

MEDICINE AND SOCIETY

Should Clinicians Intervene If They Suspect That a Caregiver Whose Child Has Cancer Is at Risk of Psychological Harm?

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Abstract

Compelling arguments suggest that pediatric oncologists who have concerns about the mental health and well-being of a child's caregiver have a duty to intervene. These arguments are rooted in fundamental principles of beneficence, nonmaleficence, and justice. Not only do patients benefit when their parents and others caregivers are happy and healthy, but when the psychological distress of a caregiver is a consequence of the experience of illness and treatment, some of the responsibility for mitigating the harm falls to those who have an active role in directing treatment—the clinicians. However, systems to support clinicians in meeting this obligation are inadequate.

Introduction

Every year, some 300,000 children and adolescents are diagnosed with cancer globally [1], with over 15,000 cases occurring in the US [2]. Despite excellent outcomes in high-income countries, with more than 80 percent of children and adolescents diagnosed with cancer in the US surviving at least five years [3], the experience of diagnosis, treatment, and recovery is still physically, psychologically, spiritually, and financially challenging [4, 5].

Nearly all of these children will share their cancer journey with a parent, grandparent, or other caregiver. Studies have shown that while many caregivers demonstrate impressive resilience in the face of a cancer diagnosis, some are at increased risk for post-traumatic stress, depression, anxiety, and somatic illness [6-8]. The additional financial burden of treatment may contribute significantly to caregivers' psychological distress [8].

Every pediatric encounter involves, minimally, a triad: the young patient, the physician or other health care professionals, and the patient's parent or guardian. Children are, by definition, not fully autonomous beings and require a parent or legal guardian to make decisions on their behalf. Although the historical standard in pediatric ethics has been for parents and other surrogate decision makers to act in children's "best interests" [9], in practice, these decision makers are often weighing competing demands and struggling

to do what is best for the entire family, and recent discussions of pediatric decision making take this into account [10, 11].

The provision of ethically optimal care to children, therefore, requires considering such care in the context of the family [11]. For many children, the family environment is the most important single influence on their emotional and psychological well-being [12]. I argue that clinicians who have concerns about the mental health and well-being of a child's caregiver have a duty to intervene in order to promote the patient's welfare and to prevent harm—the classical ethical principles of beneficence and nonmaleficence. This duty will be further explored through two clinical case studies.

Case Studies

Case 1. A two-year-old girl is diagnosed with acute lymphoblastic leukemia. She experiences several complications during induction chemotherapy and requires a prolonged hospitalization. During this time, her 23-year-old mother drops out of college, citing the stress of caring for her daughter while working two part-time jobs to support the family, which includes the patient's three-year-old brother. The mother's outburst directed at her manager results in the loss of one of her two jobs. Violent altercations with other family members have resulted in hospital security being called, and the family has been referred by hospital staff to Child Protective Services (CPS) for investigation.

Commentary. While the mother does not have an obvious or known psychiatric diagnosis, she appears to be suffering considerable stress related to her daughter's illness—expected for parents of children with cancer [13, 14]—possibly exacerbated by previous life stressors, such as financial instability, young motherhood, and a lack of support from her children's father or other family members. Her distress has already resulted in the loss of income to the family, and it may have a more direct negative impact on her daughter's physical and mental well-being in a variety of ways. She may be more likely to administer medications incorrectly at home, or she may be distracted, less attentive, and less responsive to her daughter's needs.

In this context, it is easy to appreciate the rationale for immediately addressing this mother's psychological needs: without intervention, her daughter is potentially at imminent risk of physical harm if she fails to provide necessary care. It is also important, however, to consider the potential long-term sequelae. This mother might in fact be capable of meeting her daughter's needs during the acute period of illness, but both of her children are at greater risk for poorer health in adult life. Studies have identified associations between adverse childhood experiences and poor health outcomes in adult life. Such adverse experiences include not only serious illnesses, such as cancer in childhood, but also growing up with a parent with a mental illness or substance use

disorder [15, 16]. Other studies have shown a relationship between parental stress and the likelihood of both post-traumatic stress and long-term functional impairment after childhood cancer [17, 18]. Thus the potential risks to a child with cancer, especially one whose parent is suffering psychological distress, are both immediate and lifelong.

Case 2. A 13-year-old boy with metastatic osteosarcoma responds poorly to chemotherapy. His disease progresses despite his trying second- and third-line options, including experimental therapies, and his divorced parents frequently argue about treatment options. His father has a prior history of depression and alcohol abuse. He is an only child, and the nurses caring for him have expressed concern that his father may attempt suicide if the patient dies.

Commentary. Because the patient is not expected to survive, his father's psychological distress is not likely to affect his immediate or long-term physical and mental health, although it could impede the achievement of palliative care goals and his overall quality of life. However, it would be incorrect to conclude that health care professionals have fewer obligations to the father of this child than to the mother of the first patient. When the [psychological distress of a caregiver](#) is in part a consequence of the experience of illness and treatment, some of the responsibility for mitigating the harm falls to those who have an active role in directing treatment: the clinicians [19].

What Can Clinicians Do To Help?

Implement and adhere to the psychosocial standards of care for children with cancer. Evidence- and consensus-based guidelines for providing comprehensive psychosocial care to children with cancer and their families were published in 2015 by *Pediatric Blood & Cancer*, the official journal of the American Society of Pediatric Hematology/Oncology and the International Society of Paediatric Oncology [20, 21]. Among the adopted standards included recommendations for routine assessment of psychosocial needs of patients and families and access to psychosocial support and interventions, including psychiatric or other [mental health treatment](#) as appropriate [20]. Notably, the standards specifically reference the need to ensure that parents or other caregivers have access to mental health care [21, 22]. In the above cases, adoption of these standards would mean that both families would be identified as having psychosocial risk factors early, during routine psychosocial assessments, and offered appropriate services and interventions—perhaps preventing deterioration of the first patient's situation to the point at which referral to CPS was legally mandated.

Recognize the financial impact of a childhood cancer diagnosis and help families access resources within the community. As noted previously, families of children

with cancer are at heightened risk for significant financial burden, which may negatively impact parental coping and mental health [4, 20, 22, 23]. Some evidence has even suggested a relationship between financial insecurity and risk of relapse in childhood cancer [24]. Clinicians can work with other members of the health care team, such as social workers, to ensure that all families are assessed for [financial hardship](#) at the time of diagnosis, are reassessed regularly throughout treatment, and are referred appropriately. Referrals might be made to the hospital's financial counseling office, community organizations, and governmental programs [25]. Families may also require assistance navigating state and federal safety-net programs. Regular reassessment is crucial because families who seem financially secure at the time of diagnosis may not be so six months later. For example, in the second scenario, the parents may have expended significant personal resources obtaining second opinions and pursuing clinical trials at other health care institutions, perhaps involving frequent travel and loss of income from missed work.

Explore the use of interventions to promote resilience. Resilience, the capacity to recover from adversity, is difficult to define and measure reliably [26]. It is therefore even more difficult to intentionally promote [26]. However, some pediatric oncology researchers have begun to test interventions to encourage the development of resilience in parents and caregivers (as well as patients) and have suggested a role for health care professionals in promoting resilience by offering psychosocial supportive care and optimizing communication and decision-making support [27, 28]. Resilience is associated with several positive psychosocial outcomes, including post-traumatic growth, benefit-finding, and lack of psychological distress [27]. In the first case study, greater resilience might have helped the mother to cope with her anger more constructively, rather than with an "outburst" that resulted in the loss of one of her jobs. In the second case, resilience might serve to ameliorate the father's risk of suicide after his child's death.

Promoting Systemic Change to Meet Families' Needs

Unfortunately, these obligations to meet families' psychosocial needs intersect with two historic weaknesses of the US health care system: mental health care and preventive care. Health care professionals, however, can [advocate for change](#) on multiple levels.

At the institutional level, practice guidelines and standards of care like those discussed above can be implemented to ensure that all families receive appropriate psychosocial care, rather than relying solely on the accountability of individual clinicians. As there is significant variation in psychosocial resources among institutions, clinicians may also need to advocate for the hiring of qualified individuals—including psychologists, social workers, and child life specialists—and for productive collaboration with psychiatry

departments [20]. Clinician-educators in pediatric oncology—including physician- and nurse-educators—must also support the development and implementation of training standards so that new graduates enter the specialty prepared to integrate psychosocial care into their practice [29].

Finally, the health care profession has a collective responsibility to support and advocate for the financing of research in the area of psychosocial support [30]—which receives substantially fewer federal dollars compared to cure-directed biomedical research [31]—and to support and advocate for the integration of this research into oncology care [32]. In addition, the profession has a collective responsibility to support state and federal legislation that might ameliorate the financial impact of illness and attenuate stress for parents and caregivers. Examples of the latter might include more generous family and medical leave policies and subsidized respite care programs [33].

Conclusion

Compelling arguments suggest that pediatric oncology professionals who have concerns about the mental health and well-being of a child's caregiver have a duty to intervene. These arguments are rooted not only in the basic principles of beneficence and nonmaleficence but also in justice and a broad vision of health and health care. By addressing psychological distress and mental illness affecting caregivers, clinicians can promote positive outcomes and prevent or ameliorate both short- and long-term negative outcomes. As I've argued here, because those who have already experienced other types of adversity—such as single-parent families, families with a history of mental illness or substance abuse, and low-income families—are more likely to be negatively impacted by a diagnosis of cancer, addressing psychological distress is fundamentally an issue of justice. By integrating psychosocial care of the whole family into pediatric oncology practice, pediatric oncologists and other health care professionals can achieve better outcomes for all children—particularly those at greatest risk.

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ISSN 2376-6980**