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# Childhood cancer: Impact on parents' marital dynamics



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#### ABSTRACT

*Purpose:* To explore and analyze how marital relationships are affected by the crisis generated by the diagnosis and intensive regimens required in the treatment of children with cancer.

*Method:* A descriptive study with a qualitative data analysis was conducted. In-depth individual interviews were carried out with 18 married biological parents of children with cancer. Data was analyzed using an inductive content analysis.

Results: The following themes represented the couples' experiences: (1) Abrupt changes after the child's diagnosis resulting in marital strain and need to focus on the present; (2) United but distant; (3) Exchanging roles; (4) Being parents all the time; (5) Focusing on the positive side of the experience; (6) Rescuing the marital relationship. The marital relationship of parents with a child/adolescent who has cancer may undergo either positive or negative changes, with intimacy and sexuality being negatively affected by the disease. Although the relationship may be more fragile after the illness, increased mutual commitment was observed in some couples.

Conclusions: Results indicate that health professionals should include parents as an important focus of their care. The establishment of solid bonds to enhance couples' communication is recommended as a way to provide anticipatory guidance to address the identified changes in marital relationships. The opportunities for dialog and partnership help couples to target their needs and recognize their strengths in order to mitigate the impact of a child's illness.

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#### 1. Introduction

The diagnosis of childhood cancer initiates a difficult and painful experience for families, who are confronted not only with difficult decisions and information inherent to cancer treatment but also their own feelings and insecurities (Bally et al., 2014; Rosenberg

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et al., 2014; Svavarsdottir, 2005). Living with a chronic disease such as cancer with its peculiarities and demands of frequent and long hospitalizations, separation from the family, and aggressive treatment with adverse effects can lead to a series of manifestations including anxiety, fear, guilt, anger, and suffering that are common to all family members. The adjustments to the disease lead family members to change their lifestyle and adapt to the treatment's demands (West et al., 2015; Long and Marsland., 2011; Elsen et al., 2002). The disease's impact entails increased care needs, changes in social interactions, and reassessment of the family functioning (Bally et al., 2014; Hopia et al., 2004). Moreover, financial problems and emotional instability resulting from the presence of cancer can lead to estranged family relations, including the parents' marital

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relationship (Rosenberg et al., 2014; Syse et al., 2011; Lavee and Mey-Dan, 2003; Steffen and Castoldi, 2006).

Although there is considerable evidence to support the repercussions of a child's chronic illness on the parents' marital relationship, few qualitative studies discuss specifically the marital dynamics of couples who are parents of children with cancer (Da Silva et al., 2010). It is observed that most studies remain focused on the experience of each parent (Chesler and Parry, 2001) or include fathers and mothers of different children (Brody and Simmons, 2007; Lavee and Mey-Dan, 2003). According to a recent study, researchers tend to provide incomplete information about the approach used to conceptualize the family domain of interest; authors usually operationalize "family study" by specifying the inclusion of a family-related variable or quantitative measurement of family functioning instead of generating knowledge about the intersection between family life and childhood chronic conditions (Knafl et al., 2015).

Most of the studies focused on marital relationships during the experience of childhood cancer have been quantitative, measuring and explaining variations in marital functioning (Da Silva et al., 2010; Fincham and Bradbury, 1987; Hentinen and Kyngäs, 1998 and Syse et al., 2010). There is enough quantitative evidence (Dahlquist et al., 1996; Goldbeck, 2001; Hoekstra-Weebers et al., 1998 and Yeh, 2002) of distress and negative changes in couples' relationships after their child is diagnosed with cancer; however these aspects are not necessarily associated with increased divorce rates (Syse et al., 2010).

Factors such as marital adjustment, communication, and conflict resolution strategies are important in the process of raising children and influence the quality of relationships between parents and parents and their children (Hendricks-Ferguson, 2000). Studies' results suggest the importance of considering the psychological status of the marital unit, and of each individual, over the course of the child's illness. Furthermore, children whose parents are distressed tend to be more distressed themselves (Robinson et al., 2007; Dahlquist et al., 1996).

Parents tend to be the most important and present persons in the child's life. Therefore, the marital relationship experience of parents in the course of their child's disease needs to be understood because it may not only provide relevant information for pediatric oncology nursing but also be beneficial to other healthcare providers. Hence, this study explored and analyzed the repercussions of childhood cancer on the parents' relationship.

# 2. Methods

# 2.1. Study design

A qualitative descriptive methodology (Sandelowski, 2000) was used, including in-depth interviews and inductive content analysis, to explore, describe, and analyze the impact of childhood cancer on parents' relationship.

## 2.2. Settings

The study was conducted in a public university hospital located in São Paulo State, Brazil.

## 2.3. Participants

Nine married couples who were the biological parents of children with cancer, and whose children were in treatment for at least six months, volunteered to participate in this study, totaling 18 participants. The inclusion criteria were: biological fathers and mothers of children with cancer who were either married or in a

consensual marriage relationship, living in the same household at the time of diagnosis, and both are agreeing to participate in the study. The children-related criteria were: children must be diagnosed with cancer and undergoing treatment for at least six months for parents to be eligible to participate. Parents of children in end-of-life care were excluded.

We interviewed both parents, however individually, because the literature data suggests that the inclusion of the perspective of only one parent in studies that are designed to evaluate marital relations must be avoided because this approach compromises the couple's mutual perspective of the situation, which is necessary for an unbiased evaluation (McCubbin et al., 2002; Ow, 2003). Knafl et al. (2015) suggest that the well-being and functioning of individual family members are represented in a study only if they can be linked to results about other family members. Therefore, we preferred to include only couples in which both spouses could participate.

Parents who were accompanying their child/adolescent during their hospitalization were invited to participate. Authors also invited parents during daily hospital visits, as both parents were not with their child/adolescent during hospitalization. Only couples who were willing to participate were interviewed, and all parents readily accepted the invitation to take part in the research. The literature review of studies that reported appropriate and common methods used in research involving couples suggests that couples can express themselves clearly and expose confidential information without constraints when the individuals are interviewed separately (Duman et al., 2007).

The mothers' ages varied from 24 to 46 years old and the fathers' from 25 to 50 years old. The parents' education level was mostly at elementary and secondary school level. The majority of mothers worked outside the home (N=6). The length of experience with childhood cancer since the diagnosis varied from six months to three and a half years. Only two couples were from the city where the study was conducted; the remaining participants came periodically to the institution for hospitalizations or medical appointments.

The children's age varied from 1 year and nine months to 10 years old. The most frequent type of neoplasm observed in the children was central nervous system tumors, particularly, Medulloblastoma (N = 1), Primitive Neuroectodermal Tumors (N = 1), and Gliomas (N = 1). Other diagnoses included Leukemia (N = 1), Lymphomas (N = 2), Wilms tumor (N = 1), Rhabdomyosarcoma (N = 1), and Neuroblastoma (N = 1).

## 2.4. Data collection

An informed consent was provided and signed by all participants. The duration of the individual parents' interviews ranged from 50 to 60 min, and all interviews were audio recorded with the participants' permission. The sessions were conducted in quiet and private areas of the pediatric oncology ward or the outpatient clinic.

Although it was possible that the participating couples could separate or divorce during the study period, no marital separation or divorce occurred during data collection. The data was collected through in-depth interviews conducted by the first author. Interactions with all participants started with the following probe in order to give them the opportunity to express themselves broadly: Tell me how your relationship with your partner has been after your child's illness. Depending on the parents' response, the following questions were presented: What were the positive changes in your marital relationship that you observed after your child's illness? And the negative ones? Topics such as communication and intimacy were explored based on the participant's statements.

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