FINDING HEALTH, AFTER CANCER

Optional Cases: Mike

PRESENTATION

Mike is a 26-year-old man who comes in to your office to establish care. After his 26th birthday, he aged out of his parents' health insurance, so he signed up for his employer's health plan and now comes to see you for primary care.

HISTORY

"My health is pretty straightforward. I mean, like most people it could be better. I don't exercise as much as I probably should. My diet is ok, but not super healthy.

A far as my medical history, the only major thing was when I was really little, I had leukemia when I was 4. But that was a long time ago, it's gone now. I am not sure how they treated it. I don't really remember that much from that age, but I know it's not an issue now."

TREATMENT

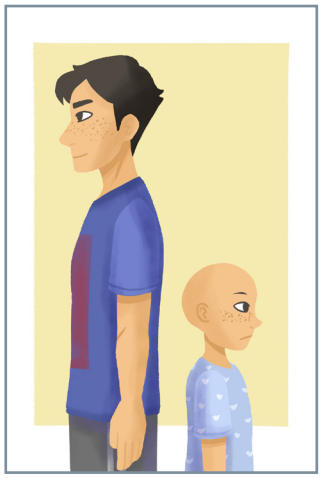
Cure rates for childhood cancer have improved dramatically from the 1960s to the 1990s to today. At the same time, there has been increased recognition that cure comes with a cost -- adult survivors of childhood cancer are at increased risk for late effects from their prior cancer treatment, including chronic health conditions, secondary malignancies, and early mortality.

For this reason, modern childhood cancer treatment is risk-adapted. This means children who are at highest risk of relapse or those whose disease may be resistant to treatment, will receive more intense treatment, while those who are very likely to be cured receive less intense treatment in an effort to reduce late effects without compromising cure.

As a result of these treatment changes, adults who were treated for cancer as children in the 1990s compared to the 1980s and the 1970s have a lower risk of chronic health conditions, secondary cancers, and early mortality.[1,2,3,4]

NOTES FOR CARE

How to piece together a childhood cancer treatment history



Many adults who had cancer when they were children do not remember the details of their diagnosis or treatment history, especially if they were very young when they were treated and depending upon how much their parents or guardians told them about the specifics.

Ideally, they should have received a Survivorship Care Plan and treatment summary when they transitioned out of pediatric oncology care, but this practice is not uniform. While some young adults have continued in routine active follow up either in pediatric oncology or in a dedicated cancer survivorship clinic, others have been "lost to follow-up" and may not have been seen by a doctor for quite some time.

NOTES FOR CARE

What resources are available to find out about someone's cancer treatment history if your patient doesn't know?

First, have them ask their parents/guardians. If they only know where they were treated (even just the city or region), you can probably identify which hospital, as the majority of children with cancer are treated at large pediatric cancer centers/referral centers. You can contact the pediatric oncology group at that hospital to try to learn more.

If you can't find their original records or a summary of their treatment, you can ask a pediatric oncologist in your own medical system, and they will likely be able to help extrapolate based on the diagnosis and approximate year they were treated, as many children are treated on clinical trials or with standardized treatment protocols. Don't be afraid to call a pediatric oncologist for help!

Patients' attitudes and perspectives related to their history of childhood cancer

Some adults who had cancer when they were kids or teens are active in young adult cancer survivor advocacy groups and communities, while others, like Mike, do not consider it part of their identity or may prefer not to acknowledge this part of their medical history.

Some look back on their experience being treated for cancer with a sense of personal growth or pride, while others have negative memories of treatment, being in the hospital or undergoing procedures.

Some may remember it all vividly, while others may hardly remember the process. **The bottom line is, we can't predict how a history of childhood cancer will affect a person and need to be sensitive to the wide range of possible attitudes and perspectives.**

Resources for late effects surveillance in adult survivors of childhood cancer

The Children's Oncology Group (COG) maintains an up-to-date resource cataloguing potential late effects of childhood cancer treatment, organized according to treatment exposure such as surgery, chemotherapy (specific chemotherapy classes), and radiation therapy (body part(s) involved). **This is available for free on the website www.survivorshipguidelines.org as a searchable PDF, which is updated every few years as new research becomes available.**

Additionally, the North American COG and several international pediatric cancer cooperative groups have come together to publish Late Effects Harmonization Guidelines in order to standardize recommendations for late effects surveillance internationally.[5]

Principles of childhood cancer late effects: Exposures and age at exposure

When caring for adults who were treated for cancer in childhood or adolescence, it is very important to understand what they were treated with, where in their body they were exposed, and when they were treated (age at treatment, decade of treatment).

The reason this is important is that their past treatment can be used to predict risk of late effects (health problems related to cancer treatment that occur after treatment has ended).

Specifically, you want to know what they were treated with: Did they have surgery? Did they have radiation? (What dose?) Did they have chemotherapy? (What chemotherapy?)

Just as important is where in their body: If surgery, which body part? If radiation, which region?

Finally, when they were treated matters, both in terms of their age at the time of treatment (developing bodies may be more susceptible) and the decade in which they were treated (due to changes in treatment over time). It is important to remember that the health consequences of childhood cancer treatment may not be evident for years (even decades) later.

Large cohort studies in North America, the United Kingdom, and Europe have been the greatest source of information about late effects of childhood cancer treatment, and there are several very active research groups continuing to investigate these topics.[6]

Cranial radiation as an example

Historically, many children with acute lymphoblastic leukemia (ALL) were treated with cranial radiation therapy to prevent relapse in the central nervous system. These children are now adults who may be in your primary care practice - so it is important to know a little about the consequences of this treatment, including neurocognitive, endocrine, and cardiovascular late effects.

Neurocognitive effects
Years after this treatment, patients can have difficulty with academic performance, memory, attention, and executive function.

Studies have shown that there are more neurocognitive problems in people who were younger at the time of treatment and if they received higher doses of cranial radiation. [7,8]
For Mike, he may have needed some extra help in school as a child, and he may still notice some differences in his memory or attention compared with his peers.

Endocrine effects
Cranial radiation in childhood increases the risk of growth hormone deficiency, particularly when treated at a younger age with a dose ≥ 18 Gy (as was commonly used for prophylaxis of CNS recurrence in childhood ALL prior to the early 2000s).[9,10]

Growth hormone deficiency in childhood causes shorter adult height and contributes to higher BMI. At higher doses of radiation (such as doses typically used for brain tumors), there is also a risk of hypogonadism and central hypothyroidism due to hypothalamic-pituitary axis dysfunction. For Mike, we'd expect that he may be shorter than his siblings.

Cardiovascular effects
Adults like Mike who were treated with cranial radiation for childhood ALL are at higher risk of obesity, especially if they were younger when they were treated.[11,12,13]

They are also at increased risk for metabolic syndrome and cardiovascular disease. **We cannot emphasize enough how important it is to address modifiable cardiovascular disease risk factors in adult survivors of childhood cancer, especially those who were treated with cranial radiation.**

CONCLUSION

Mike's case illustrates some common challenges in caring for adult survivors of childhood cancer, including incomplete treatment records and the unpredictability of survivors' knowledge of and interest in discussing their cancer history. Here are some tips to keep in mind:

Demonstrate empathy : Meet survivors where they are, be sensitive to a wide range of attitudes, and tailor your communication accordingly.

Start the discussion: You can have an impact just by sharing your awareness of the potential link between childhood cancer treatments and future health risks.

Treatment records matter: Treatment exposures are even more important than primary cancer diagnosis in predicting risk of late effects for childhood cancer survivors.

You are not alone: A cancer survivorship specialist and/or pediatric oncologist in your area may be able to help identify records and develop a survivorship care plan for your patients.

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