

The Transition from Incurable to Curable: Pediatric Leukemia, Psychological Dimensions of New Disease Cures, and Implications for HIV

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Pediatric Acute Lymphoblastic Leukemia (ALL)

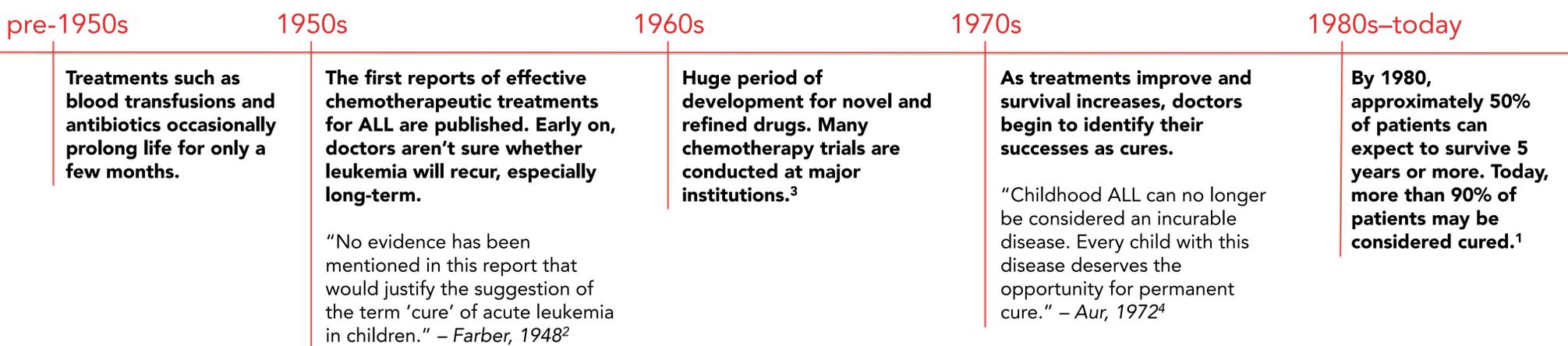
- Most common childhood cancer.
- Cancer of the blood and bone marrow, in which immature lymphocytes are overproduced, leading to infection, anemia, and easy bleeding.
- Without treatment, ALL is uniformly fatal.
- Before the 1950s, children with ALL could not expect to live more than 3–4 months.
- Today, most children who undergo treatment will be cured of the disease.¹

Introduction

- The history of medicine is a rich source for exploring how curative research transforms clinical practice and perceptions of disease over time.
- Examining the history of clinical care for pediatric acute lymphoblastic leukemia (ALL) in the United States underlines the importance of identifying and responding to psychological and social challenges of cure, alongside purely biomedical transitions.
- A “tripartite” concept of cure devised by physician and bioethicist Jan van Eys provides a framework for approaching curative research and clinical care in a pediatric population.
- As we slowly move towards an HIV cure, lessons learned from ALL and van Eys’s work may help us broadly implement such a cure more effectively in a pediatric context.

Pediatric ALL: Transition from Incurable to Curable

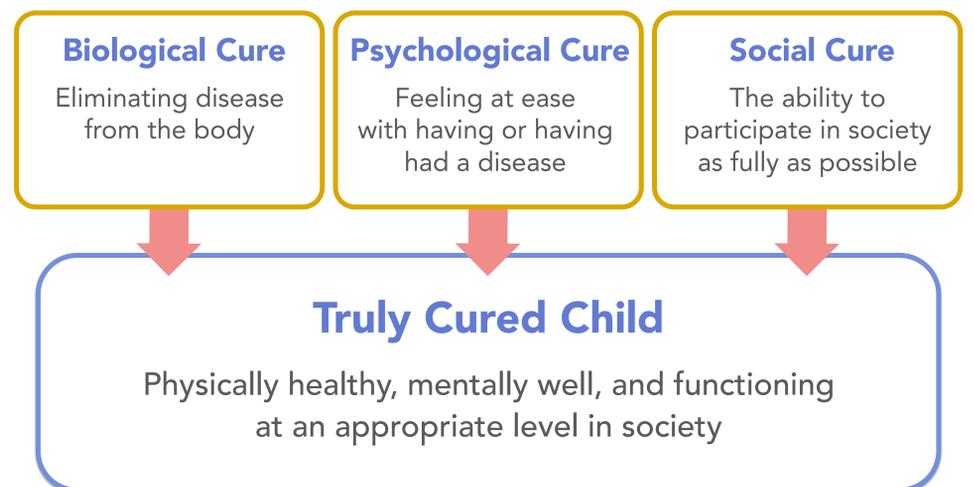
From 1950–1980, pediatric ALL was reclassified from an incurable illness to a disease with significant possibility of remission and, eventually, cure.



Jan van Eys and a new concept of cure

- In the 1970s, pediatrician and bioethicist **Jan van Eys** noticed that many patients and their caregivers were experiencing anxiety due to the uncertainty of a cure.
- He wondered: if patients indeed survived ALL, but had lasting psychological or social difficulties, were they truly cured of the disease?
- He devised a three-part concept of a “truly cured child”, encompassing biological, social, and psychological aspects.⁵
- This emphasis on quality of life was not unique to van Eys, but he was instrumental in providing clear language and reasoning to promote the concept.
- Today, many pediatric cancer patients benefit from interdisciplinary teams working to provide holistic biopsychosocial care.

The Tripartite Cure



Implications for HIV Cure

- Scientific developments indicate that HIV will mark a similar trajectory from an incurable to a curable disease. Some children worldwide are already enrolled in HIV cure research.
- Curative research will likely be prolonged and challenging, causing uncertainty and anxiety. After a cure is developed, other unmet mental health and social service needs unique to a pediatric population may arise.
- As a population, pediatric HIV patients differ from pediatric ALL patients. Even for those under medical care, children and adolescents with HIV are a particularly vulnerable group and may lack socioeconomic support structures that contribute to psychosocial wellbeing.
- The Tripartite Cure concept gives us a robust and holistic goal for an HIV cure. A focus on promoting “truly cured children” will result in a global population of people who have not only survived HIV but can thrive in its wake.

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