THE CHALLENGE OF QUALITY CARE FOR FAMILY CAREGIVERS IN PEDIATRIC CANCER CARE

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OBJECTIVES: To discuss the needs and potential interventions for parental caregivers of children with cancer.

DATA SOURCES: Published articles between 2002 and 2012.

CONCLUSION: In general, parents do adjust and cope with their child’s cancer, but a significant majority experience post-traumatic stress symptoms. Families also report that the shift to parenting a child with cancer is very disruptive to identity and family structure and can cause negative outcomes for mothers, father, and siblings. There is growing evidence of post-traumatic growth and resilience in parents of children with cancer. Recent studies have suggested that targeted interventions may relieve distress.

IMPLICATIONS FOR NURSING PRACTICE: Nurses can support families in the difficult transition to having a child with cancer and may be able to intervene to reduce long-term distress in families.

KEY WORDS: Children with cancer, parental caregiving, post-traumatic stress, resilience

“'You feel like you lose all control over your life. It’s no longer your own.'” Parent

CANCER in childhood is rare compared with cancers of adulthood, and represents only 1% of the total cancer diagnoses. Each year, there are approximately 12,060 new diagnoses of cancer in childhood. With recent medical advances, over 83% of children diagnosed with cancer today will be long-term survivors. While diagnoses rates have declined and survival rates have increased in recent years, childhood cancer is still the...
second leading cause of death in childhood.\textsuperscript{2} And regardless of prognosis or outcome, each diagnosis has a significant impact on the child, their family, and their community. This article will discuss the impact of childhood cancer on parental family caregivers and the implications for interventions to relieve distress in this population.

**CANCER IN CHILDHOOD AND ITS IMPACT ON THE FAMILY**

When a child is diagnosed with cancer, the entire family is diagnosed. Cancer in childhood can impact quality of life, mental and physical health, activities of daily living, family dynamics, identity formation, parental and sibling role, as well as sense of meaning and spirituality.\textsuperscript{3-8}

From the moment of diagnosis, the entire family is catapulted into a new reality that is both threatening and confusing. The child and their entire extended family enter a contract with uncertainty about prognosis, treatment, outcome, and impact. Emotional reactions for the family can include fear, disbelief, anger, anxiety, confusion, hope, concern, and shock.\textsuperscript{9} Cancer in childhood can impact the family in a number of practical domains, including disruption to the family equilibrium, challenges to coping strategies, changes in roles, incongruent or opposing family member reactions, and financial and support system challenges. There is risk of potential adverse outcomes for families of children with cancer, such as post-traumatic reactions, anxiety, depression, financial distress, marital/partner or familial discord, social and behavioral problems for the child and/or their siblings, and prolonged and complicated mourning.\textsuperscript{9,11}

For many families, the diagnosis of cancer is experienced as a trauma and may later cause post-traumatic stress reactions.\textsuperscript{3,12} Recent studies have shown that a majority of parents of newly diagnosed children show symptoms of acute stress, with 40% of fathers and more than 50% of mothers meeting the criteria for acute stress disorder.\textsuperscript{12} Because almost all parents in one study reported symptoms of acute stress (re-experiencing, arousal, and avoidance), it can be seen as a normative response to a life-threatening diagnosis.\textsuperscript{12} However, most families will adjust to the trauma, engage their previous coping strategies, and integrate the experience of their child’s illness into their life experiences.\textsuperscript{13}

Despite the high rates of distress, families also demonstrate optimism, resilience, and positive outlook in the face of their child’s cancer diagnosis. These traits have been shown to correlate with increased life satisfaction, positive health perception, and decreased anxiety and depression.\textsuperscript{14,15} Some studies are showing that the caregiving role itself may have a mediating impact on the traumatic impact.\textsuperscript{16-18} Because the parental role is inherently a caregiving role, a cancer diagnosis multiplies the caregiving demands of parents. Parents still maintain all of their other caregiving responsibilities, and must now adjust to these new, complicated, and critically important responsibilities. However, because parents want to protect and nurture their child, caregiving opportunities may reduce their suffering and mitigate distress.\textsuperscript{9}

While caring for a child with cancer presents extreme challenges to the parent, there is evidence that some parents may also experience post-traumatic growth in caring for their child. In a cross-sectional survey of 273 parent caregivers of children with life-limiting illnesses throughout Canada and the United States, Cadell et al\textsuperscript{14} found evidence of both caregiver burden and growth. Overall, participants expressed growth through caregiving as evidenced by the Post-traumatic Growth Inventory. As meaning in caregiving, self-esteem, and spirituality scores went up, so did post-traumatic growth scores.\textsuperscript{14} Similarly, as depression scores went up, so did caregiver burden; as depression scores went up, meaning in caregiving and spirituality scores went down; and when burden went up, self-esteem and optimism decreased.\textsuperscript{14} Overall, this may indicate that post-traumatic growth for parent caregivers is possible, but is mitigated by caregiver burden and depression. Parents in this study indicated the importance of becoming an advocate for their child and connecting with other parents.\textsuperscript{14} Parents also noted that there is a lack of support for siblings, and that siblings still desire more information and support from health care providers.\textsuperscript{14}

**EXPECTATIONS OF FAMILY CAREGIVERS/ PARENTAL CAREGIVING DILEMMA AND ROLE CONFLICT**

Because cancer is so rare and unexpected in childhood, there is no preparation for the role of...
the parent (or grandparent or sibling) of a child with cancer. During the initial diagnosis period, the family, especially the parents, must adjust to this identity and role shift. Sometimes this identity transition begins before diagnosis (parents may have suspected that their child was not well and may have brought her/him to multiple doctors before actually receiving the oncology diagnosis). This initial period of uncertainty and potential delays or misdiagnoses can also impact the caregiving role. In addition to the parental nurturing provided when a child is well, parents of children with cancer often discover that they must become advocates, counselors, and medical technicians in this new role.

Expectations of family caregivers of children with cancer are quite high. The oncology team expects parents to quickly learn and adhere to rigorous treatment protocols that often involve frequent medical appointments and/or lengthy hospital stays. Parents typically deliver home-based high-tech medical care that is often complicated and invasive. Parents become trained to identify and respond to severe and distressing side effects of treatments that can include nausea, vomiting, pain, sleeplessness, changes in attitude, mood, behavior, eating and sleeping patterns, fever and neutropenia, distress, and suffering. Parents are sometimes asked to help the medical team by getting their child to comply and cooperate with invasive procedures. The role of “caregiver” as defined by the medical team is often at odds with the definition of “caregiver” in parental terms. The parental caregiver dilemma involves parents having to provide care that is often painful and frightening to the child while simultaneously desiring to explain, hold, nurture, comfort, protect, and help their child avoid suffering and pain.

Families of children with cancer may provide medical, emotional, financial, spiritual, or physical caregiving, or more likely a combination of all of these. Medical caregiving involves the management of treatment, hospital stays, clinic visits, home care, and any number of other treatment-related tasks. The context of this caregiving can be quite emotionally taxing, as described by this mother.

“Every four or five days, we had to sterilize the place where the catheter went into Forrest’s body. The hole for the catheter was right beside his heart. Infection there would kill him quickly. We were shown how to clean the catheter site within the first few days of his diagnosis. One of our nurses demonstrated using a plastic toddler doll. But the doll didn’t squirm. The doll didn’t feel any pain. As I watched her, I knew our experience was going to be a whole different story…”

Parents report that the most frequent negative effect from parental caregiving is on their physical and emotional health. Parents indicate that the types of assistance that are most beneficial to them include respite from direct caregiving and relief from other responsibilities so they may focus on the child. According to parents in one survey, the most helpful forms of assistance to relieve caregiver burden include timely education about their child’s health status from health care providers and emotional support from family members, friends, and others.

**FACTORS THAT INFLUENCE FAMILY CAREGIVING AND PARENTAL WELL-BEING**

A number of demographic and personal factors may influence caregiving and parental well-being. First and foremost are the family structure, cultural and spiritual background, and history of illness and loss. There are a variety of family structures that exist, including multigenerational families, single-parent families, same-sex parent families, foster families, adoptive families, immigrant or noncitizen families, and families separated by distance, divorce, or separation. Each of these family constellations may have unique needs and potential barriers in the health care system. In addition to entering the medical system and trying to adjust to the emotional trauma, many families also contend with fears that the providers may not recognize their unique family structure.

In addition to family structure, culture and religious/spiritual background can impact familial caregiving roles and expectations. How a family caregiver interprets the diagnosis of cancer and the caregiving role will be greatly influenced by cultural beliefs of illness, health, wellness, and death. In the interactions in health care, there are a number of therapeutic elements that can be influenced by culture, including trust or mistrust, especially in communities that have been disenfranchised or experienced discrimination in society. It is well-documented that health
disparities exist in oncology treatment that impact both diagnosis and prognosis specifically for Latino and African American patients. Any history of cultural mistrust or language and cultural barriers may influence how the family receives information about the child’s diagnosis and about the proposed treatment protocol. Even seeking a diagnosis and receiving help, both medical and psychosocial, are greatly influenced by cultural expectations. Spiritual and religious beliefs also play a role in how parents and families enter into the health care system and approach the role of caregiver. Socioeconomic status and insurance status may also impact the child’s access to care and the family’s expectations and interactions with the health care team. Finally, a history of concurrent or prior losses, especially cancer-related, may cause the family to feel a greater sense of anxiety and despair or hope and competence upon news of a cancer diagnosis.

Gender and role expectations can impact who provides the majority of physical and/or emotional caregiving to the child. While there are many family structures and a variety of appropriate caregiving roles for both fathers and mothers, it appears that there are some unique challenges for each. In two-parent families, one parent often remains in the hospital to care for the child while the other maintains the financial caregiving responsibilities. In many, but certainly not all families, the mother is at the bedside while the father returns to work. The challenges for fathers are different than mothers. This creates unique challenges for each parent. Mothers report the emotional work of caregiving as intense and complex. Fathers report feeling distant and uninformed about the care and treatment of their child.

Siblings of children with cancer experience greater distress at the time of diagnosis and do report a sense of losing parental attention and sense of status in the family. Some siblings also report post-traumatic stress symptoms, poor quality of life, and negative emotional reactions. Siblings also show positive outcomes, such as increased capacity for empathy and psychological maturity. Parent caregivers worry about their child with cancer and about their well children; these concerns add to their parental caregiving stress.

**Caregiving When Cure is not Likely**

When cure is not likely, parents have tremendous fear that their child will suffer emotionally or physically and often worry that they may not be able to provide the support necessary. And yet, children may guide their parents in the difficult and crucial conversations about death and life as exemplified in this exchange:

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“Am I going to die, Mommy?”
Yes. Forrest, everybody dies sometime.
Do you know when?
No….do you?
I was thinking Friday.
Friday? That’s a bit soon, don’t you think?
Well when I die, I’ll miss you and you’ll miss me
and I’ll miss Daddy and Daddy’ll miss me…
Can we listen to Blue’s Clues now?”
-Forrest, age 3
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When a child is facing the end of life, parental caregiving takes on additional dimensions that involve balancing the hope for cure with the devastating reality that the child may die. Parents continue to provide all of the emotional, physical, medical, and spiritual caregiving they have during the child’s illness, but now they must also face almost inconceivable loss and grief. Parents strive to keep the child free from pain and suffering while simultaneously managing all of their own and other family member’s emotions. Parents report that end-of-life decisions for their child are the most difficult to make. As care moves from curative to palliative to end-of-life care, the decision-making suddenly shifts to the parent. Parents report feeling overwhelmed and inexperienced to make these decisions after years of having decisions dictated by a structured treatment protocol. Most parents prefer to have information but make decisions in collaboration with their health care providers. Many parents want to ensure that their child is involved and participatory in their own end-of-life decisions. Some parents seek spiritual and religious support during these decision times, while others may experience anger toward God and a rejection of previously held beliefs.

Recent studies have shown that parents want to be seen as a “good parent” to their critically ill or dying child. While the definition of a “good parent” is individual and personal, it can also be socially influenced. This desire to be seen as a “good parent” is a powerful internal motivator of decision-making and actions. Parents want positive feedback from health care providers that their
decisions are reflective of their child’s preferences and that they are still “good parents.” The parents in this study provided a clear list of attributes that defined what being a “good parent” means (see Table 1). Parents also offered distinct clinical care strategies that supported them in being a “good parent” (see Table 2).

**SURVIVORSHIP AND LONG-TERM CAREGIVING**

There are approximately 270,000 childhood cancer survivors (CCS) in the United States and, given current treatments, children diagnosed today have 5-year survival rates exceeding 80%. However, CCSs are at risk for long-term effects of their treatment. These long-term outcomes can include anxiety, depression, post-traumatic disorder, difficulties in relationships, challenges to fertility, significant physical late effects, and risks of secondary cancers. The late effects that children experience can influence their long-term caregiving needs. Additionally, research has shown that families, especially parents and siblings, are also vulnerable to struggles related to having a child or sibling with cancer. The Childhood Cancer Survivor Study, a long-term retrospective cohort study of 14,000 children diagnosed between 1970 and 1986, has demonstrated that survivors are at risk for negative late effects in the following categories: social, behavioral, psychological, and medical outcomes. According to this study, CCSs are at risk for social outcomes, such as poor educational attainment, less than optimal employment status, and interpersonal relationship issues. Overall, most survivors are psychologically healthy and satisfied with life. However, certain groups of CCSs are at higher risk, especially brain tumor survivors.

Risk factors for poor health-related quality of life and psychological distress include being female, unmarried, having low educational attainment, having an annual income of less than $20,000 or being unemployed, lacking health insurance, presence of a major medical condition, and a history treatment with cranial radiation or surgery. The presence of psychological distress in CCS predicts poor health behaviors, such as smoking and alcohol or other use, which can put them at higher risk of further health problems. Those who rate their health as poor have increases in depression, anxiety, and somatic distress. Survivors report concerns about their physical health and relapse, body image, and self-concept. Survivors also worry about adequate access to insurance, and about their future jobs and careers. Fatigue and psychological distress are significant for a subset of CCS: women, those who are unemployed or have low income, and those struggling with delayed or late effects of cancer therapy.

Survivors of childhood cancer are more likely than their siblings to have symptoms of depression and anxiety. Specifically, adolescents treated for leukemia or CNS tumors show increased scores in depression/anxiety, attention deficit, and antisocial domains. Survivors of neuroblastoma show an increase in depression/anxiety and antisocial domains, and treatment with cranial radiation or intrathecal methotrexate are specific risk factors for these negative outcomes.

<table>
<thead>
<tr>
<th>TABLE 1. Parents Definition of “Good Parent”</th>
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<tbody>
<tr>
<td>● Doing right by my child</td>
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<td>● Being there for my child</td>
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<tr>
<td>● Conveying love to my child</td>
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<tr>
<td>● Being a good life example</td>
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<td>● Being an advocate for my child</td>
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<td>● Letting the Lord lead</td>
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<tr>
<td>● Not allowing suffering</td>
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<td>● Making my child healthy</td>
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Data from Hinds et al.

<table>
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<th>TABLE 2. Clinical Care Strategies that Support Parents in Being a “Good Parent”</th>
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<tr>
<td>● All that can be done is being done</td>
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<tr>
<td>● Staff respect me and my decisions</td>
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<tr>
<td>● Staff continue to comfort my child and me</td>
</tr>
<tr>
<td>● Staff know our special needs</td>
</tr>
<tr>
<td>● Staff like our child</td>
</tr>
<tr>
<td>● Staff are pleasant</td>
</tr>
<tr>
<td>● Staff coordinate care</td>
</tr>
<tr>
<td>● Staff ask about our faith</td>
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<tr>
<td>● Give us the facts</td>
</tr>
<tr>
<td>● Staff tell us we are good parents</td>
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<tr>
<td>● Do not quit on us</td>
</tr>
<tr>
<td>● Do not forget us</td>
</tr>
<tr>
<td>● Keep including our child</td>
</tr>
<tr>
<td>● Provide more material items and support options</td>
</tr>
<tr>
<td>● Staff give us time to decide</td>
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Data from Hinds et al.
Approximately 16% of CCS show symptoms of Post-traumatic Stress Disorder (PTSD) or Post-traumatic Stress Syndrome (PTSS). Most survivors report symptoms of re-experiencing traumatic aspects of their treatment. Survivors with PTSD report more psychological problems and negative beliefs about illness. For young-adult survivors of childhood cancer, PTSD is four times greater compared with siblings. It may be that symptoms emerge as they deal with developmental tasks of young adulthood. Predictors of PTSD in young-adult survivors include intensity of treatment and receiving cranial radiotherapy at younger ages. Lower education, employment, and income levels, and being unmarried have also been shown to increase the risk of PTSD.

Rates of PTSD in families of CCS range between 5% and 25%, with higher rates when including PTSS. Rates of PTSD/PTSS are higher than those who never had a child with cancer, with 99% of families reporting one parent who meets the PTSD criteria of re-experiencing; 20% have at least one parent with current PTSD. One intervention that has shown efficacy in reducing PTSD and Acute Stress Disorder in families of newly diagnosed children is the Surviving Cancer Competently Intervention Program–Newly Diagnosed (SCCIP-ND), which uses a three-session intervention with three booster sessions. This intervention focuses on identifying caregiver beliefs about cancer and its impact, changing beliefs to enhance family functioning, and focusing on family growth and future goals.

**Psychosocial Interventions**

Interventions for family caregivers of children with cancer are beginning to be developed and tested for efficacy. In practice, pediatric oncology social workers, nurses, psychologists, and other health care providers have always offered psychosocial support, counseling, referral, and intervention to children with cancer and their families. However, in recent years, studies are being developed that hint at an evidence base for psychological interventions for families. Kazak found that the empirical evidence in psychosocial support of family caregivers has grown in the past few decades, and has focused on four key areas: 1) understanding procedural pain; 2) realizing long-term consequences; 3) appreciating distress at diagnosis and over time; and 4) knowing the importance of social relationships.

In a recent meta-analysis of randomized controlled trials in pediatric oncology caregiver intervention research, Northouse et al. found that in 29 clinical trials between 1983 and 2009, family caregivers received psycho-educational skills training and therapeutic counseling. Most interventions were delivered to caregivers in conjunction with their children, and most caregivers studied were female (64%) and Caucasian (84%). The simultaneous intervention may reflect the reality of parental caregiving in pediatrics, such that parents are usually present with their child. The demographics are consistent with other studies and do present the obvious need for increased research with fathers and ethnic minorities.

In this same analysis, Northouse et al. reported that the interventions, while small in effect, did seem to increase caregiver quality of life, coping, and self-efficacy, and reduced burden. Other recent studies since have demonstrated efficacy in the reduction of depression, anxiety, and PTSD, and improvement of well-being, hardiness, and mood, utilizing a range of interventions including problem-solving, psycho-education, reflection, care planning, information and support. See Northouse et al. for an exhaustive listing of studies in the past two decades.

While intervention research for family caregivers of pediatric patients is growing, more is needed to understand how best to support families facing the diagnosis, treatment, and survivorship of their child. Particularly understudied are ethnic minorities, fathers, and diverse family structures, such as same-sex, single, or foster/adoptive families. Also, more research is needed in pediatric palliative care and long-term survivorship.

**Parent Caregivers and Future Directions**

Parents want to provide the best care possible for their child but face incredible stress and burden as they attempt to do so. Parents want to make decisions that will both help their child and reinforce their perception of themselves as a “good parent.” Decision-making must be shared between parents and providers to best support both parents and children, especially at the end of life. Parents undergo an identity transition when becoming the parent of a child with cancer, which often involves being an advocate for their child beginning at diagnosis. Parents want to
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receive comprehensive information from their health care team and want to be listened to and respected throughout the treatment process and beyond. There is evidence that families experience both burden and growth as they care for their child with cancer. Siblings are particularly understudied and may experience long-term negative effects of having a brother or sister with cancer.

There is a need for both practice-informed research and research-based practice in care for family caregivers of children with cancer. Specifically, research is needed that focuses on understudied and vulnerable groups (such as families of children with brain tumors, economically disadvantaged, ethnic or spiritual minorities, diverse family structures, fathers, and children and families who are facing end-of-life or long-term survival).5,20,31,34

Parental caregivers of children with cancer experience significant caregiver burden and distress while caring for their sick child and trying to maintain family equilibrium. Families also demonstrate incredible resilience and potential for positive growth in the face of their children’s illness. Health care practitioners need to offer evidence-based strategies that have the potential to foster family resilience and quality of life.

REFERENCES


