

Survivorship in Severe Aplastic Anemia and Myelodysplastic Syndrome

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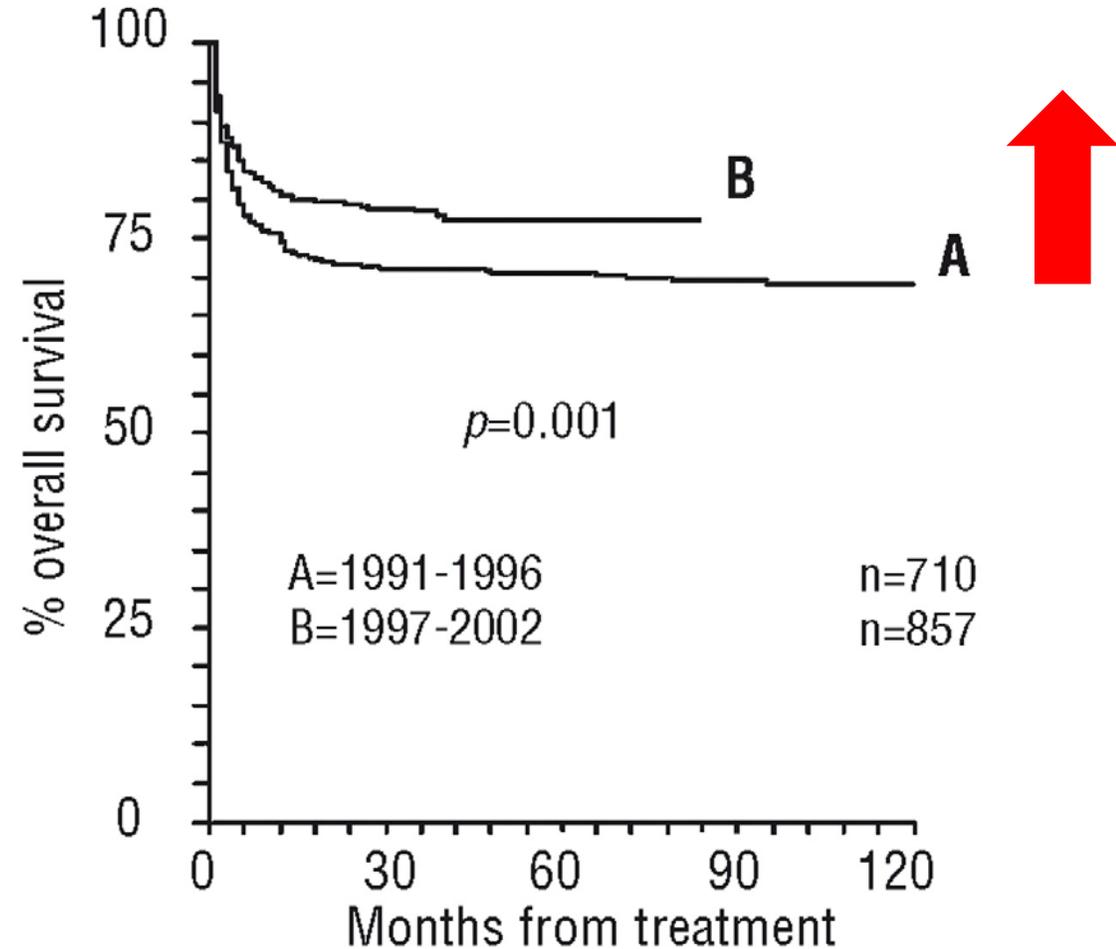
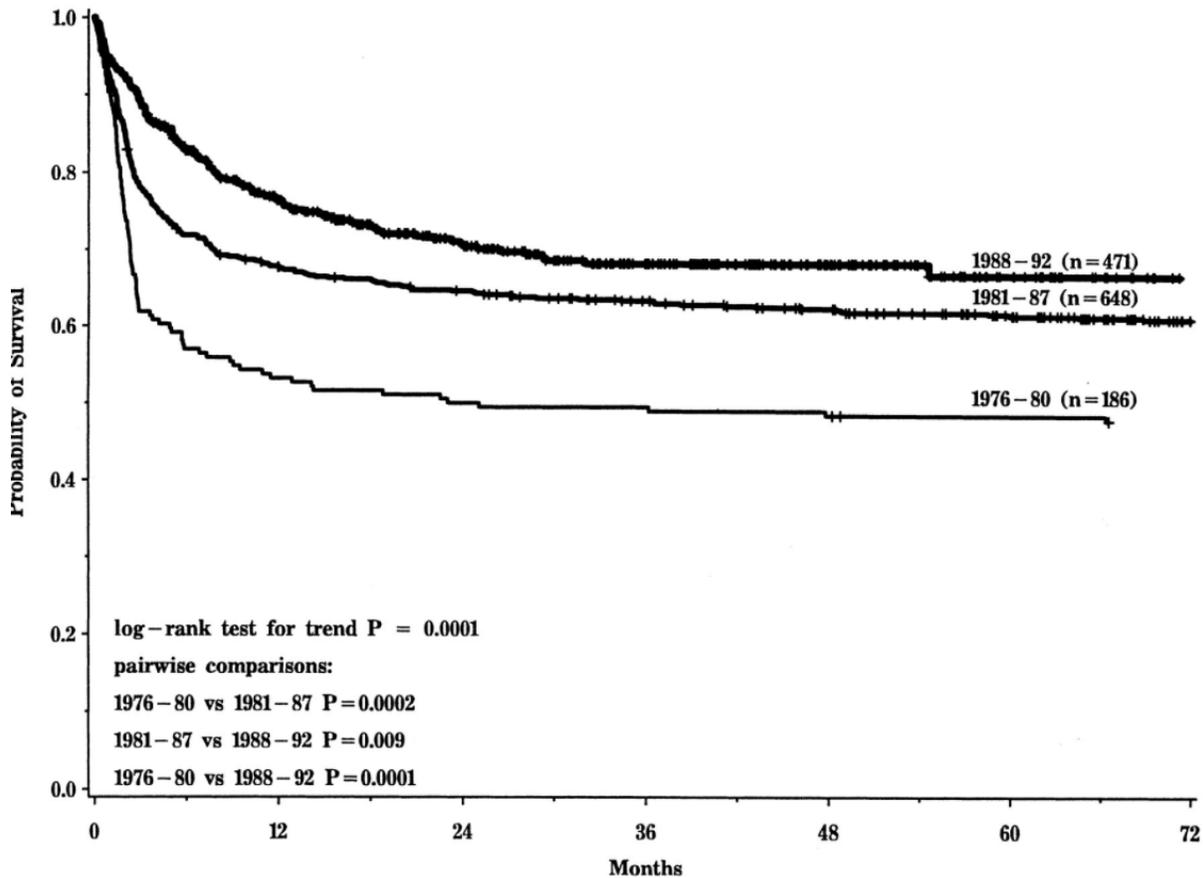
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Odds n' Ends

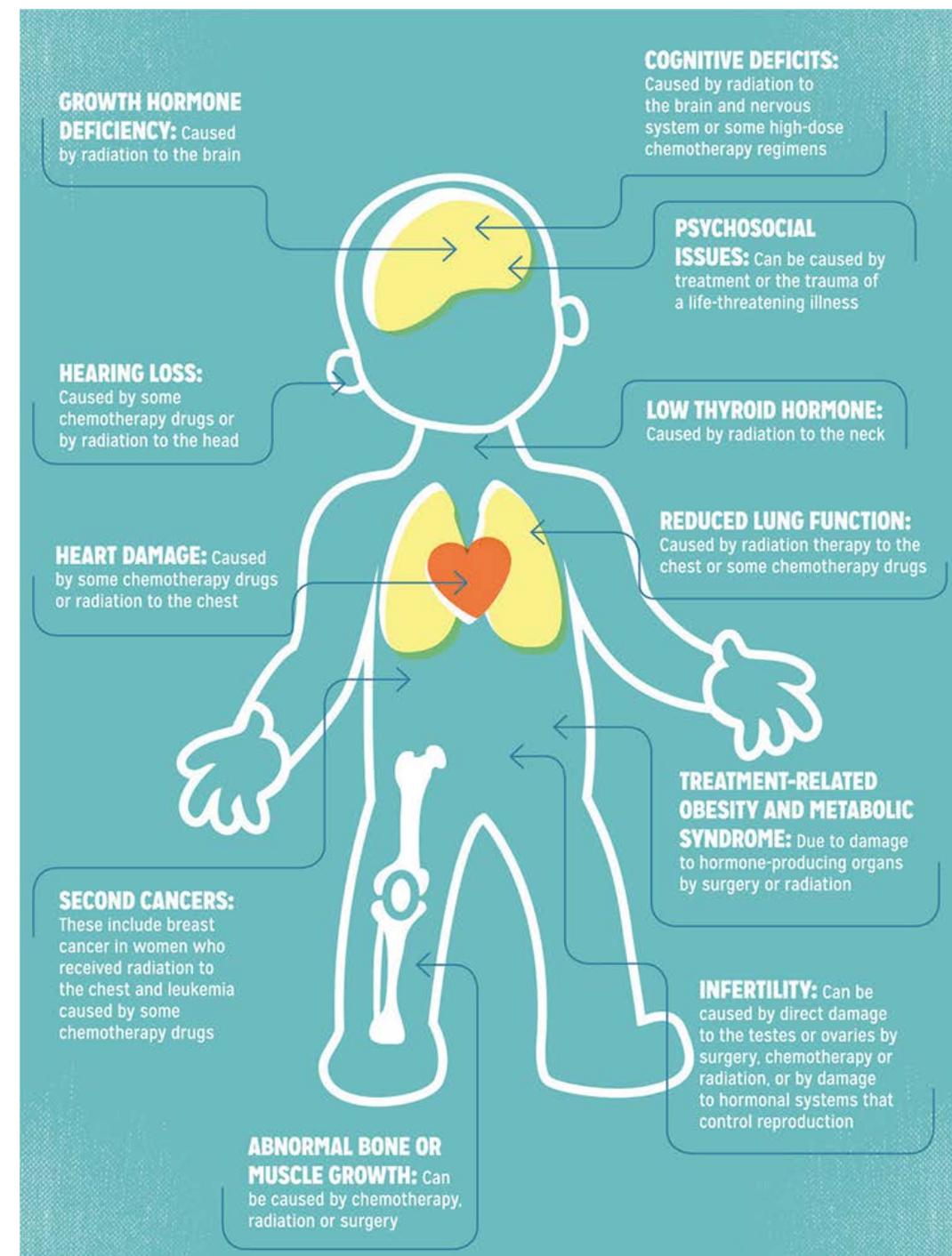
- I have no relevant conflicts of interest to disclose
- Much of the 'survivorship' literature is focused on young adult survivors of pediatric cancer
 - Aplastic anemia is not cancer
 - But many of the treatments are similar
 - Not all survivors are young adults
- Agenda
 - SAA Survivorship and Late Effects Overview
 - Patient Panel

Historical Outcomes of BMT for Aplastic Anemia Have Improved



Late Effects, in General

- Long-term health implications of surviving a disease and its treatment
 - Aplastic Anemia
 - What implications for the residual hematopoietic system (bone marrow)?
 - Chemo-Immunotherapy and Radiation
 - What impact to 'healthy tissue'?
 - E.g. how is fertility impacted by BMT conditioning
 - Complications of therapy
 - How does Graft versus Host Disease (GvHD) and GvHD treatment impact the body?
 - During treatment
 - After resolution



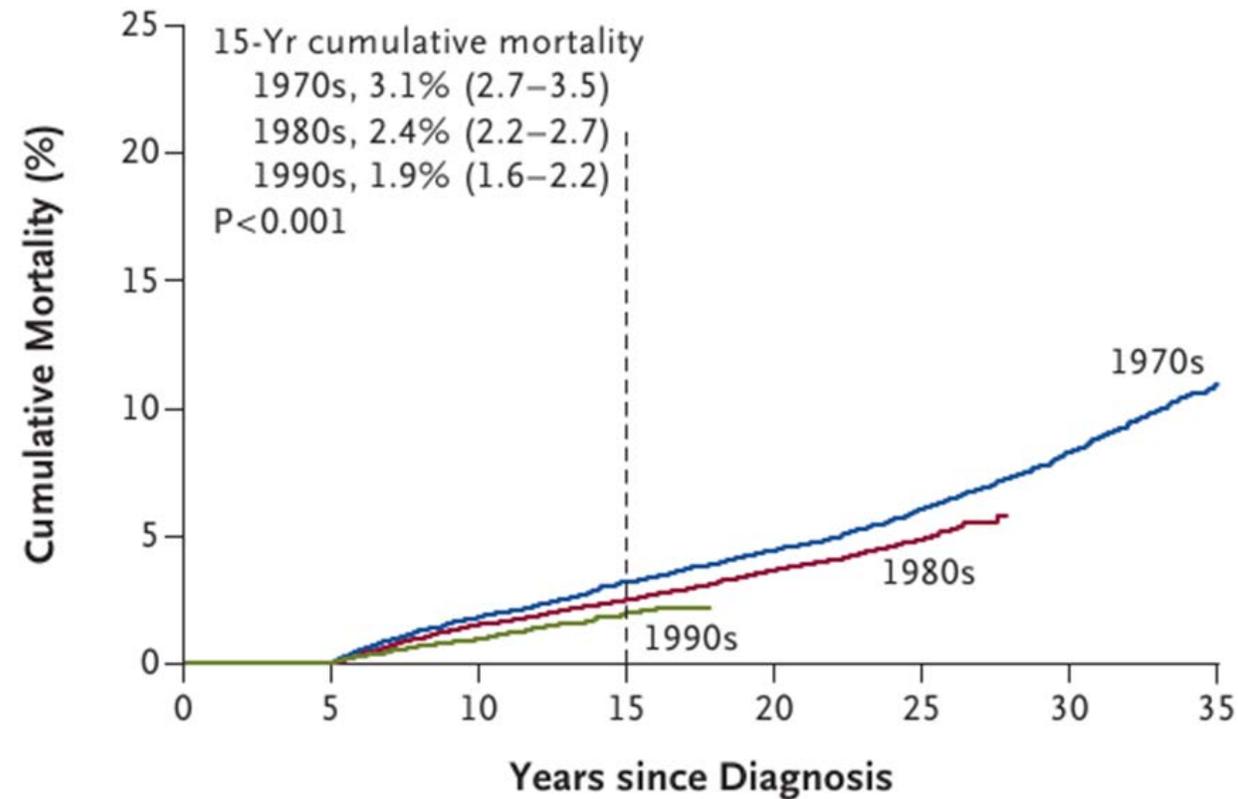
Late Effects, in General

- Late effects occur commonly, especially with specific exposures
- Some late effects are a normal part of what happens during normal aging
- Some are more severe/ life threatening
- Focused screening uncovers a lot of issues
 - Note: most issues have some sort of treatment available
- We are getting better at preventing and treating late effects!

The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

Reduction in Late Mortality among 5-Year Survivors of Childhood Cancer



How do we get make sure survivors get the best care we have available?

The Lancet 2012

Many US cancer survivors still lost in transition

A 2005 US Institute of Medicine report championed care plans for people who survive cancer. But, as Bob Kirsch reports, many survivors are still missing out on the close follow-up that they need.

New York Times 2015

Lost in Transition After Cancer

By SULEIKA JAOUAD MARCH 16, 2015 5:01 PM 289



Institute of Medicine 2005

From Cancer Patient to Cancer Survivor

LOST IN TRANSITION

It's Not the Model that Matters—Still Lost in Transition

ASCO 2013

Michael L. Kappel

General Internists' Preferences and Knowledge About the Care of Adult Survivors of Childhood Cancer

A Cross-sectional Survey

Eugene Suh, MD; Christopher K. Daugherty, MD; Kristen Wroblewski, MS; Hannah Lee, MPH; Mackenzie L. Kigin, BA; Kenneth A. Rasinski, PhD; Jennifer S. Ford, PhD; Emily S. Tonorezos, MD; Paul C. Nathan, MD, MSc; Kevin C. Oeffinger, MD; and Tara O. Henderson, MD, MPH

- Average Internist saw 1-2 childhood cancer survivors in past 5 yrs
- **72.0% of these internists never received a treatment summary.**
- **On average, internists were “somewhat uncomfortable” caring for survivors**
- In response to a clinical vignette about a young adult survivor of Hodgkin lymphoma
 - 91% of respondents did not appropriately recommend yearly breast cancer surveillance
 - 85% did not appropriately recommended cardiac surveillance

The Gaps in Care

- Hematologists don't communicate well with primary physicians.
- Long-term survivors are a rare occurrence for most primary physicians.
- Many patients become disconnected from their treating center:
 - You move on with your life.
 - Education
 - Work
 - Family
 - Patients may not want to come back!

How Can Patients and Doctors Find Late-Effects Guidelines?

- Children's Oncology Group
 - Survivorshipguidelines.org
- National Marrow Donor Program
 - Bethematch.org



Survivorship Specifics for Aplastic Anemia (in Brief)

- Immunosuppressive Therapy
 - Treatment
 - Progression to AML/MDS
- Blood and Marrow Transplantation
 - Conditioning
 - GVHD

Immunosuppression

- Need for Re-vaccination post-treatment?
- Complications of Cyclosporine
 - Kidney disease
 - Skin Cancers
- Iron overload
- Immunizations from Transfusion
- Approximately 15% of AA patients (of all ages) and 4% PNH patients develop secondary MDS/AML by 10 years of follow-up.
 - Unclear if this risk plateaus

Transplant

- Conditioning Dependent
 - Fortunately, compared to other diseases, late-effects of BMT for SAA is relatively mild
 - Fertility
 - fertility preservation consultation prior to transplant
 - Options may be available for sub-fertility post-treatment
 - Endocrine and Growth
 - Dental issue
- Conditioning Independent
 - Acute and chronic GVHD
 - Cataracts
 - Avascular necrosis and osteoporosis
 - Skin issues
 - Sexual dysfunction
 - Metabolic syndrome

Next...

- Questions?
 - Rotzs@ccf.org
- Patient Panel
 - Moderated by Taylor Buss, MSW, LISW
 - Busst@ccf.org