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In good times and in bad: What strengthens or challenges a parental relationship during a child's cancer trajectory?

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Abstract

Objectives: To identify events during a child's cancer trajectory when parents perceived their marriage/partnership to be most strengthened and/or challenged.

Research approach: Using a cross sectional qualitative design, participants completed a self-administered questionnaire addressing changes in their relationship during their child's cancer trajectory, including events perceived to strengthen/challenge their relationship, and recommendations for other parents.

Participants: 192 parents of pediatric oncology patients across 3 institutions. Data were analyzed using qualitative content analysis.

Findings: Themes included relationship-specific, illness experience-related, and external supports/stressors that impacted the relationship. Dyadic strategies, empathic communication and supportive behaviors strengthened the couple's relationship, whereas physical and emotional distance most commonly challenged the relationship. Recommendations to other parents included open communication, couple's connectedness, and use of external supports.

Interpretation: Offering psychosocial support and helping parents anticipate when their relationship can be strengthened/challenged can be an important part of ongoing care. Implications for psychosocial providers: Teaching communication and dyadic coping strategies can help parents manage stress and build cohesion.

Keywords

childhood cancer; parental relationships; dyadic coping; mothers; fathers; communication

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BACKGROUND/PURPOSE

When a child is diagnosed with cancer, there are a myriad of stressors that parents may experience. Besides handling the child's diagnosis, symptoms and treatment needs, a cancer diagnosis requires an adjustment process that includes restructuring the family's routine and roles, dealing with periods of separation, adapting plans for the future, as well as general uncertainty with regard to the child's prognosis. These must be balanced with one's work schedules and family activities.¹⁻⁵ Families can be profoundly impacted by a child's cancer diagnosis and, while the number of studies investigating the impact of childhood cancer on the parents' relationship is increasing, there are still important gaps to be addressed.^{1,5}

Parents of children with cancer experience psychological distress, such as anxiety, depression, and post-traumatic stress symptoms.^{2,3,6,7} While some studies have found levels of distress are highest at diagnosis and improve during and off treatment, others have found that some parents still present with clinically elevated levels of distress years later, which reinforces the importance of evaluating psychosocial needs over time.⁸

Gender differences have also been identified as a factor impacting illness-related beliefs, psychological distress, and coping styles, suggesting the importance of looking at different approaches in helping fathers and mothers cope with their child's cancer.⁹⁻¹¹ How parents cope with stressors over the illness trajectory can impact their relationship as a couple and as a family, including the care of the child undergoing treatment and their healthy siblings.^{2,12,13} Increased marital dissatisfaction has been reported after a child's cancer diagnosis, in particular when a child's illness persists, relapses and/or requires continued therapy.^{10,11, 14, 15} Experiencing a child's long-term illness has been associated with depletion of parental resources, sense of coherence and social supports.¹⁰ Better understanding of the times when couples and families are most vulnerable is crucial for developing meaningful, targeted interventions to support families at these times.

Several studies have investigated the factors that impact a parental relationship after a child's cancer diagnosis. These studies have described the importance of assessing interpersonal dynamics as well as individual strategies to adjust to stressors, highlighting the benefits of dyadic coping efforts couples use when facing stressors.^{9,16,17} Dyadic coping is seen as an interpersonal process used to cope with a stressor concerning both partners. This process includes identifying and interpreting partner's stress signs; individual coping responses; and joint coping efforts to deal with daily concerns, critical situations and long-term stressors.^{18,19}

Bodenmann¹⁸ divided a couple's pattern of managing stress into positive and negative dyadic coping. Positive dyadic coping refers to situations when one partner assists the other in his/her coping efforts (i.e., helping with daily tasks, offering empathetic understanding or helping the partner to reframe the situation), takes over the other's responsibilities in order to reduce the stress experienced by the other partner (i.e., one partner does groceries when the other picks up children from school), or the couple engages in the coping process symmetrically (i.e., seeking information together, jointly solving problems, or sharing responsibilities). Negative dyadic coping involves interactions that could lead to distance in

a relationship (i.e., use sarcasm or minimize the amount of stress experienced by the other partner, offer support without intention or capacity to help or one partner initiates conversations but is not truly invested in listening or understanding). Along with being a good resource to help partners reduce stress, recognizing dyadic coping patterns and prioritizing positive dyadic coping interactions can also contribute to maintaining a sense of “we-ness” (a couple’s mutual investment in their relationship and in each other, involving reciprocity and prioritization of the relationship) and to better marital functioning.^{18,19}

As part of a larger cross sectional, multi-center study examining the impact of a child’s cancer diagnosis on the quality of the parents’ relationship and parental dyadic adjustment,¹² open-ended questions were designed to better understand parents’ perception of experiences and events that brought them closer as a couple during their child’s cancer trajectory. These data are unique in that it describes parents’ perception of changes within their relationship over time. The study also uses dyadic coping theory to not only illustrate participants’ perceived challenges to the partnership, but also identify the times they felt most emotionally connected, as well as participants’ recommendations for other couples who have a child diagnosed with cancer.

METHODS

Participants

Parents of pediatric patients diagnosed with cancer treated in three different cancer centers were invited to participate in this study. Parents’ eligibility criteria included being: English-speaking; in a partnership at the time the child was diagnosed with cancer; and at least one of the participants being the biological/legal parent of the child. Both parents were not required to participate. Child-related inclusion criteria were: ages 1–21 years old at the time of diagnosis, and between 3 months post-diagnosis and 3 years post completion of therapy. The study was approved by the Institutional Review Board of the National Cancer Institute and participating sites.

Procedures

During the child’s visit to the participating institutions, parents were invited to enroll in the study. Investigators at each site introduced the study, obtained consent and then participants were asked to complete a self-administered questionnaire, either on paper or online. The questionnaire included open-ended questions about the participant’s perception of their relationship over the course of their child’s cancer trajectory.

Three open-ended questions were examined to explore the situations that significantly enhanced or caused distance for the parental partnership in addition to gathering recommendations parents had for other parents like them. The participants’ provided written responses to questions 1) “Is there any event or time that stands out in your mind that helped bring you closer together?”, 2) “Is there any event or time that stands out in your mind when you felt most distant from your partner/spouse?”, and 3) “What recommendations would you make to a couple whose child was recently diagnosed with cancer in terms of trying to keep their relationship strong?”.

Data Analysis

A thematic analysis approach²⁰ was used to analyze the data. Two investigators (LW, SZB) and one trained coder (MAC) independently read all answers, with all personal identifiers removed. Analysis began with an open coding process where the coders immersed themselves in the data to develop a thorough understanding of emerging themes and subthemes. Recurring themes and relational patterns were documented. Following open coding, categories and themes were grouped together to form a coding scheme. Themes were modified and finalized based on team consensus and a coding dictionary was then developed. The final coding system was then applied to all responses individually by the reviewers. Inter-rater reliability was determined based on the extent that the independent coders agreed on the coding of the themes. Inter-rater reliability was consistently >80% in all coding domains. Discrepancies were discussed face-to-face between reviewers and reconciled through review of the coded material until agreement was reached.

RESULTS

One hundred and ninety-two parents participated in this study, including fifty-two couples, with a response rate of 90.9%. Participants were between 19 to 62 years of age (mean of 45.4, SD = 8.1) and 63.5% mothers (biological, step or foster/adoptive) of the child with cancer. The majority of the sample were married or partnered (95.9%), with mean relationship length of 17.4 years (range 0 – 40, SD = 8.8), Caucasian (78.6%) and had children actively receiving treatment (64.6%). Most common children's diagnoses included sarcomas, blood cancers, brain and thyroid cancers. Table 1 provides demographic information. Further demographic information from this study was previously described in Wiener et al.¹² Our results are presented by the main themes and sub-themes identified within each open-ended question.

Situations that Strengthen the Relationship

Overriding themes emerged about events that were perceived to bring the couple closer together. These included strategies and issues specific to the partners' relationship, those related to the illness experience and supports external to the relationship (Table 2).

Relationship-specific issues—Managing stress as a couple was perceived to strengthen the relationship. Examples included events when one partner assisted the other in coping with a stressful situation by offering empathic understanding, providing practical advice, helping reframe an event, or expressing solidarity with the other partner. Other strategies frequently described as strengthening the relationship included joint problem solving and information seeking, sharing feelings, and having a mutual commitment.

Participants found the ability of one of the partners to take over responsibilities as a helpful strategy to reduce stress. In these situations, an explicit change in previous division of chores and responsibilities occurred, sometimes with partners reversing roles, which parents reported helped them deal with stressful moments individually or as a couple.

Participants valued their own and their partner's perceived change of priorities and perspectives. An appreciation of the "little things in life" and daily moments shared with family were highlighted.

Illness experience-related—Specific medical events across the child's illness trajectory were reported to bring the couple closer together. Examples included being together when experiencing a frightening medical event, such as an acute event and surgery, particularly when faced with the fear of a poor prognosis.

Experiencing renewed hope was also mentioned as an event that strengthened a couple's relationship. In particular, participants cited finding out about a new treatment option or deciding on a new protocol as increasing a sense of unity or "we-ness".

External supports impacting the relationship—Participants reported external sources of support helped them cope with the stressors of cancer treatment individually and as a couple. This included support from their faith community, family and friends. Faith and spirituality were described as contributing to a sense of peace, comfort, purpose, and connection to others. Some participants described being impressed by their child's resilience when facing different moments of the illness trajectory. Witnessing the child's strength of character, moral qualities and positive attitude were identified as situations that unified couples and gave them strength to overcome critical situations.

Situations that Challenge the Relationship

Participants provided examples of times they felt distant from their partner or perceived their partnership to weaken. As with situations that were perceived to strengthen the relationship, themes emerged that related to aspects of the partners' relationship, to the illness experience and to external events impacting the relationship (Table 3).

Relationship-specific issues—Distance often occurred when one partner felt the other partner dismissed their emotional needs, minimized the seriousness of their stress, left them feeling inadequate or guilty, or lacked interest in the details of their child's care. Some participants acknowledged their own role in inducing emotional distance in the relationship, for example when they didn't prioritize having time alone with their partner or avoided difficult conversations.

Participants acknowledged the impact their own stress had on their relationship. Some described how challenging it was to cope with their partner's emotional and physical needs on top of their own stress and the needs of their child(ren). Other participants described having a different coping style than their partner, which resulted in a lack of mutual understanding and more emotional distance in the relationship.

Difficulty making joint treatment decisions and lack of agreement on where or how treatment should be administered were also reported as issues that strained the relationship. For some families, decisions that pertained to daily family life (e.g. caring for the healthy siblings, having different discipline styles) were reported to cause the couple significant stress. Additionally, some participants noted that their relationship experienced the most

emotional distance at the end of treatment, at the time when they were trying to normalize their life, reorganize their routine and move forward from the cancer experience.

Illness experience-related—For many participants, physical time apart from their partner and family due to treatment was reported to have a negative impact on communication, and often resulted in a sense of isolation in the relationship. This sense of being emotionally alone was exacerbated when faced with difficult medical events, particularly those with an uncertain outcome.

External stressors impacting the relationship—Along with their child's cancer treatment, participants described having to deal with stressful events such as the needs of extended family, financial worries, and job insecurities, each of which added stress to the relationship. The child's physical and emotional needs led to limited time alone, reduced intimacy and reduced sense of needed togetherness. These situations were perceived to be an additional challenge to their relationship.

Recommendations to couples

When invited to make recommendations for other couples whose child was recently diagnosed with cancer, participants emphasized the importance of open and respectful communication. They also stressed the importance of finding ways to remain emotionally connected, emotionally and physically healthy, and of seeking and accepting outside support (Table 4).

What to do as a couple—The most common recommendation made by participants was to work towards open and respectful communication, especially during stressful times and events. They also emphasized the importance of not shielding difficult emotions from one another.

Participants underscored the need to stay emotionally connected. Suggestions included making time to be alone together, and maintaining physical touch and intimacy. Similarly, participants highlighted the importance of respecting individual coping styles and avoiding blame. While some participants suggested that parents should focus on the child and what needs to be done for his/her healing, they also reflected on the stress the child experiences when they perceive their parents are angry with each other and/or not coping well.

What to do individually—Some participants pointed out the importance of having a positive mindset during the cancer trajectory. Examples included being emotionally present and not taking any positive event, experience, or each other for granted.

Various strategies to relieve stress and maintain balance were described, such as regular physical activity, healthy eating habits, and time for oneself and to socialize with friends. Some participants emphasized the value of one's faith or spiritual beliefs in finding strength and peace during challenging times.

Utilize external resources—Participants acknowledged the importance of the support received from professionals, family and friends. Opportunities to share experiences with

other parents with a similar experience were also valued. Other participants addressed the importance of being educated about the illness and treatment. Learning from and trusting the team taking care of their child was described as important in helping couples feel less burdened by their decisions. Education about their child's disease and treatment options also provided a sense of shared responsibility with the team.

DISCUSSION

This study aimed to qualitatively explore specific factors and events during the child's cancer experience that can strengthen and/or challenge the parent's relationship. Our data offers important information on how partners perceived the impact of their child's cancer trajectory on their relationship. Three major themes emerged, which represent events and situations that resulted in emotional bonding or distancing.

First, as noted in earlier studies, opportunities for relationship growth can occur.² Factors that were perceived to strengthen the relationship included the couple's own style of relating to one another, illness-related experiences, and external stressors. Participants in this study valued their partner's provision of support and recognition of their specific emotional needs. Being able to help each other reduce stress and problem solve jointly, particularly when faced with critical moments in their child's care, resulted in feeling stronger as a couple. As noted by Compas et al.⁴ and Hoekstra-Weebers et al.¹⁷ new treatment options can also provide a sense of shared hope and the emotional energy needed to cope with the stresses ahead.

Participants in our study also acknowledged that a change in their priorities had a positive impact on their relationship. They seemed to direct more attention to family life events, and to value situations they would have previously "taken for granted". Aligned with a recent literature review on factors associated with parental distress in the context of childhood cancer,⁷ the use of social support, practicing one's spirituality, and appreciation for the child's attitude or character were also considered helpful coping strategies to maintain a healthy relationship.

Second, when asked about factors that challenged the partnership, both physical and emotional situations were described. Participants reported that their relationships were negatively impacted by external stressors (i.e., dealing with extended family, financial insecurity) and the burden of the child's illness and treatment (i.e., long hospitalizations limiting the couple's time to have meaningful conversations, make decisions or experience intimacy). Despite recognizing the negative impact on their relationship, participants described finding it difficult to make the changes needed to improve their relationship or to make their relationship a priority. Interestingly, many participants felt the most distanced from their partner when treatment was completed. Perhaps, it is not until the crisis has passed and treatment demands have lessened (a point in time when parents are expected to return to "normal life"), that they recognize the impact that their child's cancer has had on their relationship. Helping parents transition from active treatment to survivorship should include guidance on addressing relationship issues that might have been put aside due to competing priorities and needs.

Third, when asked about their recommendations for other couples after a child is diagnosed with cancer, participants often drew from their own experiences. They suggested couples utilize individual and joint strategies, as well as external resources. Individual strategies included taking care of oneself and finding ways of maintaining hope and strength throughout the child's treatment. Specifically, participants reinforced the idea that one needs to remain as emotionally and physically healthy as possible in order to take care of their child, family, and their relationship.

Recommendations for strengthening the emotional connection included establishing emphatic communication, supporting each other emotionally and learning ways to manage stress as a couple. Additionally, participants reported the importance of couples openly and honestly sharing their ideas, thoughts and worries with each other, even when their first inclination is not to burden the other. The need to respect coping styles that are different than one's own and to find moments to connect as a couple were also emphasized. Seeking (and accepting) help from others, both from professionals and their peers, was strongly recommended by participants. This reinforces the importance of medical centers working towards strong healthcare provider-family communication.

The need to assess and address parental mental health needs has recently become a standard of psychosocial care.²¹ Access to assessment and counseling for parents should be offered at all cancer centers.²² Psychosocial providers have an important role to play in helping parents anticipate events that can strengthen or challenge their relationship, increase their communication abilities, and identify possible sources of support in the community.⁷ Targeted interventions guided by dyadic coping strategies could impact parents ability to support one another by working together, learning to recognize the other's emotional needs, and sharing responsibilities when facing challenging situations.¹⁸ Better care for the parental dynamic is an important part of ongoing psychosocial care for the whole family.^{5,16}

There are several limitations to note. First, participants were only English-speaking, with an underrepresentation of ethnic minorities, and an overrepresentation of mothers. However, considering it is often a mother who accompanies the child to the hospital visit, we were pleased with one-third of the sample being fathers. Second, this was a cross sectional study. A longitudinal design would provide deeper insight into how the couples communication and quality of their relationship changes over time. Finally, participants wrote in their responses without a researcher present. Though there was no space limitation to how much could be written, 1–1 interviews might provide richer data on the impact of childhood cancer on a parents' partnership.

CONCLUSION

Specific events and partner behaviors that strengthen and/or challenge the parent's relationship during the childhood cancer trajectory were identified. Psychosocial care should include promoting couple's strengths along with dyadic stress management strategies. The data presents rich information for understanding partners' experiences that can inform the development of a couples' intervention.

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REFERENCES

1. da Silva FM, Jacob E, Nascimento LC. Impact of childhood cancer on parents' relationships: an integrative review. *J Nurs Scholarsh* 2010;42(3):250–261. [PubMed: 20738735]
2. Long KA, Marsland AL. Family adjustment to childhood cancer: a systematic review. *Clin Child Fam Psychol Rev* 2011;14(1):57–88. [PubMed: 21221783]
3. Rodriguez EM, Dunn MJ, Zuckerman T, Vannatta K, Gerhardt CA, Compas BE. Cancer-related sources of stress for children with cancer and their parents. *J Pediatr Psychol* 2012;37(2):185–197. [PubMed: 21841187]
4. Compas BE, Bemis H, Gerhardt CA, et al. Mothers and fathers coping with their children's cancer: Individual and interpersonal processes. *Health Psychol* 2015;34(8):783–793. [PubMed: 25622077]
5. Silva-Rodrigues FM, Pan R, Pacciulio Sposito AM, de Andrade Alvarenga W, Nascimento LC. Childhood cancer: Impact on parents' marital dynamics. *Eur J Oncol Nurs* 2016;23:34–42. [PubMed: 27456373]
6. Kazak AE, Boeving CA, Alderfer MA, Hwang WT, Reilly A. Posttraumatic stress symptoms during treatment in parents of children with cancer. *J Clin Oncol* 2005;23(30):7405–7410. [PubMed: 16157936]
7. Sultan S, Leclair T, Rondeau E, Burns W, Abate C. A systematic review on factors and consequences of parental distress as related to childhood cancer. *Eur J Cancer Care (Engl)* 2016;25(4):616–637. [PubMed: 26354003]
8. Wijnberg-Williams BJ, Kamps WA, Klip EC, Hoekstra-Weebers JE. Psychological adjustment of parents of pediatric cancer patients revisited: five years later. *Psychooncology* 2006;15(1):1–8. [PubMed: 15880477]
9. Clarke NE, McCarthy MC, Downie P, Ashley DM, Anderson VA. Gender differences in the psychosocial experience of parents of children with cancer: a review of the literature. *Psychooncology* 2009;18(9):907–915. [PubMed: 19319828]
10. Lavee Y. Correlates of change in marital relationships under stress: The case of childhood cancer. *Fam Soc* 2005;86(1):112–120.
11. Yeh CH. Gender differences of parental distress in children with cancer. *J Adv Nurs* 2002;38(6):598–606. [PubMed: 12067399]
12. Wiener L, Battles H, Zadeh S, Pelletier W, Arruda-Colli MN, Muriel AC. The perceived influence of childhood cancer on the parents' relationship. *Psychooncology* 2016.
13. Wijnberg-Williams BJ, Van de Wiel HB, Kamps W, Hoekstra-Weebers JE. Effects of communication styles on marital satisfaction and distress of parents of pediatric cancer patients: a prospective longitudinal study. *Psychooncology* 2015;24(1):106–112. [PubMed: 25045011]
14. Dahlquist LM, Czyzewski DI, Copeland KG, Jones CL, Taub E, Vaughan JK. Parents of children newly diagnosed with cancer: anxiety, coping, and marital distress. *J Pediatr Psychol* 1993;18(3):365–376. [PubMed: 8340845]
15. Lavee Y, Mey-Dan M. Patterns of change in marital relationships among parents of children with cancer. *Health Soc Work* 2003;28(4):255–263. [PubMed: 14679704]
16. Fife BL, Weaver MT, Cook WL, Stump TT. Partner interdependence and coping with life-threatening illness: the impact on dyadic adjustment. *J Fam Psychol* 2013;27(5):702–711. [PubMed: 23957849]
17. Hoekstra-Weebers JE, Wijnberg-Williams BJ, Jaspers JP, Kamps WA, van de Wiel HB. Coping and its effect on psychological distress of parents of pediatric cancer patients: a longitudinal prospective study. *Psychooncology* 2012;21(8):903–911. [PubMed: 21608072]
18. Bodenmann G. Dyadic coping and its significance for marital functioning. . In: Revenson TA, Kayser K, Bodenmann G, eds. *Couples coping with stress: Emerging perspectives on dyadic coping* Washington, DC: American Psychological Association; 2005:33–49.

19. Bodenmann G, Cina A. Stress and coping among stable-satisfied, stable-distressed, and separated/divorced Swiss couples: A 5-year prospective longitudinal study. *Journal of Divorce & Remarriage* 2006;44(1–2):71–89.
20. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77–101.
21. Wiener L, Kazak AE, Noll RB, Patenaude AF, Kupst MJ. Standards for the Psychosocial Care of Children With Cancer and Their Families: An Introduction to the Special Issue. *Pediatr Blood Cancer* 2015;62 Suppl 5:S419–424. [PubMed: 26397836]
22. Kearney JA, Salley CG, Muriel AC. Standards of Psychosocial Care for Parents of Children With Cancer. *Pediatr Blood Cancer* 2015;62 Suppl 5:S632–683. [PubMed: 26700921]

Table 1.

Demographic Characteristics (N = 192)

Characteristic	n (%)
Relationship to Child ¹	
Biological/Step/Foster Mother	122 (63.5)
Biological/Stepfather	70 (36.4)
Other	1 (0.5)
Parent Age	45.4 (range 19 – 62, S.D. = 8.1)
Relationship Status	
Married/Partnered/Living with Partner	184 (95.9)
Separated/Divorced	6 (3.2)
Widowed/Other	2 (1.0)
Relationship Length	17.4 years (range 0 – 40, SD = 8.8)
Child Age	11.6 (range 1 – 25, SD = 6.3)
Child Gender	
Male	108 (56.3)
Female	84 (43.8)
Child Diagnosis	
Blood/Hematological Cancers	86 (44.8)
Sarcomas	43 (22.4)
Brain Cancers	32 (16.7)
MTC/MEN2B	18 (9.4)
Other ²	13 (6.8)
Is Your Partner the Parent of the Child with Cancer	
Yes	168 (87.5)
No	24 (12.5)

¹Includes 1 stepmother, 1 foster mother and 1 stepfather²Other includes Melanoma, Diffuse Intrinsic Pontine Glioma, Gastrointestinal Stromal Tumor, Anaplastic Ependynoma, Wilm's tumor, Desmoplastic Small Round Cell Tumor, Mesothelioma

Table 2.

Situations that strengthen the relationship

Theme	Sub-Themes	Quotes
1. Relationship-specific issues	a. Managing stress as a couple	<i>The time that comes to mind is when I received bad news about my daughter's treatment. (...) I told my husband to leave me alone while we were staying in hospital. I cried so much he never left hospital. He knew I really did need him. (mother, 45 years old)</i> <i>The way that my spouse has taken care of our son, making so many sacrifices along the way, has made my love for her increase exponentially. (father, 46 years old)</i>
	b. Valuing life and family	<i>Right after my daughters first relapse my husband made a point of saying how much we wanted to make the most of life and not take life for granted. (mother, 29 years old)</i>
2. Illness experience-related	a. Specific medical events	<i>After the second relapse we realized this wasn't going to be so easy and we really started to be a team. (mother, 36 years old)</i>
	b. Hope for a new treatment	<i>Following the relapse to her lungs (...), we were told there was "nothing else" and to seek palliative care. We both believed we could not give up hope, that there was something else for her. NIH gave us both tremendous hope. (mother, 45 years old)</i>
3. External supports impacting the relationship	a. Faith and spirituality	<i>Attending the chapel, listening to father preach. All of the time the words of the bible connected to our situation. (mother, 42 years old)</i>
	b. Social support	<i>We are blessed to have each other and have a strong family unity and friends and family and neighbors to help us. (stepmother, 49 years old)</i>
	c. Child's attitude	<i>My son's mantra is to "never say never" and he will not quit fighting the disease. And so, no matter what the relationship, we, as a couple, will fight with him until he wins or loses the war-battle by battle. (father, 57 years old)</i>

Table 3.

Situations that challenge the relationship

Theme	Sub-Themes	Quotes
1. Relationship-specific issues	a. Self- and Partner-induced distance in their relationship	<i>I would like him to understand what this is like. He downplays it all. When he asks me "what's wrong"- it really bugs me. His response is "don't worry about it". There isn't an off button. (mother, 33 years old)</i>
	b. Difficulty in recognizing own and partner's emotional and physical needs	<i>After the transplant, he was very anxious and stuck in obsessive thought patterns. He was being very negative and down at a time when we should have all been feeling hopeful and enjoying each other (...) I really had trouble dealing with his negativity and depression. (mother, 45 years old)</i>
	c. Dealing with different coping styles	<i>When I cried every day because there was no treatment to help my daughter and did not see my husband suffer the same way I did. (Felt very alone and angry). He did not express his emotions and that was baffling (shocking) to me. (mother, 51 years old)</i>
	d. Difficulty making decision as a couple	<i>When because of her fathers' opinion she wanted to change the medical treatment we just agreed to minutes before. (father, 32 years old)</i>
	e. Trying to normalize and move forward	<i>I feel the distance the most as we try to regain some normalcy in our lives--i.e., as we shift our 100% focus on our sick daughter to focusing equally on everyone in our family. (mother, 50 years old)</i>
2. Illness experience-related	a. Physical distance	<i>I felt most distant my first time staying at the hospital (...) I felt so far from home, felt so alone, felt I was on my own from that day on. I felt my spouse didn't understand how I felt. We seemed very distant. (mother, 45 years old) During hospital stays when I could not stay in the room with my wife and son. (father, 42 years old)</i>
	b. Burden of illness experience	<i>Mid-treatment when my child was very ill and in ICU. I felt like I was carrying all of the burden to oversee care and medical decisions. (mother, 43 years old)</i>
3. External stressors impacting the relationship	a. Stress from external events	<i>When my wife doesn't control spending. (father, 46 years old)</i>
	b. Issues brought forth by child	<i>Bedtime is hard, our child needs one of us with him now, or won't sleep so we rarely sleep in the same bed. (mother, 44 years old)</i>

Table 4.

Recommendations to couples whose child is diagnosed with cancer

Themes	Sub-Themes	Quotes
1. What to do as a couple	a. Communicate (share thoughts and feelings, laugh, cry)	<i>Communication is totally key, listening and understanding your partner. (father, 39 years old) To hold hands, hug, cry together - don't hide those feelings from each other. (mother, 48 years old)</i>
	b. Stay connected as a couple (date and spend time together, physical touch and intimacy, be supportive and work together)	<i>Allow yourself to go out and have fun - just the two of you. A grandparent can hang out with your child. It may be going out for just a cup of coffee the first time. Start small and build up. You'll be better parents for that child if you keep your relationship strong. And it's gonna help you be a better caregiver if you allow yourself a moment away. (mother, 45 years old)</i>
	c. Have patience and respect differences	<i>Talk to each other about your stress, fears and needs. You are both going through the same thing although you may handle it differently. (mother, 46 years old)</i>
	d. Focus on the child	<i>Be patient, focus on the child and making the child feel comfortable. They are very perceptive and even more so on treatment and they need the rock of the parents to anchor themselves. (father, 48 years)</i>
2. What to do individually	a. Have a positive mindset	<i>I would tell them to allow themselves to feel each emotion and recognize that they are all valid. I would also tell them to live in the moment. Not to get ahead of yourself, make each day as it comes, enjoy when your child feels good and when they're not feeling good, keep in mind that it won't last forever. (mother, 42 years old) (...) when the good days come, soak them up and enjoy every smile!! (father, 33 years old)</i>
	b. Take care of yourself	<i>Make sure that you do not get burnt out as caregivers. It is important that each parent get some time to his/her self. (mother, 50 years old)</i>
	c. Practice your religion	<i>Reach out away from your relationship to find strength. Then you can bring that peace back into the relationship. For instance, [spouse] and I pray separately. We give our worries to God and lean on Him. Then when we come back together, we can really be there for each other with a renewed strength that is not our own. (mother, 45 years old)</i>
3. Utilize external resources	a. Get help from others (professional, social and household, meet other parents)	<i>Get counseling. Talk to other parents facing the same issues. Build a support system, so many people want to help in some way. Develop a list of things that would help you and let people choose how they feel they can help out, i.e., meals, gas cards, babysitting, driving kids, going to hospital appts with you, giving you a night out, etc. (mother's partner, 56 years old)</i>
	b. Patient treatment related (trust the team and use resources, share decision making and responsibilities, get educated)	<i>Feel comfortable with the care your child is receiving. You both have to trust your hospital. Our home clinic is like family. (mother, 45 years old)</i>