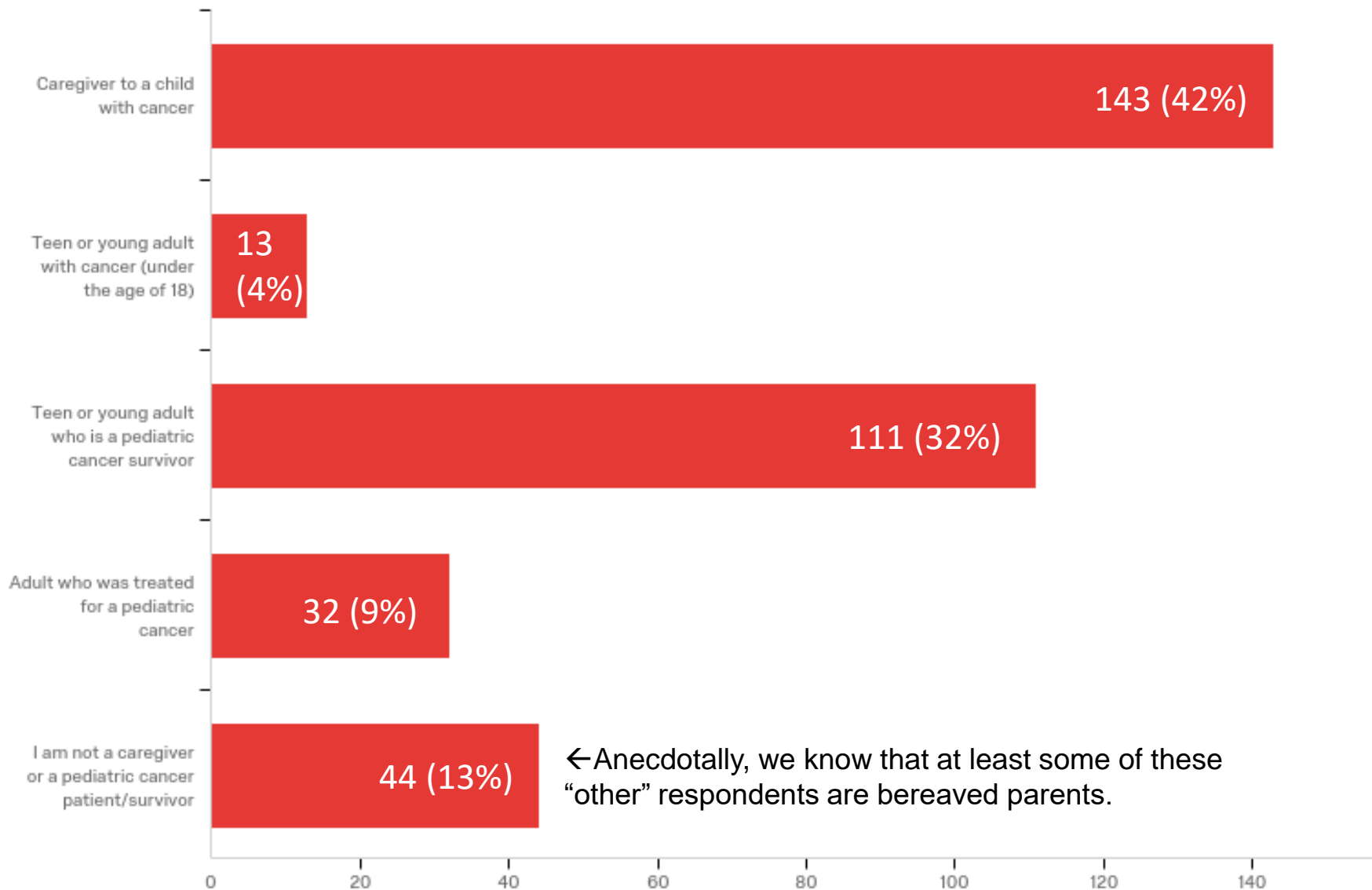


Report on Childhood Cancer Survey of Patient Needs

Survey Period: April 18 – May 25, 2017

A joint initiative of the Children's Cause for Cancer Advocacy
& the Patient Advocate Foundation

SURVEY RESPONDENTS AT A GLANCE (343 total respondents)



SURVIVOR Respondents:

PARENT/CAREGIVER Respondents:

66%
female



60% of
responding
parents
have a **male**
child with
cancer.



88% of
responses
came from
moms.



Median
household
income:
\$60,000



Median
household
income:
\$70,000

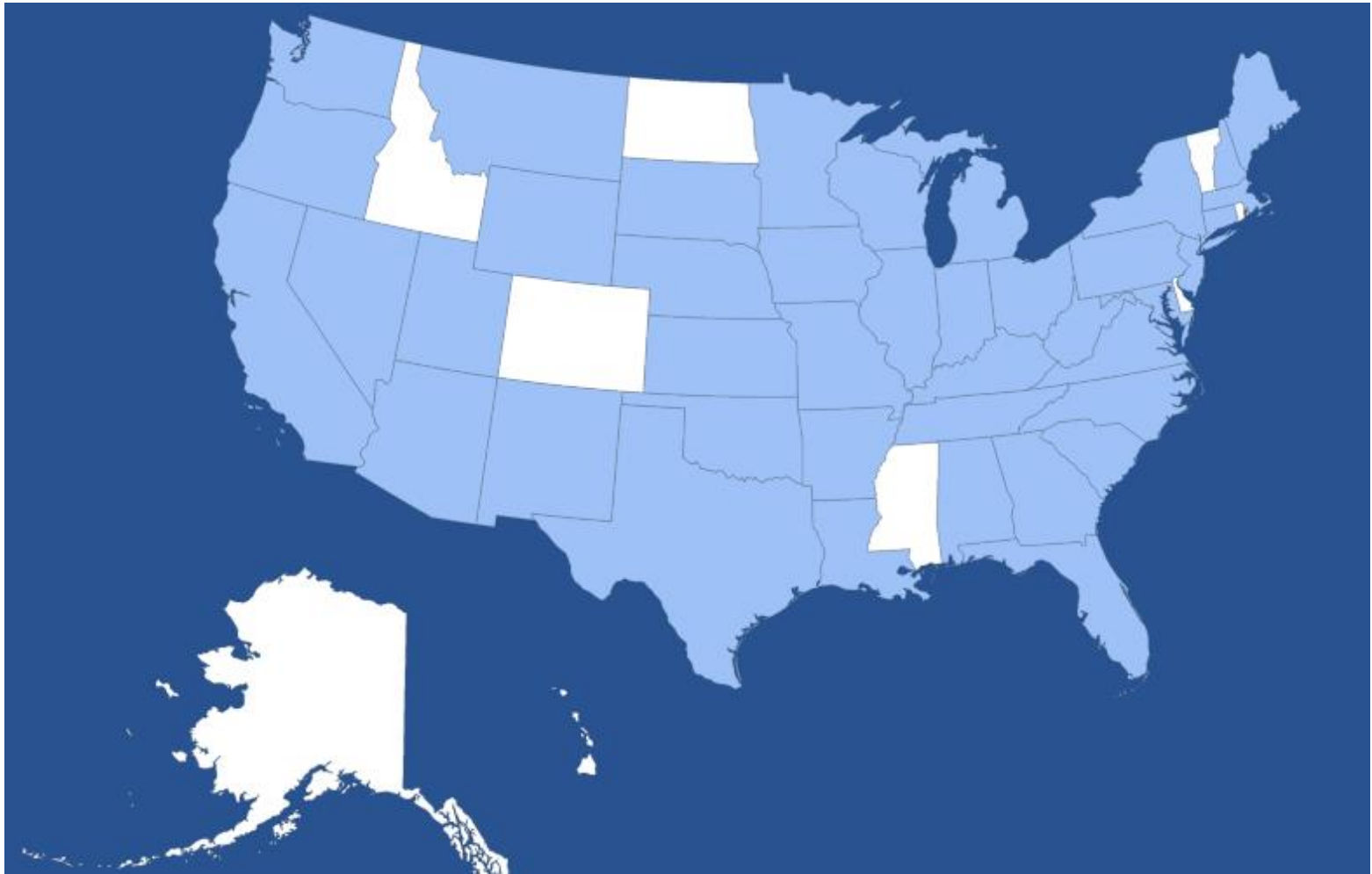
60% of
survivor
respondents
were **19-21**
years old.



Among parent
respondents,
85% of their
children with
cancer are
15-and-under

GEOGRAPHIC REPRESENTATION

At least one person answered the survey from the 41 states shaded light blue.

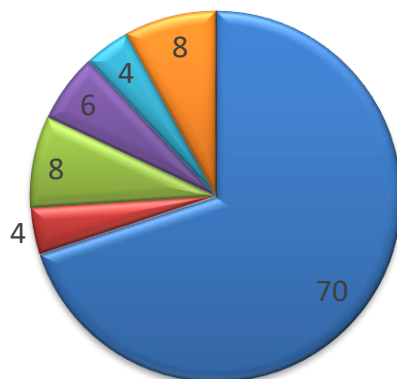


INSURANCE OVERVIEW

Is the child/survivor currently insured? → **91% YES**

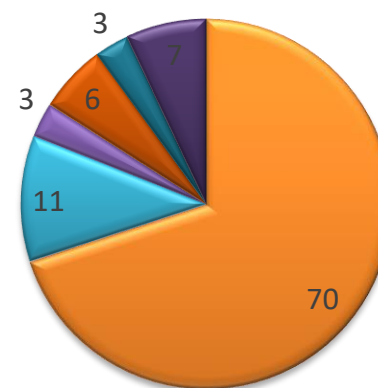
TYPE OF COVERAGE:

Parent/Caregiver Response



- Private Health Insurance through Employer
- Private Health Insurance (paid for by you or a family member)
- Medicaid
- CHIP
- State-sponsored health plan
- Other*

Survivor Response



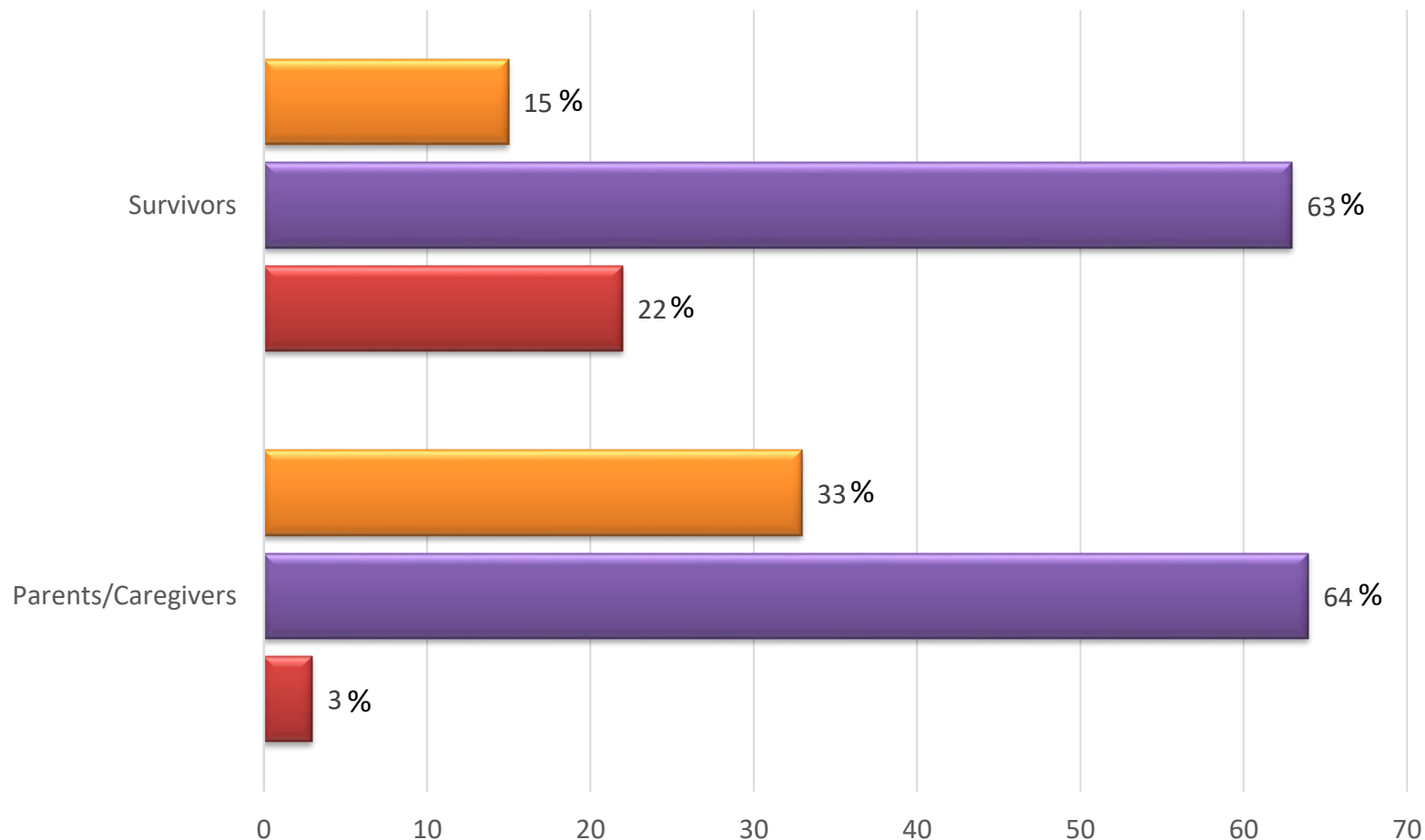
- Covered by parents' insurance
- Private Health Insurance through Employer
- Private Health Insurance (paid for by you or a family member)
- Medicaid
- Health Insurance Exchange Plan (ACA)
- Other*

*Other: military health care; combination coverage (i.e. employer + Medicaid), etc.

DENIAL OF COVERAGE

Was treatment ever denied by your health insurance carrier?

Yes No Unsure



What was the reason given for **DENIAL OF COVERAGE**?

(‘select all that apply’)



41%

Care deemed “not medically necessary”



15%

Incorrect billing or coding



32%

Experimental therapy or clinical trial



12%

Off-label indication for prescribed medication



32%

Therapy or test not covered



10%

No reason given for denial



29%

Out-of-network physicians or facility



8%

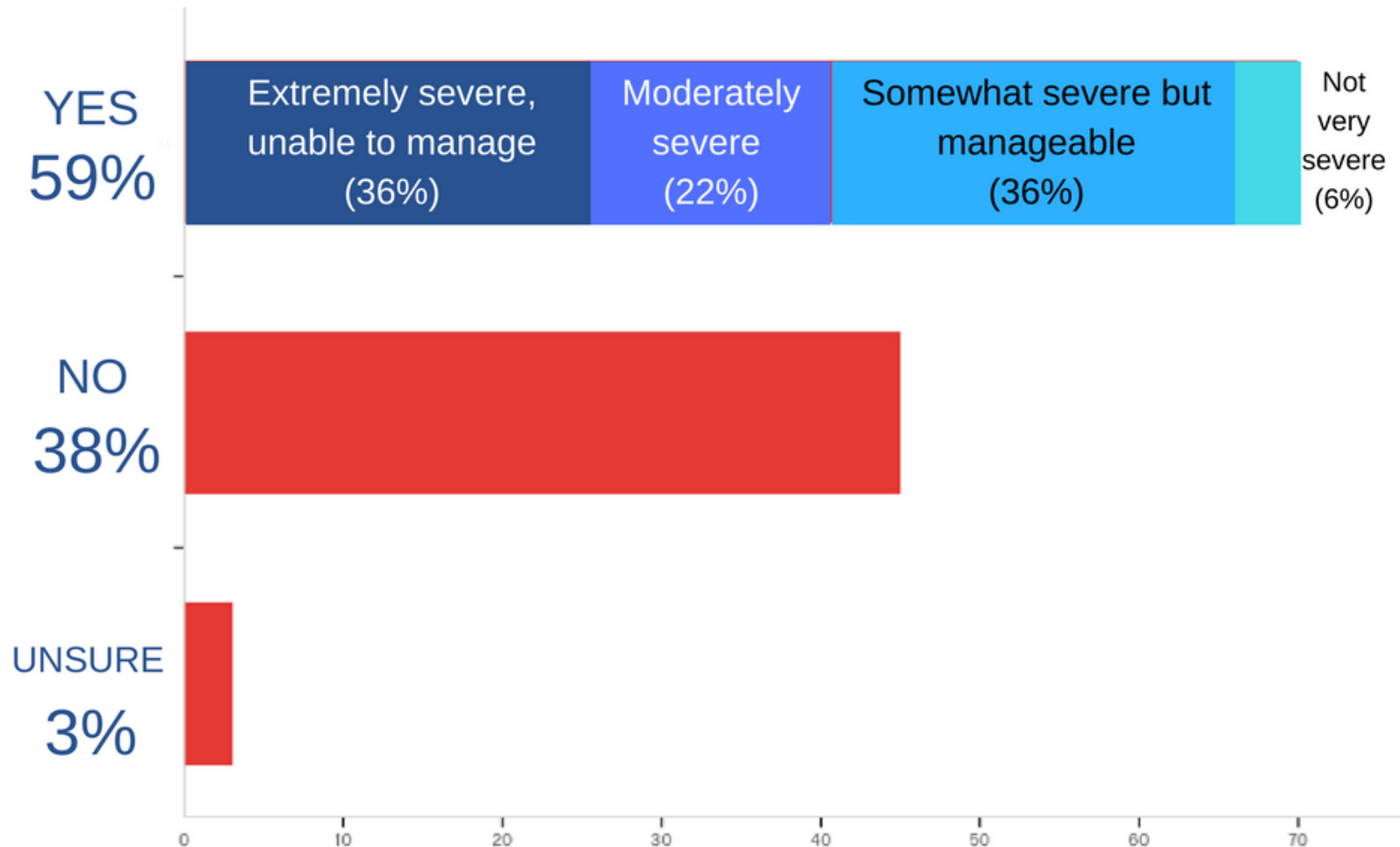
Coverage caps reached

“We appealed successfully in each instance, but it took a great deal of effort and energy.”
- parent

In the last 12 months, have you experienced a **FINANCIAL HARDSHIP** due to the cost of your child's medical care?

If yes, how severe was the hardship?

**This chart shows parent/caregiver responses only*



Among parents/caregivers who self-identified with a **FINANCIAL HARDSHIP**, what are the top sources of their financial distress? *(select all that apply)*



57%
Hospital bills



50%
Visits to medical
providers or
specialists



55%
Prescription costs



40%
Laboratory
services



36%
Lodging



52%
Transportation
costs



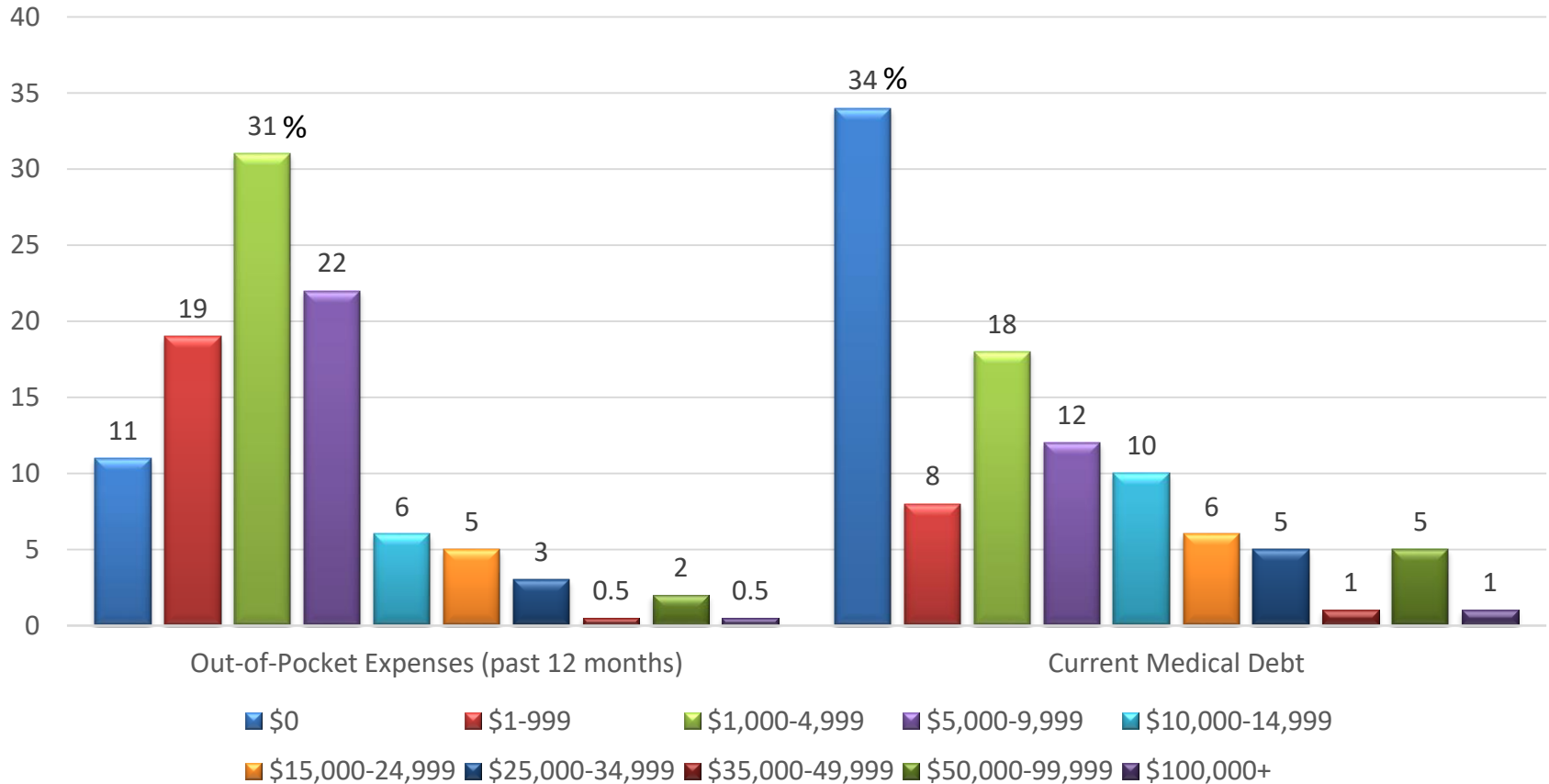
35%
Surgery

Q: At any point in your child's care, were you asked about any financial hardships your family may be experiencing related to food, energy or housing?

A: 56% answered NO.

HEALTHCARE COSTS

Parent/Caregiver Responses



Q1: In the last 12 months, how much have you paid out of your own pocket towards your child's healthcare costs outside of your monthly health insurance premiums?

Q2: How much do you estimate you currently owe (loans, credit card debt etc.) or have in outstanding balances for your healthcare costs related to your child's cancer treatment?

OUT-OF-POCKET EXPENSES

In the past 12 months
which specific costs
would you say
contributed the most to
your overall out of
pocket expenses for
the child/survivor's
treatment or care? →

The bigger the word,
the more often it
appeared in open-
ended responses.



TREATMENT-RELATED FINANCIAL HARDSHIPS

Percentage of **parents** reporting difficulty with the following over the past year: *(select all that apply)*

- **87% - maintaining a regular work schedule**
- 70% - family responsibilities
- 45% - transportation costs (gas, maintenance of vehicle)
- 37% - scheduling childcare or care for other family members

46% of parents report that one or two family members stopped working to care for the child, over the past 12 months.

One parent wrote: “Both of our cars were repossessed and we couldn’t buy Christmas gifts for the kids.”

Percentage of **survivors** reporting difficulty with the following over the past year: *(select all that apply)*

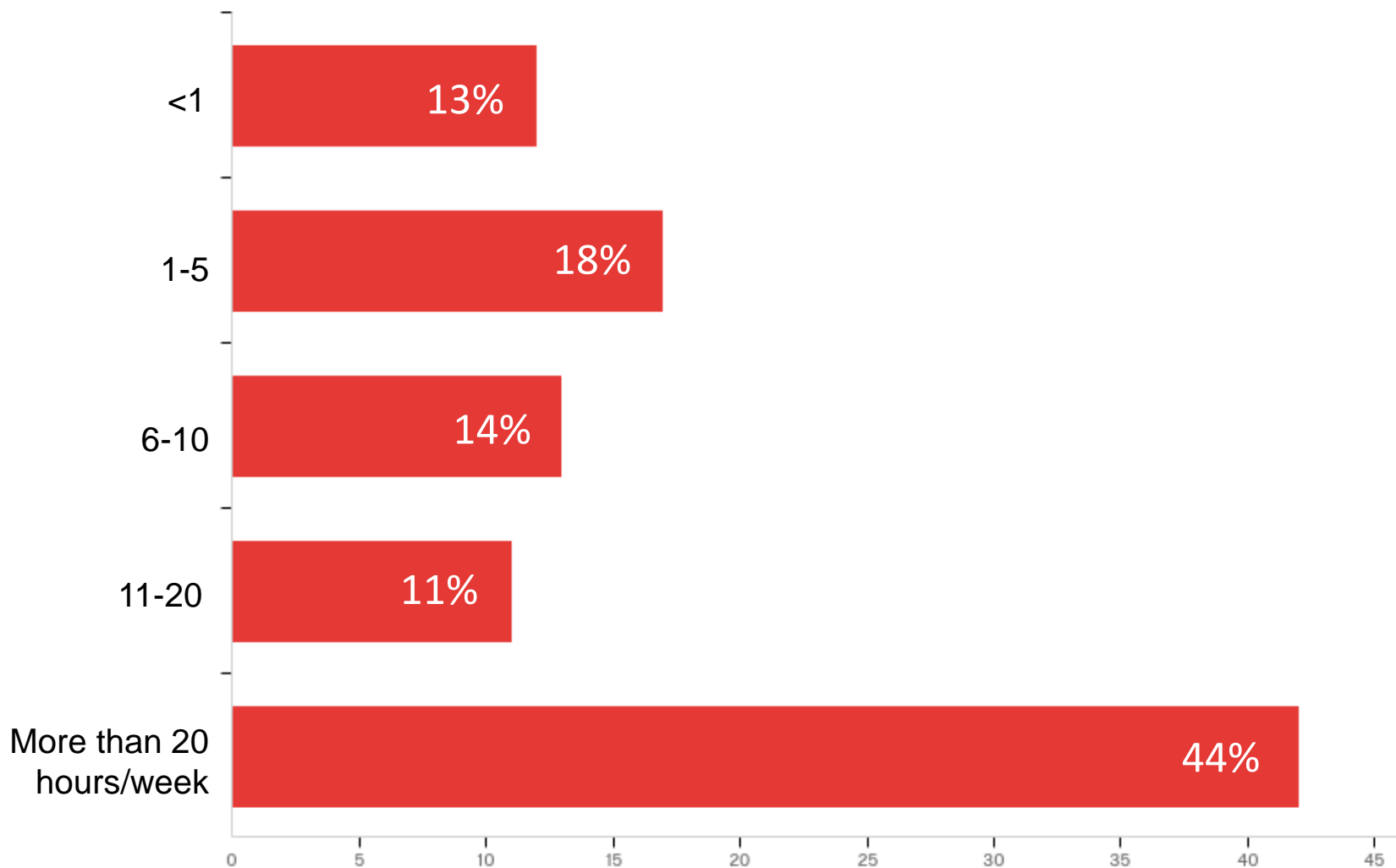
- 40% - maintaining a regular work schedule
- 35% - family responsibilities
- 27% - transportation costs (gas, maintenance of vehicle)

16% of survivors report needing to take unpaid time off for treatment or survivorship care over the past 12 months.

1-in-5 survivors stopped working or reduced work hours in the past year.

Others reported missing college classes and taking time off from school.

HOURS PER WEEK that parents or other household members spend caring for a child's needs associated with their cancer treatment and care:



TRANSPORTATION



- 95% of parents/caregivers report using their own car to get to/from medical appointments.



- Approximately 30% of all respondents (parents/caregivers and survivors) report traveling over 2 hours (one way) for the child/survivor's cancer care.



- **Over half of parents/caregivers reported difficulty in getting their child to and from appointments over the past year.**

“My appointments take place over 1500 miles from my front door. My parents and I fly to every checkup, quarterly or semiannually.”
— young adult survivor

- Top challenges: cost of transportation; vehicle problems; and securing care for other children.
- Some reported that their appointments are not within driving distance.

DRUG SHORTAGES

We waited for government subsidy to drug company to continue production.

I was unable to receive crucial maintenance for a month.

I was unable to undergo a portion of my treatment involving Cytarabine until the shortage ended.

I needed methotrexate, when the drug company was going to stop making it. Luckily, the government stepped in before it was a problem.

Treatment delay was resolved by many peer to peer conversations.

How did the drug shortage you encountered impact your child's care?

We traveled to another facility, only to find out we would still have to wait an extra day.

The chemo drug was no longer available, and my daughter had a life threatening allergy to the only available alternative. We had no choice but to start the alternate drug in the ICU at a low rate in hopes of breaking through the sensitivities and reactions.

We had to change facilities to where the drug was available & continue care there.

There was a nationwide shortage of one of the chemo drugs used to treat my cancer. They used alternate drugs for the time that were effective for me in the short term, but I relapsed a few months later.

Shortage delayed the start of a trial - originally September & ended up being December.

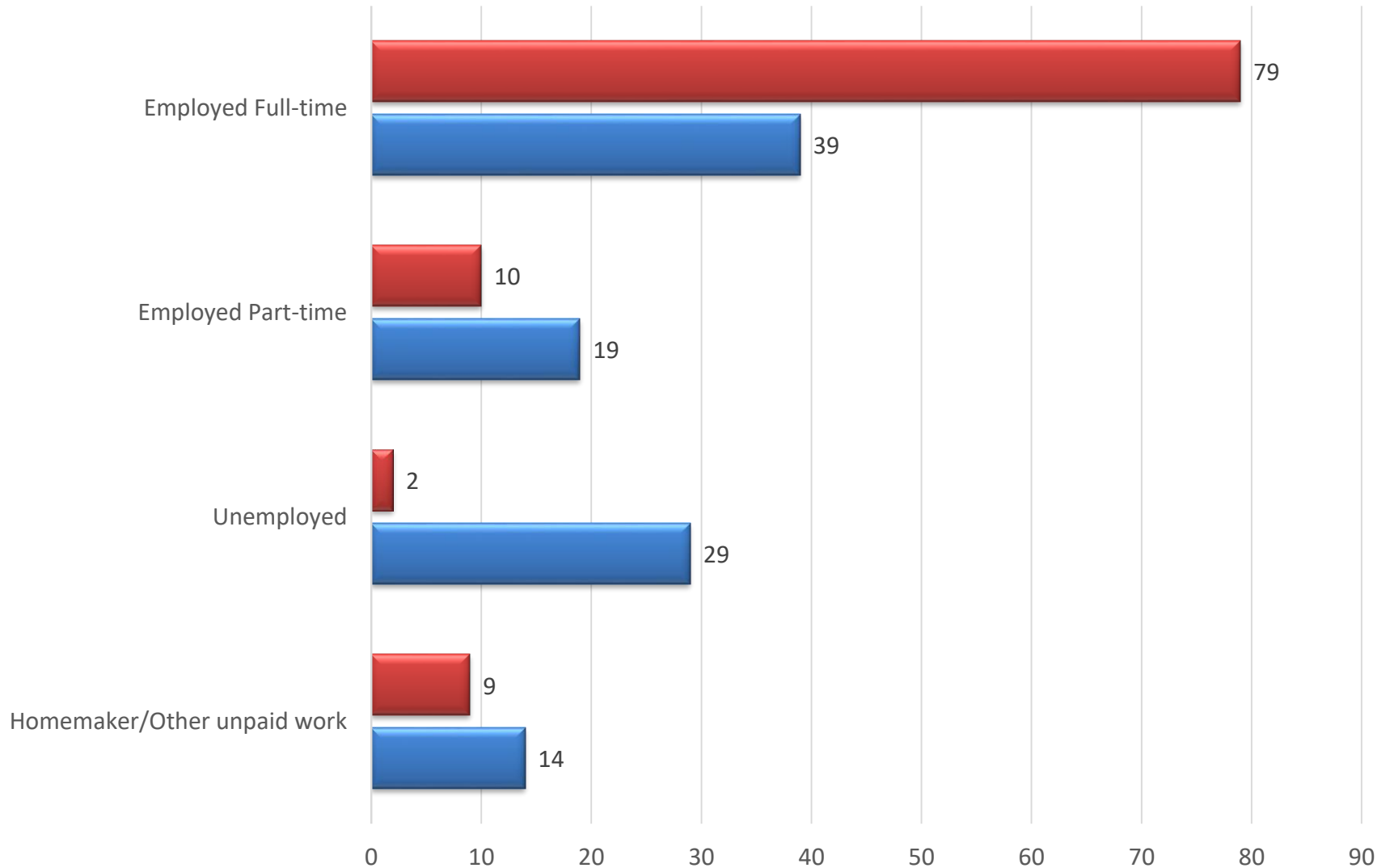
1 in 4
parents/caregivers
report that their
child's treatment
was delayed or
compromised
because of a
shortage of a drug
or a drug was
unavailable.

25% of those
parents report that
the physician was
***not** able to get the*
drug from another
source.

IMPACT ON EMPLOYMENT

Parental employment status in the month before diagnosis & now

■ Before Diagnosis ■ Currently



SURVIVOR OUTLOOK



27% of the surveyed survivors are *not* currently receiving follow-up care from a survivorship clinic. Of those, just 15% cite cost as a factor in deciding not to receive follow-up care.



24% of survivors in this study report that the cost of their cancer-related medical care impacted their ability to pursue the higher education of their choice. 1 in 4 of the impacted students delayed college or university, while most others opted to attend school closer to home (community college or an in-state university).



30% of surveyed survivors said the cost of their medical care has impacted their career course or job choice.