

## Teenage and Young Adult Cancer: A Low-Hanging Fruit or the Final Frontier?

Cancers in young persons are uncommon, though they rank second among causes of death after accidents. Within the oncology community, young persons' cancer is an unrecognized issue. Cancers of the young account for 4.3%–6.26% of the nation's total cancer burden.<sup>[1,2]</sup> The GLOBOCAN 2018 reports that of the annual burden of over a million cancers in India, 54,538 persons in the age group (15–29) were diagnosed with 30,286 (55%) deaths.<sup>[3]</sup> Survival in adolescent and young adult cancers are improving in Western countries, while survival data from India in this age group is lacking.

Defined as between 15 and 29 years, AYAs with cancer are women and men in the prime of their aspirational life. Matriculation, college, employment, or a new relationship, all grind to a halt when cancer strikes. The care pathways are unclear. Consequently, the diagnosis and therapy are delayed, if not abandoned.<sup>[4]</sup>

Do young persons with cancer need a special approach? There are many reasons: while comorbidities are common with cancers in older adults, young persons have developmental, social, economic, sexual, fertility, and psychosocial challenges complicating their cancers. In matters of access to care, the young tend to “fall through the cracks”: too old to be treated like children and too young to be managed like older adults. Most cancers in the young are generally not amenable to screening tests. Poor participation and recruitment of AYAs in clinical trials is a significant challenge to development of an evidence base for therapy of AYA cancer.

AYA cancers present unique challenges. The array of cancer diagnoses in TYAs is divided in three age epochs: first in age 15–19 years; cancers are an extension of pediatric tumors: hematological, central nervous system and bone tumors; in the 20–24 year- group, thyroid, and testicular cancers predominate, while leukemias persist. In the third, i.e., 25–29 years, the incidence of “adult” epithelial cancers, i.e., colon and breast, rises, whereas that of leukemias reduces. Primary care physicians often miss young person's cancers such as leukemia and bone tumors, resulting in delays. There are unique biological questions like the aggressive colorectal cancers, triple-negative breast cancers, or the enigma of “Ph-like” acute lymphoblastic leukemia. AYAs with cancer have achieved 5-year survival in excess of 80%.<sup>[5]</sup> However, age-appropriate symptom relief, and end of life care to those AYAs needing it, remains an unmet need not only in India but in much of the world.

Efforts to provide a focus on this age group began in the United Kingdom in the 1990s and resulted in a robust

social entrepreneurial safety net for young persons (13–24) with cancer. The Teenage Cancer Trust and the National Health Service, in tandem, provide age-appropriate cancer care and support to AYAs. The United States established unique pathways for patients in the 15–39 years group, after the Progress Review Group report cosponsored by the National Cancer Institute was published in 2006.<sup>[6]</sup>

The Indian Oncology Community began the search for a solution to the problems of young cancer patients in 2012, with annual meetings. The Teenage and Young Adult Cancer Foundation (TYAcan) was created in 2016. The Foundation is an alliance of oncology professionals, survivors, caregivers, and volunteers, with the mission to “help young persons with cancer to achieve the best outcomes and also pursue their life dream.” It addresses a composite population of (a) young persons (15–29 years) and (b) survivors of childhood cancer. This age range was defined in the National Youth Policy 2014, by the Ministry of Youth Affairs.<sup>[7]</sup>

Early TYAcan initiatives resulted in reduced abandonment among AYAs in underserved areas such as Western Madhya Pradesh and Rajasthan, with tracking efforts modeled on the Abandonment Task Force of the International Society of Paediatric Oncology Pediatric Oncology in Developing Countries.<sup>[8]</sup>

The TYAcan Foundation's upcoming projects are:

- (a) The creation of India's first age-appropriate cancer treatment center at Indore for young persons
- (b) Creating an information network for awareness
- (c) Raising a volunteer corps, to support and navigate young people through the cancer experience
- (d) Developing registries of young persons' cancers.

As we address the young person's journey in the cancer biosphere, we encounter unique Indian cultural and psychological characteristics that shape our youngsters' life before, with and after cancer. AYA cancer is an emerging subspecialty and affords us an opportunity to manage cancer in a robust, physiologically privileged age group, in a holistic and personalized way. Survival increments in AYA cancer could reach five decades. With impassioned social entrepreneurship, it could be the ultimate frontier of cancer care. Scaled up to the vast demography of India, AYA cancer care could become the “paradigm of the possible” across the spectrum of cancer medicine.

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