

Background

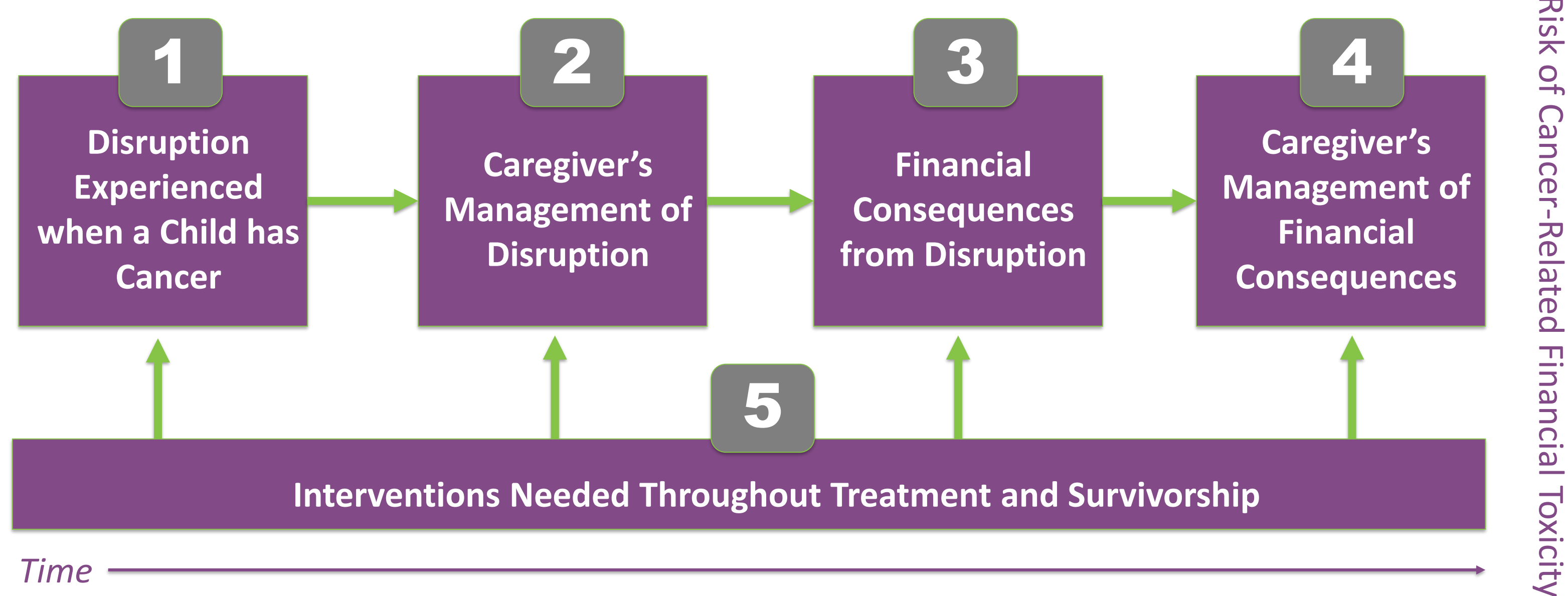
Cancer-related financial toxicity is an unaddressed side-effect of childhood cancer¹, with consequences for household financial health and quality of care, including increased risk for relapse, and decreased survival rates². This project identified opportunities along the cancer journey when interventions could reduce risk of cancer-related financial toxicity for families of children with cancer.

Methods

- 17 caregivers of children diagnosed with cancer attended focus groups (n = 3)
- Children were treated in Massachusetts or New York
- All families experienced severe financial distress during treatment
- We used the concept of “social navigation”¹ to guide thematic analysis of transcripts. Social navigation is relevant to understanding the financial side of cancer because it acknowledges and examines how people act when unanticipated disruptions (e.g. health, financial) create instability in their lives.

Results

FIVE MAJOR THEMES EMERGED FROM FOCUS GROUPS



Results (Continued)

TWENTY-FOUR SUB-THEMES EMERGED FROM FOCUS GROUPS

1 Disruption Experienced when a Child has Cancer

- Emotional shock
- Hospital stay
- Travel for outpatient care
- Unpredictability of treatment

EMOTIONAL SHOCK
“I was literally not able to do anything”

2 Caregiver's Management of Disruption

- Time-off from work
- Restructured routines

TIME-OFF FROM WORK
“This [child's treatment] became not a second job. This became a first job.”

3 Financial Consequences from Disruption

- Reduced income
- Direct and indirect medical expenses
- Accumulation of debt

REDUCED INCOME
“When we first got diagnosed, we were in the hospital for a couple of weeks. Then finally we went home. On Monday they cut my salary 20 percent and took away my management position. And my wife stopped working mainly because she had to stay home.”

4 Caregiver's Management of Financial Consequences

- Increased work hours
- Navigated insurance coverage
- Requested financial assistance
- Cut-back on expenses
- Used financial reserves
- “Fight for everything”

INCREASED WORK HOURS
“[. . .] picking up as many hours as I can. Lucky for me, the shop lets me work all night long till the morning, and not even sleep. I don't get overtime because I'm flat rate, but I could pull-in as much money as I could.”

5 Interventions Needed throughout Treatment

- Financial Assistance
- Proactive support for insurance and resource navigation
- Credit advocacy
- Housing and meals during inpatient stays
- Parking support
- Online workshops
- Streamlined application process
- Expanded eligibility criteria
- Research on treatment that can be administered at home

PROACTIVE SUPPORT
“Those in that condition [diagnosed with cancer] can't get help at any time. It should be the beginning. It should be the middle, it should be the end. We should always be able to get some financial help.”

Conclusions

- Focus groups identified opportunities for interventions to reduce cancer-related financial toxicity for families of children with cancer throughout the cancer journey.
- With collective actions from the ecosystem of for-profit, non-profit, and public sectors these opportunities can become programs that may benefit cancer patients, families, and society.

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References

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