Published in final edited form as:

Psychooncology. 2017 December ; 26(12): 2109–2117. doi:10.1002/pon.4313.

The perceived influence of childhood cancer on the parents' relationship

L Wiener^{1,*}, H Battles¹, S Zadeh¹, W Pelletier², MNF Arruda-Colli¹, and A Muriel³

¹Pediatric Oncology Branch, Center for Cancer Research, National Cancer Institute, National Institutes of Health, Bethesda, MD

²Alberta Children's Hospital, Calgary, Canada

³Dana Farber Cancer Institute

Abstract

Objective—When a child is diagnosed with cancer, parents are faced with many practical and emotional challenges that can significantly affect their relationship. This study explores how having a child with cancer affects the quality of the parents' relationship; categorizes time points and events during the child's treatment when the relationship becomes most stressed and/or strengthened; identifies factors that help couples remain emotionally engaged throughout their child's cancer treatment; and assesses parental interest in a counseling intervention.

Methods—This is a cross sectional, multi-center study conducted via a semi-structured self-administered questionnaire that included The Revised Dyadic Adjustment Scale.

Results—192 parents of children diagnosed between the ages of 1–21 participated. Forty percent felt their relationship moved in a negative direction. Diagnosis and relapse of disease were cited as the most individually stressful time points in the disease trajectory, with hospitalizations and relapse being most stressful on the relationship. Participants felt most emotionally connected at diagnosis, and least emotionally connected at the start and end of treatment. The majority of couples indicated interest in counseling to address ways to support their relationship. Soon after diagnosis and during treatment was reported as the preferred time to offer these interventions.

Conclusion—This study identified specific events and parent behaviors that strain the couples' relationship during the childhood cancer trajectory. This information can inform the development of a couple's intervention. Prospective research is needed to better understand how childhood cancer affects caregivers' partnerships through survivorship and beyond.

Keywords

Childhood cancer; parental relationships; dyadic coping; mothers; fathers

Contact Author: Lori Wiener, PhD, Co-director, Behavioral Science Core, Psychosocial Support and Research Program, ¹Pediatric Oncology Branch, Center for Cancer Research, National Cancer Institute, 10 Center Drive, Bldg. 10, Room 1-6466, Bethesda, MD 20892, wienerl@mail.nih.gov, Phone: 301-451-9148, Fax: 301-480-3714.

Introduction

The diagnosis and treatment of childhood cancer is a significant source of stress for the parents of an estimated 15,780 children and adolescents diagnosed in the US annually [1]. Even with increasing survival rates, cancer treatment requires prolonged, complicated and intensive treatment protocols that can significantly affect quality of life for the child as well as the whole family [2]. In addition to the stressors and toxicities associated with treatment, many parents caring for a child with cancer experience transient and chronic stressors that can potentially affect the parental relationship and communication between partners.

From the time a child is suspected of having cancer, parents are often faced with disruptions in daily routines and family life, including changing caregiver or spousal roles [3–5], threats to employment and financial strain [6–8], and emotional challenges [9–11] that significantly contribute to the cancer experience. These additional stressors in combination with caring for non-ill family members and maintaining other relationships can be extremely difficult for couples. Physical distance between partners can reduce ongoing communication as one parent (typically the mother) stays with the child at a treatment facility that may be far away from home, while the other parent (frequently the father) is left to be the source of income and otherwise manage the home for the remaining family members [4, 12, 13]. The parent who is not present with the ill child may not be a part of the day-to-day medical decisions [14]. Couples often lose their communication skills during stressful times [15]. A lack of communication or poor quality of communication between parents regarding care for the family, and medical decisions for the treatment of the ill child can lead to further stress and anxiety.

Despite a reported increase in marital dissatisfaction up to two years from the child's cancer diagnosis, marital adjustment in relation to psychological distress has only been explored in a handful of studies [16]. Considerable variability in regard to the timing, direction and nature of changes in marital satisfaction has been reported, with a significant subset of parents reporting persistent marital problems. Along with strains and positive changes throughout the cancer trajectory, parents may put the needs of the marriage and partner on hold during intense treatment stages, and struggle with incongruent coping styles [2].

Research also supports that mothers and fathers experience and cope with the stress of having an ill child differently. Divergent coping styles have been associated with increased marital dissatisfaction [17–19]. Mothers have been found to experience overall higher levels of psychological distress than fathers [20]. What remains unknown is the extent to which mothers and fathers perceive differences in communication and role-related expectations at different times in their child's cancer experience. Understanding the specific stresses that occur in the diagnostic period and during the course of treatment and beyond is critical to developing effective interventions. Dyadic coping is a process in which the coping reactions of one partner take into account the stress signals of the other partner. Studies have demonstrated that dyadic stress management strategies, such as helping each other reduce daily stresses and listening with understanding to how the other partner experiences the stresses, have helped couples cope better with external stresses, such as serious illness [15,

21, 22]. These studies have not been replicated to date with parents whose children have cancer.

Despite the myriad of issues demonstrated in the literature regarding relationship challenges that can evolve as a result of a childhood cancer diagnosis, there are limitations to the research thus far. Most studies to date lack the examination of the experiences of both mothers and fathers parenting a child with cancer [4]. There is also a need for information regarding the individual differences in caregiving stress and for information across different time points of the illness trajectory [2]. Furthermore, the literature thus far does not include research related to the interventions needed to enhance the coping skills in these parents [6] or information regarding the format of intervention that parents would find helpful.

The study objectives for this cross sectional, multi-center study were to explore how having a child with cancer affects the quality of the parents' relationship, to examine dyadic adjustment, to describe the time points and events during the child's treatment when the relationship is perceived to become most stressed and/or strengthened, and to assess interest in and barriers for couples counseling. This information can inform the development of an effective intervention to improve communication and coping skills in the relationship of parents of children with cancer.

Methods

Participants

The sample was composed of 192 parents of children between the ages of 1–21 being treated for cancer or returning for follow-up after completing therapy within the past 3 years. The child must have been diagnosed with cancer at least 3 months prior to participation and the parent must have been in a partnership at the time the child was diagnosed. Both parents were eligible to participate. At least one participant must have been the biological/legal parent of the child; the partner may or may not be a biological/legal parent. Divorced parents who separated or divorced during or after the child's treatment were eligible to participate in this study.

Participants ranged in age from 19 to 62, with a mean age of 45.4 (SD = 8.1). The child with cancer needed to be diagnosed with cancer before their 22nd birthday and ranged in age from 1–25 (mean of 11.6, SD = 6.3) at the time of data collection. The sample included 78.6% who reported their race/ethnicity as Caucasian, 19.4% Hispanic, 4.2% African American, 3.6% Asian and 2.1% American Indian/Alaskan Native. Participant and child characteristics are included in Table 1.

Procedures

Participants were recruited for participation in this study at the time of the child's regularly scheduled appointment at each of three participating sites. Two hundred eleven parents were approached and 192 agreed to participate for a response rate of 90.9%. After reviewing and signing the informed consent, each participant was individually provided (based on parent preference) a self-administered questionnaire to complete during either the child's hospital or clinic visit or web instructions to access the questionnaire via a secure NCI website. All

participants who agreed to participate completed the entire questionnaire, for a completion rate of 100%. The Institutional Review Boards at each participating institutions approved the study.

Measures

Parent Questionnaire—A 51 item self-administered questionnaire that included multiple-choice and open-ended questions was designed specifically for this study. The questionnaire included select demographic information and explored information that addressed the individual's perception of the spouse/partner relationship, coping styles, and perceived stressful events related to the child's illness.

The questionnaire included 2 standardized measures addressing marital/relationship issues. The Revised Dyadic Adjustment Scale (RDAS) is a standardized assessment of marital stress which evaluates factors within marital adjustment that are challenged including consensus (e.g. decision-making), cohesion (e.g. working together, discussion) and satisfaction with the marriage (e.g. frequency of quarrels, considering separation). The RDAS is designed to distinguish between distressed and non-distressed partners. The RDAS is a 14-item revised version of the 32-item Dyadic Adjustment Scale (DAS) [23] and has demonstrated good construct validity with the DAS. The RDAS has good internal consistency (Cronbach's $\alpha = 0.90$) and excellent split-half reliability (Gutman split half = .94 and Spearman-Brown split half = .95) with estimates larger than the DAS [24]. Cronbach's α for the current study is .87. Three items from a 17-item publically available clinical marriage screening tool (Gottman-17) were adapted to explore the perceived changes that have taken place in the marriage/partnership. Specifically, we used the items related to emotional connection, and handling stress effectively together. The Gottman-17 is a widely validated and extensively used measure of marital functioning and distress that has been used to reliably predict marriage dissolution [25].

No validated survey items were available for some constructs related to specific challenges throughout the treatment trajectory. Therefore, the investigators used literature review and clinical consensus to inform the development of the remainder of the questionnaire. Using cognitive interviewing methods, these questionnaire items were piloted and tested with 5 parents whose child was receiving cancer treatment. Respondents described their understanding of each question. We assessed clarity, ease of recall of the information requested and the ease with which personal responses could be fit to the response options provided. Revisions were made (to non-standardized questions) until respondents consistently understood all of the questions included in the final tool.

Analysis

Statistical analyses were performed using SPSS Version 21 (IBM, Chicago, IL). Descriptive statistics were used to characterize the sample, and to describe the key variables. Categorical variables were compared using chi-square analyses, and continuous variables measured pre-post diagnosis were analyzed using paired samples t-tests.

Qualitative analysis was performed by using thematic analysis at the latent level [26] based on written responses to open-ended questions. Three raters (authors Wiener, Zadeh & Colli) independently read and coded text to identify themes that emerged and then compiled common themes throughout each of the questions. Themes were modified and finalized based on team consensus. A coding dictionary was then developed. The final coding system was applied to all responses. Raters then met as a group and discrepancies were reconciled through review of the coded material until agreement was reached. Verbatim quotes are presented that represent the themes elicited by participants to the open-ended questions.

Results

Relationship quality

On the questionnaire, over half of the participants (53.2%) reported that their marriage/relationship was challenged since their child's diagnosis, 3.6% had considered separation and 3% had already separated. Over one quarter (26.6%) reported that their marriage/relationship had gotten stronger. Finally, 13.5% reported no change in their relationship since their child's cancer diagnosis. Asked differently, participants rated their marriage/relationship favorably for the year before the child's diagnosis (86.5% good/very good/excellent, 13.5% poor/fair). When asked the same question about the quality of their relationship now, 77.1% as good/very good/excellent and 22.9% rated it as poor/fair (Figure 1). On this pair of questions, 39.6% indicated that their relationship moved in a negative direction. Treating this same scale continuously where "poor" = 1 and "excellent" = 5, mean relationship quality decreased from the year before diagnosis to now (3.7 vs 3.3, $t = 5.7$, $p < .001$, Cohen's $d = .41$, indicating small to medium effect size).

Emotional Connection

Participants were asked about several different topics on a 5-point scale (never, sometimes, often, almost always, always), which was then dichotomized to never/sometimes and often/almost always/always. Significant differences between time points were found in the sense of togetherness experienced in the relationship ($\chi^2 = 47.6$, $p < .001$), feeling lonely in their marriage/relationship ($\chi^2 = 27.1$, $p < .001$), the degree of intimacy/sexual relationship ($\chi^2 = 22.5$, $p < .001$), ability to make decisions together ($\chi^2 = 21.1$, $p < .001$), anger ($\chi^2 = 10.5$, $p < .01$), tension between partners ($\chi^2 = 16.0$, $p < .01$) and ability to communicate about their child's needs ($\chi^2 = 45.1$, $p < .001$) (Table 2).

Participants were also asked about a series of time points in the diagnostic and treatment trajectory when they felt most and least connected to their partner. They reported feeling most connected at the cancer diagnosis (34.9%) and the period before diagnosis (21.9%). They felt least connected at the start of treatment (40.6%) and at treatment completion (19.3%) (Figure 2).

Participants reported, from the Gottman-17, about what has negatively affected their emotional connection with their partner since their child's cancer diagnosis and rated how problematic the use of six specific relationship strategies was for them: Not being able to spend time together (72.9%), feeling taken for granted (67.7%), reporting that they or their

partner is emotionally disengaged (61.4%), challenges talking to each other (51.6%), and not feeling that their partner “knows me well now” (49.0%) were the most frequently identified stresses. When asked specifically whether dealing with cancer and treatment makes you both irritable, 72.4% said “yes”.

Dyadic Adjustment

Respondents completed the RDAS and were assigned scores on the Consensus, Cohesion, Satisfaction subscales as well as given an overall dyadic adjustment score. Comparing these mean scores to those reported by Busby et al. [23], the current sample scored significantly lower than the normative non-distressed sample on all RDAS scales (Consensus, Satisfaction, Cohesion and total, $p < .001$). The mean scores were then categorized into low, average and high with low representing greater than 1 s.d. below the mean normative score for non-distressed samples, and high representing greater than 1 s.d. above the mean for non-distressed samples [23]. Low scores reflect lower levels of dyadic adjustment. Overall, over one third (37.5%) scored in the low range for dyadic adjustment (total scale score), 54.7% in the average range and 7.8% in the high range. Cohesion and overall dyadic adjustment scores were significantly higher for parents of children 12; $F=3.3$, $p<.05$ for both. Relationship length has a weak but significant association with RDAS satisfaction ($r=.17$, $p<.01$). There were no significant differences in RDAS scores between men and women, between sites or by treatment completion.

Time Points Most Stressful to Participants

Participants identified time points they found to be “Very Stressful” or “Extremely Stressful” which included: waiting to find out what was wrong with their child (83.9%), the cancer diagnosis (65.6%), making treatment decisions (68.3%), the start of treatment (63.5%), hospitalizations (61.4%), and changing treatments (61.4%).

Issues Reported to be Stressful

Participants were asked about a series of issues that may pose stress to themselves, their partner and their relationship. They were then asked which of these issues was most stressful. Overwhelmingly, participants reported that fear about their child’s disease outcome was most stressful to themselves (no difference by gender), their partners and to their relationship. Hospitalizations and relapse were reported as most stressful to the relationship. Gender differences were found in what was perceived as stressful to themselves (Figure 3), with women more likely to report that helping their child’s siblings was stressful ($\chi^2 = 6.9$, $p < .01$), while men were more likely to report that being away from work and lack of intimacy were stressful ($\chi^2 = 6.3$, $p < .05$; $\chi^2 = 6.6$, $p < .05$, respectively).

Handling Stress

Most participants (69.3%) reported that they are handling the stress related to caring for their child with cancer “somewhat” effectively with their partner (from the Gottman-17), 12.5% reported handling their stress completely and 18.2% reported they were challenged in this area. To better understand the nature of the stresses experienced, participants were asked about areas that could be problematic for their relationship. For each area, they were asked

to rate whether the area was “Not a Problem”, “Sometimes a Problem”, or “Often a Problem”. Items endorsed as “Sometimes” or “Often a problem” by over half of the participants included helping each other reduce daily stress (79.7%), talking about stresses together (60.4%), talking about stress in a helpful manner (59.9%), and listening with understanding about each other’s stresses and worries (59.4%).

What Would Strengthen Your Marriage/Relationship?

Both closed and open items were used to obtain insights on what would strengthen a couple’s relationship after a child is diagnosed with cancer. Most often endorsed practical suggestions included having the partner more involved in household chores (35.9%), sibling chores (20.8%), and helping with day-to-day medical issues (19.8%).

The major themes identified from the open-ended questions embedded within the questionnaire reflected the importance participants placed on the interpersonal aspects of their relationship with their partner. These included compassionate communication, having a shared perspective, and dyadic coping strategies.

Compassionate communication—Participants valued communication as a strategy for connecting emotionally with their partner, helping them handle stress, and with knowing they can cope with difficult situations together.

“By keeping communication open, I believe helps keep us stay emotionally connected. He is my strength when I need it and I do the same for him. Reminding ourselves we are a couple as well as parents helps keep our relationship strong. If there are challenges we discuss our feelings and we come to a solution together.”

Shared perspective—Participants wrote about sharing the same outlook on current and future goals and methods of reaching their shared goals.

“We just focus on our son and making him better, doing whatever we have to make that happen.”

Dyadic adjustment—Dyadic adjustment was reflected by recognizing the other person’s feelings, being mindful of the other person’s needs, respecting the other person’s opinions, partner support, and listening with understanding to how the other partner experiences the stresses.

“Our stress handling is different. I externalize stress, he internalizes. Knowing what the other needs help. I need a sounding board and he needs space. We try to provide that for each other....He also lets me vent without trying to fix everything.”

Participants also expressed the ability to utilize external releases (exercise, support from others, therapy), be flexible, adapt family roles and routines, and share faith as strategies that have helped strengthen their relationship.

Counseling Services: Interest, Timing and Location

Participants were asked if they would have been interested in counseling to address ways to support/strengthen their marriage/relationship if it were offered. Almost half of the

participants (46.4%) responded “Yes”, 19.8% responded “No”, and 33.9% were “Not Sure”. Women were marginally more likely than men to express interest in counseling (52.5% vs. 34.8%, $p = .052$).

When asked about the best time to be offered counseling to support or strengthen a marriage/relationship, 24.5% of participants reported “soon after the child’s diagnosis” and another 24.5% “during the child’s treatment”. The majority of participants would prefer this service to be offered at the hospital (43.2%) or in the family’s home community (26%).

Barriers to participating in a counseling/supportive marital intervention were also explored. Limited time (45.3%), cost (33.3%), difficulty of both partners being able to attend together (25.5%), difficulty talking about issues in the relationship (20.8%), and concern that the partner would not attend (18.2%) were most frequently endorsed. Only 6.8% said they would not be interested in a supportive marital intervention. Participants were asked if they would be interested in non-face-to-face counseling/support (e.g., Skype™, online video-conference) and 32.3% said yes. Those who were not interested described the impersonal nature of this type of intervention.

Discussion

In this study we found that over half of the participants reported their relationships as challenged following the diagnosis of childhood cancer, with close to 40% feeling their relationship had worsened since diagnosis and over a third scoring low on dyadic adjustment. This speaks to the impact that childhood cancer can have on both healthy and dysfunctional parental relationships and the importance of assessing relationship quality as part of routine psychosocial care throughout the illness trajectory.

Maintaining Emotional Connection and Communication

Importantly, the quality of the relationship, particularly in terms of how participants perceived their emotional connectedness to their partner, changed as well. Due to the child’s treatment often taking place at a distant treatment center, the most frequently identified difficulty in emotional connection was not being able to spend time together. Longer periods of illness have been associated with depletion of parental resources [20], a lower sense of cohesion and weaker social supports [20, 27]. Encouraging parents to establish, in advance, a set time during the day when they can re-connect with their partner about how they are each doing emotionally, along with their child’s medical updates, can be very helpful. Other challenges to emotional connection included feeling taken for granted, reporting that they or their partner is emotionally disengaged, and not feeling that their partner “knows me well now”. As the diagnosis is accepted, feelings of sadness and fear may become most prominent. It is therefore critical for clinicians to ask how parents cope with the diagnosis together in order to guide needed interventions, particularly around their emotional reactions to the situation and to each other.

Other communication challenges emerged, such as not being able to talk about stresses together, talking about stress in a helpful manner, and listening to and understanding each other’s stresses and worries. These data implicate communication within couples as a

potential mechanism underpinning couples' perceptions of stress and marital satisfaction throughout the cancer experience. These specific identified areas can guide interventions to enhance partners' ability to clearly communicate stress.

Managing Stress

This study also identified how participants report handling stress on their own and in their relationship. The majority of participants reported dealing with their child's diagnosis well as a couple. Yet, specific stresses to the relationship evolved through the course of treatment. Helping each other reduce daily stress was endorsed as "Sometimes" or "Often a problem" by over half of the participants. Struggling to work, provide childcare, maintain a home and finances while caring for their sick child and other family members can be overwhelming. This can be especially burdensome for parents who do not feel they have the support they need to care for the psychosocial needs of their children [28] and for those who perceive themselves to be a "lone" parent when caring for their child with cancer [29]. Participants identified what would strengthen their relationship including having the partner more involved in household chores, sibling chores, and helping with day-to-day medical issues. Clearly defining roles/responsibilities after a child is diagnosed may help strengthen the relationship of the couple after a diagnosis. Differences were found in responses between male and female participants with women more likely to report that helping their child's siblings to be most stressful, while men were more likely to report that being away from work and lack of intimacy (e.g. "mismatched sex drives") as most stressful. These findings support earlier research [3] that described mothers being more likely to share their thoughts and emotional state, whereas fathers felt a need to be "strong" for their family. Fathers' lack of communication can cause their spouses to feel unsupported, which in turn, can negatively affect marital quality [3]. Importantly, many of the fathers reported interest in increasing their communication skills with their partner/spouse.

Intimacy is directly linked to the couple's communication and interaction. The couple's distancing, whether affective, geographical, or physical can contribute to reduce marital satisfaction [30, 31, 32].

Stressful Points During the Illness Trajectory

This study identified time points where participants reported the highest levels of stress for themselves. Waiting to find out what was wrong with their child, the actual cancer diagnosis, making treatment decisions, the start of treatment, hospitalizations and changing treatments were cited as the most stressful time points throughout the disease trajectory. This speaks to the importance of screening and supporting parents during these time periods. Hospitalizations and relapse were reported as most stressful to the relationship. Assessment of dyadic coping may therefore be most useful during these times.

Despite being recognized as a stressful time, the period between when the child became ill, and the time the cancer diagnosis was confirmed was also identified as time points when participants felt most emotionally connected to their partner. Asking about the bond that helped them cope together before the diagnosis may be an important reminder of how to cope during stressful times on treatment.

Participants also reported two specific time points when they felt the least emotionally connected to their partner. One of these time points was at the start of treatment. This is when families may be separated for lengthy periods of time and when anxiety concerning treatment outcomes and side effects comes to the forefront. Families may undergo periods of questioning their treatment decisions as they try to support their child who may be moody, sad, and uncooperative due to very unpleasant side effects [28]. The second time point when participants felt the least emotionally connected to their partner is at the completion of therapy. For parents who have put their problems ‘on hold’, this time can be particularly stressful. Changes and growth that have taken place in each family member should be discussed, encouraging an awareness of achievement while preparing the family for the challenges of long-term cancer survival [28]. Additionally, separation from the treatment team, on whom the family has depended for so long, may generate uneasiness in parents who may believe that not actively fighting the disease may make relapse more likely [33, 34]. Families require extra support and education at this junction [35, 36]. At the end of treatment, many parents could benefit from support transitioning and reintegrating back into activities that had been on hold.

Counseling as a Possible Intervention

The majority of parents were interested in counseling to address ways to support their relationship after their child is diagnosed with cancer. Soon after diagnosis was reported as the preferred time to offer services. As noted earlier, this is also when participants reported feeling most emotionally connected to their partners. Another suggested time point to offer intervention was during the child’s treatment. Perhaps teaching couples communication strategies and how to cope with stress more effectively soon after the diagnosis is made and offering ‘booster’ sessions during hospitalization and at other high stress times (e.g. relapse and end-of-treatment) could address new challenges, coping strategies, and ways to remain emotionally connected to one another. Importantly, along with the known stresses associated with childhood cancer, opportunities for relationship growth can occur. Compassionate communication and dyadic coping emerged as important mechanisms to manage stress and build cohesion in the relationship. Therefore, sessions should consider training in communication and dyadic coping strategies. Specifically, recognizing the partner’s emotional needs, helping each other reduce stress, and joint-problem solving were the most helpful dyadic coping strategies identified along with cherishing shared values and having external releases when coping with stressful situations.

Reported barriers to marriage/couple interventions include time, financial cost, and difficulty of exposing emotions. Interventions that can be offered as part of the child’s treatment, while the family is at the medical center and apart from home/work external stresses may help reduce these barriers. It was interesting that participants reported being able to attend a session at the same time as a barrier to a couples intervention, yet the majority of participants were not interested in an online interventions (“too impersonal”). Perhaps the first and last sessions being held face-to-face, with online sessions with the same therapist offered in between, can help balance the need for connection with the therapist and the time commitment.

Limitations

This study is limited by only English speaking participants, under representation of ethnic minorities, and over representation of mothers. While men were not equally represented, one third of the sample consisted of men, which is higher than most caregiver studies. Additionally, due to the cross sectional design, the data was dependent on recall and perception of the relationship prior to their child's cancer diagnosis. As usually only one parent accompanied the child to his/her hospital visit, only 27% of the cohort included both parents. Because of the resulting small sample size of couples, we did not conduct nested analyses. Nevertheless, this is the first study to identify specific events and partner behaviors that threaten and strengthen the couple's relationship during the childhood cancer trajectory. Approximately one third of the parents indicated that their children had completed treatment, indicating that the experiences of those undergoing treatment and those in survivorship were included in the same analysis. There were, however, no significant differences between these families on the RDAS scales.

Conclusion

The study data presents rich information for understanding what happens to parental relationships following a child's cancer diagnosis. Helping parents identify time points during the cancer trajectory when their relationship can be strengthened can be an important part of ongoing psychosocial care. Couples often lose their communication skills during stressful times [15]. Teaching couples communication strategies and how to cope with stress more effectively soon after the cancer diagnosis is confirmed may improve or maintain satisfaction with relationship quality. Prospective research is needed to better understand how childhood cancer affects caregiver's partnerships through survivorship and beyond.

Acknowledgments

This work is supported in part by the Intramural Research Programs of the NIH, National Cancer Institute, Center for Cancer. The authors have no conflict of interest to report. The authors acknowledge the support of several individuals who helped make this work possible. We thank Caitlyn Loucas, BA for helping with recruitment at Dana Farber Cancer Institute and Joan Galil, LCSW-C for helping with recruitment at the National Cancer Institute.

Mostly, we thank the participants for openly sharing their valuable time, experiences and opinions with us.

References

1. Ward E, DeSantis C, Robbins A, Kohler B, Jemal A. Childhood and adolescent cancer statistics. *CA Cancer J Clin.* 2014; 64(2):83–103. DOI: 10.3322/caac.21219 [PubMed: 24488779]
2. Long KA, Marsland AL. Family adjustment to childhood cancer: A systematic review. *Clin Child Fam Psychol Rev.* 2011; 14:57–88. DOI: 10.1007/s10567-010-0082-z [PubMed: 21221783]
3. Chesler MA, Parry C. Gender roles and/or styles in crisis: An integrative analysis of the experiences of fathers of children with cancer. *Qual Health Res.* 2001; 11(3):363–384. [PubMed: 11339080]
4. 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. DOI: 10.1111/j.1547-5069.2010.01360.x [PubMed: 20738735]
5. Schulz MS, Cowan PA, Cowan CP, Brennan RT. Coming home upset: Gender, marital satisfaction, and the daily spillover of workday experience into couple interactions. *J Fam Psychol.* 2004; 18(1): 250–263. [PubMed: 14992625]

6. Compas BE, Bemis H, Gerhardt CA, Dunn MJ, Rodriguez EM, Desjardins L, Preacher KJ, Manring S, Vannatta K. Mothers and fathers coping with their children's cancer: Individual and interpersonal processes. *Health Psycho.* 2015; 34(8):783–793. DOI: 10.1037/hea0000202
7. 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. DOI: 10.1093/jpepsy/jsr054 [PubMed: 21841187]
8. Corden A, Sloper P, Sainsbury R. Financial effects for families after the death of a disabled or chronically ill child: A neglected dimension of bereavement. *Child Care Health Dev.* 2002; 28(3): 199–204. [PubMed: 12027937]
9. Iobst EA1, Alderfer MA, Sahler OJ, Askins MA, Fairclough DL, Katz ER, Butler RW, Dolgin MJ, Noll RB. Problem solving and maternal distress at the time of a child's diagnosis of cancer in two-parent versus lone-parent households. *J Pediatr Psychol.* 2009; 34(8):817–821. DOI: 10.1093/jpepsy/jsn140 [PubMed: 19129268]
10. 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. DOI: 10.1200/JCO.2005.09.110 [PubMed: 16157936]
11. Norberg AL1, Lindblad F, Boman KK. Coping strategies in parents of children with cancer. *Soc Sci Med.* 2005; 60(5):965–975. [PubMed: 15589667]
12. Goldbeck L. Parental coping with the diagnosis of childhood cancer: Gender effects, dissimilarity within couples, and quality of life. *Psychooncology.* 2001; 10(4):325–335. [PubMed: 11462231]
13. Leavitt M, Martinson IM, Liu CY, Armstrong V, Hornberger L, Zhang JQ, Han XP. Common themes and ethnic differences in family caregiving the first year after diagnosis of childhood cancer: Part ii. *J Pediatr Nurs.* 1999; 14(2):110–122. [PubMed: 10337122]
14. Kars MC, Duijnstee MS, Pool A, van Delden JJ, Grypdonck MH. Being there: Parenting the child with acute lymphoblastic leukaemia. *J Clin Nurs.* 2008; 17(12):1553–1562. DOI: 10.1111/j.1365-2702.2007.02235.x [PubMed: 18482117]
15. Bodenmann G, Shantinath SD. The couples coping enhancement training (CCET): A new approach to prevention of marital distress based upon stress and coping. *Fam Relat.* 2004; 53(5): 477–484.
16. 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. DOI: 10.1002/pon.3617 [PubMed: 25045011]
17. Yeh CH. Gender differences of parental distress in children with cancer. *J Adv Nurs.* 2012; 38(6): 598–606.
18. 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]
19. Hoekstra-Weebers JEHM, Heuvel F, Jaspers JPC, Kamps WK, Klip EC. Brief Report: An Intervention Program for Parents of Pediatric Cancer Patients: A Randomized Controlled Trial. *J Pediatr Psychol.* 1998; 23(3):207–214. [PubMed: 9640900]
20. Lavee Y. Correlates of change in marital relationships under stress: The case of childhood cancer. *Fam Soc.* 2005; 86(1):112–120. DOI: <http://dx.doi.org/10.1606/1044-3894.1883>.
21. Bodenmann, G. Dyadic coping and its significance for marital functioning. In: Revenson, TA, Kayser, K., Bodenmann, G., editors. *Couples coping with stress: Emerging perspectives on dyadic coping.* Washington: American Psychological Association; 2005. p. 33-39.
22. Bodenmann, G. New themes in couple therapy: The role of stress, coping, and social support. In: Hahlweg, K, Grawe, M., Baucom, DH., editors. *Enhancing couples. The shape of couple therapy to come.* Cambridge: Hogrefe Publishing; 2010. p. 142-156.
23. Spanier GB. Measuring dyadic adjustment: New scales for assessing the quality of marriage and similar dyads. *J Marriage Fam.* 1976; 38:15–28.
24. Busby DM, Christensen C, Crane DR, Larson JH. A revision of the Dyadic Adjustment Scale for use with distressed and nondistressed couples: Construct hierarchy and multidimensional scales. *J Marital Fam Ther.* 1995; 21:289–308. DOI: 10.1111/j.1752-0606.1995.tb00163.x

25. Gottman, JM. The marriage clinic: A scientifically based marital therapy. New York, NY: W. W. Norton; 1999.
26. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006; 3:77–101. <http://dx.doi.org/10.1191/1478088706qp0630a>.
27. Bodenmann G, Ledermann T, Bradbury TN. Stress, sex, and satisfaction in marriage. *Pers Relatsh*. 2007; 14(4):551–569. DOI: 10.1111/j.1475-6811.2007.00171.x
28. Wiener, L., Alderfer, M., Pao, M. Psychiatric and Psychosocial Support for Child and Family. In: Pizzo, PA., Poplack, DG., editors. *Principles and Practice of Pediatric Oncology*. 7. Philadelphia: Lippincott; 2015. p. 1124–1140.
29. Wiener L, Pao M, Zadeh S, et al. Socio-environmental factors associated with lone parenting chronically ill children. *Child Health Care*. 2013; 42(3):264–280.
30. Silva-Rodrigues FM, Pan R, Sposito AMP, Alvarenga WA, Nascimento LC. Childhood cancer: Impact on parents' marital dynamics. *Eur J Oncol Nurs*. 2016; 26:34–42. DOI: 10.1016/j.ejon.2016.03.002
31. Lavee Y, Mey-Dan M. Patterns of change in marital relationships among parents of children with cancer. *Health Soc Work*. 2003; 28:255–63. [PubMed: 14679704]
32. Khoury MN, Huijter HA, Doumit MA. Lebanese parents' experiences with a child with cancer. *Eur J Oncol Nurs*. 2013; 17(1):16–21. DOI: 10.1016/j.ejon.2012.02.005 [PubMed: 22456333]
33. Björk M, Nordström B, Wiebe T, et al. Returning to a changed ordinary life—families' lived experience after completing a child's cancer treatment. *Eur J Cancer Care*. 2011; 20:163–169. DOI: 10.1111/j.1365-2354.2009.01159.x
34. McKenzie SE, Curle C. "The end of treatment is not the end": parents' experiences of their child's transition from treatment for childhood cancer. *Psycho-Oncology*. 2012; 21:647–654. DOI: 10.1002/pon.1953 [PubMed: 21394822]
35. Wakefield CE, Butow P, Fleming CAK, et al. Family information needs at childhood cancer treatment completion. *Pediatr Blood Cancer*. 2012; 58:621–626. DOI: 10.1002/pbc.23316 [PubMed: 21910212]
36. Ringner A, Jansson L, Graneheim UH. Parental experiences of information within pediatric oncology. *J Pediatr Oncol Nurs*. 2011; 28(4):244–251. DOI: 10.1177/1043454211409587 [PubMed: 21653912]

Figure 1.
Relationship quality before and after diagnosis

Figure 2.
Time points did you feel most/least emotionally connected to your partner

Figure 3.
Issues most stressful to participant

Table 1

Demographic Characteristics (N = 192)

Characteristic	n (%)
Site	
1	115 (59.9)
2	50 (26.0)
3	27 (14.1)
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)
Parent Education	
Less than/Some High School	6 (3.1)
High School Graduate	24 (12.5)
Some College	66 (34.4)
Bachelors Degree	54 (28.1)
Masters/Doctoral Degree	34 (17.7)
Other	8 (4.2)
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 years (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)
Treatment Status	
On active treatment	64.6%
Completed treatment	35.4%

Characteristic	n (%)
Parent Race/Ethnicity ³	
Hispanic	18 (19.4)
Non-Hispanic White	151 (78.6)
Non-Hispanic Black/African American	8 (4.2)
Non-Hispanic Asian	7 (3.6)
Non-Hispanic American Indian/Alaskan Native	4 (2.1)
Child Race/Ethnicity ³	
Hispanic	19 (9.9)
Non-Hispanic White	149 (77.6)
Non-Hispanic Black/African American	8 (4.2)
Non-Hispanic Asian	6 (3.1)
Non-Hispanic American Indian/Alaskan Native	6 (3.1)
Is Your Partner the Parent of the Child with Cancer	
Yes	168 (87.5)
No	24 (12.5)
Are there other children in the household?	
Yes	166 (86.5)
No	26 (13.5)
Time Apart for Child's Treatment	
Never	43 (22.4)
1–2 days/month	47 (24.5)
1–2 weeks/month	30 (15.6)
1–3 months/year	39 (20.3)
3 months per year or more	33 (17.2)

¹Includes 1 stepmother, 1 foster mother and 1 stepfather

²Other includes Melanoma, Diffuse Intrinsic Pontine Glioma, Gastrointestinal Stromal Tumor, Anaplastic Ependynoma, Wilm's tumor, Desmoplastic Small Round Cell Tumor, Mesothelioma

³Four participants are missing race/ethnicity information

Table 2

How much of the time you have “Almost always”/“Always”/“Often” felt the following **BEFORE & AFTER** your child’s diagnosis.

	Before	After
Feeling lonely in the marriage **	14.1%	33.9%
Feeling a sense of togetherness in the marriage **	70.8%	54.7%
Experience degree of intimacy/sexual relationship **	60.4%	39.1%
Able to make decisions together **	58.3%	62.0%
Anger *	17.7%	32.3%
Tension/stress between partner and self **	17.7%	37.5%
Able to communicate about child’s needs **	75.0%	69.8%

*
p <.01

**
p<.001