



Parents with Cancer and the Children Who Care for Them: **Findings from the Young Caregivers Study**

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MEET OUR TEAM

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STUDY BACKGROUND

This research study focused on cancer survivors and survivors' children. The goal was to learn about the ways in which young people support or care for their parents when their parents have cancer.

We chose to focus on young people's roles and experiences because young people are often excluded from family caregiver research (Kavanaugh et al., 2019; Lewis, 2021). In the United States, more than 5.4 million caregivers are below 18 years of age. While a relatively understudied population, several recent studies of young caregivers have shown that they help with a range of tasks such as medication management, functional mobility, toileting, and emotional support (Kavanaugh et al., 2016) and that they often adjust their caregiving to family needs and circumstances (Hunleth, 2017).

Cancer is a main health condition for which people receive family care (NAC, 2020), and because cancer is known to create and exacerbate distress and financial strain in families (Kent et al., 2016).

Learning from cancer survivors and the young people who care for them is critical to identifying the strengths and needs families face when confronted with a cancer diagnosis. The lessons we learn from them also play a pivotal role in helping to design programs and policies that best support cancer survivors and their children.



A note on the term “young caregiver”

Terms are important because they raise attention. In this case, young caregiver is used to show that caregiving isn't something exclusively done by adults. However, terms can also be limiting and misleading. For example, not all young people who care think of themselves as “young caregivers.” Because of this, we use the term generally when we wish to direct attention to whose care we are focusing on. But we also intentionally avoid using the term in reference to any one participant.



OUR OBJECTIVES

OBJECTIVE 1

To understand young people's ways of caring.

OBJECTIVE 2

To elucidate how young caregivers and cancer survivors conceptualized care.

OBJECTIVE 3

To identify how to best support cancer survivors and children during cancer at the individual, household, interpersonal, community, and societal levels.

OUR METHODS

01

We recruited cancer survivors from the Siteman Cancer Center Patient Registry and through community contacts. We then invited the children (ages 11-18 years) of these cancer survivors to participate after completing an interview with the cancer survivor.

02

All participants had the option to interview in-person, on Zoom, or over the phone. Interviews were conducted in English or Spanish.

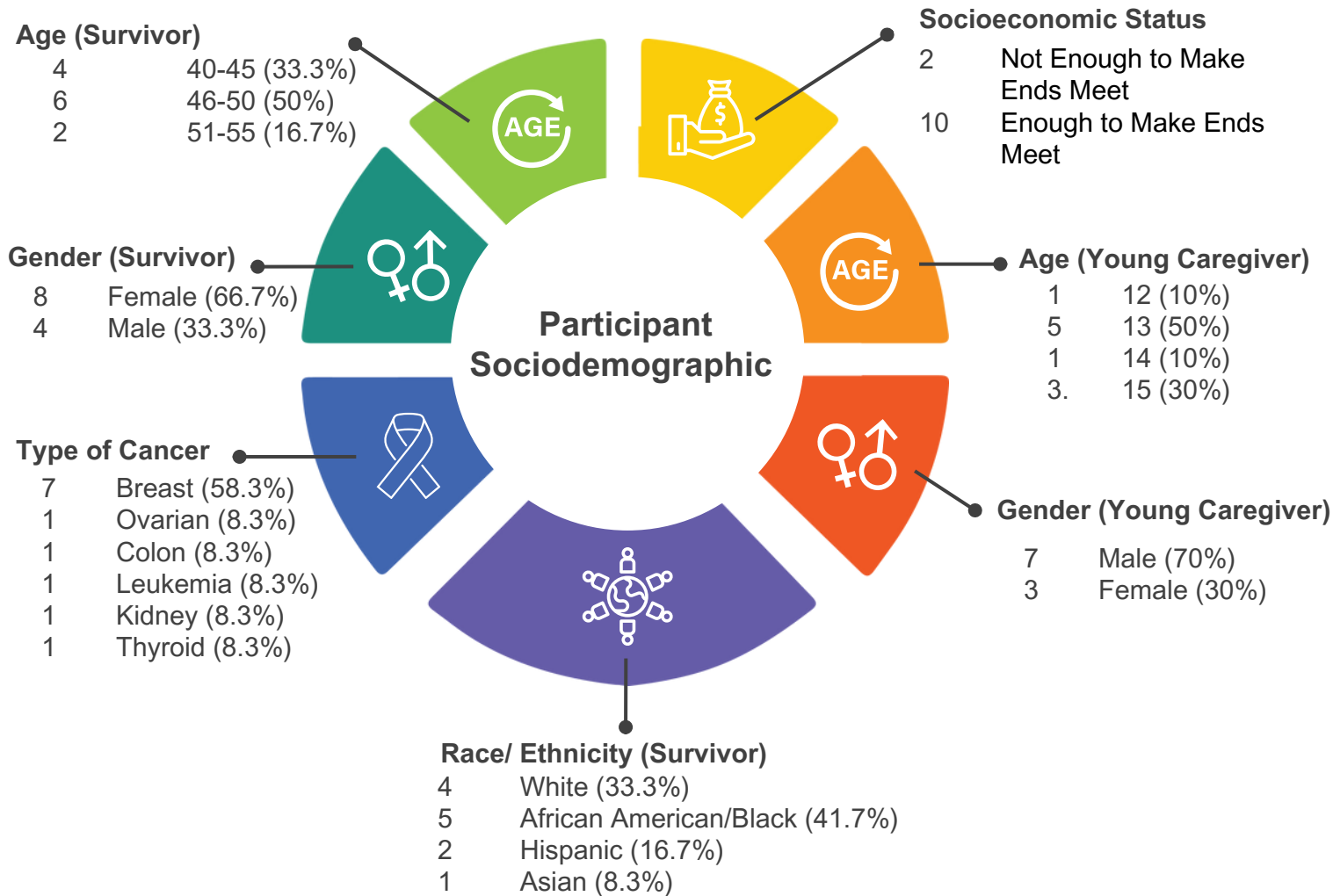
03

The young caregivers were also invited to participate through photography. We invited them to take photos that represented the care they provided for their parent survivor and were given space in the second interview to discuss each photo with the interviewer. This method is referred to as photovoice.



Photovoice is a type of participatory action research. In the Young Caregivers study, the participants took photos related to how they care for their survivor parent. They then discussed these photos with us during an interview. The goal was to have the young people share their stories and experiences of caregiving and identify their strengths and needs from their perspectives.

PARTICIPANT SOCIODEMOGRAPHICS



*Those who reported having “plenty of money left over” at the end of the month were not eligible to participate.

**Every survivor who was asked reported that “their finances were negatively impacted by cancer” (n=11)

***20 participants were interviewed in English and two in Spanish. Without interviewing in Spanish, we would not have had any Hispanic participants as the two Hispanic survivors both spoke Spanish and young caregivers were recruited through their parents.

Objective 1: Young People's Ways of Caring



The young people were already doing a number of things for their parents. These forms of care took shape in many ways. They included an increase in domestic responsibility and caring for younger siblings. They also included emotional and physical support for the survivor, keeping their parent active and happy, and even privately researching cancer. Below we have compiled a summary list based on responses from both young people and survivors:



EMOTIONAL AND RELATIONAL

- Keeping survivor upbeat and positive
- Spending time together
- Talking about each other's days
- Maintaining a close relationship
- Being cute, silly, and funny
- Giving the survivor strength and courage
- Visiting survivor in the hospital, bringing gifts



HOUSEHOLD

- Cleaning the bathroom
- Doing the dishes, laundry, and taking out trash
- Vacuuming
- Cleaning the survivor's bedroom
- Taking care of siblings
- Petcare
- Cooking
- Coordinating care tasks amongst themselves
- Contributing to the household finances



PERSONAL

- Stopping what they are doing to give care
- Not causing drama or trouble at school
- Being more responsible
- Taking themselves to the bus stop/school
- Staying at another family member's house
- Giving space and staying out of the way
- Keeping good grades



MEDICAL

- Giving medication reminders
- Cleaning wound sites
- Bringing supplies
- Maintaining COVID-19 safety procedures
- Preparing baths and showers
- Researching



PHYSICAL

- Going for walks together
- Driving for the survivor
- Getting the survivor up and engaged in an activity
- Helping survivor walk and change positions
- Reaching, lifting, and carrying heavy items
- Staying close by

Objective 2: How Young Caregivers & Cancer Survivors Conceptualized Care



The participants in Young Caregivers came from various backgrounds. The type of cancer and context in which they gave and received care also varied. As the previous pages show, the forms of care young people gave also varied, including over time. However, across the many activities and different participants, we found some commonalities. The following four themes offer an understanding of the young people's approaches to caregiving.

Theme 1: Caring for cancer: "I ended up doing more"

"I end up doing more when he found out he had cancer. I was helpin' out more and stuff like that. Just because I knew he couldn't move because he had surgery and stuff like that. He wasn't able to move around like before he had cancer." 1003_01

Across the study, and as 1003_01 put it, young people did more to help around the house and care for their parent during cancer treatment. However, two things remained consistent in how they talked about the added care or help they gave.

The same responsibilities, just more

Many young people had household responsibilities and chores prior to their parents' cancer diagnosis. This meant they already had knowledge of what needed to be done and how to do it, as Tracy said: *"She can cook herself a whole meal if she needed to...I really think it's because of just how she was raised. That didn't have nothing to do with the cancer, she's just been like that."* The cancer, however, meant more was needed, primarily when a parent who did such housework was no longer able. This was especially the case when mothers, who often carried out a greater share of the housework, had cancer. As 1004_01 put it, her mother did "98% of the housework but this wasn't possible when she was sick. 1002_01 described how this created a need and, *"Well, I just see it as it needs to get done. Someone has to do it, so I would just do it."* His mom was in remission during his interviews, *"she's able to do that stuff now, but I'll cook and stuff sometimes."*



All names in this report are pseudonyms to maintain the confidentiality of the participants.

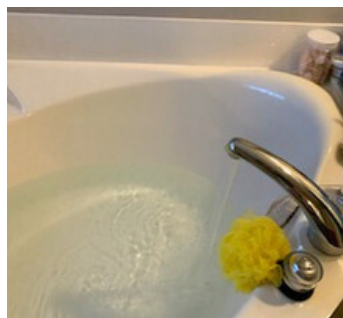
Objective 2: How Young Caregivers & Cancer Survivors Conceptualized Care



Learning to care for cancer

In addition to taking on more of their usual household responsibilities, they also took on more direct care for the parent. For example, 1003_01 and his brother helped their dad up and down the stairs in the house, cooked and brought him meals, helped set up his showers, folded the laundry by his bedside while keeping him company, and changing his colostomy bag. This required learning new ways of caring through carefully watching and listening to a parent's directions and through self-directed learning.

Online content was important. 1003_01's dad told his children about his colostomy bag and showed it to them. 1003_1 said, ***"I wanted to learn [more] about it...I seen a couple YouTube videos of people changin' their bags and stuff like that and how to take care of it."*** They learned how to adjust their care through time as new needs surfaced, such as when chemotherapy affected a parent's memory. One family had creative names for their mom and what she needed from them at different times in her treatment: "Chemo Mom," "Steroid Mom," and "T-Rex Mom." Chemo Mom was sluggish and need to rest while Steroid Mom was hyperactive and would come around to handout projects to everyone. T-Rex Mom was different still with her arms tucked into her chest after surgery like a T-Rex, and who couldn't do the physical tasks in the home.



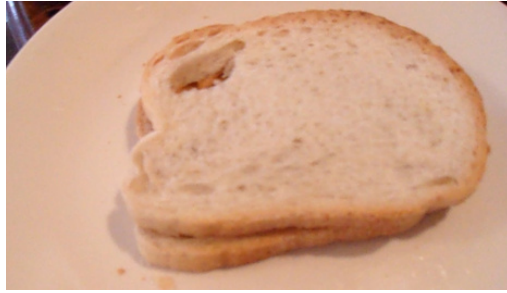
How much more were they doing?

How much more housework and nursing care the young people did varied a lot, often by gender and capability of the young person and the cancer survivor. It also depended on the resources available and on who else was in their household.

young
Caregivers



Objective 2: How Young Caregivers & Cancer Survivors Conceptualized Care



Theme 2: Staying close by: “Is proximity the right word?”

Interviewer: What was it like to do these activities with your mom?

1012_01: I think it helped her. Is ‘proximity’ the right word? More like near her because I needed to take care of her because I think I got to bond with her more watching tv and movies... I helped her if she was in need of any help. If she needed water or she needed any help getting up. I would help her get up or get that water. And sometimes if she was resting I would just finish some chores like doing dishes.

Interviewer: How did doing this stuff together bring you closer?

1012_01: We also have similar opinions on tv and shows. Sometimes with both thing that what the main character did was illogical and so we would laugh about it.

“Staying close by, as 1012_01 showed, helped the young people to know and tend to their parent’s immediate physical and emotional needs and was a way to bond with them. The cancer survivors noted this closeness. Cancer survivor Warren mentioned this closeness, saying **“my son actually slept in here with me at the end of the bed so if I needed anything, he can get it.”** And Ricardo said of his daughter, **“she even sleep next to me because she wanted to be attentive to what I needed. That’s why I told her she was my primary doctor.”** Young people also talked about staying at the house, or in the next room, or having their phone nearby. Such proximity also gave them a time to cheer up their parents and bond with them. 1010_01 photographed a television where he and his mom watched Netflix nightly as “the one thing we could do together,” when he “found out more about her day” and, when his mother was worried about her cancer, he “would always try to reassure her.”

Giving Space

1004_01 said she went to a sleepaway camp so that her mom could “get a break from me...because she’s been around me too long,” she laughed, “even though I wanted to come home.” Giving space was a form of care because a lot of their care entailed staying close by.

Objective 2: How Young Caregivers & Cancer Survivors Conceptualized Care



Theme 3: Sharing and Connecting Through Cancer

Staying close offered a time for cancer survivors and their children to create shared experiences, tastes, feelings, and identities. Creating such connections was another practice of care we identified in the Young Caregivers study. This practice united different activities mentioned on page 7, such as cooking, watching tv, playing games, listening to music. For example, 1008_01 would play music from her mother's native country and brought out a board game from her mom's childhood. She identified that games, music and cooking during illness create a "sense of family and comfort. Playing games might help you reconnect." 1010_01 and 1010_02 made this connection evident throughout their interviews by using the collective pronoun, "we" to describe their care.

Care through watching TV:

"We'd always just watch those together if we could...We mostly saw comedy or action. That's just the sort of stuff we like, and it cheers both of us up. I think it was just easy, and we both liked it. It was just the one thing we could do together."

1010_01



Care through cooking:

"We love to eat grilled cheese" and "we love smoothies" when he talked about the simple foods he would make for his mom and his brother when his mom was in treatment.



And what wasn't shared...

There were aspects of both caregiving and cancer survivorship that were not shared because of the many differences between the young people and survivors. Survivors said that there were things that the young people could not do because of differences like age, gender, and not knowing the feeling of cancer and treatment in their bodies. **"I don't feel like they could understand what I was going through on any level,"** one survivor told us. Perhaps understanding this disconnect, that survivor's child described trying to understand the cancer experience using a surgery that he had gone through. Similarly, the young people said that their survivor parents may not have recognized or fully acknowledged the stress they experienced as they managed life across demands at home, school, and elsewhere.

Objective 2: How Young Caregivers & Cancer Survivors Conceptualized Care



Theme 4: Reducing Stress and Worry

The young people showed us that keeping the survivor happy and reducing their stress during cancer was a form of care. They did this specifically through acting in ways that they knew were more acceptable to and desired by parents. They listened to their parents, went on family walks, got off their electronics, avoided fights and “mouthing back,” stopped behaviors that their parents disapproved of, went to school without complaint, and held conversations with their parents about their day. Notably, the young people did not always want to do these activities, and they may not have done them at all or willingly pre-cancer. For example, 1004_01 showed us a photo of going on a walk with her mother, saying ***“I didn’t feel like going walking, but I did it.”***

To avoid worrying the survivor, they also told us that they concealed their feelings and fears from their parents. They tried to remain lighthearted and silly and not express their fears to avoid putting extra burden on the survivors. 1008_01 said, ***“I don’t really like to bring up bad health possibilities. I don’t know. I just don’t want people to worry, like I don’t want my worry to worry other people.”***



Creating Normalcy

The cancer survivors also wished to avoid stressing and worrying their children by keeping things as normal as possible for their children, a word that came up in many interviews. They stuck to family routines and ensured that their children continued going to school and to extracurricular activities. They did not always let their children know how much physical pain they were in or about their fears or sadness.

In some cases, they shielded their children from information about their cancer. But even when young people were not told, it did not mean that they were unaware of difficulties their parent was experiencing. As Mike told us, “they don’t know what’s going on, but they just know.”

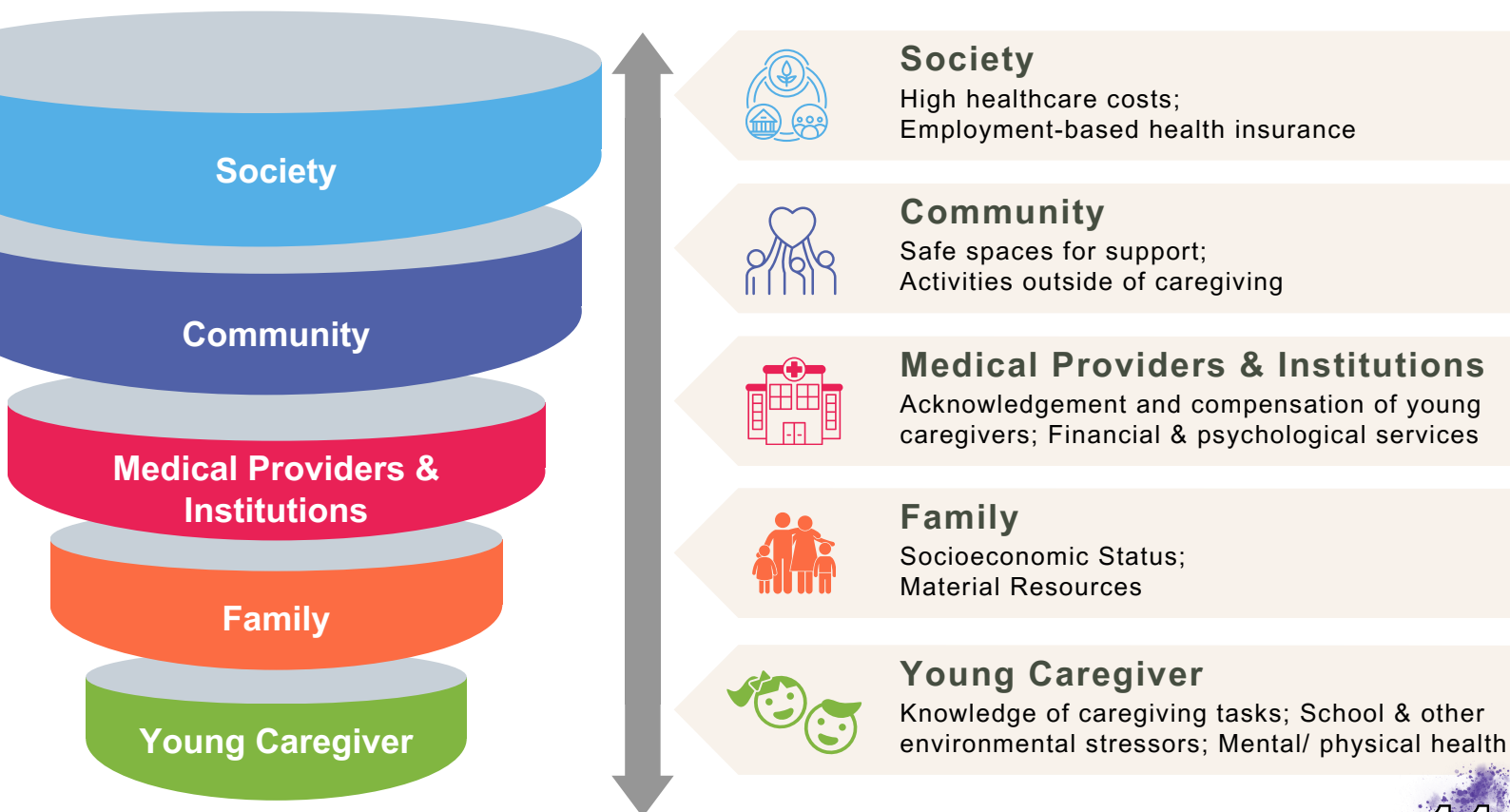
Objective 3: Supporting Young Caregivers and Their Families



Findings from the Young Caregivers study will support efforts to advocate for programs and policies that help young caregivers and their families when a parent/guardian has cancer. As our previous section showed, young people's care for parents was complex. Young people were doing a lot of activities to support their parents and families (see page X). Not all of these activities are traditionally considered as care, and some activities looked like things that they were already doing. Their feelings about their involvement as caregivers related to how they conceptualized care and what their care did for their relationship with their parent and the family. Therefore, there is no one-size fits all way to support survivors and the children who care for them. Instead, programs and policies need to be tailored to their situations, including the multiple factors that make it difficult for young caregivers to provide the care they wish to provide, while not putting undo strain on the young caregivers, survivors, and families.

Multilevel interventions can assist young caregivers and their families

Multiple factors make it difficult to provide care in meaningful ways. They can be viewed at different levels, such as the individual, family, medical provider, community, and societal.



Objective 3: Supporting Young Caregivers and Their Families



Young Caregiver

The **young caregivers** in our study brought many strengths to caregiving and also experienced challenges. Many young caregivers knew how to do basic domestic chores, such as cooking and cleaning. They also sought guidance from the internet for different activities and to learn about cancer. There was some—but not a lot—of interest in classes on daily care tasks. There was greater interest in having someone to talk to or groups to help them cope or de-stress. Some participants acknowledged that young people could be financially supported in ways that would help them in the future.



Family

Cancer was stressful for **families**, not least because of how it affected a family's financial situation and concerns for the survivor's, young person's, and family's future. These factors can be exacerbated by a family's socioeconomic status. Young people wanted to provide care that brought them closer to the survivor and strengthened their relationship. Sometimes this included cooking, cleaning, and nursing tasks. However, the amount of work that needed to go into maintaining the household and caring for the family could be too much for survivors and young people. Providing material resources and/or help with domestic chores could reduce the stress on the family and enable young people and survivors to focus on what mattered to them.



Medical Providers & Institutions

Medical providers and institutions affected young people's caregiving. Young people and survivors often identified a lack of psychological and financial assistance as they navigated cancer diagnosis or treatment. Providers rarely acknowledged how cancer might affect young people or that young people might help care for their parent. One survivor looked for counseling services for her children from the cancer center, but these did not exist. Programs at this level could educate providers on how best to acknowledge young people in their clinical conversations and also create services and groups for young caregivers within hospitals and medical clinics.

Objective 3: Supporting Young Caregivers and Their Families



Community

The participants identified that young people need safe spaces to receive support outside of the household, and in the **community**. There were not many formal places for young people to go for community support when caring for parents. Community support came in a variety of forms, from meeting young people in similar situations, to having extracurricular activities, such as sports and spending time with friends, that allowed them to take their mind off of caregiving responsibilities. Programs at this level could leverage the infrastructure of places like schools or libraries, though there is also a more general need in the U.S. to create more community spaces that are welcoming of young people.



Society

At the **societal** level, the costs of cancer created and worsened financial challenges and had implications for survivors, young caregivers, and families. The survivors discussed having to maintain full time employment throughout cancer treatment to ensure a stable source of income and access to employer-sponsored health insurance. Financial support often did not exist, had income-based eligibility requirements (e.g., means-testing), or required too much effort during an already challenging time. The young people were aware of parents' financial stress and, at times, tried to help their parents manage this stress. Some young people took up odd jobs, quit extracurricular activities to save on cost, or translated bills for parents who did not speak English. Support for young caregivers and families at this level could look like: implementing universal health insurance coverage that is not based on employment status so that survivors do not have to work throughout their cancer treatment; acknowledging and compensating caregivers for providing a necessary labor; and creating government subsidies for the medical costs of cancer.

CONCLUSION

In sum, the challenges faced by young caregivers and their families require programs at these different levels. Simply focusing on young caregivers might help incrementally improve the caregiving experience, but it will not have the long-lasting impact on the financial and social difficulties of navigating cancer in the United States. Therefore, in the future we aim to combine efforts across levels to meaningfully support young caregivers and their families.

GET IN TOUCH!

If you have further questions, thoughts, or ideas about these findings and our future directions, please contact Dr. Jean Hunleth via email, listed on page _____.

Ethical Considerations

Approval to conduct this study has been obtained by New York University (IRB-FY2022-6586) and Washington University in St. Louis (IRB ID #: 202205008).

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