Parenting a Child with Cancer

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ABSTRACT
Childhood cancer impacts the family system, drastically changing the context within which parenting occurs. Parents of children diagnosed with cancer are profoundly influenced by their child's diagnosis and associated treatment demands at a time completely out of sync with the broader family developmental cycle. This review synthesizes literature examining the impact of childhood cancer on parent psychological well-being, as well as parental roles and reciprocal influences on the ill child's adjustment and development. Potential differences between mothers, fathers, and families of diverse composition are highlighted; the impact of childhood cancer on the spousal/partner relationship, the parent-child relationship, parenting style, and the potential for both parents and children to find benefit from the childhood cancer experience is also highlighted. Research examining parent and child adjustment to childhood cancer within the broader family system remains an important area of study if we are to support such families to better cope long term.

RÉSUMÉ
Le cancer chez l'enfant a des répercussions sur le système familial, ce qui change de façon dramatique le contexte au sein duquel se déroule le parentage. Les parents des enfants diagnostiqués d'un cancer sont profondément influencés par le diagnostic de leur enfant et les exigences des traitements qui lui sont associées désynchronise complètement le cycle de développement de la famille plus large. La présente étude passe en revue la littérature ayant pour objet l'impact du cancer de l'enfant sur le bien-être psychologique des parents, ainsi que les rôles parentaux et les influences réciproques sur l'ajustement et le développement de l'enfant malade. Des différences potentielles entre les mères, les pères et les familles de diversement constituées sont mises en lumière; de plus, l'examen de l'impact du cancer de l'enfant sur la relation conjoint/partenaire, la relation parent-enfant, le style de parentage et la possibilité que les parents et l'enfant trouvent un aspect positif dans l'expérience du cancer de l'enfant. La recherche qui se penche sur l'ajustement parent et enfant au cancer au sein d'un système familial large demeure un domaine important d'étude si nous voulons appuyer ces familles pour mieux s'ajuster à long terme.

According to the Canadian Cancer Society (2008), approximately 850 Canadian children under 14 years of age will develop cancer each year. When a child is diagnosed with cancer, it can become the central focus of the family system, with a pervasive and stressful impact on all family members, including parents (Bayat, Erdem, & Kuzucu, 2008) and healthy siblings (Houtzager et al., 2004). Given that the majority of childhood cancer patients survive into adulthood (i.e., approximate survival rate of 82%; Canadian Cancer Society, 2008), parents continue to be formative in the ill child's development. This review synthesizes research on the impact of childhood cancer on parents, as well as parental roles and influences on the ill child's adjustment and development. It focuses on issues of parenting during active treatment for the child's cancer and into survivorship; it is unable to adequately discuss important and related issues of parental involvement and coping with end-of-life care or adjustment to the loss of a child to cancer (see Kars et al., 2011 and McCarthy et al., 2010 for recent research).

Parent Psychological Adjustment

Parenting a child with cancer is very distressing, with parents reporting a sense of loss of control, uncertainty, anxiety, depression, sleep disturbance, and lowered self-esteem (Boman, Lindahl, & Bjork, 2003). Poorer parental well-being is associated with poorer child well-being (e.g., behavior problems, child depression and anxiety) and clinical factors of the child's disease (e.g., currently in active treatment, poorer prognosis for the child, more hospitalizations; Klassen et al., 2007). Parents describe their experience immediately following the child's cancer diagnosis as particularly distressing, characterized by fear, sadness, grief, loneliness, and dependence on others (Bjork, Wiebe,

& Hallstrom, 2005; Fornider & Norberg, 2010). Parents report feeling governed by their child's disease, with lengthy hospitalizations taxing the family system by removing the child from the home when support is most needed (Miller & Janosik, 1980), while simultaneously reducing parents' opportunities to work and increasing financial strain (Enskar et al., 1997). This experience reflects a fundamentally changed view of the world, drastically altering the conditions within which parenting occurs (Fornider & Norberg, 2010).

Six categories of supportive care needs are outlined throughout the cancer journey (i.e., practical, spiritual, psychosocial, informational, emotional, physical; Fitch, 1994), with the highest percentage of parents identifying emotional and informational support as most critical (e.g., wanting a full understanding of child's treatment and procedures, and coping with fears about cancer spreading or the child's wellbeing; Kerr et al., 2007). Despite increasing effort to support families dealing with childhood cancer (e.g., parental guide; Canadian Cancer Society, 2009), parents continue to report many unmet supportive care needs (Mitchell, Clarke, & Sloper, 2006).

Research suggests possible differences between mothers' and fathers' experiences of parenting a child with chronic illness (Jones et al., 2010), with mothers reporting greater stress, particularly regarding childcare and parental tasks, and risk for emotional distress (Pelchat, Lefebvre, & Levert, 2007). Mothers report a sense of obligation to remain physically near their child (e.g., staying with them in hospital; Young, Woods, Findlay, & Heney, 2002) and an increase in responsibility in helping the child to manage their illness and treatment, providing both emotional and practical support. Mothers' heightened management of day-to-day tasks for the ill child can bring additional strain and impaired functioning in other familial relationships (i.e., with other children and partners; Young et al., 2002) and shifting of roles (i.e., disequilibrium) within the family system (Miller & Janosik, 1980).

Investigations have recently examined the role of fathers in childhood cancer. Fathers recount trying to regain control of the family's situation and striving for normalization by actively engaging in practical daily activities, minimizing the impact of the illness, and encouraging the family's re-engagement in everyday life (Hill, Higgins, Dempster & McCarthy, 2009). Fathers also describe "maternal gate-keeping" where their involvement in caring for the ill child is frequently peripheral, largely dictated by the mother's preferences and reinforced by the medical team. Despite dissatisfaction with this peripheral role, fathers perceive themselves as having significant responsibility in helping their family to cope (Hill et al., 2009; Jones et al., 2010). Parents' differing experiences of their child's cancer may, in part, arise from attempts to fulfill traditional family roles, and by the differences in how mothers and fathers relate to their ill child (Pelchat et al., 2007).

Impact on Spousal/Partner Relationship

Childhood cancer poses an atypical stressor for parents given the stage of the family's life cycle, bringing additional challenges at a time of typical significant family change (Pelchat et al., 2007). Parents adjust their relationship to make space for young children and are fulfilling new parenting roles (Carter & McGoldrick, 1999). Evidence is mixed regarding whether parents of a child with cancer experience greater marital dissatisfaction as compared to couples with healthy children (Dahlquist et al., 1993). Greater marital distress was observed among parents with highly discrepant levels of anxiety regarding the child's cancer and who used coping strategies that focused intently on the child's cancer (Dahlquist et al., 1993). However, parents of a child with cancer do not appear to be at greater risk for divorce (Syse, Loge, & Lyngstad, 2010).

Parents of children with cancer reveal greater togetherness and less marital strain during the most strenuous times of their child's cancer with increased difficulty during more restful periods (Enskar et al., 1997). Other research suggests that marital distress is most prominent immediately following diagnosis when parents are separated during the child's frequent and lengthy hospital stays (Lavee & Mey-Dan, 2003). It may be that parental roles require continual re-evaluation and adjustment as the stressors evolve throughout the cancer journey (i.e., diagnosis to treatment to survivorship), placing increasing and ever changing demands on the family (Miller & Janosik, 1980). Regardless, mutual spousal support appears important for both members of the couple (Pelchat et al., 2007).

Role of Family Composition

To date, research in childhood cancer has focused primarily on two-parent families. However, a number of children with cancer are embedded within single parent or blended/stepparent family homes. Single parents may experience increased burden caring for the ill child, greater financial stress, and may have generally fewer resources from which to draw upon (Brown et al., 2008). Single mothers appear more depressed, although they do not report higher levels of posttraumatic stress or using different problem-solving strategies (Iobst et al., 2009). However, pediatric cancer survivors from single parent homes appear to be at increased risk for behavioural problems (Brown et al., 2008). Given the inherent shifting of family structure boundaries facing stepfamilies, they may face unique challenges and potential sources of conflict when dealing with childhood cancer (Kelly & Ganong, 2011).

Impact on Parenting and the Parent-Child Relationship

The parent-child relationship is likely altered as a result of their shared experience with childhood cancer. Chronic illness disrupts the typical parent-child attachment process (Odegard, 2005) as repeated hospitalizations simultaneously exacerbate and challenge attachment needs (Goldberg, 2000). Parents' ability to support developing child autonomy can become impaired by increases in child and parent anxiety, substantial continued parental involvement due to the child's illness and treatment, as well as continued dependency on clinicians (Odegard, 2005). Despite desiring autonomy, adolescents with a life-threatening illness, such as cancer, rely more on their parents for support, consequently limiting their opportunities for peer interaction and relationship development (Knapp et al., 2010).

Differences in parenting have been observed between parents of healthy children and parents of children with cancer. Parents report greater worry about their child's health, a tendency to be overprotective, allow less independence, are more lenient in disciplining, and perceive their child to be vulnerable (Hillman, 1997), often resulting in less parental attention for other healthy siblings (Forinder & Norberg, 2010). However, the greater the time since diagnosis, the more closely parenting appears to approximate that of healthy families (Hillman, 1997). This may be due to parents' developed knowledge and use of effective strategies, as well as a greater sense of mastery, for managing their child's health condition over time (Klassen et al., 2007). More research is needed to understand potential differences in parenting as survivors of childhood cancer have higher levels of depression and anxiety, and display more antisocial behaviours and deficits in attention, as compared to their healthy siblings (Schultz et al., 2007). Parenting style is relevant to treatment outcomes as children with cancer whose parents have a "supportive" style (e.g., seek child input, are nonrestrictive and nurturing) are more likely to attend all treatment appointments and are quicker to report adverse treatment reactions (Manne et al., 1993).

Impact of Parents on Child Adjustment

Parents' experience of the child's cancer significantly impacts child adjustment, as parent and child distress are strongly related (Robinson, Gerhardt, Vannatta, & Noll, 2007). Positive parental coping, family support, and quality of the parents' relationship are associated with better outcomes for the child (Suzuki & Kato, 2003). Parents experience a variety of caregiver demands, such as physical and emotional care of the child, financial management, maintenance of family roles, and communication with the child's care team. Increased caregiver demands are associated with poorer child adjustment (Wolfe-Christensen et al., 2010). Children exhibit fewer internalizing problems when parents report low parenting stress, despite high caregiver demand (Wolfe-Christensen et al., 2010). Higher levels of parenting stress and overprotection are related to later internalizing and behavioural problems for the child (Fedele et al., 2011). Parental uncertainty regarding the child's illness (e.g., greater fears of death, unpredictable treatment side effects and late effects, and interruptions in school and peer relationships) has been associated with higher child uncertainty and increases in child anxiety and depression (Stewart, Mishel, Lynn, & Terhorst, 2010).

Potential Resources for Families Dealing with Childhood Cancer:

Canadian Cancer Society (2009). Childhood Cancer: A guide for families. Toronto, Canada.
Canadian Cancer Society: www.cancer.ca
Childhood Cancer Canada: www.childhoodcancer.ca
Children's Oncology Group: www.childrensoncologygroup.org
American Childhood Cancer Organization: www.acco.org
Cure Search: www.curesearch.org
Local children's hospitals typically have a list of recommended resources available to families dealing with childhood cancer.

Parents' decisions around what and how to communicate with their child about the cancer can also influence the child's experience. Honest and direct communicate between parents and children about the child's cancer diagnosis and prognosis, is associated with better child adjustment, less distress, higher social competence, and closer parent-child relationships (Suzuki & Kato, 2003). Furthermore, parents play a pivotal role in encouraging their cancer-surviving children to maintain healthy lifestyles to counteract late treatment effects (e.g., physical activity; Norris, Moules, Pelletier, & Culos-Reed, 2010).

Family Resiliency and Ability to Find Benefit

Although childhood cancer is undoubtedly a traumatic experience, research suggests that childhood cancer survivors and their parents report some ability to find benefit from the cancer experience (referred to as posttraumatic growth; Barakat, Alderfer, & Kazak, 2006). Childhood cancer survivors and their parents were more likely to report post-traumatic growth when the child was older at the time of diagnosis and when greater life threat and treatment intensity were perceived. Most often they report positive changes regarding how they think about their lives, their plans for the future, and how careful they are (Barakat et al., 2006). After experiencing childhood cancer, parents recount renewed strength, improved communication, trust, conflict resolution, and mutual support in the spousal relationship (Brody & Simons, 2007; Lavee & Mey-Dan, 2003). Families engage in behaviours and attitudes geared towards mending their broken lives soon after the shock of the initial diagnosis has subsided (i.e., "striving to survive"; Bjork et al., 2005). These efforts to cope positively include feelings of hope and optimism, and actions intended to help the family regain closeness with others and control over their lives.

These findings are consistent with the family resilience framework, which emphasizes strengths that contribute to the well-functioning family unit and offers the possibility for positive family growth after a difficult experience (Walsh, 2003). Identified resiliency factors include the rapid mobilization and reorganization of the immediate family to the initial diagnosis, prolonged hospitalizations, ability to recognize both positive and negative impacts (McCubbin et al., 2002), and support from various systems surrounding the family (i.e., child's oncology team, extended family, community, parents' workplace; McCubbin et al., 2002). Parents with lower social support are more likely to report feeling hopeless and depressed (Bayat et al., 2008). Informal support from parents of other children with cancer may be particularly helpful, as parents report that many individuals outside of the family do not understand the experience and the impact on the entire family (Hill et al., 2009).

Conclusion

The impact of childhood cancer on families is far-reaching, dramatically altering the manner in which the family system functions. Parents experience substantial distress and their roles within the family, both marital and parental, must adjust. Parents' distress influences the ill child's adjustment and can lead to strain within the marital relationship. Mothers and fathers appear to perceive and manage their child's cancer differently and changes in parenting are observed as the ill child is seen as vulnerable and in need of greater protection. Although these differences in parenting may lead to later child behavioural and psychological difficulties, parents and children identify potential benefits arising from the cancer experience. The ability of families to respond with such resiliency in the face of challenge is something all families can foster when facing difficult situations. Areas highlighted for future research, include the potential differential experience of single-parent and blended/stepparent families, differences in parenting between healthy children and those with cancer, as well as when and how to best support parents throughout the cancer journey. Additionally, families from minority groups remain underrepresented in this area of research overall. Research examining familial factors in childhood cancer remains an important area of study if we are to support such families to better cope long term.

References

Barakat, L.P., Alderfer, M.A., & Kazak, A.E. (2006). Posttraumatic growth in adolescent survivors of cancer and their mothers and fathers. *Journal of Pediatric Psychology, 31*(4), 413-419.

Bayat, M., Erdem, E., & Kuzucu, E.G. (2008). Depression, anxiety, hopelessness, and social support levels of the parents of children with cancer. *Journal of Pediatric Oncology Nursing, 25*(5), 247-253.

Bjork, M., Wiebe, T., & Hallstrom, I. (2005). Striving to survive: Families' lived experiences when a child is diagnosed with cancer. *Journal of Pediatric Oncology Nursing*, 22(5), 265-275.

Boman, K., Lindahl, A., & Bjork, O. (2003). Disease-related distress in parents of children with cancer at various stages after the time of diagnosis. *Acta Oncologica, 42*(2), 137-146.

Brody, A.C. & Simons, L.A. (2007). Family resiliency during childhood cancer: The father's perspective. *Journal of Pediatric Oncology Nursing*, 24, 152-165.

Brown, R.T. et al. (2008). Single parents of children with chronic illness: An understudied phenomenon. *Journal of Pediatric Psychology*, 33(4), 408-421.

Canadian Cancer Society (2009). *Childhood Cancer: A guide for families.* Toronto, Canada.

Canadian Cancer Society/National Cancer Institute of Canada (2008). *Canadian Cancer Statistics.* Toronto, Canada.

Carter, B. & Mc Goldrick, M. (1999). Overview: The expanded family life cycle: Individual, family, and social perspectives. In B. Carter & M. McGoldrick (Eds.), *The expanded family life cycle: Individual, family, and social perspectives, 3rd Edition.* (pp.1-26). Boston, MA: Allyn and Bacon.

Dahlquist, L.M., Czyzewski, D.I., Copeland, K.G., Jones, C.L., Taub, E., & Vaughn, J.K. (1993). Parents of children newly diagnosed with cancer: Anxiety, coping, and marital distress. *Journal of Pediatric Psychology, 18*(3), 365-376.

Enskar, K., Carlsson, M., Golsater, M., Hamrin, E., & Kreuger, A. (1997). Parental reports of changes and challenges that result from parenting a child with cancer. *Journal of Pediatric Oncology Nursing, 14*(3), 156-163.

Fedele, D.A., Mullins, L.L., Wolfe-Christensen, C., & Carpentier, M.Y. (2011). Longitudinal assessment of maternal parenting capacity variables and child adjustment outcomes in pediatric cancer. *Journal of Pediatric Hematology & Oncology*, 33(3), 199-202.

Fitch, M.I. (1994). *Providing supportive care for individuals living with cancer.* Toronto, Canada: Ontario Cancer Treatment and Research Foundation.

Forinder, U. & Norberg, A.L. (2010). "Now we have to cope with the rest of our lives". Existential issues related to parenting a child surviving a brain tumor. *Supportive Care Cancer, 18,* 543-551.

Goldberg, S. (2000). *Attachment and Development.* London, UK: Arnold Publishers.

Hill, K., Higgins, A., Dempster, M., & McCarthy, A. (2009). Fathers' views and understanding of their roles in families with a child with acute lymphoblastic leukaemia. *Journal of Health Psychology, 14*(8), 1268-1280.

Hillman, K.A. (1997). Comparing child-rearing practices in parents of children with cancer and parents of healthy children. *Journal of Pediatric Oncology Nursing, 14*(2), 53-67.

Houtzager, B.A., Oort, F.J., Hoekstra-Weebers, J.E.H.M., Caron, H.N., Grootenhuis, M.A., & Last, B.F. (2004). Coping and family functioning predict longitudinal psychological adaptation of siblings of childhood cancer patients. *Journal of Pediatric Psychology, 29*(8), 591-605.

Iobst et al. (2009). Brief report: Problem solving and maternal distress at the time of a child's diagnosis of cancer in two-parent versus lone-parent households. *Journal of Pediatric Psychology, 34*(8), 817-821.

Jones, B.L., Pelletier, W., Decker, C., Barczyk, A., & Dungan, S.S. (2010). Fathers of children with cancer: A descriptive synthesis of the literature. *Social Work in Health* Care, 49, 458-493.

Kars, M.C., Grypdonck, M.H.F., de Korte-Verhoef, M.C., Kamps, W.A., Meijer-van den Bergh, E.M.M., Verkerk, M.A., & van Delden, J.J.M. (2011). *Supportive Care in Cancer, 19*(1), 27-35.

Kelly, K.P. & Ganong, L.H. (2011). "Shifting family boundaries" after the diagnosis of childhood cancer in stepfamilies. *Journal of Family Nursing, 17*(1), 105-132.

Kerr, L.M.J., Harrison, M.B., Medves, J., Tranmer, J.E., & Fitch, M.I. (2007). Understanding the supportive care needs of parents of children with cancer: An approach to local needs assessment. *Journal of Pediatric Oncology Nursing*, 24(5), 279-293.

Klassen, A., Raina, P., Reineking, S., Dix, D., Pritchard, S., & O'Donnell, M. (2007). Developing a literature base to understand the caregiving experience of parents of children with cancer: A systematic review of factors related to parental health and well-being. *Supportive Care in Cancer, 15*, 807-818.

Knapp, C., Quinn, G.P., Murphy, D., Brown, R., & Madden, V. (2010). Adolescents with life-threatening illnesses. *American Journal of Hospice & Palliative Medicine*, 27(2), 139-144.

Lavee, Y. & Mey-Dan, M. (2003). Patterns of change in marital relationships among parents of children with cancer. *Health & Social Work*, 28, 255-263.

Manne, S.L., Jacobsen, P.B., Gorfinkle, K., Gerstein, F., & Redd, W.H. (1993). Treatment adherence difficulties among children with cancer: The role of parenting style. *Journal of Pediatric Psychology, 18*(1), 47-62.

McCarthy, M.C., Clarke, N.E., Ting, C.L., Conroy, R., Anderson, V.A., &

Heath, J.A. (2010). Prevalence and predictors of parental grief and depression after the death of a child from cancer. *Journal of Palliative Medicine, 13*(11), 1321-1326.

McCubbin, M., Balling, K., Possin, P., Frierdich, S., & Bryne, B. (2002). Family resiliency in childhood cancer. *Family Relations, 51*(2), 103-111.

Miller, J.R. & Janosik, E.H. (Eds.) (1980). *Family-Focused Care*. New York, NY: McGraw-Hill Book Company.

Mitchell, W., Clarke, S., & Sloper, P. (2006). Care and support needs of children and young people with cancer and their parents. *Psycho-Oncology, 15*, 805-816.

Norris, J.M., Moules, N.J., Pelletier, G., & Culos-Reed, S.N. (2010). Families of young pediatric cancer survivors: A cross-sectional survey examining physical activity behavior and health-related quality of life. *Journal of Pediatric Oncology Nursing, 27*(4), 196-208.

Odegard, W. (2005). Chronic illness as a challenge to the attachment process. *Clinical Child Psychology & Psychiatry, 10*(1), 13-22.

Pelchat, D., Lefebvre, H., & Levert, M.-J. (2007). Gender differences and similarities in the experience of parenting a child with a health problem: Current state of knowledge. *Journal of Child Health Care, 11*(2), 112-131.

Robinson, K.E., Gerhardt, C.A., Vannatta, K., & Noll, R.B. (2007). Parent and family factors associated with child adjustment to pediatric cancer. *Journal of Pediatric Psychology, 32*(4), 400-410.

Schultz, K.A.P., Ness, K.K., Whitton, J., Recklitis, C., Zebrack, B., Robison, L.L., Zeltzer, L., & Mertens, A.C. (2007). Behavioral and social outcomes in adolescent survivors of childhood cancer: A report from the childhood cancer survivor study. *Journal of Clinical Oncology, 25*(24), 3649-3656.

Stewart, J.L., Mishel, M.H., Lynn, M.R., & Terhorst, L. (2010). Test of a conceptual model of uncertainty in children and adolescents with cancer. *Research in Nursing & Health, 33*, 179-191.

Suzuki, L.K. & Kato, P.M. (2003). Psychosocial support for patients in pediatric oncology: The influences of parents, schools, peers, and technology. *Journal of Pediatric Oncology Nursing*, 20(4), 159-174.

Syse, A., Loge, J.H., & Lyngstad, T.H. (2010). Does childhood cancer affect parental divorce rates? A population-based study. *Journal of Clinical Oncology, 28*(5), 872-877.

Walsh, F. (2003). Family resilience: A framework for clinical practice. *Family Process, 42*(1), 1-18.

Wolfe-Christensen, C., Mullins, L.L., Fedele, D.A., Rambo, P.L., Eddington, A., & Carpentier, M.Y. (2010). The relation of caregiver demand to adjustment outcomes in children with cancer: The moderating role of parenting stress. *Children's Health Care, 39*, 108-124.

Young, B., Dixon-Woods, M., Findlay, M., & Heney, D. (2002). Parenting in a crisis: Conceptualising mothers of children with cancer. *Social Science & Medicine, 55*, 1835-1847.