

# Clinical Challenges and Ethical Dilemmas in Allocating Financial Resources to Pediatric Oncology Families

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# Objectives

- Articulate the importance of recognizing financial hardship among pediatric oncology families.
- Describe ethical considerations in assessing the financial needs of families when a child is diagnosed with cancer.
- Highlight clinical challenges in allocating limited resources amongst families in need.
- Promote shared problem solving in assessing and responding to financial insecurities among pediatric oncology families.

# Why is the Topic Relevant?

- Financial insecurities are a well-documented risk for pediatric oncology families.
- The Pediatric Psychosocial Oncology Standards of Care include assessment of financial burden and referral.
- Most clinicians spend a considerable amount of time on assessment and distributing resources.
- Impacts clinical relationship with the family.
- Ethical challenges are inherent in assessing need and managing allocation of limited resources.



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**“For fast relief from stress, depression and anxiety,  
four out of five doctors recommend money!”**

# Reconciling the Dilemma

- Social workers do not judge others as good, bad, worthy or unworthy
- NASW Code of Ethics (2017) states, “Ethical decision making in a given situation must apply the informed judgment of the individual social worker”



# Literature Review

## **Pervasive Financial Hardship in Pediatric Oncology**

- Increased financial hardship is common among pediatric oncology families (Pelletier & Bona, 2015; Bona et al., 2014)
- Pediatric oncology families can experience changes in employment status, including job loss/resignation, changes in income, as well as, experiencing added costs related to cancer treatment (Long & Marsland, 2011)

# Literature Review

## Parent and Child Well-Being

- Financial hardship during pediatric cancer is associated with depressive symptoms and increased emotional burden and distress among caregivers/parents (Edmond, Graves, Whiting, & Karlson, 2016; Creswell, Wisk, Litzelman, Allchin, & Witt, 2014)
- More information has been arising that suggests poverty may have implications for pediatric oncology health outcomes and child well-being (Bona, London, Geo, Frank, & Wolfe, 2016)

# Literature Review

## Assessing for Financial Hardship

- Assessment for risk of financial hardship & referral to appropriate resources should occur at multiple points across the illness trajectory (Warner, Kirchhoff, Nam, & Fluchel, 2014)
- Some risk factors to consider (Pelletier & Bona, 2015; Bona et al., 2014):
  - new diagnosis
  - single-parenting
  - care at distant sites
  - unexpected/prolonged hospital admissions
  - employment changes
  - pre-diagnosis financial challenges
  - long treatment trajectories

# Ethical Considerations

- As we think about assessment...
  - Variable and subjective
  - Self-report as an assessment tool
- As we think about allocation...
  - No consistent formula
  - Using our best judgment
  - Lack of financial guidance education/  
training requirements



"I guess it's ethical. Let me run it through my 'Ethics Check' app."

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# Case # 1

Billy is a 6 year old boy newly diagnosed with leukemia (ALL). He is the 2<sup>nd</sup> of 4 children to parents who have been together, but not married, for 12 years. His siblings are 9, 4 and 2 years old. Parents are both 28 years old. They live in an apartment in a poor community. Mom completed her GED but dad did not complete high school or his GED. Mom has never worked, and dad is currently unemployed. He has worked episodically and infrequently in their relationship. They pay market value rent for their apartment and live on the SSI benefits for their older son (who has hearing loss and behavioral issues) and their youngest son (who has a G-tube, failure to thrive and a questionable genetic anomaly). They have been approved for SSI for Billy. They receive food stamps and fuel assistance.

As Billy began his therapy, mom would accompany him to all his visits while dad stayed home with the younger children. Neither parent drive or have access to a vehicle. They receive free medical transportation through a Medicaid program in Massachusetts.

Billy is a really nice boy and beloved in school. Very soon after his diagnosis you learn the school has taken up collections providing gifts, food and clothes to the family. Billy's mom, Susan is excited to tell you about this. You come to know Susan well, but every time she comes to clinic she looks for you and needs something. Sometimes it is supermarket gift cards, money for laundry, or funds to pay the rent.

# Case #1 continued

- Has cancer impacted family's financial situation?
- How does this become part of the decision making for providing assistance?
- How do you decide what to give?
- What consideration is given to the impact on government benefits?
- How does it make you feel to interact with this family?
- Does your decision making on what you give them impact your relationship with them?

## Case #2

Rita is a 9 year old girl with a diagnosis of non-metastatic osteosarcoma of the tibia. Rita is the younger of two children (brother is 12) living with her married parents in a working class community outside of Boston. Prior to her diagnosis, Rita's mom worked as a cashier in Walmart, where she had been for 5 years. Her boss was kind and understanding so when Rita's mom could not go to work, he held her job until she was able to return. She did not however get paid for the many months while she cared for Rita and could not go to work. Dad is employed as a house painter and his work schedule changes frequently over time. There were times he was busier than others, and his income has often been unpredictable.

Both parents were devastated when they learned that Rita had cancer. Much of the social work intervention was in helping them access their strengths and maintain hope for Rita's future. The parents needed much emotional support and denied offers of care and support from their extended family and church community. None of their family could help them financially, even if they were willing to accept it. Family had never received financial assistance in the way of cash benefits or food stamps. They were independent and self reliant and always managed to get by.

As the Social Worker aware of their likely financial needs, I attempted to raise the issue of the financial burdens of parents of children with cancer. My intention was to normalize the experience and encourage discussion about need. The parents would respond that they "couldn't think about it" or "we'll manage" and could only talk about their fears and sadness about Rita. After about 7 months of treatment, when attempting to revisit this issue, the family acknowledged that they were now two months behind in their rent as well as their utilities and were worried about what to do.

## Case #2 continued

- How directive should clinicians be with families in addressing financial concerns? What if the concerns are identified by the medical team, but not acknowledged by the family?
- How might the therapeutic alliance with the family be impacted by continuing to bring up the issue of financial insecurity?
- How might you approach this?

## Case #3

Simone is a 5 year old girl with neuroblastoma currently undergoing radiation treatment. Simone splits her time between her divorced parents who have a discordant relationship which has become further fractured in the setting of Simone's illness. Simone's mother is single, lives in government housing, receives child support, and had been planning to return to work right before she was diagnosed, but has now suspended plans to work given the many months of treatment ahead. Simone's father lives in a private home and works full time.

Simone's mother approaches you early on in her treatment asking for financial assistance and requesting that you not share her financial circumstances with Simone's father. She tells you that Simone's father is financially stable and has even received money from friends and family fundraising on Simone's behalf. Simone's mother reports that she had previously asked about financial assistance from their medical oncology team and when Simone's father found out, he was angry that no one had discussed available resources with him.

## Case #3 continued

- How would you respond to Simone's mother's request? How might your response affect your relationship with either parent?
- How would your approach differ (or not) if both parents reported financial hardship?
- Does receiving financial assistance through family and friends impact your referral practices to hospital/community programs?

## Case #4

Sherri is a 14 year old girl with a medulloblastoma. You have frequently met with her parents, Debbie and Bob for emotional support in this difficult journey. Sherri has a 17 year old brother. Family lives in a middle class community in a Boston suburb where dad works full time as a project manager and mom works a day or two a week as a hairdresser. Family commutes about 25 miles for Sherri's frequent medical treatment. She initially has many struggles related to neurocognitive challenges and side effects from therapy. In the early stages of her diagnosis and treatment, family shares information about several fundraisers which were held in Sherri's honor. Large sums of money were collected to benefit the family with ancillary costs of care. As part of your assessment you also learn about generous grandparents who have offered their financial assistance if needed.

Sherri does better with her therapy over time and her visits diminish. About 8 months after her diagnosis, mom asks you to sign off and submit a letter of support for the family to receive a large grant from a community program which supports families of children with cancer. While the organization expects their funds will go to families in need, there is no means test. You reluctantly write the letter which you affirm the child's diagnosis and parents care of her. You have other families of lesser means that could benefit from such a grant, but you can only request this for 5-6 families a year. Family does receive the grant, and mom announces they will use the money to go on a much needed family vacation to Bermuda.

## Case #4 continued

- Were you correct in agreeing to write this letter of endorsement for the family?
- How would this impact your relationship if you had said no?
- If they had sought out another member of the care team to write the letter, would you have interceded?
- How do you think about this situation in the context of financial insecurities related to a child's cancer diagnosis?

# Special Considerations



- Families who discuss resources with each other in the treatment setting
- Those who have accessed an abundance of resources at another institution or through their social network
- Managing limited resources and responsibly allocating resources from community partners
- Addressing needs identified post treatment completion

# Clinical Challenges

- Impact of giving or not on the therapeutic relationship
- Being fair and/or equitable
- Being perceived as withholding
- Emotional and/or moral distress for the Social Worker
- Labor intensive and limited time to complete applications





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