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Excess mortality convergence after paediatric allogeneic transplantation: a caveat for the right to be forgotten. Comment on: "Decreasing excess mortality after allogeneic stem cell transplantation for acute leukemia"

by Tang-Her Jaing and Yi-Lun Wang

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Excess mortality convergence after paediatric allogeneic transplantation: a caveat for the right to be forgotten. Comment on: "Decreasing excess mortality after allogeneic stem cell transplantation for acute leukemia"

Tang-Her Jaing[1], Yi-Lun Wang[1]
[1]Division of Pediatric Hematology/Oncology, Chang Gung Memorial Hospital, Linkou, Taiwan

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Corresponding author: Tang-Her Jaing; jaing001@cgmh.org.tw
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Frietsch and colleagues link real-world data from the German Registry for Hematopoietic Cell Transplantation and Cell Therapy (DRST) and the German Pediatric Registry for Stem Cell Transplants and Cell Therapies (PRSZT) to the ongoing debate over a right to be forgotten (RTBF) for cancer survivors: excess mortality after allogeneic hematopoietic stem cell transplantation (AHSCT) for acute leukemia falls steeply once patients reach relapse-free survival, illustrated vividly by the patient vignette that opens the paper[1]. As pediatric transplant physicians, though, we think several aspects of the analysis need a closer look before it is used to set an RTBF threshold for children specifically.

The children, adolescents and young adults (CAYA) group spans ages 0 to 39, so a five-year-old and a 35-year-old sit in the same category. That matters, because the reassuring convergence toward general-population survival by five years event-free (hazard ratio 31.1, 95% confidence interval 14.8-65.3) comes from that pooled group, and a child transplanted before puberty has decades more ahead for late effects to surface than a young adult transplanted at age 35. Endocrinopathies, growth and fertility impairment, cardiopulmonary dysfunction, and second malignancies in childhood AHSCT survivors keep showing up well past the five-to-seven-year window in Figure 1E of this report[1,2], and several long-term cohorts report mortality still rising 10-20+ years post-transplant, mostly from non-relapse causes[3-6]. A hazard ratio measured at year five will not capture any of this. It also remains roughly eightfold higher than the ~4.0 reported for older adults at the same landmark, and neither has reached the background population rate; the authors should clarify why five years, rather than a longer horizon, is the appropriate cutoff.

A related design issue is survivor (immortal-time) bias: conditional-survival hazard ratios are computed only among patients alive and relapse-free at each landmark, so early deaths and relapses are excluded from the risk set by construction. This selection, not necessarily a true biological plateau, can account for part of the observed convergence, and the resulting estimates apply only to that already-selected survivor subgroup rather than to all AHSCT recipients.

There is also a numbers problem: the CAYA group thins out quickly beyond five years event-free (n=412, fewer still thereafter), so its confidence interval remains consistent with

meaningfully elevated risk in the youngest survivors. A cause-of-death breakdown limited to the pediatric subgroup, and hazard ratios split by children (0-12), adolescents (13-17), and young adults (18-39) rather than one CAYA figure, would strengthen the policy case, since it is exactly the youngest patients for whom insurers and lenders apply the longest risk horizon.

The estimates are also unadjusted: only univariable Cox regression is reported, without accounting for disease subtype, disease status, donor type, conditioning intensity, graft-versus-host disease, or calendar year, all of which independently affect long-term mortality and likely differ by age and treatment era. A multivariable model, or an explanation for its absence, would help separate a genuine decline in age-specific risk from shifting case-mix.

We do not think any of these undercuts what Frietsch and colleagues have shown, or how urgent the RTBF debate is. But harmonizing eligibility around a five-year mark is, at bottom, a policy choice rather than a conclusion the mortality data alone can carry financial, psychosocial, and functional outcomes matter to RTBF eligibility as much as mortality risk does. The German findings may also not generalize directly to countries with different insurance systems and healthcare financing, where the practical stakes of RTBF eligibility differ. We would ask that any harmonized timeline draw on longer follow-up, adjusted and age-stratified late-mortality data, rather than a single five-year cutoff extrapolated from a conditional-survival cohort spanning early childhood to age 39.

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