Effects of Pediatric Cancer on the Family: An Evidence Based Practice Analysis

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Abstract

The diagnosis of cancer in a child is a traumatic experience for both the ill child and the family. Childhood cancer involves the whole family: the child, parents, and the siblings (Peek & Melnyk, 2010, p. 306). There has been a great deal of research into how cancer affects the diagnosed child and physical and psychosocial health of the child. However, there has been far less research into how cancer affects the parents and siblings of the child and there is often little attention paid to the psychosocial wellbeing of the family. The purpose of this paper is to examine how cancer affects the family members of the diagnosed child. Included are recommendations to utilize the evidence to improve the psychosocial wellbeing of the family.

*Keywords:* pediatric cancer; mothers; siblings; psychosocial adjustment; evidence
Effects of Pediatric Cancer on the Family: An Evidence Based Practice Analysis

Pediatric cancers affect approximately 14,000 children in the United States each year (Alderfer et al., 2010, p. 789). Extensive research and advances in medicine have greatly improved the outcomes of many children diagnosed with cancer. “Increasingly complex and intensive treatments have led to five-year survival rates just over 80% across cancer types” (Alderfer et al., 2010, p. 789). Being cured of cancer has been defined as extending beyond biological/physical outcomes to include health within social, emotional, and psychosocial domains (Alderfer et al., 2010, p. 789).

The diagnosis of cancer is a traumatic experience for both the child and the family (Peek & Melnyk, 2010, p. 306). Life changes for them in one instant, in one conversation with a physician. The family goes from a life of healthiness to one of an uncertain future. “Childhood cancer involves the whole family: the diagnosed child, the parents, and the siblings” (Peek & Melnyk, 2010, p. 306). Families of children with cancer face increased responsibilities in caring for the child’s needs in addition to caring for other family members during the diagnosis and treatment periods (Fletcher, 2010, p. 164). All parents must try to maintain some sense of normalcy for the family, while at the same time trying to cope with the intense feelings involved in dealing with the diagnosis of cancer in a child. Parents often experiences feelings of anger, fear, guilt, and grief as well as some marital conflict. Siblings of the child diagnosed with cancer must also cope with a variety of feelings such as fear, isolation, jealousy, and guilt (Sidhu, Passmore, & Baker, 2006, p. 580). “Changes in family routines and roles may disrupt day-to-day functioning of siblings, with some siblings assuming more household chores and responsibilities” (Alderfer et al., 2010, p. 790). These changes occur while siblings are
witnessing physical changes in their brother or sister and worrying that he or she will die (Alderfer et al., 2010, p. 790).

Often, when a child is diagnosed with cancer, there is so much focus on the treatment and well-being of the child that the effect of the diagnosis on the rest of the family is given very little attention. The aim of this paper is to provide an evidence based analysis of the literature on the effects of pediatric cancer on the family.

**Descriptions of Research Articles**

**Article One**

The first article reviewed, “My Child has Cancer: The Costs of Mothers’ Experiences of Having a Child with Pediatric Cancer”, is an exploratory research article to examine the experiences of female caregivers of children with cancer during diagnosis, treatment, and the period thereafter (Fletcher, 2010, p. 164). Paula C. Fletcher, PhD (2010) explains that the effects of childhood cancer are devastating for both the child and the family members involved in the child’s life (p. 164). Having a child with cancer is one of the most stressful experiences a family can endure. Families must confront the costs resulting from their experiences with cancer not only of the financial realm, but they must also deal with emotional, physical, social, and spiritual costs (Fletcher, 2010, p. 165). Fletcher (2010) further discusses that there is limited research in the area of costs incurred by the family of children with cancer and existing studies have typically focused on the financial costs (p. 165). The purpose of this exploratory research was to examine the experiences of female care providers of children with cancer, specifically the costs related to all aspects of one’s life in caring for these children (Fletcher, 2010, p. 165). The study analyzed data collected for the period during diagnosis, treatment, and the time after treatment (Fletcher, 2010, p. 165).
Methodology.

Participant recruitment.

Purposive sampling, a strategy which emphasizes the use of individuals who are knowledgeable about the topic at hand, was used to identify participants for the study (Fletcher, 2010, p. 166). The inclusion criteria of the original study was: 1) female at least 16 years of age; 2) a relative of a child under the age of 17 treated for cancer in the past 5 years or a health care worker who works with families of children with cancer; and 3) involved in the care of the child with cancer (Fletcher, 2010, p. 166). Nine mothers and three health care workers volunteered, however the health care workers were excluded from the analyses due to the inability to offer much personal insight into the costs experienced by the family (Fletcher, 2010, p. 166).

Procedure.

The study was explained to the potential participants via phone or email and after consenting to participate, information letters and consent forms were sent to the participants via email along with a background questionnaire (Fletcher, 2010, p. 166). The questionnaire, which was used to guide a face-to-face or telephone interview, contained questions related to socio-demographic information, relationship to the child with cancer, and information about the child’s cancer (Fletcher, 2010, p. 166). The questions posed to the mothers during the interviews focused on the following: description of the child’s diagnosis and treatment, care and assistance provided by the family, benefits and costs associated with diagnosis, and coping mechanisms (Fletcher, 2010, p. 167).

Data analysis.

The theoretical orientation used to guide the analysis of data was phenomenology (Fletcher, 2010, p. 167). “Phenomenology investigates how human beings make sense of,
experience and transform experiences into consciousness, both individually and as shared meaning” (Fletcher, 2010, p. 167). After the data were collected, a critical content analysis was conducted for the sources of data. The data were analyzed independently by the investigators who then met to discuss emerging themes within the data (Fletcher, 2010, p. 168).

Results.

The nine mothers that participated in the study ranged in age from 32 to 47 and all were either married or in common-law relationships (Fletcher, 2010, p. 168). The ages of the children at diagnosis ranged between 9 months and 16 years of age (Fletcher, 2010, p. 168). At the time of the study, only one child was receiving treatment and four had died (Fletcher, 2010, p. 169). The mothers discussed the costs that they incurred during the diagnosis, treatment, and the period after the treatment. The themes related to costs included: financial and work issues, health of family, upheaval of family life, and a lost life (for the mothers of the children who passed away) (Fletcher, 2010, p. 169).

The financial and work situation for all of the mothers was affected in some way. They had to alter their work schedules, take unpaid leaves of absence, and/or quit their jobs in order to care for their child with cancer (Fletcher, 2010, p. 169). Most of the women said that their financial situations were still tenuous despite some of them receiving assistance from various sources (Fletcher, 2010, p. 170). While the financial and work situations were not the same for all of the women, the diagnosis of cancer affected every family to some extent, with many of them still trying to “get back on their feet” (Fletcher, 2010, p. 170).

Another cost resulting from a child being diagnosed with cancer that the mothers discussed was the health implication for the other family members. They talked about the physical and psychological health issues that they incurred during the diagnosis and treatment
phases of their children (Fletcher, 2010, p. 171). The mothers discussed issues such as weight loss and gain, difficulties sleeping, headaches and back pain, and overwhelming stress and anxiety while their children were being treated. They also talked about the lack of time to attend to their own health and having to let health issues go untreated (Fletcher, 2010, p. 172). The mothers of the children who had already completed treatment discussed the physical and psychological health issues that persisted such as gastrointestinal problems, anxiety, and fear of relapse (Fletcher, 2010, p. 173).

All of the mothers discussed how their child’s diagnosis of cancer affected the lives of the entire family. They explained how life had to be rearranged to care for the child with cancer such as the significant amounts of time that were spent taking them to medical appointments (Fletcher, 2010, p. 175). The mothers talked about being physically separated from family when they stayed in the hospital with their children (Fletcher, 2010, p. 176). They also explained the effects of the child’s diagnosis of cancer on their marriages and how it created tension and placed huge strains on the marriage (Fletcher, 2010, p. 176). Another common problem that the mothers discussed was the lack of time for the other children and the difficulties of trying to maintain normalcy for the siblings (Fletcher, 2010, p. 177).

Fletcher (2010) explains that the ultimate cost was faced by four of the mothers that were interviewed; the loss of their children to the cancer (p. 178). These four mothers discussed the grief that accompanied the death of their children and the overwhelming anguish that they feel. They also talked about the how the death has affected the sibling of the child (Fletcher, 2010, p. 179). “The death of a child and the accompanying grief is undeniably the greatest cost endured by mothers and other family members” (Fletcher, 2010, p. 180).
Discussion.

The study, based on the narratives of the nine mothers of children with cancer, revealed the existence of four costs resulting from their children’s cancer (Fletcher, 2010, p. 181). The three costs that were evident among all of the women were: financial and work issues, health of the mothers and other family members, and the upheaval of family life. The fourth theme, a lost life, only affected the women who had lost a child to cancer (Fletcher, 2010, p. 181).

Fletcher (2010) explained that previous research was utilized to support the theme of financial and work issues and findings reported that a significant burden is placed on families facing a diagnosis of pediatric cancer (p. 182). In the review of literature, it was found that parents who lived farthest away from the treatment centers reported the highest expenses along with those whose children had extensive treatment times (Fletcher, 2010, p. 182). It was also suggested in the review of literature that costs would potentially affect the daily lives of the children with cancer (Fletcher, 2010, p. 182). It was argued that the inclusion of the views of children with cancer in the research process was necessary to truly depict the influence of cancer on their lives (Fletcher, 2010, p. 182). Fletcher (2010) concluded her discussion of the study by expressing that more research is needed into the costs that all members of the family encounter throughout the cancer journey in order to lobby for alterations in the healthcare system (p. 183).

Limitations.

Fletcher (2010) states that several limitations need to be addressed concerning this study (p. 183). The first issue is that the experiences reflect the views of just the mothers and information from other members of the family would provide more detailed information about the specific experiences of each person involved (Fletcher, 2010, p. 183). It is also pointed out that the mothers in this study may not represent the experiences of all mothers of children with
cancer and furthermore, the retrospective nature of the study may have hindered the mothers’ abilities to recall the specifics surrounding their experiences (Fletcher, 2010, p. 182).

**Article Two**

The second article that I reviewed, “Psychosocial adjustment of siblings of children with cancer: a systematic review”, aims to promote an understanding of the psychosocial impact of childhood cancer on siblings (Alderfer et al., 2010, p. 789). Research has been done regarding the psychosocial effects of cancer for parents and review of literature have indicated that parents show increased distress and some marital conflict within the year after diagnosis. However, the impact of childhood cancer on healthy siblings is less clear (Alderfer et al., 2010, p. 789). Alderfer et al. (2010) explain that siblings of children with cancer may experience emotional consequences as a result of their brother’s or sister’s illness (p. 790). There are several factors that play a part in the emotional distress of siblings. Parents are often physically and emotionally unavailable for the siblings due to the need for at least one parent to attend to the ill child (Alderfer et al., 2010, p. 790). The authors further discuss that there are changes in family routines which may disrupt the day-to-day functioning of the siblings often resulting in the siblings assuming more chores and responsibilities (Alderfer et al., 2010, p. 790). These changes may result in the limiting of after-school or social activities. In addition to these changes, the siblings are witnessing physical changes in the brother or sister and worrying that he or she will die (Alderfer et al., 2010, p. 790).

The authors of this article discuss previous literature reviews regarding siblings of children with cancer. In 2005, a review of qualitative research summarized 27 studies published between 1979 and 2004 (Alderfer et al., 2010, p. 790). The reviews revealed three themes: 1) tremendous change within the lives of the siblings, including losses and gains; 2) intense
feelings; and 3) unmet sibling needs (Alderfer et al., 2010, p. 790). The authors noted shortcomings in the previous reviews such as diffuse findings and the adherence to specific qualitative research designs (Alderfer et al., 2010, p. 790). These past reviews called for a more thorough research methodology. The authors have undertaken a new systematic review of the literature which includes work from several disciplines, including medicine, psychology, and nursing and integrates finding from qualitative and quantitative studies (Alderfer et al., 2010, p. 790). Five broad topics related to the psychosocial adjustment of siblings are summarized in the review: psychological adjustment, family functioning, social/school adjustment, somatic issues and resilience/growth (Alderfer et al., 2010, p. 790). The authors also attempted to examine the relationships of adjustment and time since diagnosis, developmental level of sibling, and gender (Alderfer et al., 2010, p. 790).

**Method.**

The authors explain that they adhered to the strict scientific methodology of systematic review in order to guarantee comprehensiveness, minimize biases, and ensure reliability of their conclusions (Alderfer et al., 2010, p. 790). The methodology included “careful planning of the scope of the review, upfront specification of research questions, thorough literature searching and data extraction, evaluation of research quality, synthesis of findings, and distillation of implications” (Alderfer et al., 2010, p. 790).

**Literature search.**

The authors performed both computerized and manual searches to identify relevant articles. Titles and abstracts of each identified paper were independently screened by two reviewers. The reviewers included five doctoral level professionals and a psychology graduate student (Alderfer et al., 2010, p. 791). The manuscripts that were included need to meet these
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criteria: 1) be empirical; 2) examine siblings of children with cancer; 3) include interpretable data; and 4) report outcomes relevant to psychosocial adjustment (Alderfer et al., 2010, p. 790). After reviewing the articles and determining if criteria were met, 65 papers were rated with findings extracted (Alderfer et al., 2010, p. 792).

Of the 65 papers reviewed, 37 of them were quantitative, 22 of them used qualitative methods, and just 6 of them used mixed-methods designs (Alderfer et al., 2010, p. 792). There was a broad age range of siblings that were studied, including preschoolers through adults. Across the studies, time since cancer diagnosis ranged from a few weeks to 30 years post-treatment (Alderfer et al., 2010, p. 792).

Results.

Psychological functioning of siblings of children with cancer.

The majority of the studies provided data regarding psychological functioning of siblings, assessing clinical levels of emotional and behavioral maladjustment, anxiety, depression, symptoms of post-traumatic stress, quality of life, and emotional functioning (Alderfer et al., 2010, p. 792). Overall, it was found that siblings of children with cancer do not experience elevated levels of psychiatric symptoms such as behavioral problems, anxiety disorders, or depression (Alderfer et al., 2010, p. 796). There were, however, elevated percentages of siblings that fell into the at risk ranges of these areas. The authors further explained that a significant subset experiences negative emotional reactions, a lack of positive emotions, and cancer-related post-traumatic stress (Alderfer et al., 2010, p. 796).

Family functioning related to siblings of children with cancer.

There were twenty-eight studies addressing the family context of siblings of children with cancer with most of them being qualitative in nature (Alderfer et al., 2010, p. 797). The findings
revealed in the studies included themes relevant to siblings’ experiences of childhood cancer including: the loss of attention and status with the family, changes in family roles and relationships, and disruptions in normalcy and the sense of security a family typically provides (Alderfer et al., 2010, p. 797). Siblings also reported spending less time with their parents and feeling neglected, ignored, isolated, and lonely (Alderfer et al., 2010, p. 797).

School and social functioning of siblings of children with cancer.

There were twenty-four studies that addressed school and social functioning of siblings. The authors report that there were two primary themes that emerge regarding school: 1) disruption in school performance and behavior due to changes in routine, fatigue, worry, desire for attention, and wanting to be with their sibling with cancer; and 2) a need to be more independent and responsible regarding schoolwork (Alderfer et al., 2010, p. 797). Overall, school difficulties were documented in half of the studies (Alderfer et al., 2010, p. 799). There were also findings that reported decreased opportunities for social activities for the siblings and an increased need for support, such as transportation, to maintain friendships and social pursuits (Alderfer et al., 2010, p. 797). Overall, the authors report that the findings indicate that social problems were rarely reported and when they were it occurred closer to diagnosis (Alderfer et al., 2010, p. 797).

Somatic complaints of siblings of children with cancer.

There were nineteen studies that examined somatic complaints of the siblings. The overall finding indicated that in general, somatic complaints and physical functioning do not seem to differ greatly from other children; however, siblings in early childhood may be at risk for somatic distress within 2 years of diagnosis (Alderfer et al., 2010, p. 798).
Discussion.

Adoption of and adherence to theoretical models is the best way to gain a focused and detailed view of the cancer experience in an effort to advance this field (Alderfer et al., 2010, p. 801). The author’s research was guided by three primary models. They first found a post-traumatic stress framework useful in understanding the nature of both cancer-related distress and growth (Alderfer et al., 2010, p. 801). They explain this framework “accepts that cancer-related distress is a normal reaction to a potentially life threatening stressor” and “recognized feelings of fear, horror and helplessness; and symptoms such as intrusive thoughts, avoidance of anything cancer-related, and episodes of physiological arousal” (Alderfer et al., 2010, p. 801). The authors also utilize a family/systems model that considers the adjustment of the siblings during a time of family disorder caused by the diagnosis and treatment of cancer (Alderfer et al., 2010, p. 801). The final model that the authors have found useful is the developmental social ecology model. They explain that this model suggests that the characteristics of the child, such as gender and biological predispositions, help to partially determine the way in which he or she develops, but events occurring in his or her life and the social context in which he or she lives also shape development and adjustment (Alderfer et al., 2010, p. 801).

The authors discuss the quality of this systematic review of the psychosocial adjustment of sibling of children with cancer. They performed this review in a search for more relevant and substantial research regarding the siblings. According to the authors; “these calls have not been answered” (Alderfer et al., 2010, p. 799). They further explain that “the past ten years have shown few improvements in research in this topic area” (Alderfer et al., 2010, p. 799). It is noted that there are many potential reasons for this lack of improvement. The first reason is that childhood cancers are relatively rare compared to cancers of adults, therefore they receive less
research attention (Alderfer et al., 2010, p. 800). Secondly, most of the government and foundation research dollars are devoted to issues of cure rather than psychosocial issues (Alderfer et al., 2010, p. 800). Finally, the third reason is that psychosocial research regarding children with cancer has typically focused on patients and parents (Alderfer et al., 2010, p. 800). These barriers are making this a rather difficult area to study.

Despite the difficulties in the research of this topic, it is evident in the studies that are present that siblings of children with cancer do have psychosocial needs that should be recognized. The demands of caring for a child with cancer often limit the parents’ physical and emotional availability to fully meet the needs of the healthy children in the family (Alderfer et al., 2010, p. 802). The authors conclude by recommending that extended family, the oncology-care team, the siblings’ physician, school staff, and community members considers the needs of the siblings in addition to the needs of the family generally and the child with cancer (Alderfer et al., 2010, p. 802).

**Critical Appraisal of the Evidence**

**Article One**

The article written by Paula Fletcher, PhD examining the experiences of mothers of children with cancer is a fairly strong source of evidence to support my research on the topic of the effects of pediatric cancer on the family despite some limitations found in the study. In my appraisal of the evidence I will provide a brief critique of the article followed by the support for my conclusion that it is a strong source of evidence.

The introduction of the article provided excellent background into the issue of pediatric cancer and its effects on the family. The author clearly defines “costs” as it pertained to this study. The purpose of the study is clearly stated as “exploratory research to examine the lived
experiences of female care providers of children with cancer” (Fletcher, 2010, p. 165). A review of literature was reported by Fletcher (2010) but literature mainly pertaining to financial costs was discussed (p. 182). The theoretical orientation of the study was phenomenology and Fletcher (2010) provides a good explanation of “phenomenology” (p. 167). There is a very good description of the participant recruitment and of the characteristics of the participants. This, however, is where I see the greatest limitation in the study. There were very few participants, only nine, which I feel could bias the results. Fletcher (2010) also discusses this limitation along with noting that the retrospective nature of the study could also be a limitation (p. 183). Data-collection was obtained through interview which I believe was the best means to view the mothers’ experiences. The results of the study are presented narratively through the “voices” of the mothers giving a very clear picture of their experiences.

Overall the article provides a strong source of support for the effects of pediatric cancer on the family because it provides an insight into the experiences of who is often the main care taker of the children diagnosed with cancer. The narrative form gives very detailed examples of the effects or “costs” that the mother and other family members endure during this very stressful and often traumatic time.

Article Two

The second article, written by Alderfer et al. (2010), is also fairly strong evidence to support the suggested findings. This systematic review of evidence studying the psychosocial development of siblings of children with cancer aimed to build upon previous research on this topic. While the authors claim that this current review has shown very few improvements in research of this topic over the past ten years, there remains to be clear evidence that psychosocial
needs of siblings of children with cancer need to be addressed and they are at risk of significant distress.

The authors have presented a very well written article providing a detailed account of the systematic review they undertook. The introduction of the article gives a clear picture of pediatric cancer and the psychosocial impacts it can have on the family, specifically the siblings of the children diagnosed. The authors effectively describe the methodology of the review specifically describing the selection of literature and inclusion criteria. Results of the review are reported in an organized manner divided into four areas: psychosocial functioning, family functioning, school and social functioning, somatic complaints, and positive outcomes. The authors then provide a detailed discussion of the review and provide recommendation for improved research on the topic of psychosocial adjustment of siblings of children with cancer as well as recommendations for clinical practice.

The main limitation of this study is the limited research on the topic and the lack of quality of the studies. The authors explain that the quantitative studies often utilize small, heterogeneous samples and rely on cross-sectional designs while qualitative studies often fail to specify a theoretical approach to data analysis (Alderfer et al., 2010, p. 799). As explained in the above discussion, the authors identify a variety of reasons for the lack of methodological advancement in the research of siblings of children with cancer.

Overall, the article written by Alderfer et al. (2010) describing their systematic review is a good source of evidence because it portrays the effects of pediatric cancer on the siblings of the diagnosed children.
How the Evidence is Affected by my Experiences

The evidence related to the effects of pediatric cancer on the family is affected by my experiences on a personal level. I spent a year caring for my nephew who at age thirteen was diagnosed with Ewing’s Sarcoma. During this year I lived in the home of my sister and her family to provide skilled nursing care to my nephew as well as provide support to my sister and her other three children. Overall, as would be expected, this was a very difficult time for him and his family. Because of the intensity of his treatment, which was successful, the family experienced a great deal of change. The diagnosis of his cancer was devastating to the family and my sister dealt with extreme distress during diagnosis and treatment, as well as following treatment. She suffered from many of the emotional and physical effects discussed in my description of article one and had symptoms of post-traumatic stress following completion of treatment. The siblings of my nephew also experienced distress during diagnosis and treatment and identification is notable between them and the siblings described the second article I discussed. The hospital that my nephew was treated at did strive to deal with the distress often experienced by siblings of children diagnosed with cancer by utilizing a program called “Super Sibs” (www.supersibs.org). However, the program does not replace what is lost and completely meet the needs of those suffering from stress related to their brother’s or sister’s diagnosis of cancer. Based on my experiences with pediatric cancer, the evidence that I have discussed would be very beneficial in practice in caring for children with cancer. My research and experiences prove that it is not only the diagnosed child that suffers but also the rest of the family. Attention must be given to treat the family as a whole to meet the psychosocial needs of all those involved.
Recommendations

When the diagnosis of pediatric cancer affects a family, there are several recommendations that I would make. In concern to the parents, I would recommend the development of a strong support system. A support group, consisting of parents of other children with cancer, would be very beneficial to those mothers experiencing distress. Support groups give individuals the opportunity to identify with others and voice their concerns and feelings in a safe environment in which others are experiencing the same feelings. Siblings of the child diagnosed with cancer would also benefit from a support group setting in which they could have the opportunity to relate to other children who also have a brother or sister with cancer. In my above discussion of article two, the authors pointed out the recommendation of involving others (extended family, physicians, teachers, etc.) in the care of the siblings. I would agree that this is an excellent recommendation to help build the esteem of the children who are experiencing very difficult emotions. My final recommendation is to individually assess the needs of all members of the family because not every individual will process the diagnosis in the same manner.

Conclusion

Pediatric cancer is a devastating experience for the child as well as every member of the family. Too often, much of the focus is placed on the ill child and very little attention is given to other members of the family. As the first article above discusses, mothers experience a great deal of distress during diagnosis and treatment. This distress is evident by fear, worry, sadness, and grief; and it is often accompanied by physical symptoms such as headaches, back pain, weight loss or gain, and/or sleep disturbances. Siblings, too, experience a great deal of distress often at times when they still developing physically and emotionally. There are reported feelings
such as fear, sadness, loneliness, jealousy, anger, and worry. They also, often, must assume a
greater deal of responsibilities and may have to give up after school and social activities. These
reported effects of pediatric cancer on the family provides evidence of the need to provide
support all those involved in the life of the child diagnosed with cancer.
References


## Paper #1 Evidence-Based Group Project Paper

### Grading Criteria

30% of grade for paper can be deducted for APA errors including Spelling and grammar after paper graded.

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