

A Model Telehealth Adolescent and Young Adult Oncology Program



Adolescent and young adult (AYA) oncology patients are defined by the National Cancer Institute as individuals diagnosed with cancer between 15 and 39 years of age.¹ According to Miller et al., an estimated 90,000 AYAs were diagnosed with cancer in the United States in 2020 and overall cancer incidence increased in all AYA age groups from 2007 to 2016.² These national data, as well as state-specific data (including low to moderately populated states, such as Wisconsin³), support the fact that AYAs make up a growing percentage of oncology patients.

In addition to representing a relatively large number of patients, AYA oncology patient care is critical given these individuals have unique oncologic diagnoses, morbidities, and psychosocial concerns that are inadequately met through conventional healthcare models. With regards to diagnoses, younger adolescents (15 to 19 years old) are more commonly diagnosed with lymphomas, germ cell tumors, and leukemias, whereas older AYAs (20 to 29 years old) are more commonly diagnosed with carcinomas.⁴ Combining these unique diagnoses with lower cancer survival rates in some AYA diagnoses,⁴ there is a crucial need to develop and implement AYA-dedicated services that take into consideration this vulnerable population's unique needs in an effort to increase patient quality of life and overall cancer survival.

Development of an AYA Oncology Program

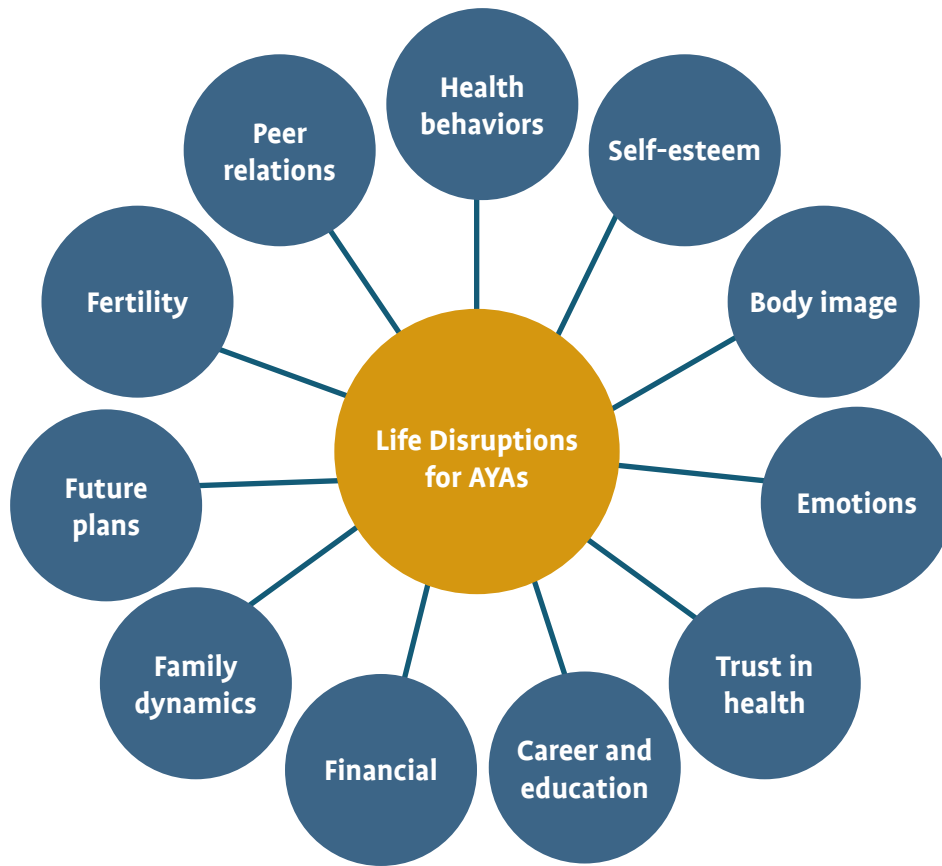
Given the intersection of age-specific developmental tasks with the complexities of cancer, AYAs have a variety of largely unaddressed needs. Unmet psychosocial needs, including those shown in Figure 1, page 46, have been associated with disparities in clinical treatment, lower survival rates, and poorer physical- and mental health-related quality of life.⁵ These challenges negatively

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impact patients' abilities to make treatment-related decisions and treatment adherence.^{6,7} Disparities in psychosocial and supportive care contribute to poorer outcomes and support the need for dedicated AYA services given the inadequate provision of psychosocial care in our current healthcare model. To meet the individual needs of AYAs, the University of Wisconsin Carbone Cancer Center sought to create a new patient-centered care model that identifies and addresses AYAs' particular needs before, during, and after treatment through the the Adolescent and Young Adult (AYA) Oncology Program at the University of Wisconsin Carbone Cancer Center. Due to resource limitations common to many cancer programs (e.g., clinic space), we developed our AYA Oncology Program using an innovative telehealth-based model.

The mission of our AYA Oncology Program is to improve the patient experience, quality of life, and long-term survival of AYAs diagnosed with cancer by providing age- and developmentally appropriate psychosocial and supportive care services from pro-

Figure 1. Common Life Disruptions for AYAs⁵



professionals with AYA expertise. This mission is addressed through three important initiatives: clinical, research, and education. The research and education initiatives meld seamlessly with the clinical aspect of the program, supporting the development of a forum to exchange multidisciplinary research to:

- Advance the field of AYA oncology
- Create training opportunities for AYA-dedicated oncology providers
- Provide clinical care to support the patient experience.

It is the authors' hope that the following description of the clinical model of our AYA Oncology Program will serve as an innovative approach to delivering AYA-dedicated care, with the understanding that many resource limitations exist among institutions and facilities everywhere.

Needs and Limitations

When approaching a new program, it is important to consider the needs that are being addressed and the possible limitations in meeting those needs. Table 1, right, shows the three critical needs we identified, along with the potential limitations in creating

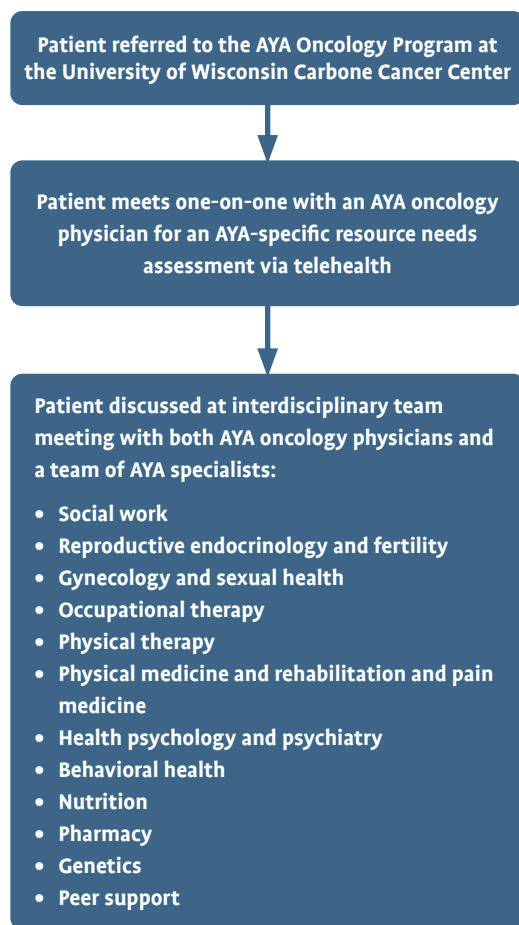
and establishing our AYA Oncology Program. First, we encountered a common limitation when conceiving the program: finite clinic space. We needed to address the physical aspects of the AYA Oncology Program within the limitations of the University of Wisconsin Carbone Cancer Center. Considering our limited physical clinic space, we followed the growing evidence amid the COVID-19 pandemic that showed that telemedicine was acceptable to AYAs⁸ and developed the first consultative AYA Oncology Program that follows a telemedicine clinical model. Using telemedicine as our foundation provided several key advantages, such as nearly eliminating the need for physical clinic space and expanding the reach of the program to AYAs from distant or rural residential locations. Patients do not need to travel to the cancer center to take advantage of the benefits of the AYA Oncology Program and can more easily fit the clinic visit in between all their other responsibilities.

A second need we identified that was imperative to program success was the participation of multidisciplinary AYA-focused providers. We needed supportive care resources tailored to AYA patients, and we made it a goal to have all supportive care services

Table 1. Needs and Limitations in the Creation of an AYA Oncology Program

Needs	Limitations
Dedicated AYA Program	Clinic space
Supportive care resources, preferably from AYA-focused providers	Limited availability of AYA-focused supportive care providers
Integration of medical and psychosocial care using interdisciplinary providers	Funding to support salary for interdisciplinary care providers

Figure 2. AYA Oncology Program Structure



provided by AYA-focused providers. Unfortunately, despite this universally identified need, we found that our current healthcare system has limited availability of AYA-focused supportive care providers. To address this limitation, we created an interdisciplinary team of diverse providers who are dedicated to AYA patient care. The establishment of our AYA interdisciplinary team allowed for the identification of AYA-focused providers within the cancer program, as well as bi-directional AYA-specific education to team members, thus allowing for the ongoing development of an AYA-specific skill set within the cancer center.

Finally, we identified a critical need for the integration of medical and psychosocial care using interdisciplinary providers. It is well established that the identification of patients' needs and the provision of services to meet those needs require interdisciplinary care. Our inability to immediately procure funding to support the salaries of dedicated interdisciplinary care providers was one of the largest limitations we faced in implementing our AYA Oncology Program. To overcome this barrier, we employed a tumor board-style interdisciplinary team meeting approach. This approach means that patients first have a telemedicine-based clinic visit with an AYA-oncology physician to complete a resource needs assessment. This visit is then followed by an AYA interdisciplinary team meeting four days later, where providers receive insight into the available resources necessary to meet patients' identified needs. This approach allows for interdisciplinary consideration of all AYA patient cases, while only requiring one hour per week from all AYA interdisciplinary team members. Resources identified by the team in this meeting are then arranged through the cancer center's standard referral pathways.

Program Launch

With this structure set, we launched our AYA Oncology Program in January 2021. Figure 2, right, shows the program's structure. Patients are referred to the AYA Oncology Program by providers in the cancer center or through external referrals. Patients are eligible to be seen at our AYA oncology clinic if they are currently

between the ages of 15 years to 39 years and have ever been diagnosed with cancer. Patients may be long-term survivors of childhood cancer, newly diagnosed, or several years off therapy. Patients are first seen by one of our two AYA-focused oncology physicians—one adult and one pediatric hematologist/oncologist. This appointment is a 60-minute telemedicine video visit that includes an AYA-specific resource needs assessment. During this visit, the patient's underlying cancer diagnosis and subsequent treatment are confirmed and the remainder of the visit is spent discussing the most frequent topics of concern for AYA patients with cancer. The goal of the visit is to explore the multitude of ways patients' lives are altered by a cancer diagnosis and work together to seek resources to address their individual needs. Four days later, all patients are presented at the AYA interdisciplinary team meeting, which is attended by both AYA oncology physicians and AYA-focused providers representing a multitude of fields, including:

- Social work
- Reproductive endocrinology and fertility

- Gynecology and sexual health
- Physical therapy
- Physical medicine and rehabilitation/pain medicine
- Health psychology and psychiatry
- Occupational therapy
- Behavioral health
- Nutrition
- Pharmacy
- Genetics
- Peer support, which includes community programs that are available to patients.

At this meeting, the AYA interdisciplinary team discusses each patient that was seen the previous week in AYA clinic. Working collaboratively, the team identifies available in-house and community-based resources that meet patients' identified needs and considers possible barriers, such as patients' residential location and insurance status. In addition to interdisciplinary consideration of each patient's unique psychosocial resource needs, the AYA oncology program also provides survivorship care plans tailored to each patient's unique exposures from their diagnosis or treatment. Our clinic can also serve as a conduit to establishing care with a primary care provider in the community.

Program Benefits

Since launch, we have seen that this innovative clinical model offers a slew of benefits to our patients. A visit with a dedicated AYA oncology physician is critical for identifying patients' needs and the supportive care services that are essential to meet those needs. With the telemedicine model, we are decreasing the resources and provider time required for such consultations. Another benefit that is critical for AYA patients who are balancing work, family, and their other priorities and responsibilities is that this program gives them flexibility, so they can better balance their medical care with their day-to-day responsibilities. Instead of adding additional travel time to the cancer center or the need to find childcare, patients can participate in our AYA Oncology Program in the location most convenient for them.

Our providers have also seen great benefits from the program. The combination of a dedicated one-on-one resource needs assessment consultation and AYA interdisciplinary team meeting helps already busy clinicians identify and support the psychosocial concerns of patients that have been shown to negatively impact patient care, including treatment compliance. Our AYA Oncology Program documents in the electronic health record all critical care components discussed in the team meeting, including fertility, contraception, and sexual health, which are key measures of quality and are supported through national guidelines (e.g., National Comprehensive Cancer Network Guidelines™).⁹ Moreover, our AYA Oncology Program creates meaningful survivorship care plans that are informed by patient visits and that help guide their ongoing survivorship care.

Program Metrics

As is true with any new program, one must use metrics to establish a program's viability and benefits to patients and the cancer center. As seen in Table 2, right, considering the first 35 patients seen in our AYA Oncology Program, we found a statistically significant increase in resource utilization. Prior to their visit with the AYA oncology physician, patients used an average of 2.51 resources per individual. After the initial AYA telemedicine consult, an additional 2.54 novel resources were identified per patient. Most notable, however, was the incredible importance of interdisciplinary team care, with an additional 1.91 average novel resources identified per patient after the AYA interdisciplinary team meeting held four days after the initial AYA telemedicine consult.

Considering the unique AYA-specific resources separately, we noticed that prior to our AYA telemedicine consultation, patients were most likely to be referred to social work and genetics, with limited connection to vocational or peer support resources. After the AYA telemedicine consultation, patients were most likely to be referred to health psychology or psychiatry and peer support, reflecting the importance of mental health services for these patients. These needs and resources are currently under-recognized and underutilized in our current healthcare system, and our AYA Oncology Program ensures that we address the mental health needs of our patients. Finally, following the AYA interdisciplinary team meeting, there was a broad representation of novel resources previously not used by patients, including physical therapy and occupational therapy, additional peer support options, and patient-specific resources (termed "other" in Table 2), such as:

- Physical medicine and rehabilitation
- Pain medicine
- Sleep clinic
- Financial resources
- Behavioral health
- Substance abuse.

These data suggest an incredible opportunity for AYA-specific programs to meet the unique needs of this patient population. Our telemedicine-based AYA Oncology Program generated an average of 4.45 new resources per patient over the course of their one-on-one visit with an AYA oncologist and case discussion with the AYA interdisciplinary team. This figure represents a statistically significant increase in resource identification and utilization ($p < 0.001$). Considering these data, our AYA Oncology Program has been both feasible and successful, despite initially facing logistic barriers common to healthcare systems and oncology programs and practices. The use of a telemedicine-based consultative model certainly helped with logistic issues related to limited clinical space, expanded the research of the program, and decreased time requirements for both patients and providers. Through this program, we have shown the critical importance of an interdisciplinary approach and added further data to support the need for AYA-dedicated patient care in oncology. Success of such novel approaches adds support to the belief that AYA-dedicated oncology

Table 2. Incremental Benefit of a Staged Approach to AYA Oncology Care: Distribution of AYA-Specific Resources Identified Before the AYA Encounter, During the Physician Visit, and at the AYA IDT Meeting

	Social Work n (%)	Fertility and Sexual Health n (%)	Genetics n (%)	Psychology and Psychiatry n (%)	Physical and Occupational Therapy n (%)	Vocational Resources n (%)	Peer Support n (%)	Nutrition n (%)	Other*	Average Novel Resources per Patient
Resources utilized pre-AYA clinic	14 (40.0)	11 (31.4)	16 (45.7)	11 (31.4)	16 (45.7)	0 (0.0)	4 (11.4)	8 (22.9)	8 (22.9)	2.51
Novel resources following one-on-one AYA physician clinic visit	5 (14.3)	11 (31.4)	8 (22.9)	14 (40.0)	8 (22.9)	4 (11.4)	19 (54.3)	10 (28.6)	10 (28.6)	2.54
Novel resources following AYA interdisciplinary teammeeting	6 (17.1)	6 (17.1)	6 (17.1)	4 (11.4)	10 (28.6)	3 (8.6)	8 (22.9)	8 (22.9)	16 (45.7)	1.91

*Other resources include physical medicine & rehabilitation, sleep clinic, financial resources, pain medicine, survivorship, behavioral health and substance abuse. AYA = adolescents and young adults; IDT = interdisciplinary team

programs need not be isolated to large cancer centers and supports adoption of feasible practices to better support AYAs.

Amanda Parkes, MD, is a former assistant professor and director of the AYA Oncology Program at the University of Wisconsin Carbone Cancer Center and Cathy Lee-Miller, MD, is an assistant professor of pediatric hematology/oncology and director of the the AYA Oncology Program at the University of Wisconsin Carbone Cancer Center at the University of Wisconsin-Madison, Madison, Wisc.

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