outcomes, access to care, and accrual to clinical trials than on developing a physical network of AYA units. The NCI, with support from the Lance Armstrong Foundation, created a Progress Review Group in 2006 to analyze the AYA problem and make executive recommendations concerning awareness, educa-

tion, prevention, diagnosis, treatment, biology research, quality of life, and psychological and other issues.¹⁸ One of the recommendations was “to ensure excellence in service delivery across the cancer control continuum” via establishments of standards of care and collaboration of stakeholders, and a subsequent task group has met to produce a set of guidelines on the appropriate training of an AYA professional and the components of an AYA center of care in the United States.

However, it has been left to individual centers to decide whether and how to attempt to address services for the AYA population. To date, there are no dedicated physical units in the United States (in part because pediatric and medical oncology inpatient care are frequently financially separate), but several institutions have worked to develop “virtual” AYA programs. At The University of Texas M. D. Anderson Cancer Center in Houston, TX, an AYA program was initiated around 1999. Originating in the Pediatric Oncology Center, the program has focused mainly on psychosocial support of the AYA patient, including psychologists, educational, vocational, adolescent life, and young adult life specialists (in contrast to child life specialists). An AYA Program was attempted at Dana-Farber Cancer Institute from 2004 to 2009, including fertility preservation services, psychosocial support, and consultative care. At the Oregon Health Science University Knight Cancer Institute (OHSU), an AYA program has been in place since 2005, consisting mainly of a consultative service, initially to patients in medical oncology, then also for pediatric oncology. Other programs under development in North America are at McGill University, Montreal, Quebec, Canada; University of California, Irvine and Children’s Hospital of Orange County, CA; Vanderbilt-Ingram Cancer Center, Nashville, TN; University Hospitals/Rainbow Babies’ and Children’s Hospital, Cleveland, OH; Children’s Hospital of Pittsburgh, PA; Van Elslander Cancer Center, Detroit, MI; and Seattle Children’s Hospital, Seattle, WA, among others.

A few sites in Europe outside of England have attempted to start AYA programs. In Italy, for instance, the proposed creation of an AYA unit generally met with disapproval, with the exception of the Youth Area Project dedicated to 14- to 24-year-olds at the Centro di Riferimento Oncologico in Aviano, Italy, which opened in January 2007. This project was devised with a trans-departmental dimension, not as the property of a single department, where different specialists retained their own roles and specialties. In Denmark, at the Aarhus University Hospital, the adult oncology ward designated a Youth Ward after a project, spearheaded by nurses and funded by the County Council, the hospital, and a patient advocacy group, set out to improve the care of 15- to 21-year-old patients with cancer at their hospital.³⁰ In the Netherlands, the Department of Medical Oncology at Radboud University Nijmegen Medical Center has recently developed an AYA program that includes both inpatient and outpatient units.

In Australia, recognizing that 90% of the 15- to 25-year-old population is treated in adult institutions, the onTrac@PeterMac program was established entirely within an adult comprehensive cancer center and has provided dedicated AYA care to more than 500 young patients with cancer since 2004. This unit combines both adult and pediatric expertise, providing supportive care and holistic services and promoting clinical trials, but without offering direct medical care.

The following section summarizes the themes we found in our personal experiences developing AYA programs, our knowledge of other programs, and the results of a 12-question survey given to the leaders of a sample of AYA programs at six international sites (Table

1), chosen to provide a breadth of responses in terms of health care structure, approach to the issue, challenges, and degrees of success.

KEY THEMES IN DEVELOPING AN AYA ONCOLOGY PROGRAM

Relationship Between Pediatric and Medical Oncology

First of all, simply striving to improve the communication and cooperation between pediatric oncologists and medical oncologists is important. A common sentiment among current AYA programs is that true success will not come without genuine collaboration and shared ownership. A nascent AYA program perceived solely as an expansion of either pediatric or medical oncology will be hampered by “turf” and cultural issues. This collaboration, however, is often one of

the most difficult steps to achieve in forming an AYA program. As stated previously, pediatric and adult oncology groups come from different backgrounds and have different priorities and goals. Even when they deal with similar diseases, they often adopt different classification, staging, and grading systems, as well as different practices relating, for example, to data collection—and consequent difficulties when it comes to sharing data. Ironically, both have much to gain from cooperating with one another. Pediatric and adult oncologists can exploit synergies, for instance, by pooling the pediatric oncologists’ experience of multidisciplinary cooperative protocols with the adult oncologists’ experience of novel therapies.⁹

There is a common perception that medical oncologists are less willing than pediatric oncologists to “buy in” to an AYA program.

Table 1. Summary of a Survey Given to the Leaders of a Sample of AYA Programs at Six International Sites

Question	Peter Mac (Australia)	CRO Aviano (Italy)	Nijmegen (Netherlands)	DFCI (Boston, MA)	OHSU (Portland, OR)	M. D. Anderson (Houston, TX)
Environment	Academic comprehensive cancer center with adult population linked to pediatric institution	Cancer research institution	Adult cancer center	Academic comprehensive cancer center and clinics linked to adult and pediatric hospitals	Academic comprehensive cancer center with adult population linked to pediatric institution	Academic comprehensive cancer center with pediatric and adult inpatient and outpatient
Key elements	Supportive care integrated into existing dedicated disease- and discipline-specific multidisciplinary teams Web site Research and education program	Inpatient common space for interdepartmental interactions Primarily medical but highly integrated with supportive care Educational program for peers	Special AYA OPD with dedicated and specialized personnel (medical and nonmedical) Web site	Medical AYA consult service Supportive care program for AYA Fertility preservation and education program AYA patient/family advisory council	Medical AYA consult service Supportive care program for AYA Research (psychosocial) and educational program Fertility preservation program	Supportive care program, including disease-specific supportive care
Personnel	Medical oncologist Pediatric oncologist Social worker Psychologist Education advisor Nurse Research officer Administrative assistant Partners: psychiatry, fertility services, disease-specific MDTs, palliative care	Pediatric oncologist Pediatrician Radiation oncologist Translational hematology oncologist Psychologist Educator/librarian Nurse coordinator, (part-time) Data manager (part-time) Partners: subspecialties who have particular interest in AYA patients	Senior medical oncologist Junior medical oncologist/PhD Nurse practitioner Social worker Psychologist Partners: oncologists from all department treating and referring AYA patients with cancer: orthopedics, surgery, urology, head and neck, gynecology, etc	Medical/pediatric oncologist Nurse practitioner Administrative assistant Psychologist Partners: separate young women with breast cancer program with dedicated nurse coordinator and medical oncologist Nondedicated social worker-run AYA support group Psychooncology researcher	Medical oncologist Psychosocial researcher Nurse coordinator (part-time) Assistant clinic manager (part-time) Pediatric oncologist (part-time) Partners: 3 social workers staff in communications and community relations at cancer institute; radiation oncologist researcher; fertility service staff; other medical oncologists	Pediatric oncologist Medical oncologist Vocational counselor 2 Child life specialists Pediatric psychologist Partners: dedicated oncologist within breast clinic
Physical space	Office space for AYA team No dedicated AYA space	Dedicated AYA inpatient rooms and common areas	Dedicated AYA outpatient areas AYA inpatient common room	Office space for AYA team	AYA inpatient common room No dedicated AYA clinical space	AYA outpatient common room No dedicated AYA clinical space
Funding	Philanthropy Government Research grants	Philanthropy Research grants Institutional support	Philanthropy Health insurance Research grants	Institutional support Philanthropy	Philanthropy Health insurance Research grants	Institutional support Grants Philanthropy
Population served	Age 15-25 years No survivor program Serves population outside institution	Age 14-24 years Survivor program included	Age 17-35 years	Age 18-30 years Survivor program separate	Age 15-40 years	Age 15-40 years

NOTE. Questions concerned the following: (1) Environment in which the AYA program was built (academic, one or more hospitals, cancer center)? (2) Key elements of the program? (3) Personnel (training, department)? (4) Physical space? (5) Funding? (6) Relationship between the AYA program and the pediatric oncology/medical oncology program? (7) Key to cross from a virtual program to reality? (8) Population served by the program? (9) Metrics to improve? (10) Biggest challenges? (11) Best successes? (12) Top recommendations to a place trying to start a program?

Abbreviations: AYA, adolescent and young adult; CRO, Centro di Riferimento Oncologico; DFCI, Dana-Farber Cancer Institute; OHSU, Oregon Health Science University; OPD, outpatient department; MDT, multidisciplinary team.

Perhaps this is due in part to the umbrage generated by early assertions that pediatric oncologists treat patients more effectively than adult oncologists (the history of which lies beyond the scope of this article) and in part due to greater resource limitations and differences in priorities. However, several of the programs we surveyed are programs that have in fact been built from and within the medical oncology side (onTrac@PeterMac, OHSU, Nijmegen) and have proven that, with time, adult oncologists are willing to utilize the services of an AYA program. Indeed, depending on the upper age limit, the majority of AYA patients are currently seen in medical rather than pediatric oncology practices.^{8,31-33}

Who Are AYA?

There are several subgroups to consider within the AYA population, and the very definition is a common point of discussion and contention for those starting a program. Most pediatric oncology providers agree that patients newly diagnosed with cancer between 14 and 18 years of age benefit from services distinct from those of younger patients. Indeed, pediatric oncology programs, when practicable, are usually happy to have a program focusing on these patients. Such a program might even attract new referrals of those older adolescents historically seen by medical oncologists. However, a program stopping there would only be an adolescent, not an AYA, oncology program. The next subgroup are patients age 18 to 25 or 30 years, and it could be divided further into three groups: patients with cancers more commonly seen in childhood (rhabdomyosarcoma, Wilms tumor, neuroblastoma), those seen in both pediatric and medical oncology (leukemia, lymphoma, sarcoma), and finally, those seen most commonly in medical oncology (carcinomas). An AYA program must decide whether to target inclusion of one or more of these subgroups, as the expertise needed to treat these diseases varies. For some, including the NCI, the definition of AYA has extended to 40 years of age. These older AYAs have slightly different psychosocial needs, and the diseases are those seen in older adult populations, albeit with probably unique biology.³⁴ Providing AYA care to these patients may require yet other models of care. For example, as the most common malignancy in this group is breast cancer, some medical oncology centers have started Young Breast Cancer programs as subsets of their breast cancer divisions, rather than as part of an AYA program (DFCI, M. D. Anderson Cancer Center).

The last group that is sometimes considered part of the purview of an AYA program is the young adult survivor of a childhood cancer. Certainly this group has distinct issues that are not often met by either the pediatric clinic focused on acute care or the medical oncology clinic (unaccustomed to young adults or long-term survivors), and survivors' psychosocial needs may overlap with those of young adults on therapy. However, an AYA program should carefully choose whether to make the care of these survivors part of its mission for many reasons, including the infrastructure and resource implications of meeting the needs of a large population of survivors.

Staffing

Although appealing, it is initially unlikely that most programs will be able to fully create a new department of AYA oncology with multiple specialties represented (each with an AYA focus and expertise). Most AYA programs have team members who begin as part-time figures with responsibilities in a home department as well (such as pediatric oncology, psychology, and nursing). Our survey of programs

found that the most common dedicated or paid staff included an oncologist (pediatric and/or medical), a nurse (often with a focus on coordination and education rather than clinical care), a psychologist and/or a social worker, a child life or recreation therapist, and administrative support. Other involved individuals included radiation oncologists, researchers (health services or psychosocial), fertility specialists, vocational rehabilitation, and palliative care. The most recommended positions on which to invest spending were a nurse coordinator and a psychosocial provider.

As noted, it is unclear what spectrum of disease expertise the AYA oncologist will have and whether he will serve as the primary director of treatment or as a consultant. In most of the programs we surveyed, the AYA oncologist had a disease expertise (usually sarcoma or hematologic malignancy) and served as the primary provider for the subset of AYA patients (and non-AYA patients) with that cancer, as well as in a consultative role for patients with other cancers. Especially at the onset, some programs (Nijmegen, onTrac@PeterMac) focused more on the nonphysician staff (nursing, psychology, social work, child life) and allowed the same physicians as had provided care previously to continue, therefore avoiding some of these conflicts. In such models, the AYA oncologist may serve mainly in an administrative and strategic role: overseeing the multidisciplinary staff, promoting system change, managing clinical trial and research development, and so on.

Clinical Trials

A key desire of an AYA program is to increase access of AYAs to clinical trials. As some published (mainly retrospective) studies in sarcoma and leukemia suggest a survival advantage for AYA patients treated according to pediatric rather than adult protocols,³⁵⁻⁴³ some pediatric studies have raised their upper age limits of eligibility. However, many AYA programs still confront the problem of access to relevant clinical trials, thwarted by separate institutional review boards (IRBs) and low accrual targets. For example, a Children's Oncology Group trial with an upper age limit of 30 years cannot be opened at an adult institution which, although connected to a pediatric hospital, is not a member of Children's Oncology Group and has a separate IRB. A key issue for adult institutions is prioritization of scarce resources, particularly when faced with a trial that has a targeted accrual of one patient per year.

Patient and Family Advocacy

In our survey of AYA programs, the importance of establishing local support from AYA patients and their families was repeatedly mentioned. Patients can contribute greatly to strategic planning, as they are often best suited to recognize the priority needs in a given environment. Furthermore, when medical providers cannot agree on the needs of the program (or even the need for a program), patients can be a powerful contingency to exert influence on the politics of the situation. Both DFCI and M. D. Anderson had patient and family advisory committees that met regularly with program staff, providing feedback, grassroots support, and volunteer service time. Given the value of peer support (but also the energy, independence, and motivation of young adulthood), AYA patients can certainly be mobilized, with supervision, to organize support groups, write orientation manuals, and so on.

Philanthropic Financial Support

Because AYA programs will be perceived as additional (ie, added-cost) services, it is beneficial to consider the economic implications of developing an AYA unit. This can be done in at least three ways:

(1) Demonstrate the lack of added cost by building the AYA unit from a rearrangement of current resources (Centro di Riferimento Oncologico, Aviano).

(2) Demonstrate the possible revenue growth and indirect benefits of an AYA program (OHSU). Efforts should be made to obtain projections of predicted increase in volume from new referrals and the ability to bill for added services (consults, fertility preservation, psychology services). However, it is a reality that an AYA program is unlikely to be purely solvent from revenue. Value will come from community and media recognition and from improved patient satisfaction and other clinical outcomes (eg, enrollment in clinical trials), the metrics of which should be carefully collected and routinely presented (see Metrics section). It is important to note that many health systems funded by public investment, for example in Canada, Australia, and the United Kingdom, will not be able to raise funds using the billing models that apply in the United States.

(3) Raise external discretionary funds. Most commonly this is done through philanthropy (DFCI, onTrac@PeterMac) but can also work through research grants (OHSU, onTrac@PeterMac). Of course, reliance on philanthropy to support AYA services is not sufficient because a sustainable model of care needs institutional, community, and government support and, in an academic environment, peer-reviewed research funding. Fortunately, there is increasing interest in funding research into the poor outcomes for this age group.

Services on Which to Focus

An AYA program has to have clear “wins” to be sustainable. The advice from current programs surveyed was to find beneficial and concrete ancillary services that complement existing services. Programs that had a physical unit were at an advantage in this regard. Those without a physical unit sought to provide services that would add value to patients and providers and not be perceived as competitive. The two most common services were AYA-specific psychosocial/educational support and fertility services, preferably backed by policy and procedure changes. An example is the Fertility Preservation Service at DFCI, where a written policy dictated that all newly diagnosed children were considered for fertility preservation, and a computer program sent e-mail reminders to all adult providers before they saw a new patient. Likewise, the IRB at OHSU has dictated that a template be inserted into all clinical protocols requiring a discussion of fertility preservation.

Research

Just as a policy and procedure provides familiar structure in clinical care, a research protocol can provide an acceptable change in practice. Especially at academic centers, the research protocol is an accepted currency that crosses departments and is nonthreatening because it does not suggest best practice directly, but rather in an open-ended manner. It was the experience of OHSU and onTrac@PeterMac that a research trial concerning a psychosocial assessment tool or clinical intervention increased engagement with existing service providers and access of AYA patients to the AYA unit. In academic settings, basic science studies of tumor biology across the age spectrum are also appealing, because they do not mandate clinical care changes.

Space

It is the exception for new AYA programs to be given dedicated inpatient or outpatient space. This seems especially difficult to obtain in centers where pediatric and medical oncology space is not controlled by the same financial group. When available, the most common “first” space appears to be inpatient bed space; often this can be arranged by a relatively efficient redistribution or regrouping of current admissions, without requiring true infrastructure costs. This was the first step in the successful creation of TCT units in England, and there are currently inpatient units in Italy and Australia that follow this model as well. However, such units are often located within either predominantly pediatric or predominantly adult health centers, with consequent limitations on the age range of patients who have access to these units. Standalone AYA units equidistant between pediatric and adult cancer services are uncommon; the TCT unit in Manchester, United Kingdom, is an exception. In addition, a communal physical space for AYAs is important for socialization and recreation, and this has been developed as part of inpatient (OHSU) or outpatient areas (M. D. Anderson).

Metrics

Any proposed change is motivated by the belief that the effort will result in improved outcomes. One of the challenges in developing an AYA program is in defining and measuring those desired outcomes. Unfortunately, the gold standard of improved survival rates will be impossible to measure at a local level. Conversely, although measurable, quantitative metrics such as number of AYA consults do not actually reflect a change in behavior or outcome. Finally, it is important to consider patient-reported experiences of AYA services, particularly with respect to psychosocial and other support. Our survey and other discussions have developed a list of potential metrics that AYA programs can follow (Table 2), but further discussion and research should more clearly delineate and validate these for the AYA oncology community.

BARRIERS TO ESTABLISHING AYA PROGRAMS

Starting an AYA program is not easy, and more centers are struggling with the challenge than succeeding. Despite the enthusiasm of the converted instigators, the proposal of a unit specifically dedicated to AYA patients may not be met with eagerness by all. In some cases to date, strong opposition has emerged, often relating to cultural, administrative, and logistic issues; prioritization; or costs. The funding issues are significant for most nascent AYA services, because philanthropic funds are an uncertain resource for the development of services that ought to be regarded as standards of care. In systems where the total health budget is limited, reassignment of resources from an existing set of services to AYA services will be met with resistance, unless handled sensitively and collaboratively. Finally, the differences in resources that are regarded as normal within pediatric and adult cancer services may lead to differences in expectations and ability to provide care. Fortunately, the increasing evidence of systemic failures to address the needs of AYA patients is leading to increasing community and government willingness to provide the resources to address the gap.

In many cases, barriers are put up out of diffidence or because physicians are afraid of losing their patients or position of expertise. Many organizational issues need to be addressed in establishing a

Table 2. Possible Metrics to Follow in Development of an AYA Oncology Program

Category	Possible Metrics
Accrual	1. No. of patients seen by designated AYA providers (as denominator of all patients in age range seen by center) 2. Growth in number of patients age 15-40 years seen at institution (compare with growth in other age groups) 3. Outreach to broader community (AYA patients not seen at center)
Space and resources	4. Dedicated AYA inpatient rooms 5. Dedicated AYA common areas 6. Presence of Web resources (eg, e-mail, Web site) 7. Written patient navigator tools (scientific library)
Patient care	8. No. of uncontrolled symptoms and side effects (acute and late) 9. Adherence, timing, and completion of planned therapy 10. Percentage of patients receiving fertility preservation information/consult 11. Percentage of patients of school age receiving teaching support in the AYA unit
Patient education and social interaction	12. No. of AYAs participating in retreats and support groups 13. No. of AYAs participating in conferences attended by peers 14. AYA Web site visits
Patient satisfaction	15. Standardized patient satisfaction surveys (eg, Press-Ganey) 16. Quality of life or impact of cancer measurements 17. Specific AYA patient satisfaction survey
Provider knowledge and satisfaction	18. Informal consults/phone calls to AYA program from providers 19. Provider satisfaction 20. Didactic sessions for providers and staff 21. Fellows knowledge of AYA oncology issues
Research	22. Percentage of patients screened for and enrolled in clinical trials 23. AYA research (activity, publications)
Finances	24. Clinical revenue 25. Grants 26. Philanthropic donations

Abbreviation: AYA, adolescent and young adult.

clinical unit that crosses age groups and, therefore, may cross different divisions defined according to patient's age and/or tumor type. For instance, to which team does the AYA psychologist belong? Are they appointed to the AYA service or to the psychology department? Who has professional accountability? An increasing challenge is resistance to splitting of nascent cancer disciplines by the new AYA units, which includes both professional integrity as well as caseload. Ironically, the addition of resources to stretched health care systems may be viewed negatively as a consequence of professional turf issues, regardless of the added benefit to patients.

In conclusion, the times when too little attention and too few resources were dedicated to studying and treating older teenagers and young adults with cancer seem to be coming to an end. In recent years, numerous steps have been taken to draw the attention of the oncology community (and the public health system in general) to their problems. The path toward dealing with all the issues—our understanding of the tumor's biology, access to treatment, compliance with therapy, and psychosocial issues unique to patients with cancer in this particular age group—has been paved with good intentions, but also strewn with obstacles. Many involved with this population believe the goal is to create a new discipline, adolescent and young adult oncology, with

its own training programs, clinical and translational research, and national and international organizations.^{18,19} But there are admittedly counter-arguments, important challenges, and implications. In the meantime, we propose that the best way to bridge the gap in the care of AYA patients and enable them to catch up with the progress made in younger and older patients is to centralize their care within dedicated programs with an AYA focus. What have been the essential components? Philanthropy, federal support, local collaboration of pediatric and medical oncologists, and dedicated providers, including support staff, and, preferably, a physical space. The development of an AYA program will benefit from identifying key services that are perceived as worthwhile and valuable enhancements to a center.

Anyone wishing to establish a new AYA-focused program should look to past and present experiences and seek the key elements for success. Local efforts ought to be complemented by a comprehensive multi-pronged approach, involving numerous organizations, health care providers, and academic societies, governments, and international oncology cooperative groups.^{18,20} Moreover, it is key to recognize that the sustainable development of AYA services will require acceptance as a standard of care at the community and government level.

Although it is true that many of the existing schemes have arisen in the pediatric oncology setting, several have succeeded originating from the medical oncology side, and it should be clear to all that real results can only be achieved if there is a genuine cooperation between, and leadership by, both pediatric oncologists and medical oncologists. Although historically adult and pediatric health care professionals may be unaccustomed to working with each other, their respective experiences and resources should be pooled for the benefit of the AYA patient. It is encouraging to know that willing hands are reaching out to cross the divide. Finally, although rules and recommendations might be defined to improve our chances of success, the human element remains essential: No progress will be made without the fundamental influence of forward-thinking, charismatic heads willing to dedicate their professional lives to AYA patients.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

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REFERENCES

1. Albritton K, Bleyer WA: The management of cancer in the older adolescents. *Eur J Cancer* 39:2584-2599, 2003
2. Eden T: Keynote comment: Challenges of teenage and young-adult oncology. *Lancet Oncol* 7:612-613, 2006
3. Senior K: Teenagers with cancer: An improving picture. *Lancet Oncol* 7:366, 2006
4. Whelan J: Where should teenagers with cancer be treated? *Eur J Cancer* 39:2573-2578, 2003
5. Bleyer A, Montello M, Budd T, et al: National survival trends of young adults with sarcoma: Lack of progress is associated with lack of clinical trial participation. *Cancer* 103:1891-1897, 2005
6. Bleyer A, Budd T, Montello M: Adolescents and young adults with cancer: The scope of the problem and criticality of clinical trials. *Cancer* 107:1645-1655, 2006
7. Bleyer A, Morgan S, Barr R: Proceedings of a workshop: Bridging the gap in care and addressing participation in clinical trials. *Cancer* 107:1656-1658, 2006 (suppl)
8. Albritton KH, Wiggins CH, Nelson HE, et al: Site of oncologic specialty care for older adolescents in Utah. *J Clin Oncol* 25:4616-4621, 2007
9. Burke ME, Albritton K, Marina N: Challenger in the recruitment of adolescents and young adults to cancer clinical trials. *Cancer* 110:2385-2393, 2007
10. Ferrari A, Montello M, Budd T, et al: The challenges of clinical trials for adolescents and young adults with cancer. *Pediatr Blood Cancer* 50:1101-1104, 2008 (suppl)
11. Ferrari A, Bleyer A: Participation of adolescents with cancer in clinical trials. *Cancer Treat Rev* 33:603-608, 2007
12. Ferrari A, Dama E, Pession A, et al: Adolescents with cancer in Italy: Entry into the national cooperative paediatric oncology group AIEOP trials. *Eur J Cancer* 45:328-334, 2009
13. Liu L, Krailo M, Reaman GH, et al: Childhood cancer patients' access to cooperative group cancer programs: A population-based study. *Cancer* 97:1339-1345, 2003
14. Eiser C, Kuperberg A: Psychological support for adolescents and young adults, in Bleyer A, Barr R, Albritton K, et al (eds): *Cancer in Older Adolescents and Young Adults*. Heidelberg, Germany, Springer Verlag, 2007, pp 365-385
15. Hollis R, Morgan S: The adolescent with cancer—at the edge of no-man's land. *Lancet Oncol* 2:43-48, 2001
16. Lewis I, Morgan S: Models of care and specialized units, in Bleyer A, Barr R, Albritton K, et al (Eds): *Cancer in Older Adolescents and Young Adults*. Heidelberg, Germany, Springer Verlag, 2007, pp 341-352
17. Rosenbaum P, King S, Law M, et al: Family centered service: A conceptual framework and research review. *Phys Occup Ther Pediatr* 18:1-20, 1998
18. US Department of Health and Human Services: Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer. Bethesda, MD, NIH publication 06-6067, 2006
19. Brown M, Lipscomb J, Synder C: The burden of illness of cancer. *Annu Rev Public Health* 22:91-113, 2001
20. Bleyer A, Barr R: Highlights and challenges, in Bleyer A, O'Leary M, Barr R, et al (eds): *Cancer Epidemiology in Older Adolescents and Young Adults 15 to 29 Years of Age, Including SEER Incidence and Survival: 1975-2000*. Bethesda, MD, National Cancer Institute, NIH publication 06-5767, 2006, pp 173-189
21. Bleyer A: Adolescent and young adult (AYA) oncology: The first A. *Pediatr Hematol Oncol* 24:325-336, 2007
22. Wilkinson J: Young people with cancer: How should their care be organised? *Eur J Cancer Care (Engl)* 12:65-70, 2003
23. Leonard RC, Gregor A, Coleman RE, et al: Strategy needed for adolescent patients with cancer. *BMJ* 311:387, 1995
24. Souhami R, Whelan J, McCarthy JF, et al: Benefits and problems of an adolescent oncology unit, in Selby P, Bailey C (eds): *Cancer and the Adolescent*. London, United Kingdom, BMJ Publishing Group, 1996, pp 276-283
25. Clerici CA, Massimino M, Casanova M, et al: Psychological referral and consultation for adolescents and young adults with cancer treated at pediatric oncology unit. *Pediatr Blood Cancer* 51:105-109, 2008
26. Coventry University: Cancer Care for Teenagers and Young Adults PgCert Course. <http://www.wm.coventry.ac.uk/postgrad/postgraduate/pages/pgft.aspx?itemID=15>
27. Lewis IJ, Fallon S, van Dongen-Melman J, et al: Cancer and the adolescent: The Second Teenage Cancer Trust International Conference, Royal College of Physicians, London, England, March 2001. *Med Pediatr Oncol* 39:198-201, 2002
28. Whiteson M: The Teenage Cancer Trust—advocating a model for teenage cancer services. *Eur J Cancer* 39:2688-2693, 2003
29. National Institute for Health and Clinical Excellence Guidance on Cancer Services: Improving Outcomes in Children and Young People With Cancer. August 2005. <http://www.nice.org.uk/nicemedia/pdf/C&YPMannual.pdf>
30. Olsen PR, Harder I: Keeping their world together: Meanings and actions created through network-focused nursing in teenager and young adult cancer care. *Cancer Nurs* 32:493-502, 2009
31. Desandes E, Lacour B, Sommelet D, et al: Cancer adolescent pathway in France between 1988 and 1997. *Eur J Oncol Nurs* 11:74-81, 2007
32. Howell DL, Ward KC, Austin HD, et al: Access to pediatric cancer care by age, race, and diagnosis, and outcomes of cancer treatment in pediatric and adolescent patients in the state of Georgia. *J Clin Oncol* 25:4610-4615, 2007
33. Mitchell AE, Scarcella DL, Rigutto GL, et al: Cancer in adolescents and young adults: Treatment and outcome in Victoria. *Med J Aust* 180:59-62, 2004
34. Bleyer A, Barr R, Hayes-Lattin B, et al: Oncology, Biology and Clinical Trials Subgroups of the US National Cancer Institute Progress Review Group in Adolescent and Young Adult Oncology: The distinctive biology of cancer in adolescents and young adults. *Nat Rev Cancer* 8:288-298, 2008
35. Boissel N, Auclerc MF, Lheritier V, et al: Should adolescents with acute lymphoblastic leukemia be treated as old children or young adults? Comparison of the French FRALLE-93 and LALA-94 trials. *J Clin Oncol* 21:774-780, 2003
36. de Bont JM, van der Holt B, Dekker AW, et al: Significant difference in outcome for adolescents with acute lymphoblastic leukemia treated on pediatric versus adult ALL protocols in the Netherlands. *Leukemia* 18:2032-2035, 2004
37. Ferrari A, Dileo P, Casanova M, et al: Rhabdomyosarcoma in adults: A retrospective analysis of 171 patients treated at a single institution. *Cancer* 98:571-580, 2003
38. Ferrari A, Gronchi A, Casanova M, et al: Synovial sarcoma: A retrospective analysis of 271 patients of all ages treated at a single institution. *Cancer* 101:627-634, 2004
39. Klein-Geltink J, Shaw AK, Morrison HI, et al: Use of paediatric versus adult oncology treatment centres by adolescents 15-19 years old: The Canadian Childhood Cancer Surveillance and Control Program. *Eur J Cancer* 41:404-410, 2005
40. Meadows AT, Kramer S, Hopson R, et al: Survival in childhood acute lymphocytic leukemia: Effect of protocol and place of treatment. *Cancer Invest* 1:49-55, 1983
41. Nachman J, Sather HN, Buckley JD, et al: Young adults 16-21 years of age at diagnosis entered onto Childrens Cancer Group acute lymphoblastic leukemia and acute myeloblastic leukemia protocols. Results of treatment. *Cancer* 71:3377-3385, 1993 (suppl)
42. Paulussen S, Ahrens S, Juergens HF: Cure rates in Ewing tumor patients aged over 15 years are better in pediatric oncology units: Results of GPOH CESS/EICESS studies. *Proc Am Soc Clin Oncol* 22:816, 2003 (abstr 3279)
43. Ramanujachar R, Richards S, Hann I, et al: Adolescents with acute lymphoblastic leukaemia: Emerging from the shadow of paediatric and adult treatment protocols. *Pediatr Blood Cancer* 47:748-756, 2006