



Significant gaps in services available to families impacted by a childhood cancer diagnosis

Background

Each year there are approximately 600-800 children diagnosed with childhood cancer in the state of Oregon. This means there are tens of thousands of Oregon families who are navigating treatment, survivorship, and unfortunately, bereavement.

UKANDU has served families experiencing a childhood cancer diagnosis for over 38 years. Over this time, we have received feedback from families indicating the desire for increased services outside of the hospital environment. It is our belief that each member of the family (patient, sibling, and caregivers) are impacted by a childhood cancer diagnosis in unique ways and thus require specific and intentional programming tailored to their individual needs. This led us to pursue formal research to better identify what gaps, if any, exist for patients, survivors, parents, and siblings impacted by a childhood cancer diagnosis.

Methods

Focus Groups

We held multiple focus groups with parents, patients/survivors, and siblings. The conversations were recorded so key themes and takeaways could be extracted.

Surveys

We distributed a survey amongst our target audience. There were separate sections for parents/caregivers, patients/survivors, and siblings. The responses were organized by demographic and evaluated as such.

Observational

The observational research was conducted over two weeks of residential camp with our target population. There were 32 participants observed during the first week of camp and 56 observed during the second week of camp. We recorded key takeaways from the weeks of camp.



"I wish there were more resources past the point of age. When you are 18, 19... you age out of everything. You age out of the support and resources."

Results

Our findings indicate three major gaps in services: mental health, community/connection outside of the hospital, and continuing care/services for those transitioning into survivorship/post-treatment.

93.8% of patients/survivors report a loss of hope and/or joy at the time of treatment

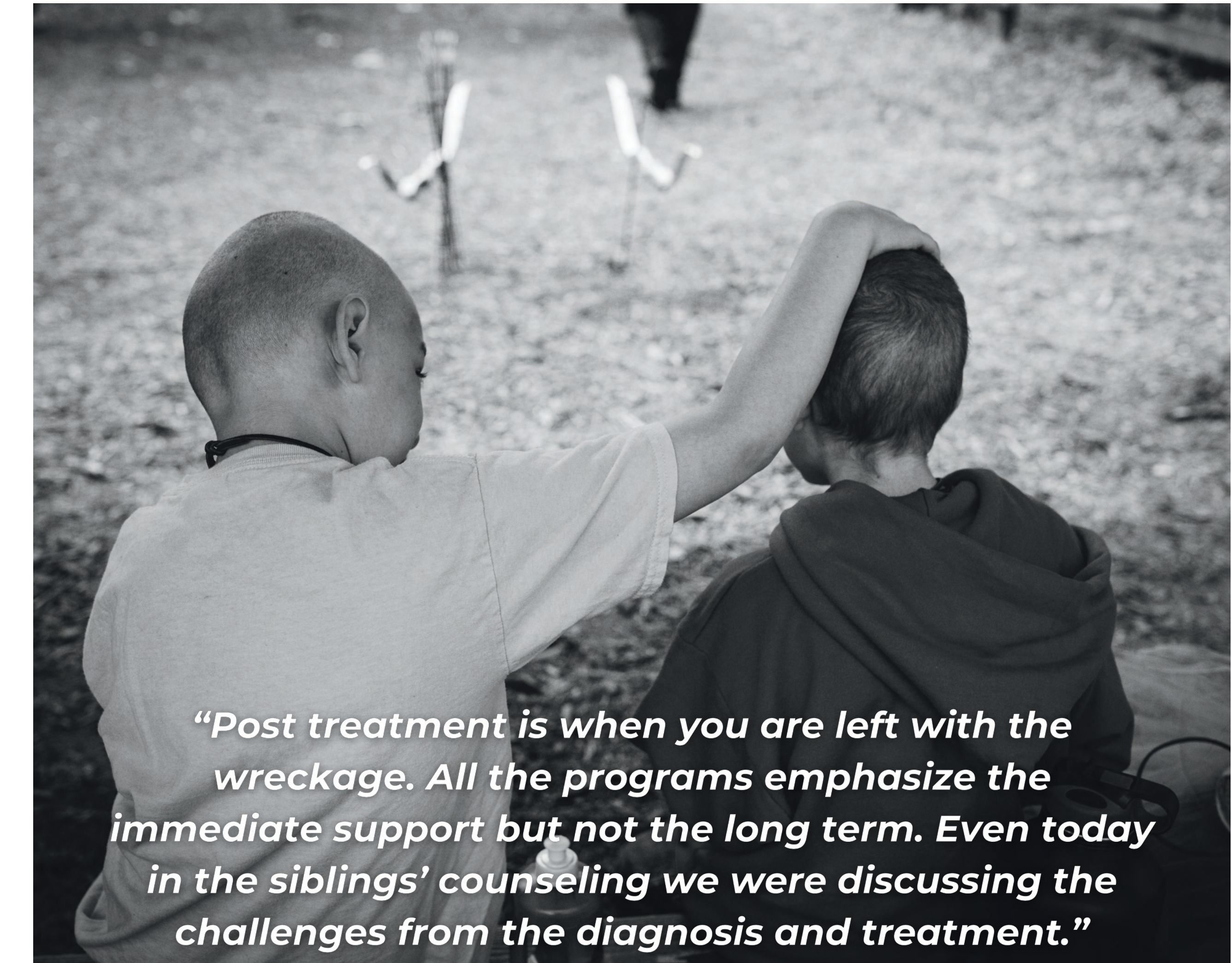
24% of caregivers feel confident in gaining access to the resources available to them

10.7% of caregivers strongly agree that their family's emotional/mental health needs were taken care of during treatment

12.2% of respondents report their families emotional, mental, and physical needs being taken care of in the 5 years following treatment

"Mental health support still carried a stigma in the hospital. The mental struggles for the whole family were significant and largely unaddressed."
- Parent/Caregiver

Participants reported seeking connection to a community where their "abnormal" is recognized and understood as (a new) normal. Such a community allows for unvarnished, authentic interactions among community members in casual conversation, engagement and socialization. Access to a 'knowing community' of peers are offered by various interactions and various organizations at intermittent times throughout the year, but respondents clearly indicate that more opportunities to relate among a group of peers is critical to their emotional and mental health.



"Post treatment is when you are left with the wreckage. All the programs emphasize the immediate support but not the long term. Even today in the siblings' counseling we were discussing the challenges from the diagnosis and treatment."

Conclusions

These findings indicate a clear need for additional services and will help UKANDU continue to shape ongoing program development in the years to come. UKANDU is intent on continuing to have conversations with families and prominent leaders in the childhood cancer community to identify the ways to best serve this population.

Contact Information

Jason Hickox, UKANDU Chief Executive Officer, jhickox@ukandu.org
Sage Palmer, UKANDU Marketing Director, spalmer@ukandu.org
Robin Emerick, UKANDU Program Director, remerick@ukandu.org