

BACKGROUND

- Childhood cancer crude incidence (2013-2017) was reported as being highest in New Hampshire and the Northeast (Siegel 2018).
- In response, the NH State Legislature set aside funds to explore childhood cancer issues in the Granite State
- This funding allowed a multi-disciplinary team led by the New Hampshire State Cancer Registry (NHSCR) to conduct several childhood cancer projects, including the survivor study to better understand experiences of childhood cancer patients and their families

Objectives

- Identify core challenges and supports for survivors and parents during active cancer treatment
- Describe survivors' and parents' experiences with the transition to survivorship care
- Elicit recommendations to improve the experience of pediatric cancer and survivorship care

METHODS

Study Design

- Qualtrics online survey to collect sociodemographic characteristics
- Focus groups and individual semi-structured interviews to elicit open-ended perspective
- Project timeline Jan-June 2021

Recruitment

- Letters mailed to qualified patients and families after review of patient list by oncologist at DHMC
- Social media advertising
- Recruitment lasted 2 months (April-May 2021)

Analysis

- Two CPDE evaluators conducted focus group (90 minutes) and interview (60 minutes) following a semi-structured guide
- All sessions conducted virtually over zoom
- Transcripts were uploaded and coded using Dedoose research data app (v. 8.3.47, SocioCultural Research Consultants, LLC) using a mixed deductive and inductive approach
- Coding and thematic statements were consensus between two analysts

Childhood Cancer Survivors Study
If you live in NH, are over the age of 18, and you or your child experienced pediatric cancer in the past 10 years, **we need your help!**
The NH Division of Public Health Services and Dartmouth-Hitchcock wants to understand the challenges faced by patients and families who experience pediatric cancer.
To read about the study and determine if you are eligible, visit: <https://tinyurl.com/dartmouthpedstudy>
Participants will receive a \$80 gift card at the end of the study.

Parents of childhood cancer survivors:	Childhood cancer survivors:
>= 18 years of age	18-25 years of age
English-speaking	English-speaking
Child diagnosed with cancer in the past 10 years and was <=18 at time of diagnosis	Diagnosed with cancer in the past 10 years
You and your child were New Hampshire residents at the time of treatment; medical treatment may have occurred within or outside NH (e.g., Boston)	You were a New Hampshire resident at the time of treatment; medical treatment may have occurred within or outside of NH (e.g., Boston)
Treatment included either chemotherapy or radiation	Treatment included either chemotherapy or radiation
Your child is currently living and has finished cancer treatment	You have finished cancer treatment

CHALLENGES

- Short timeline design and complete study
 - Issues with use of college or medical center IRB
 - Challenges with rules regarding participant honorarium
 - IRB related delays led to very short time left in study period for recruitment and study completion

LIMITATIONS

- Small sample size with only 2 survivor participants
- Parent participants were all mothers

RESULTS

Participant Characteristics	N	%
11 Parents		
2 Childhood Cancer Survivors		

Family-Level Characteristics*	N	%
Insurance Status		
Employer-sponsored	5	38.5
State-sponsored/ Medicaid	5	38.5
Both	2	15.4
Household Income		
<\$50,000	5	38.5
\$50,000-\$99,999	4	30.8
>=\$100,000	4	30.8
Participant Demographics^		
Ethnicity/ Race		
White	10	76.9
Black	2	15.4
Hispanic	1	7.7
Gender		
Female	11	84.6
Male	2	

Patient Cancer History*	N	%
Gender (female)		
Female	9	69.2
Male	4	
Age at Diagnosis (years)		
0-4	5	38.5
5-11	3	23.1
>=12	5	38.5
Cancer Type		
Leukemia	8	61.5
Lymphoma	2	15.4
Solid Tumor	3	23.1
Treatment Type		
Chemotherapy	6	46.2
Chemotherapy + Surgery	5	38.5
Chemotherapy + radiation + other	2	15.4
Travel Time for Treatments		
30-60 minutes	7	53.8
1-2 hours	4	30.8
>2 hours	2	15.4

* Patient and Family Characteristics at time of diagnosis with cancer
^ Characteristics of study participant, patient or parent

THEME: Patients and families have variety of ongoing mental health needs

About half of participants identified mental health needs including anxiety, depression, and PTSD for patient, parent or siblings associated with cancer diagnosis and treatment

"I often felt his quality of life really took a back seat to treating the cancer, which of course, is the most important thing. I want him alive and healthy first. But a lot of the side effects that came with the emotional piece... and I often felt like I was just yelling into the wind, trying to find some respite for him for the emotional roller coaster that he was going through." (Parent)

"You cannot overstate the effect on the entire family. This diagnosis didn't just happen to her, it happened to him [her non-cancer son], it happened to all of us, and we're still struggling with some of the emotional effects after... All these pieces come together, the isolation, the fear, the anxiety just seems to linger for a long time after." (Parent)

THEME: Financial toxicity is common

"We could have lost our house... if we didn't have the support of family that were able to financially help us, because just cutting your income in half for a year and a half, most people can't support that. Even with a good deductible, it's still so expensive, and there has to be something available to families from the State." (Parent, employer-sponsored insurance)

THEME: School support is inadequate for children with cancer

- Prolonged school interruptions and older children were associated with increased negative impact
- Challenges with continuing accommodations after treatment ended
- Lack of knowledge among school personnel about ongoing or late effects of cancer treatment
- Fatigue with respect to needs to repeatedly advocate for child's needs

THEME: Families experience lack of support during transition to survivorship

"It felt we were almost going through a war zone for two and a half, three years, and then it ended, and we just felt like we were adrift for so long. Just to have some continued intervention... whether it's somebody to help me put all those pieces together of the after-effects of both the physical, emotional, and psychological effects after treatment." (Parent)

"Just to realize that even though you're out of treatment not all the services should stop." (Parent)

"I wish somebody had told me that, 'After cancer...' I remember talking to somebody and they were like, 'Yea, you'll be just fine.' But fine is like, you'll be fine after cancer because you're alive. Right? But what is that reality? A lot of things change. And if I knew that going into cancer and afterwards, that would have been a bit easier on myself." (Survivor)

"They [high school teachers] just didn't understand. And I could only explain so much. And there were a couple of teachers that really cared and really tried. But a few of them just, were done. Because I've been out in and out of school for three years. So they were like, 'Well you seem fine. I don't understand why you're not able to do the work.'" (Survivor)

DISCUSSION

Our study identified significant challenges faced by NH childhood cancer patients and their families both during and after treatment. Particular areas of need include:

- Interpersonal and mental health support
- Financial resources
- School based support
- More comprehensive survivorship care

FUTURE DIRECTIONS

- Ongoing discussion with NH Department of Health through Childhood Cancer Projects regarding increasing statewide networking and resources
- Evaluating DH resources for partnership for childhood cancer survivor care at NCCC
- Considering additional grant support for ongoing study and project development in the field of childhood cancer survivor care for residents of Northern New England