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The transition from incurable to curable: Pediatric leukemia, psychological dimensions of new disease cures, and implications for HIV

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Background: Although many aspects of HIV cure research are entirely without precedent, the history of medicine offers a rich source for exploring how curative research transforms clinical practice and perceptions of disease over time. This paper examines the history of clinical care for children with acute lymphoblastic leukemia (ALL) as research turned the disease from incurable to curable, and identifies potential implications for pediatric HIV cure research.

Methods: We conducted archival research using primary sources from the M.D. Anderson Cancer Center and reviewed published secondary sources to explore the history of pediatric ALL as it transitioned from an incurable illness in the 1950s to a curable disease by the 1980s. We examined how this transition influenced health systems for clinical management of ALL and perceptions of the disease.

Results: Prior to the 1950s, ALL was a uniformly fatal disease. Children with ALL were not expected to live more than a few months and treatment was largely palliative. However, new chemotherapies developed beginning in the 1940s opened up the possibility of cure, and by the 1980s, half of all patients could be expected to survive five years or longer. With survival now a viable endpoint, psychosocial care for patients had to likewise transition from preparing patients and their families for death to preparing them to deal with an ambiguous future. Dr. Jan van Eys, a pediatrician and bioethicist, claimed in the late 1970s that patients could not truly be called “cured” until their bodies, minds, and lives were healthy. He conceptualized a “tripartite cure”, consisting of biological, psychological, and social elements. This new framework encouraged multi-disciplinary teams to care for children with ALL and develop non-clinical interventions to improve holistic functioning of children.

Conclusions: Children worldwide have enrolled in HIV cure research, but we are likely many years from a durable pediatric HIV cure. The history of ALL and van Eys’ “tripartite cure” remind us that children enrolled in curative trials will have complex psychosocial needs that extend beyond the purview of traditional clinical research. Holistic, multi-disciplinary care will be essential for pediatric disease cure research.