

Improvements in paediatric oncology and increased survival rates after childhood cancer.

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The improved outcome for children with cancer represents one of the major biomedical advances of the past four decades.

The long-term survival (cure) has improved significantly in the majority of European countries from less than 20% in 60's, to 75% in 90's (Eur J Cancer 42, 2183-90, 2006).

Major reasons for the success are: better organization of Pediatric Cancer Units, a multidisciplinary approach (pediatric oncologists, surgeons, radiologists, psychologists, biologists), and research (clinical and biological).

Some essential data describing the dimension of the problem:

- a) The incidence of childhood cancers across Europe increased significantly ($p < .0001$) from a ASR (age-standardised rate) of 120 per million children in 1978-82 to 141 per million in 1993-97. The annual percentage increase was 1.1% with no sign of slowing in the last five year period.
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| total population of the 27 European Union countries | ~ 488,5 million |
| percentage of the population aged 0-14 years | ~ 16% |
| population aged 0-14 years | ~ 78,2 million |
| new cases of cancer aged 0-14 years | ~ 11,000/year |
| overall conservative 5-year survival | 70% |
| increase of the population of long-term survivors (LTS) | ~ 8,000/year |

We can state today that the problem of the long-term survivors is a relatively new topic of increasing importance, not only for pediatric oncology, but also for internal medicine. Pediatric cancer survivorship could well be considered a "new science" (A.Meadows). Studies of issues of long term survival should incorporate and clarify data based on the heterogeneity of the patients, the different treatments received, including the more recent ones, and possible late effects. There is currently very limited information on survivors who are now two or more decades off-therapy.

The methodological approach should consider the global objective of the strategy: "total cure" as:

- Total medical cure: long-term monitoring, preventing, and treating possible side effects and adverse outcomes.
- Total educational cure: helping the children/adolescents to complete their curricula of studies, developing their personal abilities.

- Total psychological cure: it is known that facing the trauma of the disease could promote either so-called "post-traumatic stress" in about 20% of subjects, or, more frequently (about 80%), "post-traumatic growth", also called "resilience". This positive-outcome evolution is a relatively new field of research and should be better analyzed and promoted.
- Total social cure: the "cured" subjects have the right to face their future life as adults without childhood-cancer-related barriers that concern education, employment, insurance and other family and social opportunities.

Recently a large group of international experts from Europe and USA (pediatric oncologists, psychologists, parents, survivors, nurses, epidemiologists) published the "Erice Statement", describing a consensus on the definition of "cure" and the details of an appropriate strategy of cure and care to be implemented in every pediatric cancer unit (PCU).

In summary:

- Cancer survivorship is, in some way, a "new science" requiring investments in research and in personalized intervention, based on evidence and what is critical.
- The scientific and social community should be sensitized to the problem of childhood cancer and to the rights of a large and increasing population of survivors (cured) to be completely integrated into the society.
- The general public needs to be made aware of and recognize the reality of the cure of childhood cancer: that significant progress over the past 30 years in the treatment of childhood cancers has resulted in hundreds of thousands of survivors who are cured and are now completing school, entering adulthood, and living full lives as active members of society.
- A possible instrument could be the collection of narratives of adult survivors: our experience with this approach has been of great interest, describing, in the majority of cases, the survivors' resilience and positive approach to personal and social life.