Childhood Cancer Fact Library

All statistics below are for U.S. children from birth through 19 years old unless stated otherwise. This summary relies on the most recent published data with respect to its contents, some of which dates back one or more years.

Diagnosis

- The incidence of childhood cancer is on the increase, averaging 0.6% increase per year since mid-1970's through 2009 and 0.8% per year during 2010-2014, resulting in an overall increase of 24% over the last 40 years.\(^{(1,7F)}\)
- 1 in 285 children was diagnosed with cancer in 2014.\(^{(1)}\)
- 43 children per day or 15,780 children per year are expected to be diagnosed in with cancer (10,450 ages 0 to 14, and 5,330 ages 15 to 19).\(^{(1)}\)
- The average age at diagnosis is 8 overall (ages 0 to 19), 5 years old for children (aged 0 to 14), and 17 years old for adolescents (aged 15 to 19).\(^{(9)}\), while adults’ average age for cancer diagnosis is 65.\(^{(7A)}\)
- Childhood cancer is not one disease - there are more than 12 major types of pediatric cancers and over 100 subtypes.\(^{(1)}\)

Long Term Health-Effects Associated with Treatments & Survival

- More than 95% of childhood cancer survivors will have a significant health related issue by the time they are 45 years of age.\(^{(2)}\); these health related issues are side-effects of either the cancer or more commonly, the result of its treatment. 1/3rd will suffer severe and chronic side effects; 1/3rd will suffer moderate to severe health problems; and 1/3rd will suffer slight to moderate side effects.\(^{(2)}\)

Mortality

- Cancer is the number one cause of death by disease among children.\(^{(4)}\)
- About thirty five percent of children diagnosed with cancer will die within 30 years of diagnosis.\(^{(8)}\)
- On average, about 17% of children die within 5 years of diagnosis. Among those children that survive five years from diagnosis, 18% will die within 30 years of diagnosis.\(^{(8)}\)
- The overall cancer death rate for children ages 0-14 years decreased an average of 1.5 percent per year during 2011-2015.\(^{(7F)}\)
- Those that survive the five years have an eight times greater mortality rate due to the increased risk of liver and heart disease and increased risk for reoccurrence of the original cancer or of a secondary cancer.\(^{(8)}\)
- There are 70 potential life years lost on average when a child dies of cancer compared to 15 potential life years lost for adults.\(^{(7F)}\)
- Brain cancer is 29.9% of total childhood cancer deaths while leukemia accounts for 24.9%.\(^{(7F)}\)

Treatment, Research, Funding

Since 1980, only four drugs have been approved in the first instance for use in children. Three, teniposide (1980), clofarabine (2004), and tisagenlecleucel (2017) are used in the treatment of ALL. The third, dinutuximab was approved in 2015 for use in high-risk neuroblastoma. From 1980 to early 2017, 11 total drugs, consisting of the four above and a few others first approved for use by adults (most recently pembrolizumab and avelumab, along with others such as imatinib, daunorubicin, methotrexate, PEG-formulated asparaginase, and binotumomab have been approved for use in children with cancer – compared with hundreds of drugs that have been developed specifically for adults only. Equally important, for many of the childhood cancers, the same treatments that existed in the 1970’s continue with few, if any, changes.\(^{(7)}\)
- The average cost of a stay in a hospital for a child with cancer is $40,000 per stay.\(^{(5)}\)
- On average, pediatric hospitalizations for cancer cost almost five times as much as hospitalizations for other pediatric conditions.\(^{(5)}\)
- From 2007 through 2016, the National Cancer Institute (NCI) spent an average of 3.94% of its research funding on pediatric cancers research.\(^{(7C)}\)
- Prostate cancer (patient average age at diagnosis, 66 years)\(^{(7A)}\), receives more research funding from NCI than all childhood cancers combined (patient average age at diagnosis, 8 years).\(^{(9)}\)
Survival

Pediatric Cancer 5-Year Observed Survival Rates for 2 Time Periods, Ages Birth to 19 Years

The table below contrasts the estimated 5-year survival rates for various types of childhood cancers for the 1975-1979 and 2003-2009 time periods. It should be noted the survival rates listed below reflect general rates and in no way are a representation of an anticipated actual survival outcome for any individual child.
The average 5-year survival rate for childhood cancers when considered as a whole is 83%\(^{[1,3]}\). Cancer survival rates vary not only depending upon the type of cancer, but also upon individual factors attributable to each child.\(^{[6]}\) Survival rates can range from almost 0% for cancers such as DIPG, a type of brain cancer, to as high as 90% for the most common type of childhood cancer known as Acute Lymphoma Leukemia (ALL).\(^{[1]}\) The average 5-year survival rate, not including children with ALL, is 80%.\(^{[1]}\) In 2013 there were nearly 390,000 childhood cancer survivors in the United States. This number is projected to grow to more than 500,000 by 2020.\(^{[27]}\) Approximately 1 in 530 young adults between the ages of 20 and 39 is a survivor of childhood cancer.\(^{[1]}\)

### Psychosocial Care\(^{[20]}\)

- Childhood cancer threatens every aspect of the family's life and the possibility of a future, which is why optimal cancer treatment must include psychosocial care.\(^{[1]}\)
- The provision of psychosocial care has been shown to yield better management of common disease-related symptoms and adverse effects of treatment such as pain and fatigue.\(^{[12]}\)
- Depression and other psychosocial concerns can affect adherence to treatment regimens by impairing cognition, weakening motivation, and decreasing coping abilities.\(^{[13]}\)
- For children and families, treating the pain, symptoms, and stress of cancer enhances quality of life and is as important as treating the disease.\(^{[14]}\)
- Childhood cancer survivors reported higher rates of pain, fatigue and sleep difficulties compared with siblings and peers, all of which are associated with poorer quality of life.\(^{[15]}\)
- Changes in routines disrupt day-to-day functioning of siblings.\(^{[16]}\) Siblings of children with cancer are at risk for emotional and behavioral difficulties, such as anxiety, depression, and post traumatic stress disorder.\(^{[17]}\)
- Symptoms of post traumatic stress disorder are well documented for parents whose children have completed cancer treatment.\(^{[18]}\)
Chronic grief has been associated with many psychological (e.g., depression and anxiety) and somatic symptoms (e.g., loss of appetite, sleep disturbances, fatigue), including increased mortality risk. Cancer survivors in the United States reported medication use for anxiety and depression at rates nearly two times those reported by the general public, likely a reflection of greater emotional and physical burdens from cancer or its treatment. Financial hardship during childhood cancer has been found to affect a significant proportion of the population and to negatively impact family wellbeing. Adolescents with cancer experienced significantly more Health Related Hindrance (HRH) of personal goals than healthy peers, and their HRH was significantly associated with poorer health-related quality of life, negative affect, and depressive symptoms. Peer relationships of siblings with cancer are similar to classmates, though they experience small reductions in activity participation and school performance. Chronic health conditions resulting from childhood cancer therapies contribute to emotional distress in adult survivors. Parents have been found to report significant worsening of all their own health behaviors, including poorer diet and nutrition, decreased physical activity, and less time spent engaged in enjoyable activities 6 to 18 months following their child’s diagnosis.

Endnotes

1 American Cancer Society, Childhood and Adolescent Cancer Statistics, 2014

2 St. Jude Children’s Research Hospital, (JAMA. 2013:309 [22]: 2371-2381)

3 National Center Biotechnology Information, Declining Childhood & Adolescent Cancer Mortality, Cancer 2014


5 Healthcare Cost and Utilization Project (HCUP), Statistical Brief #132, Pediatric Cancer Hospitalizations 2009

6 American Society of Clinical Oncology
   http://jco.ascopubs.org/content/28/15/2625.short

7 National Cancer Institute, http://www.cancer.gov/research/areas/childhood
   tisagenlecleucel https://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm574058.htm
   Seven drugs noted above also approved for use in adults:
   teniposide, daunorubicin, methotrexate, PEG-formulated asparaginase,:
   Hirschfeld et al., 2003 (Journal of Clinical Oncology, 2196), p. 1066-1073.)
   blinatumomab, Imatinib, pembrolizumab, avelumab:
   http://www.centerwatch.com/drug-information/fda-approved-drugs/

8 National Cancer Institute, SEER Median Age of Diagnosis 2008-2012, Table 1.12

   http://jnci.oxfordjournals.org/content/93/5/341.full

10 National Cancer Institute, NIH/NCI Budget
    https://www.hhs.gov/about/budget/budget-in-brief/nci/index.html

11 National Cancer Institute, NIH/NCI Budget
    https://fundedresearch.cancer.gov/nciportfolio/search/SearchForm?formType=simple

12 Centers for Disease Control and Prevention, https://www.cdc.gov/nchs/products/databriefs/db257.htm

13 National Cancer Institute, SEER Cancer Statistics. Annual Report to the Nation 2018
Psychosocial care addresses the effects that cancer treatment has on the mental health and emotional wellbeing of patients, their family members, and their professional caregivers. Psychosocial care is not provided by a single profession alone: Instead, every patient-healthcare provider interaction provides an opportunity to assess the stressors and concerns of children and their family members.

Hawkins et al., 2017 (Journal of Clinical Oncology, 5 (1), 78-87)
Bona et al., 2014 (Journal of Pain Symptom Management, 47 (3), 594-600)
Schwartz & Brumley, 2017 (Journal of Adolescent & Young Adult Oncology, 6 (1), 142-149)
Alderfer et al., 2015 (Journal of Pediatric Psychology, 40 (3) 309–319)
Vuotto et al., 2017 (Cancer, 123 (3), 521-528)
Wiener et al., 2016 (Journal of Pediatric Oncology Nursing, 33(5), 378–386)

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