



Elevating the Voice of the Survivor to Improve Survivorship Care Planning

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Background/Purpose: Many pediatric and adolescent cancer survivors are not receiving sufficient survivorship care planning^{1 2}. To address this issue,

¹ Mobley EM, Moke DJ, Milam J, Ochoa CY, Stal J, Osazuwa N, Bolshakova M, Kemp J, Dinalo JE, Motala A, Baluyot D, Hempel S. Disparities and Barriers to Pediatric Cancer Survivorship Care . Technical Brief No. 39. (Prepared by the Southern California Evidence-based Practice Center under Contract No. 75Q80120D00009.) Rockville, MD: Agency for Healthcare Research and Quality; March 2021. DOI: <https://doi.org/10.23970/AHRQEPCTB39>

² Nathan PC, Greenberg ML, Ness KK, Hudson MM, Mertens AC, Mahoney MC, Gurney JG, Donaldson SS, Leisenring WM, Robison LL, Oeffinger KC. Medical care in long-term survivors of childhood cancer: a report from the childhood cancer survivor study. *J Clin Oncol*. 2008 Sep 20;26(27):4401-9. doi: 10.1200/JCO.2008.16.9607. PMID: 18802152; PMCID: PMC2653112

Children's Cancer Cause has worked with pediatric cancer survivors and caregivers to ensure that their voices are heard by key stakeholders who have the capacity to improve post-treatment care planning.

Methods: Conducting an annual survivorship survey to learn about the top health concerns among pediatric and AYA survivors and hosting a Food and Drug Administration (FDA) approved externally-led patient-focused drug development (EL-PFDD) conference to hear directly from survivors and caregivers on a significant late effect, which both exemplify the importance of survivorship care planning for life-long health issues.

Results: Our survey gleans valuable insights about survivors' top health concerns, including fear of relapse or second cancers, mental health issues, and fertility. Responses revealed the gaps in consistent, long-term follow-up care: only half of the survivors surveyed (51%) report that they are currently receiving follow-up care from a survivorship clinic; 29% report that they are "receiving follow-up care but not from a survivorship clinic"; and 17% are not receiving follow-up care (Figure 1). Thirty percent of respondents answered that they

don't know or did not receive a summary of care or treatment history which is vital as they transition to primary care. These findings are critical to establishing policies that provide for successful transitions and meet the specialized needs of pediatric cancer survivors as part of survivorship care planning. These findings are critical to advocating policies that provide for successful transitions and meet the specialized needs of these survivors as part of survivorship care planning.

Another key finding that one out of five survivors surveyed (21%) listed cardiac effects as one of their top three health concerns, helped inform the development of CCC's EL-PFDD conference on reducing cardiac late effects in these survivors. The perspectives shared by survivors living with significant, life-long, cardiac late effects provide vital patient-centered information to identify gaps in meeting their health care needs as they face other co-morbidities and require long-term follow-up care. Their experiences help inform survivorship care planning needs critical to managing cardiac and other late effects (Figure 1).

Conclusions: Advocacy organizations such as Children's Cancer Cause play an important role in providing opportunities for pediatric cancer survivors and caregivers to share their perspectives with stakeholders as a critical element for improving survivorship care planning. Furthermore, the voice of the patient and their experiences help inform public policy efforts to improve care.



FIGURE 1:
CHILDHOOD CANCER
SURVIVOR SURVEY
Summer 2022

TOP SURVIVORSHIP CONCERNS: RELAPSE, SECOND CANCERS

One out of every two survivors we surveyed expressed a fear of relapse as one of their top three health concerns. More than half are concerned about a secondary cancer diagnosis.



Other priority concerns are listed below, with the percentage of surveyed survivors who named this issue as one of their top three health worries.



MENTAL HEALTH (40%)



NEUROLOGIC (31%)

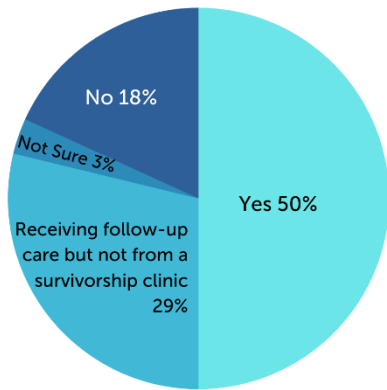


FERTILITY (40%)



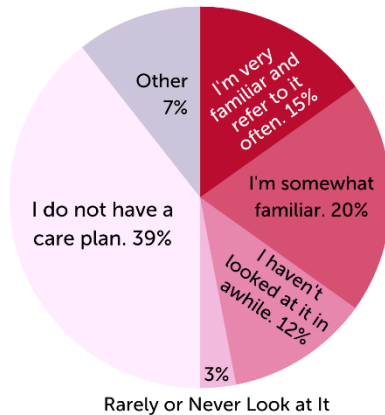
CARDIAC (21%)

Q: ARE YOU CURRENTLY RECEIVING REGULAR FOLLOW-UP CARE FROM A SURVIVORSHIP CLINIC?



“People think that just because you are cancer-free that you’re ok. That’s just not the case for all of us. The after-effects can wind up being worse than the treatment. I have had seven joint replacement surgeries in five years.”

Q: HOW FAMILIAR ARE YOU WITH YOUR SURVIVORSHIP CARE PLAN?



“No one has talked to me about long term effects and I am interested in learning about them, especially when it comes to watching out for specific symptoms.”



FIGURE 2: VOICES FROM THE
2022 FDA-APPROVED MEETING ON
REDUCING CARDIAC LATE EFFECTS

QUOTES FROM SURVIVORS:

“When I completed [cancer] therapy, I was told everything was over and I could go on with my life. What I endured the next 30 years was unexpected, frustrating, physically challenging, and scary, but [it] made me who I am today.”

“I somewhat jokingly tell people that my health is my full-time job.”

“Existing clinical trials for cardiac late effects are limited and we need more investment in research that will result in new interventions that can be tested.”

“We long survivors need to have teams of specialists to rely on who apply personalized but standard treatments. Survivors often need to beg attention from doctors, oncologists themselves while embarking in new secondary late effects (such as new cancers) and advocate for their rights.”

Aging as a survivor of pediatric cancer is terrifying.

“My mental health has become as important as my physical health to me, they are unavoidably linked.”

“My continued concern is that even though I had the heart transplant, that now I am still [able] to see my own mortality, because heart transplants don’t last forever. They do have an expiration. So, I continue to deal with mortality issues as being a young cancer survivor... Even though I am living my best life, thinking something could happen always worries me.”

“My cardiologist told me I am a walking cardiac event, which is scary to hear but it’s reality and I take a lot of medicine daily just to maintain my ability to function.”

“The treatments that saved my life now seem to be slowly stealing it, and on difficult days, I feel as if survivorship is a progressive terminal illness.”

QUOTES FROM PARENTS:

“Parents hold a very heavy burden on whether they made the best decisions on treatment, especially when serious lifelong effects are being experienced, like heart issues.”

“I have a dual role as a mom and a survivorship coordinator.”

“People have no idea of the late effect ticking time bomb [inside my daughter] ... [she] harbors intense anxiety about her body. Not the typical teenage stuff like ‘does my hair look okay,’ [but] deep, hidden, and isolating fear.”

“The most effective things that have helped [my daughter] were good pediatric cardiology care follow up. That changed when she became an adult, and we had a hard time finding adult cardiologists that were really in tune to the needs of these patients.”