Growing (up) together: understanding lymphoma in the adolescent and young adult population

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“No matter how hard we try to be mature, we will always be a kid when we all get hurt and cry”—J. M. Barrie, Peter Pan [1911]

There is that space in time between childhood and adulthood, quite unlike the other two. It is ungainly enough under normal circumstances, but particularly unsettling when disrupted by disease. This year, roughly 70,000 young people between the ages of 15 and 39 years, the now called adolescent and young adult (AYA) population, will be diagnosed with cancer, according to the statistics of the National Cancer Institute. This figure represents 5% of all cancers in the US, and is 6-fold greater than diagnosed in the pediatric population.

Those in the AYA age group often remark that they are misunderstood. Nowhere is this more true than when diagnosed with cancer, of which lymphoma is one of the most common types. Uncertainty exists in the biologic underpinnings of AYA lymphomas which in turn impacts the development of clinical trials and effective treatments. Optimal care delivery, including the management of survivorship and late effects, remains variable across pediatric and adult care models.

To attempt to answer many of these questions, and to identify others that need addressing, the Lymphoma Research Foundation (LRF), the nation’s largest non-profit organization dedicated exclusively to lymphoma research and patient advocacy, established a wholly unique AYA Lymphoma Consortium dedicated to recognizing AYAs as a distinct group of lymphoma patients and to better understand lymphoma in this population. One important result was an inaugural scientific workshop convened in Spring 2019, bringing together leading investigators in the field of lymphoma in general, and in the AYA population in particular. What became clear was that there were more questions than answers regarding the etiology of the lymphomas, their biology, explanations for the difference in distribution of subtypes, variations in treatment using pediatric versus adult regimens, reasons for limited participation in clinical trials, as well as issues of quality of life, patient outcomes and long-term survivorship.

In this issue of Annals of Lymphoma, participants in the LRF AYA Workshop present their deliberations with an aim to better understand the current landscape and to offer a platform for collaboration. Their conclusion was that a call to action was warranted for the creation of a national blueprint to address this critical unmet medical need. There was a recognition that success will require diverse stakeholders across the scientific and healthcare arenas to make the progress that is so sorely required to improve outcomes for the AYA patient population.

We shall certainly follow the progress of this program with great hope and anticipation, so that as a community we may reduce the challenges and pain faced by patients diagnosed with lymphoma during the precious time between childhood and adulthood.

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