

Exploring a Lost Generation:  
Adolescent & Young Adult Oncology in the Academic Setting

Exploratory Paper

Susan van der Sommen, FACHE, FACMPE, MHA

March 7, 2017

This paper is being submitted in partial fulfillment of the requirements of Fellowship in  
the American College of Medical Practice Executives

## Abstract

Each year, approximately 70,000 adolescents and young adults between the ages of 15 and 39 (commonly referred to as *AYAs*) are diagnosed with cancer, yet historically, few programs have been developed to address their unique clinical, social and emotional needs. Representing a scant 6% of all cancer diagnoses, the disease is a leading factor of death among this age group. Whereas their adult and pediatric counterparts have experienced greater overall success in outcomes and survivorship, *AYAs* have become a “lost generation”, achieving suboptimal results. There is a growing sense of importance among academic medical centers to develop programs designed to meet the unique needs of this population and address disparities in their care. Health care administrators are required to balance multiple priorities with limited resources in an ever-evolving, rapidly changing health care environment. By exploring the unique needs of the *AYA* cohort of the oncology population and the growing imperative to address their needs, the author will reveal historical and current obstacles and recommend strategies designed to achieve improved outcomes through programmatic development and collaborative models of care.

## Exploring a Lost Generation:

## Adolescent &amp; Young Adult Oncology in the Academic Setting

Each year, approximately 70,000 adolescents and young adults between the ages of 15 and 39 (commonly referred to as *AYAs*) are diagnosed with cancer, yet historically, few programs have been developed to address their unique clinical, social and emotional needs (Shaw et al., 2015). Commonly referred to as “AYAs”, those in this age group represent a scant 6% of all cancer diagnoses (National Cancer Institute & Livestrong Alliance, 2006), yet are eight times more likely to be diagnosed than children who are in their first fifteen years of life (Docherty, Kayle, Maslow, & Santacroce, 2015). Cancer is a leading factor of death among this age group when excluding homicide, suicide and unintentional injury (National Cancer Institute & Livestrong Alliance, 2006). With these factors taken into consideration, for females, it remains the single most common cause of death; in males, it is second only to heart disease (National Cancer Institute & Livestrong Alliance, 2006).

In recent years, there has been greater attention paid to this unique population of patients based on the reported suboptimal outcomes compared to other age groups (Docherty et al., 2015). This paper will focus on the evolution of understanding the overarching characteristics of this population, and how, through programmatic development and collaboration, their unique needs can be met in an academic medical center’s model of care.

Through an extensive literature search, examination of existing practice trends and drawing on professional experience, the author will outline the challenges faced by this cohort of patients and the benefits of developing an adolescent and young adult cancer program in an academic medical center. The author intends to depict the growing urgency for change based on historical and current obstacles relating to their care and define strategies to address their distinctive needs through programmatic development and collaborative models of care.

### **Adolescent & Young Adult Oncology – A Brief History**

Childhood cancer became a focus of study, research and clinical practice in the early 1950s, with adults added as a priority in 1971 after the passage of the National Cancer Act (Keegan, et al.). As noted by Keegan et al. (2016), the prognosis of AYAs in those early years was on par with and often surpassing their pediatric and adult counterparts. However, survival rates have since declined (Docherty et al., 2015). As a result, the AYA population has gained international attention in recent years initiated by the National Cancer Institute (NCI) and Livestrong Foundation's jointly sponsored effort, *Adolescent and Young Adult Oncology Progress Review Group* (National Cancer Institute & Livestrong Alliance, 2006). The resulting report, *Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer*, provided an initial, yet definitive, outline of what defines the AYA population, factors that have led to their limited success in achieving optimal cure rates, and recommendations for addressing their unique needs.

It is important to note that the types of cancer vary considerably within this age range, with the younger group (15-19) being more afflicted with lymphomas, germ cell tumors and leukemia (National Cancer Institute & Livestrong Alliance, 2006). These cancers decline between the ages of 20 and 39, when breast, cervix and colon cancer tend to be more prevalent. It is, therefore, not the *diagnosis* or *disease* that binds this population together; rather, it is their unique characteristics, noting that, as a group, they can be labeled neither as children or adults.

### **Unique Characteristics of the AYA Population**

Although the AYA population are at different stages of life, they are characterized largely by *transition* (Docherty et al., 2015). Generally speaking, unlike younger (pediatric) and older (middle-age to geriatric) oncology patients, the AYA population can be at various stages of education, employment, sexual identity and practices, and personal relationships. Their present day "life goals" are often put at risk due to the diagnosis, adding to their emotional and

psychological stress (National Cancer Institute & Livestrong Alliance, 2006).

Frequently recognized for their predominant sense of invincibility, youthful optimism and diminished regard for their own mortality, the younger echelon of this age group are more likely to engage in precarious, and often risky, activities including smoking, alcohol use and unprotected sex (Quinn et al., 2015). Generally, all AYAs tend view themselves as irrepressible, or, at the very least, unsusceptible to a life-threatening illness or injury, leading Quinn et al. (2015) to conclude that this cohort will tend to ignore symptoms or dismiss them as something that “will pass”.

Occupying a space somewhere between childhood and adulthood, AYAs are at a decided disadvantage because they often do not have an adequate “medical home” intended to address their clinical, emotional and social needs (Shaw et al., 2015). Shaw et al. (2015) further note that this puts the AYAs in the “no-man’s land” between the differing worlds of pediatric and adult oncology. They have paid a heavy price. Deficits in clinical trial enrollment, inadequate communication and collaboration, and high quality professional care are among the shortcomings AYAs contend with throughout the course of their treatment and beyond (Keegan, et al.).

**Similarities and differences within the AYA cohort.** AYAs in the younger echelon (ages 15-21) are often seeking to exert their sense of autonomy, while still maintaining dependence on their family unit (Quinn et al., 2015). The older of the cohort tends to be more focused on education, career development, marriage and children (National Cancer Institute & Livestrong Alliance, 2006). Physical changes due to treatment, however, isolates all AYAs from their peers (including hair loss, weight changes, scarring, etc.) and fear that their body will never return to its original state serves to compound their insecurities (Ramphal et al., 2016).

The risk of receiving suboptimal care is also a concern for this population. As previously noted, there is often there is a delay in diagnosis. This is often due to low suspicion of cancer in this age group (Ramphal et al., 2016). Care setting is also a factor, ranging from a multitude of

options including an adult practice, community health center, academic medical center or pediatric setting. According to Ferrari et al. (2010), pediatric centers are better designed to treat 3-4 years old patients who are under parental control, while medical oncologists routinely treat older adults who are independent. Community health centers are often both familiar and convenient for patients, yet practitioners in this setting don't always have access to the latest clinical trials and subspecialties that might be available in an alternative, less convenient setting (i.e., academic) (Ferrari et al., 2010). There is a dearth of data to guide patients with regard to the appropriate setting and treating physician, and optimal medication regimens and protocols are not always known in every treatment setting (National Cancer Institute & Livestrong Alliance, 2006). Ferrari et al. (2010) further point out that barriers to finding the ideal treatment center add to the stress of an already underserved and undervalued patient population.

**Psychosocial Needs.** Psychosocial issues among AYAs are awakened with a cancer diagnosis, with many of these needs remaining unmet for a variety of reasons (Ramphal et al., 2016). The common challenges faced by AYAs during this tenuous life period include, but are certainly not limited to, developing a sense of personal identity, navigating changes in their bodies, and life-altering decisions relating to pursuing their formal education, all of which are exemplified with an oncologic diagnosis (Barr et al., 2016). Coping with the general developmental stages in this time of life including body image, sexuality, personal and professional goals, marriage and/or possibly parenthood, among others, are further complicated by a cancer diagnosis (Rosenberg & Wolfe, 2011). Studies show that some AYAs have experienced difficulty in developing new relationships, while others reported challenges with maintaining existing friendships after diagnosis (Ramphal et al., 2016).

Additionally, some AYAs reported being woefully unprepared to deal with the

emotional, social and physical challenges that are inevitable with a cancer diagnosis (Kent, et al, 2013) and further note that it disrupts the already complex multitude of changes during this time in one's life (Barr et al., 2016).

Fear, a common result of the anxiety, angst and stress accompanied by a cancer diagnosis in AYAs, complicates matters even further, and their "distorted body image" during a critical period of developing their sexual identity serves to amplify the effect (Ramphal et al., 2016). Kent et al. (2013) point out that social isolation after diagnoses increases sensitivity to every day stressors and can lead to negative outcomes. Additionally, there is a lack of evidence about late effects of cancer diagnosis and treatment for AYA patients and limited survivorship resources (Marjerrison & Barr, 2018), both of which can lead to undue stress for their future. A comprehensive, multi-disciplinary approach to care involving professionals who can address emotional, physical and psychological concerns is necessary, according to Rosenberg and Wolfe (2011), to ensure adherence to treatment and the promise of more favorable outcomes.

**Insurance.** AYAs have historically had among the highest rates of uninsured or underinsured individuals (Shaw et al., 2015). Studies show that patients with health insurance have better outcomes, while those without tend to present with more advanced disease due to lack of early intervention and treatment (Keegan et al., 2016). Although some improvements have been noted since the inception of the Affordable Care Act, this indicator significantly affects their access to primary health care services (Shaw et al., 2015). The resulting delay in diagnosis remains a factor as to why outcomes for the AYA cancer patients have lagged behind their older and younger counterparts (National Cancer Institute & Livestrong Alliance, 2006).

**Clinical Trial Enrollment.** A principle result of improved outcomes for the general oncology patient population is related to their enrollment in clinical trials (Ramphal et al., 2016). Research specifically denotes this to be the case for AYAs with cancer (Baweja et al., 2017). Whereas enrollment of children under the age of 14 is estimated to be approximately 70%, this

number drops significantly in patients ages 15-19 with a 24% enrollment rate and a negligible rate of <2% for patients in the 20-30 year age range (Weiss et al., 2015). Patients treated in a community health center setting often do not have access to clinical trials due to multiple factors including, but not limited to, geographic location and a lack of resources required to enable data collection for research studies (National Cancer Institute & Livestrong Alliance, 2006). It is the conclusion of Baweja et al. (2017) that improved clinical trial enrollments will lead to a better understanding of the disease in this population, ideally rendering improved outcomes.

**Fertility Preservation.** All patients, regardless of age or diagnosis, have a right to understand complications and treatment effects relating to their disease. Of the 70,000 new diagnoses among the AYA population each year, many are at risk of infertility due to treatment regimens (Gorman, 2017). To that end, it is important for health care providers to advise their patients as early as possible of their risk for infertility (Oktay et al., 2018). This is particularly true of AYAs, according to Oktay et al. (2018) as they are considered to be of “child-bearing” age. Surveys show that fewer than 50% of physicians practicing in the United States inform their patients about fertility preservation, as “having to give a patient a cancer diagnosis is hard enough” (Gorman, 2017). Oktay et al. (2018) notes, however, that such discussions can reduce stress and facilitate a greater quality of life, as the patient is informed of choices at this critical stage.

Fertility preservation for oncology patients is often not covered by insurance and can be prohibitively expensive, particularly for younger patients, with access to such resources varying by geographic location (Gorman, 2017). Whereas a cancer diagnosis does not prohibit a family from choosing adoption, a prospective parent must be in “generally good health” and cancer free for at least “a few years” (Benedict, Thom & Kelvin, 2016). Sometimes, it is the only parenting option for cancer survivors, and with the overarching uncertainty with regard to adoption policies, it can cause additional angst (Gardino, Russell, & Woodruff, 2010).

### **Building an AYA Program: Making the Case for Change**

An ever-evolving and rapidly changing health care environment provides a great challenge to health care administrators. Health and payment reform, leadership competencies, emerging payment models, population health management, community and partner engagement are among the many issues facing leaders today. Determining where to expend limited resources in an effort to meet the demands of the population adds another dimension to existing challenges.

**Advocating for Change.** Strategically preparing for change has become a primary competency among health care leaders (Kash et al, 2014). With issues such as health reform, corporate mergers, and “disruptors” entering the health care market (such as Amazon, Apple, Google and others), administrators must position themselves not only for growth, but also for market differentiation. By investing in research and development for a niche population (as is exemplified at Cleveland Clinic and MD Anderson, among others), health care administrators can position their organization as a market “expert”, *the* organization to seek out for a primary or second opinion or as a final option for patients when others have been exhausted (Gamble, 2015).

According to the Institute of Medicine (2004), a key function of leadership is to “achieve a collective purpose”, which often requires advocating for change. Yet despite compelling evidence to support the development of a program focused on the adolescent and young adult with a cancer diagnosis, few medical centers have adopted a comprehensive, focused model of care. Healthcare organizations – regardless of whether private, academic or community-based – are faced with multiple initiatives and priorities, all requiring a plethora of skills. A key skill in this regard is advocating for and leading through transformational change.

**AYAs, Health Disparities and Cultural Competence.** Current buzz words in the population health realm include “addressing health disparities” and “cultural competence” in dealing with different racial and ethnic groups. The author contends that the AYA population has experienced disparities and a lack of culturally competent care. This is evidenced by their

suboptimal outcomes when compared and contrasted with their older and younger counterparts. From understanding their unique life perspectives to discussing fertility preservation, AYAs have largely been left to fend for themselves. Bentencourt et al. (2005) note that increasing competencies in this regard are necessary to address consumerism (relatively new to health care), reduce disparities, and provide all patients – regardless of *age*, race or gender – with access to the highest quality of care. Thus a well-developed AYA program can address not only ethnic and racial disparities, but also the unique needs of the “generation”, improving outcomes, patient engagement and satisfaction.

**Making the Case.** A healthcare administrators’ role in developing a program designed to focus on the AYA population can be likened to improving patient satisfaction or developing an innovative model for a facile check-in process. However, focusing on this “lost generation” will provide a unique opportunity for academic medical administrators to achieve the triple aim: improving the patient experience of care, improving the health of a vulnerable population and reducing the overall cost of care due to increased focus, resulting in more optimal outcomes.

**Addressing Challenges.** As with all models involving change, there are inherent challenges in developing an AYA program, as the age group spans across the pediatric and medical (adult) oncology sectors.

In the pediatric setting, care is most routinely provided based on standard clinical protocols with a higher proportion of required resources including, but not limited to, teachers, social workers, nutritionists (Ferrari, et al., 2010) and sometimes even art and music therapists. There is a triad approach – parent, patient, oncologist – with a system of care designed to be supportive and interactive (Ferrari, et al., 2010).

Medical (adult) oncology programs are designed to treat older patients who are independent and prepared to determine their own course (Ferrari, et al., 2010). When compared with the more comprehensive pediatric model, the adult patient is often treated in a community

center where care is more fragmented, with patients often being referred to specialists only as an acute need arises (Ferrari et al., 2010).

An AYA patient falls in the realm between pediatric and medical oncology, not fitting neatly into either setting of care (Institute of Medicine, 2013). As one survivor pointed out, in the pediatric setting, “Dora the Explorer” was featured in the waiting room; in the adult center, she was offered AARP magazine (Institute of Medicine, 2013). This is congruent with one of the major concerns expressed by AYA patients – have their own physical space (i.e., waiting room, inpatient lounge, etc.) (Ferrari et al., 2010).

According to Ferrari et al. (2010), the first step is defining the ideal model then charting barriers to making the change. In smaller academic settings, a “virtual base” approach to care might be necessary (defining a referral process to specialists outside the system), whereas in larger settings, a multi-disciplinary team may be available more locally (Barr et al., 2016). A physician champion is a requisite resource. Barr (2016) also notes that close collaboration between pediatric and adult centers is essential to success for transitions of care – whether live or virtual. Engaging a team of AYA patients will provide great insight into their needs. Reconfiguring an existing space may serve as a great first step in making the AYA population feel more included and valued. As AYA oncology became a more prevalent concern in the United Kingdom in the early 1980s, early programs were small in scope, with between four and 10 dedicated beds and a small “parent-free” recreation space (Ferrari & Barr, 2017). Thus with a focused, evidence-based and purposeful approach, an AYA program can be initiated with limited resources.

Finally, advocacy and engagement at a more global level is a key to success in making progress towards improving the care for this very distinct population (Barr et al., 2016). There are several organizations – both nationally and internationally – that are making great strides and providing exceptional resources (both financial and educational) for developing a comprehensive

care model. It is, therefore, possible to develop a strong case for a targeted and well-defined approach to this unique and distinct population without exhausting extensive resources.

A program with well-designed programmatic and evidence-based clinical initiatives that will engage and appeal to this generation of cancer patients is essential to achieving optimal outcomes. By utilizing existing resources, leadership competencies, advocacy skills, physician collaboration and engagement, health care administrators in the academic setting have a unique opportunity to lead the way in developing a model of care that can positively affect a currently lost generation of patients, improving their potential for survivorship and an enhanced quality of life for years to come.

## References

- Barr, R., Ferrari, A., Ries, L., Whelan, J., & Bleyer, A. (2016, May). Cancer in adolescents and young adults: a narrative review of the current states and a view of the future. *Journal of American Medicine Pediatrics*, 170(5), 495-501. Retrieved February 2018, from <https://jamanetwork.com/journals/jamapediatrics/fullarticle/2504263>
- Baweja, A., Schiller, G., Bergman, J., Litwin, M., Goldman, J., Davies, S., & Casillas, J. (2017, January 19). Clinical trial enrollment of adolescent and young adult patients with cancer: a systematic review of the literature and proposed solutions. *Clinical Oncology in Adolescents and Young Adults*, 51-59. doi:10.2147/COAYA.S70375
- Bentacourt, J.R., Green, A.R., Carillo, J.E., Park, E.R. (2005). Cultural competence and health care disparities: key perspectives and trends. *Health Affairs*, 24(2) (2005):499-505. DOI: 10.1377/hlthaff.24.2.499
- Docherty, S., Kayle, M., Maslow, G., & Santacroce, S. (2015, August). The adolescent and young adult with cancer: a developmental life course perspective. *Seminars in Oncology Nursing*, 31(3), 186-196.
- Ferrari A. & Barr, R.D. (2017, September) International evolution in AYA oncology: Current status and future expectations. *Pediatric Blood Cancer*, 64(9). DOI: 10.1002/psc.26528.
- Ferrari, A., Thomas, D., Franklin, A. R., Hayes-Lattin, B., Mascarin, M., van der Graaf, W., & Albritton, K. (2010). Starting an adolescent and young adult program: some success stories and some obstacles to overcome. *Journal of Clinical Oncology*, 28(32), 4850-4857. Retrieved from [http://ascopubs.org/doi/abs/10.1200/JCO.2009.23.8097?url\\_ver=Z39.88-2003&rft\\_id=ori%3Arid%3Acrossref.org&rft\\_dat=cr\\_pub%3Dpubmed&](http://ascopubs.org/doi/abs/10.1200/JCO.2009.23.8097?url_ver=Z39.88-2003&rft_id=ori%3Arid%3Acrossref.org&rft_dat=cr_pub%3Dpubmed&)
- Gamble, Molly (2015, February 4). 7 strategies for health systems to distinguish themselves. Becker's Hospital Review. Retrieved from <https://www.beckershospitalreview.com/hospital-management-administration/7-strategies-for-health-systems-to-distinguish-themselves.html>
- Gardino, S., Russell, A., & Woodruff, T. (2010). Adoption after cancer: adoption agency attitudes and perspectives on the potential to parent post-cancer. *Oncofertility*, 156, 1-17. doi:10.1007/978-1-4419-6518-9\_11
- Gorman, A. (2017). *Preserving fertility when it is threatened by life-saving medicine*. San Francisco, CA: Henry J. Kaiser Family Foundation. Retrieved from <https://khn.org/news/preserving-fertility-when-it-is-threatened-by-life-saving-medicine/>
- Institute of Medicine. (2013). Identifying and address the needs of adolescents and young adults with cancer: a workshop summary. The National Academies Press. Washington, DC.

- Kash, B., Spaulding, A., Johnson, C., & Gamm, L. (2014, Jan-Feb). Success factors for strategic change initiatives: a qualitative study of healthcare administrators' perspectives. *Journal of Healthcare Management*, 59(1), 65-81.
- Keegan, T., Ries, L., Barr, R., Geiger, A., Vollmer-Dahlke, D., Pollock, B., & Bleyer, W. (2016). *Comparison of cancer survival trends in the united states of adolescents and young adults with those in children and older adults*. National Cancer Institute, Washington, DC.
- Kent, E., Wilder Smith, A., Keegan, T., Lynch, C., Xiao-Cheng, W., Hamilton, A., . . . Group, A. H. (2013). Talking about cancer and meeting peer survivors: social information needs of adolescents and young adults diagnosed with cancer. *Journal of Adolescent and Young Adult Oncology*, 2(2), 44-52. Retrieved March 2018, from <https://www.liebertpub.com/doi/pdf/10.1089/jayao.2012.0029>
- Marjerrison, S., & Barr, R. (2018, June 2018). Unmet survivorship care needs of adolescent and young adult cancer survivors. *JAMA Network Open*, pp. 1-3. doi:10.1001/jamanetworkopen.2018.0350
- National Cancer Institute & Livestrong Alliance (2006). *Closing the Gap: Research and Care Imperatives for Adolescents and Young Adults with Cancer*. Washington, DC: National Institutes of Health NIH Publication No. 06-6067.
- Oktay, K., Harvey, B., Partridge, A., Quinn, G., Reinecke, J., Taylor, H., . . . Loren, A. (2018, July 18). Fertility preservation in patients with cancer: ASCO clinical practice guideline update. *Journal of Clinical Oncology*, 36(19), 1994-2003. doi:10.1200/JCO.2018.78.1914
- Quinn, G. P., Goncalves, V., Sehovic, I., Bowman, M. L., & Reed, D. (2015). Quality of life in adolescent and young adult cancer patients: a systematic review of the literature. *Patient Related Outcome Measures*, 6, 19-51. Retrieved from <http://doi.org/10.2147/PROM.S5>
- Ramphal, R., Aubin, S., Czaykowski, P., DePauw, S., Johnson, A., McKillop, S., . . . Rogerson, P. (2016). Adolescent and young adult cancer: principles of care. *Current Oncology*, 23(3), 204-209. Retrieved April 7, 2018
- Rosenberg, A., & Wolfe, J. (2011, May 15). Palliative care for adolescents and young adults with cancer. 2323-2328. *Cancer*, 117(10 Suppl), 2323-2328. doi:10.1002/cncr.26044
- Shaw, P., Reed, D., Yeager, N., Zebrack, B., Castellino, S., & Bleyer, A. (2015, April). Adolescent and young adult (AYA) oncology: a specialty in its late adolescence. *Journal of Pediatric Oncology*, 37(3), 161-169.

Weiss, A., Hayes-Lattin, B., Kutny, M., Stock, W., Stegenga, K., & Freyer, D. (2015, August). Inclusion of adolescents and young adults in cancer clinical trials. *Seminars in Oncology Nursing*, 31(3), 197-205.