Parenting a child with cancer: a couple-based approach

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Abstract

Couples co-parenting a child with cancer face significant stressors that can adversely affect their couple relationship. How parents respond as a couple may affect the psychological adjustment of each parent and the child, as well as the ability of the family to cope with the child's illness. The purpose of this study was to assess the feasibility and acceptability of a couple-based intervention for parents of children with cancer. We conducted a randomized pilot intervention study ($N = 21$ couples randomized with a 2:1 allocation to the couple-based intervention or education control) testing a six-session, telephone-based intervention that trained couples in relationship skills to help them care for their child, strengthen their relationship, and support each other. We examined feasibility and acceptability of the intervention to the parents. In this study, 56% of eligible couples agreed to participate; 82% of randomized couples completed post-intervention surveys, and 62% completed all six sessions. Satisfaction with the intervention was high (mean = 3.3 on a 4-point scale). Changes in both groups were small in magnitude and mixed in direction, with some outcomes favoring the couple-based intervention and other favoring the education condition. Supporting couples is important to optimize individual and parental functioning when a child has cancer. However, there are significant challenges to delivering couple-based interventions to these parents. More research is needed to establish optimal timing and content of couple-based interventions for these parents as well as feasible methods of delivery.

Keywords

Pediatric cancer, Couples, Parents, Intervention

INTRODUCTION

Couples who have a child with cancer face multiple and pervasive stressors from the time of the child's diagnosis, through treatment, and beyond. For couples in two-parent families, the challenges associated with childhood cancer can be grouped into three broad domains. First, parents must care for the physical and emotional needs of their sick child. These challenges are well documented and a source of significant stress for parents. Even after treatment is complete, parents often face ongoing challenges because of late occurring and long-term treatment effects that can have negative effects in multiple domains of the child's life [1–7]. Second, parents are coping with their own individual distress about the child's condition. Clinical levels of psychological distress as well as feelings of helplessness and uncertainty are common in both mothers and fathers and

Implications

Practice: Couples who are parents of children with cancer may benefit from interventions to strengthen their relationship and ability to support each other.

Policy: Effective psychosocial care for the families of children with cancer should include support for the parents' couple relationship.

Research: Future research is needed to establish optimal timing and content of couple-based interventions for parents of children with cancer, as well as feasible methods of delivery.

can persist over time [1,8–12]. Finally, parents must attend to their relationship with their partner that can be negatively affected by having a child with cancer [13–17].

Although there has been considerable research focused on parents' (and particularly mothers') individual adjustment to having a child with cancer, the impact on the parents' couple relationship has received less attention. A recent systematic review of studies that assessed couple functioning following a pediatric cancer diagnosis concluded that most couples adapted well in terms of their general marital satisfaction and adjustment, but that some reported increases in conflict as well as difficulties in the domain of sexual intimacy [18]. The review also noted significant limitations in the research, including small and heterogeneous samples, lack of assessment of both members of the couple, and the fact that only half the studies included quantitative data.

In a subsequent study using a mixed-methods design, Wiener et al. [19] studied 192 parents of children with cancer and assessed the perceived impact of childhood cancer on the parents' couple relationship. They found that over half of the participants reported that their relationship was challenged since the child's diagnosis; 40% felt that their relationship worsened in that time, and over a third scored low on dyadic adjustment. Frequently reported relationship challenges included not being able to spend time together, difficulties talking about stresses together in

a helpful manner, and listening and understanding each other's thoughts and feelings. Other recent studies found that a third of couples reported marital distress at one time point during the first year of pediatric cancer treatment [20], and that marital distress resulted in later increases in parent-child conflict [21].

Taken together, the research indicates that although many couples are resilient, having a child with cancer poses challenges to their couple relationship, which can spill over to other members of the family. Interestingly, however, there has been little if any research examining associations between couple functioning, individual parental functioning, and child and/or family functioning in the context of childhood cancer. Research from the broader literature on marital and family functioning has consistently demonstrated that when couples are unhappy in their relationship, both individual partners are more likely to be distressed [22,23], and their children are more likely to show poor health, psychological distress, and behavior problems [24–28]. Findings among noncancer pediatric populations also indicate that family conflict is associated with detrimental medical outcomes (e.g., poor adherence and metabolic control among children with diabetes [29]). Thus, it is likely that the way in which parents work together *as a couple* to meet the challenges of having a child with cancer will affect their own adjustment as well as that of their child and family.

Given the negative impact of childhood cancer on couples' relationships and the central role of couple functioning in helping the family adjust to a child's cancer, interventions that promote and strengthen parents' relationships may alleviate distress in both members of the couple and perhaps even in their child(ren) [13]. A number of researchers have recommended interventions to support couple's relationships in the context of pediatric cancer [19,20,30], and in one study the majority of couples surveyed reported that they would be interested in couple counseling [19]. However, to date, there have been no studies testing the feasibility or acceptability of a couple-based intervention for these parents.

Cognitive-behavioral couple-based interventions have been shown to significantly improve couples' relationships and the individual adjustment of both partners [22,31]. There is also evidence that they can positively affect child and family functioning [32]. In addition, cognitive-behavioral couple-based interventions emphasize relationship skills, such as providing each other with support and improving communication, which couples have identified as particular challenges when a child has cancer [19]. Thus, it is likely that cognitive-behavioral principles could be adapted to create a novel and efficacious couple-based intervention in the context of childhood cancer.

The aim of this study was to examine the feasibility and acceptability of a couple-based intervention for parents of children with cancer. We developed a six-session cognitive-behavioral couple-based intervention to address the specific needs of couples who are parents of children with cancer. We hypothesized that the intervention, delivered by telephone, would be feasible and acceptable to couples.

METHOD

Participants

Couples were included if (a) they were parents of a child (age ≤ 17 years) who had a first diagnosis of leukemia, lymphoma, solid tumor, or brain tumor; (b) the child was currently undergoing treatment with chemotherapy and/or radiation; (c) the couple was married or in a committed relationship (including opposite- and same-gender parents, stepparents, foster parents, adoptive parents, and partnered grandparents); and (d) both partners were willing to participate, at least age 18, and could speak and read English. On the basis of previous experience suggesting the difficulty of recruiting families into psychosocial research studies close to the time of diagnosis [33], we did not approach couples until at least 3 months after the child's diagnosis. Parents of children receiving palliative care were excluded.

Procedures

All procedures were approved by the Institutional Review Board at Duke University School of Medicine. Couples were recruited from the Duke University Medical Center Divisions of Pediatric Neuro-Oncology and Pediatric Hematology-Oncology. Potential participants were introduced to the study by their health care provider, either in person or via an introductory letter. Couples who agreed to participate were consented on the telephone using a standardized institutional review board-approved protocol and completed written consent via mail.

Following consent, participants completed the baseline questionnaires. They were then randomly assigned with 2:1 allocation to (a) Couple-Based Relationship Enhancement (CBRE) or (b) Education. The statistician generated the randomization sequences and informed the Project Coordinator of the treatment condition to be assigned to the couple. Couples then participated in six biweekly telephone sessions as described later. At the end of the 12-week treatment protocol, all participants completed the posttreatment assessment. All assessments were conducted via mail (self-report questionnaires) and telephone (couple conversations; not described here). Participants received \$50 at each assessment.

Measures

Relationship functioning

Relationship functioning was assessed using the (a) Dyadic Adjustment Scale (DAS) and (b) Support Satisfaction subscale of the Source-Specific Social Provisions Scale. The DAS [34] is the most widely used self-report measure of global marital adjustment. The DAS has demonstrated excellent validity [31] and internal consistency [35]. It is worded in a manner that makes it applicable to both unmarried and married couples. The Source-Specific Social Provisions Scale [36] is a 12-item inventory adapted from a broader Social Provisions Scale [37] that assesses perceived frequency of and satisfaction with social support from romantic partners. For the current study, we used the six-item scale assessing satisfaction with support received.

Individual partner functioning

Individual partner functioning was measured using the Parent Experience of Childhood Illness scale (PECI) and the Posttraumatic Growth Inventory. The PECI assesses each partner's illness-specific adjustment to their child's cancer, including both subjective distress and perceived emotional resources [38,39]. The PECI has been used with parents of children undergoing cancer treatment as well as parents of cancer survivors [39–41] and of children with other medical problems [42,43]. There are four subscales: Guilt and Worry, Emotional Resources, Unresolved Sorrow and Anger, and Long-term Uncertainty. The Posttraumatic Growth Inventory [44] was developed to measure positive growth that occurs as a result of a traumatic event. It has been used in a wide variety of populations including parents of children with cancer [45,46].

Couples' parental functioning

Couples' parental functioning was measured using the (a) General Parenting Alliance subscale of the Family Experiences Questionnaire [47] and (b) Parenting Self-efficacy. The General Parenting Alliance subscale of the Family Experiences Questionnaire evaluates partners' perception of the degree of mutual respect and support in the co-parenting relationship and their satisfaction with shared values and goals for parenting. Internal consistency for this subscale is excellent ($\alpha = 0.95\text{--}0.96$) [48]. Parenting self-efficacy was measured using an adapted version of the Caregiver Appraisal Scale [49]. The Caregiver Appraisal Scale is a six-item scale that assesses caregivers' perceived ability to handle stressors related to their child's illness. We adapted the scale to a couples' context by modifying the stem to assess self-efficacy to work together with one's partner. For example "How confident are you that you can make decisions about your child's medical treatment?" became "How confident are

you that, together with your partner, you can make decisions about your child's medical treatment?"

Treatment acceptability

Parents completed the Client Satisfaction Questionnaire (CSQ-8 [50]) posttreatment as a measure of treatment acceptability. Additional questions assessed the convenience of the telephone format, reactions to the number and length of sessions, and aspects of the intervention that they found most and least helpful (open ended).

Interventions

General factors

Both interventions involved six, 60 min biweekly telephone sessions conducted with the two parents together. Content of the sessions for each intervention is described in Table 1. Therapists were two master's level social workers experienced in working with couples in the context of cancer. Sessions for both treatment conditions included both didactic and experiential components, and information was summarized in handouts given to the couple. Several steps were taken to ensure that the treatment protocols and delivery were uniform. First, therapists received training in the protocols by the study investigators (L.S.P., D.H.B., and A.E.K.). Therapists followed detailed treatment manuals for each session. All sessions were audio recorded, reviewed by the study investigators, and discussed with the therapists in biweekly supervision sessions.

Couple-Based Relationship Enhancement

The CBRE intervention was adapted from previous interventions that we have tested in couples in which one of the adult partners has cancer [51,52]. It systematically trained couples in a variety of relationship skills to address their cancer-related roles in three domains: (a) attending to their own relationship as a couple, (b) supporting each partner as an individual, and (c) caring for the emotional and physical needs of their child with cancer. In each domain, couples were assisted in finding a balance between managing the stresses of cancer and increasing positive aspects of life. Although the relationship skills taught were the same for all couples, the couples themselves chose which specific issues to discuss in each session, thereby ensuring that the intervention was applicable to all couples despite variations in factors such as the child's developmental stage. Following each session, the couple was given home practice assignments focusing on ways to incorporate material from the session into daily life.

Education

Sessions provided couples with (a) information, resources, and recommendations on topics relevant to their child's treatment and recovery (e.g., sleep,

Table 1 | Intervention content

Session	Couple-Based Relationship Enhancement	Education
1	Rationale for addressing childhood cancer from a couple's perspective Overview of intervention content Couple tells their story, including how the family has been affected by cancer	Overview of intervention content Discussion of educational resources (websites and institutional) Couple tells their story
2	Teaches communication skills for sharing thoughts and feelings, along with effective listening skills Couple applies skills to discussing their roles as parents, emphasizing concerns, hopes, and wishes regarding their child who has cancer	Fatigue: describe signs, symptoms, and causes of fatigue in both parents and children; information on strategies for managing fatigue relevant to both parents and children
3	Teaches communication skills for problem-solving/decision-making Couple applies skills to make decisions about issues regarding parenting their child with cancer (e.g., educational needs, peer relationships, physical issues, emotional concerns of the child, future medical treatment)	Sleep: describe the importance of sleep and its role in maintaining quality of life for both parents and children; describe causes of sleep disturbance; provide strategies for helping children and parents with sleep difficulties
4	Discuss effect of cancer on the couple's relationship Couple applies communication skills with a focus on addressing issues or concerns regarding their relationship (e.g., finding time together as a couple, rethinking roles/responsibilities, finding time for enjoyable activities)	Nutrition: provide description of nutrition's role in health maintenance for both parents and children; present nutritional guidelines and suggestions for healthy eating; identify appropriate goals to improve family's diet
5	Discuss each partner's individual needs and coping Couple applies communication skills with a focus on how they can support each other as individuals	Physical activity: provide description of physical activity's role in health maintenance for both parents and children; present guidelines for physical activity in adults and children; identify appropriate ways to incorporate physical activity into the family's routine.
6	Address remaining issues related to supporting the couple's relationship or each other as individuals Review material from previous sessions Discuss what the couple will likely need to address in the future	Review material from Sessions 1–5 and address remaining issues Discuss how parents can obtain information to address additional concerns they anticipate relative to their child's cancer survivorship

nutrition, physical activity; see Table 1), and (b) the opportunity to discuss their experiences with these aspects of their child's illness while receiving support from the therapist. These sessions were conducted by the same therapist who delivered CBRE. No specific relationship skills taught in CBRE were included in the Education condition.

Statistical analyses

This was an exploratory pilot study meant to assess preliminary feasibility and acceptability [53]. As such, a sample size calculation was not performed. We measured key outcome domains for completion rates, estimates, and 95% confidence intervals between the control and intervention groups. As recommended by guidelines for pilot studies with small sample sizes [54,55], we did not conduct statistical tests of group differences.

RESULTS

Participants

Participants were 21 heterosexual couples. On average, mothers were 37.6 years old ($SD = 5.3$) and fathers were 40.4 ($SD = 8.8$). Seventy-five percent

were Caucasian. Families had an average of 2.5 children ($SD = 1.0$, range = 1–4). The children with the cancer diagnosis were on average 8.1 years ($SD = 5.3$). Fifty-five percent were male. Thirty-eight percent were diagnosed with leukemias, 24% with central nervous system malignancies, 14% with a sarcoma, and 24% other cancers. The median time since diagnosis was 15 months (range = 3–54 months).

Study enrollment and participation

A total of 71 patients (children) were prescreened and their parents were approached about participation (see Fig. 1). Of these, 21 were deemed ineligible, 24 declined, and 28 couples (56% of those eligible) agreed to participate. Seven couples withdrew after randomization, one because of the child's disease progression, three because of competing demands (e.g., moving, death of another family member), and three were lost to contact. Twenty-one couples completed the baseline assessment and were randomized, 15 to the CBRE intervention and 6 to the Education control condition. Among those randomized, 62% (13 of 21) received all 6 intervention sessions. Eighty-one percent of couples randomized (17 of 21) completed the post-test assessment. Of the four couples

Fig 1 | Pilot intervention study consort.

who did not complete the post-test assessment, three had experienced a recurrence of their child's disease, and one couple was lost to contact following randomization and before starting the intervention; notably, this couple reported extremely high marital distress on the DAS at baseline.

Acceptability

Examination of responses on the post-intervention satisfaction survey indicated an overall mean satisfaction rating of 3.32 ($SD = 0.52$) on a 0–4 scale. Means by parent and treatment condition are shown in Table 2. Overall, 86% thought the number of sessions (6) was about right; 100% thought that the length of the sessions (45–60 min) was about right; and 92% thought that the telephone sessions were “mostly” or “very” convenient.

Participant comments regarding the most and least helpful aspects of the interventions are shown in Table 3. Participants in the education condition noted that they found it helpful to come together and talk about their situation with a supportive and skilled therapist. One parent commented favorably about the content of the sessions, including the practical advice. However, another reported that much of the content was not relevant to the current phase of their child's cancer treatment and would have been more helpful at the very beginning of treatment. Among participants in the CBRE condition, the majority of favorable comments (9 of 11) focused on some aspect of communication, including the time set aside to have conversations, the skills training,

and the feedback provided by the therapist. Several participants also commented favorably on the flexibility afforded by the telephone format. Aspects of the program that were least helpful included the exclusive focus of the intervention on the couple relationship rather than the parent–child relationship, and the fact that six sessions was not enough time to deal with some difficult issues. One participant also commented that it came too late after diagnosis.

Outcome domains

Means on outcome variables are shown in Table 2. Mean difference scores suggest that fathers in the education intervention reported greater improvements in relationship adjustment, individual adjustment, and parental functioning than fathers in the CBRE arm. Among mothers, findings were mixed, with those in the CBRE arm reporting greater improvements in most measures of individual adjustment as well as parenting self-efficacy, whereas mothers in education reported greater improvements in dyadic adjustment and parenting alliance. Overall, changes in both groups were small in magnitude. Analyses performed including only those couples who attended at least three of six intervention sessions ($n = 9$ CBRE, $n = 5$ Education) yielded similar findings.

DISCUSSION

A small but growing literature suggests the importance of couples' relationship functioning in the

Table 2 | Means and 95% confidence interval (CI) on study measures

	Mothers			Fathers		
	CBRE (n = 15) Mean (95% CI)	Education (n = 6) Mean (95% CI)	Difference ^a Mean (95% CI)	CBRE (n = 15) Mean (95% CI)	Education (n = 6) Mean (95% CI)	Difference ^a Mean (95% CI)
DAS						
Baseline	114.3 (99.7, 129.0)	129.5 (114.5, 144.5)	-1.3 (-11.7, 6.5)	116.1 (103.3, 129.0)	122.3 (110.0, 134.6)	-9.6 (-44.5, 22.1)
Post	119.3 (108.7, 129.9)	132.8 (119.7, 145.9)		113.9 (88.3, 139.5)	130.2 (119.5, 140.9)	
Partner support						
Baseline	2.9 (2.3, 3.5)	3.2 (2.8, 3.7)	0.2 (-0.7, 0.6)	3.1 (2.6, 3.6)	2.9 (1.8, 4.0)	-0.4 (-1.1, 0.4)
Post	3.1 (2.6, 3.7)	3.2 (2.6, 3.9)		3.4 (3.1, 3.7)	3.6 (3.1, 4.0)	
Guilt/Worry						
Baseline	2.0 (1.6, 2.4)	1.4 (0.5, 2.2)	-0.2 (-4, 0.2)	1.3 (1.0, 1.6)	1.2 (0.6, 1.8)	0.0 (-0.5, 0.4)
Post	1.5 (1.2, 1.9)	1.4 (0.4, 2.4)		1.3 (0.7, 1.8)	1.1 (0.3, 1.9)	
Sorrow/Anger						
Baseline	1.8 (1.3, 2.2)	1.0 (0.4, 1.6)	-0.2 (-0.6, 0.3)	1.1 (0.8, 1.4)	1.1 (0.4, 1.8)	-0.0 (-0.6, 0.4)
Post	1.5 (1.0, 1.9)	0.8 (0.2, 1.4)		0.9 (0.6, 1.4)	0.8 (-0.1, 1.6)	
Uncertainty						
Baseline	1.7 (1.2, 2.3)	1.2 (0.4, 1.9)	0.1 (-0.5, 0.4)	1.2 (0.8, 1.6)	1.1 (0.4, 1.8)	0.2 (-0.3, 0.3)
Post	1.5 (0.9, 2.1)	0.9 (0.3, 1.6)		1.2 (0.7, 1.8)	0.84 (-0.2, 1.8)	
Emotional resources						
Baseline	2.7 (2.3, 3.0)	3.2 (2.7, 3.7)	0.0 (-0.7, 0.5)	3.0 (2.7, 3.2)	2.8 (2.1, 3.5)	-3 (-1.5, 0.8)
Post	2.9 (2.5, 3.2)	3.2 (2.3, 4.1)		2.8 (2.0, 3.5)	2.9 (1.8, 3.9)	
Posttraumatic growth						
Baseline	62.8 (50.8, 74.8)	74.5 (55.0, 94.0)	4.5 (-12.9, 11.0)	57.6 (44.5, 70.7)	66.0 (50.4, 81.6)	0.1 (-13.9, 8.9)
Post	69.3 (61.0, 77.5)	81.0 (59.0, 102.9)		57.4 (41.0, 73.9)	65.6 (51.8, 79.4)	
Parenting alliance						
Baseline	104.7 (95.3, 114.0)	109.5 (98.0, 121.0)	-2.5 (-12.6, 6.4)	110.4 (104.0, 116.8)	111.7 (105.1, 118.2)	-4.2 (-16.8, 8.0)
Post	110.0 (102.6, 117.4)	113.8 (101.8, 125.8)		110.8 (101.3, 120.3)	115.6 (106.9, 124.3)	
Parenting self-efficacy						
Baseline	85.9 (80.7, 91.0)	91.4 (83.2, 99.5)	6.2 (-2.3, 5.4)	84.9 (76.5, 93.2)	80.8 (71.1, 90.6)	-5.0 (-16.3, 6.9)
Post	87.4 (81.6, 93.2)	89.7 (80.1, 99.2)		83.5 (76.1, 90.9)	87.3 (76.3, 98.3)	
Treatment credibility						
Post ^b	3.4 (3.0, 3.8)	3.2 (2.3, 4.0)		3.34 (2.8, 3.8)	3.4 (2.6, 4.0)	

DAS Dyadic Adjustment Scale.

^aThis is the difference of Couple-Based Relationship Enhancement (CBRE) versus education on change score (post minus baseline on study measures) where positive difference means indicate CBRE group improved more on measure than Education group.^bFor treatment credibility post, scores, n was 12 for mothers and fathers in the CBRE arm and 5 for mothers and fathers in the Education arm.

Table 3 | Participants’ comments on open-ended questions regarding the most/least helpful aspects of the interventions

Education	
Most helpful	Least helpful
Things of practical importance, such as diet and nutrition advice. (F)	The necessary pace. (F)
Talking out issue of concern—open dialogue. (F)	Almost all the information we already knew or have/had dealt with earlier in our child’s treatment.
That you can come together and talk about the situation. (F)	Therefore, the program didn’t seem relevant to our current phase of cancer treatment. (M)
Talking to the therapist (she’s great) about simply remembering to take care of yourself. (M)	There was nothing in the study that were least helpful. (M)
I feel all of them were helpful. I would definitely encourage the fathers to speak as sometimes are more secretive with our feelings. (F)	
The therapist was terrific! We will miss talking with her. (M)	
Couple-Based Relationship Enhancement	
Most helpful	Least helpful
Learning how to approach a conversation with spouse in this time period. Most of all of our conversations were helpful. (F)	It was really hard to find definite time to do them, and that’s due a lot to us being so epically unorganized. (M)
We loved the phone conversations with each other . . . when we did get time to have a conversation it was very helpful. (M)	The notebooks/folder. They are good but felt a little incomplete. (M)
Setting time aside to converse with my partner—being intentional; having guidelines about how to have a productive discussion. (F)	I really do not have any areas that were not helpful. (M)
How flexible the therapist was to meet us on phone late at night after kids in bed. (M)	I wish the service was geared actually to my son who has cancer or even his brother. I feel they would have benefitted a lot as well. (F)
The focus on communication regarding about our child’s care and our relationship with one another. This aspect was successful in large part due to the excellent facilitation by the therapist. (F)	Six weeks is not long enough. It opens up wounds and then the program is over just as you start to deal with them. It came too late from diagnosis. (M)
I very much appreciated the opportunity to participate via the phone—we would not have been able to participate otherwise. Also, I feel that the therapist was very insightful into our relationship and communication struggles. Her feedback was always helpful. (M)	Really could use this better as a parent/child focused session. These kids need more psychological treatment. Parenting these kids is very challenging.
Having a third person to help me and my wife communicate with each other. We were very comfortable having conversations with each other while on the phone with our counselor. (F)	Balancing rules, school, homework, etc. (M)
Learning how to be a more effective listener, staying focused on a particular topic, learning what type of conversation we need to have and when. (M)	
The one-on-one attention and ability to do the program over the telephone. (F)	
Understanding my partner better. (M)	
Having some guided discussions. (M)	

context of parenting a child with cancer, and a number of researchers have recommended couple-based interventions to strengthen the couple relationship and enhance their ability to support each other and meet the demands of parenting their child with cancer [19,20,30] To our knowledge, this is the first study to test the feasibility and acceptability of a couple-based intervention to parents of children with cancer. Findings were mixed. Fifty-six percent of eligible couples enrolled in the study and completed baseline assessment, an enrollment rate that compares favorably with those of couple-based intervention studies involving adult patients with cancer (generally 25%–50%; [52,56,57]). This suggests that couples are interested in interventions that help support and strengthen their relationships. However, only 62% of randomized couples completed all six sessions, a rate significantly lower than we have found in couple-based studies with adult patients when interventions are conducted by telephone or video-conference [56,58].

Couples commented favorably on the telephone format of the sessions and the flexibility of scheduling sessions in the evenings and weekends to accommodate couples’ schedules. Nonetheless, many found it difficult to make time together to participate in the sessions. This likely speaks to the chaotic nature of family life, the competing and unrelenting demands associated with caring for a child with cancer, and the priority that those demands take over any other commitments. In contrast to couples coping with cancer in one of the adult partners, many of whom do not have young children or active careers, many of these couples were juggling the responsibilities of caring for several young children and traveling to and from the medical center, while at least one parent was working at a paid job. Although we attempted to minimize the burden associated with participation in the research study by conducting assessments by mail and interventions sessions by telephone, multiple sessions requiring the joint participation of both partners may not be feasible for many couples.

With regard to the intervention effects, it was surprising that fathers in particular seemed to benefit more from the education condition than the relationship enhancement intervention. These findings are very preliminary given the very small sample and lack of a standard care control group. However, it is possible that the relationship enhancement intervention was perceived as more burdensome because of the focus on learning and practicing relationship skills, including home practice assignments between sessions. The CBRE intervention was also more emotionally intense as it entailed couples sharing their thoughts and feelings about the child's cancer and its effect on them. In contrast, in the education condition, couples spent time together in a supportive environment and discussed ways to care for themselves and their children. This may have also contributed to higher attendance rates in the education condition. However, it is noteworthy that many parents in the CBRE condition, including both mothers and fathers, reported that the communication skills training and facilitated conversations were the most helpful aspect of the program.

Overall, our findings point to several key questions for the development of future couple-based interventions for parents of children with cancer with regard to the optimal timing, mode of delivery, and content. Regarding timing, parents in one study reported that they would like to receive couple counseling soon after child's diagnosis or during their child's treatment [19]. In our study, couples were recruited during their child's treatment, although we deliberately did not approach families until at least 3 months after diagnosis based on previous experience that recruiting families earlier than this was problematic [33]. Nonetheless, some parents in our study reported that they thought it would have been more helpful closer to the time of diagnosis. Future studies may want to consider strategies to engage parents shortly after diagnosis in ways that minimize burden (e.g., minimal assessment and a brief introductory session), with additional assessment and sessions conducted at intervals throughout the child's treatment.

Regarding the format of treatment delivery, parents in our study appreciated the flexibility afforded by the telephone sessions. Although it is possible that the less personal nature of the intervention may have contributed to low attendance, it is more likely that attendance was influenced by the competing demands of caring for their child with cancer. In one study, parents who were surveyed reported that they preferred an in-person format delivered in the hospital [19]. However, our experience and that of others suggest this is likely not feasible for the majority of couples. Videoconference may be a good option as it retains the flexibility of telephone sessions but enhances connection with the therapist. We have used videoconference successfully in

previous studies to deliver couple-based interventions to adults with cancer [56]. To address conflicting desires for and abilities to participate in intervention, we would suggest a hybrid model in which an initial session is delivered in person with the couple at the hospital (ideally as part of the child's routine care), followed by telephone or videoconference sessions.

With regard to intervention content, our relationship enhancement intervention was guided by cognitive-behavioral principles and contained elements of empirically validated cognitive-behavioral couple therapy. We have found evidence of efficacy for similar interventions tested in couples where one partner is diagnosed with cancer [52,56]. Previous research on couple functioning in the context of childhood cancer have also pointed to the potential importance of interventions that teach skills for effective communication, recognizing partners' emotional needs, and joint problem solving [19]. Parents in the intervention also commented favorably on the focus on communication. Given the small sample size of this study, it is too early to conclude that the content of the intervention was ineffective. However, the suggestion that the control condition may have been helpful, particularly for fathers, is also noteworthy. For some couples, spending time together in a supportive environment, and encouraging self-care, may be sufficient. Future studies may want to screen couples for evidence of difficulties in communication and support before assigning them to a skills-based intervention, and/or use stepped care approaches. An intervention that combines relationship skills with psychoeducation may also be beneficial as it may meet the needs of a range of couples and perhaps be more helpful for fathers than an intervention that focuses on relationship skills alone. However, the potential benefits of this approach would need to be balanced against the additional time it would take.

In summary, this study provides a number of lessons learned in the implementation of a couple-based intervention for parents of children with cancer. Future research is needed to determine how to deliver such interventions effectively so as to support couples and families in the context of childhood cancer.

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Compliance with Ethical Standards

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Ethical Approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The study was approved by the Duke Medical Center IRB.

Informed Consent: Informed consent was obtained from all individual participants included in the study.

References

1. Stam H, Grootenhuys MA, Brons PP, Caron HN, Last BF. Health-related quality of life in children and emotional reactions of parents following completion of cancer treatment. *Pediatr Blood Cancer*. 2006;47(3):312–319.
2. Butler RW, Mulhern RK. Neurocognitive interventions for children and adolescents surviving cancer. *J Pediatr Psychol*. 2005;30(1):65–78.
3. Oberfield SE, Sklar CA. Endocrine sequelae in survivors of childhood cancer. *Adolesc Med*. 2002;13(1):161–169, viii.
4. Boman KK, Bodegård G. Life after cancer in childhood: Social adjustment and educational and vocational status of young-adult survivors. *J Pediatr Hematol Oncol*. 2004;26(6):354–362.
5. Gurney JG, Krull KR, Kadan-Lottick N, et al. Social outcomes in the Childhood Cancer Survivor Study cohort. *J Clin Oncol*. 2009;27(14):2390–2395.
6. Hays DM, Landsverk J, Sallan SE, et al. Educational, occupational, and insurance status of childhood cancer survivors in their fourth and fifth decades of life. *J Clin Oncol*. 1992;10(9):1397–1406.
7. Katz E, Rubinstein CL, Hubert NC, Blew A. School and social integration of children with cancer. *J Psychosoc Oncol*. 1988;6:123–140.
8. Patiño-Fernández AM, Pai AL, Alderfer M, Hwang WT, Reilly A, Kazak AE. Acute stress in parents of children newly diagnosed with cancer. *Pediatr Blood Cancer*. 2008;50(2):289–292.
9. Maurice-Stam H, Oort FJ, Last BF, Grootenhuys MA. Emotional functioning of parents of children with cancer: The first five years of continuous remission after the end of treatment. *Psychooncology*. 2008;17(5):448–459.
10. Norberg AL, Boman KK. Parent distress in childhood cancer: A comparative evaluation of posttraumatic stress symptoms, depression and anxiety. *Acta Oncol*. 2008;47(2):267–274.
11. Manne S, Miller D, Meyers P, Wollner N, Steinhilber P, Redd WH. Depressive symptoms among parents of newly diagnosed children with cancer: A 6-month follow-up study. *Child Health Care*. 1996;25(3):191–209.
12. Sloper P. Predictors of distress in parents of children with cancer: A prospective study. *J Pediatr Psychol*. 2000;25(2):79–91.
13. 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.
14. Schuler D, Bakos M, Zsámbor C, et al. Psychosocial problems in families of a child with cancer. *Med Pediatr Oncol*. 1985;13(4):173–179.
15. 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.
16. Grootenhuys MA, Last BF. Adjustment and coping by parents of children with cancer: A review of the literature. *Support Care Cancer*. 1997;5(6):466–484.
17. 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.
18. Van Schoors M, Caes L, Alderfer MA, Goubert L, Verhofstadt L. Couple functioning after pediatric cancer diagnosis: A systematic review. *Psychooncology*. 2017;26(5):608–616.
19. Wiener L, Battles H, Zadeh S, Pelletier W, Arruda-Colli MNF, Muriel AC. The perceived influence of childhood cancer on the parents' relationship. *Psychooncology*. 2017;26(12):2109–2117.
20. Katz LF, Fladeboe K, Lavi I, et al. Trajectories of marital, parent-child, and sibling conflict during pediatric cancer treatment. *Health Psychol*. 2018;37(8):736–745.
21. Fladeboe K, Gurtovenko K, Keim M, et al. Patterns of spillover between marital adjustment and parent-child conflict during pediatric cancer treatment. *J Pediatr Psychol*. 2018;43(7):769–778.
22. Epstein N, Baucom DH. *Enhanced Cognitive-Behavioral Therapy for Couples: A Contextual Approach*. Washington, DC: American Psychological Association; 2002.
23. Halford KW, Bouma R, Kelly A, McD Young R. Individual psychopathology and marital distress. Analyzing the association and implications for therapy. *Behav Modif*. 1999;23(2):179–216.
24. Cummings EM, Davies PT. Effects of marital conflict on children: Recent advances and emerging themes in process-oriented research. *J Child Psychol Psychiatry*. 2002;43(1):31–63.
25. El-Sheikh M, Elmore-Staton L. The link between marital conflict and child adjustment: Parent-child conflict and perceived attachments as mediators, potentiators, and mitigators of risk. *Dev Psychopathol*. 2004;16(3):631–648.
26. Kelly JB. Children's adjustment in conflicted marriage and divorce: A decade review of research. *J Am Acad Child Adolesc Psychiatry*. 2000;39(8):963–973.
27. Fishman EA, Meyers SA. Marital satisfaction and child adjustment: Direct and mediated pathways. *Contem Fam Ther*. 2000;22(4):437–452.
28. Cowan CP, Cowan PA. *When Partners Become Parents: The Big Life Change for Couples*. Mahwah, NJ: Erlbaum; 2000.
29. Lewin AB, Heidgerken AD, Geffken GR, et al. The relation between family factors and metabolic control: The role of diabetes adherence. *J Pediatr Psychol*. 2006;31(2):174–183.
30. Burns W, Péloquin K, Rondeau É, et al. Cancer-related effects on relationships, long-term psychological status and relationship satisfaction in couples whose child was treated for leukemia: A PETALE study. *PLoS One*. 2018;13(9):e0203435.
31. Baucom DH, Shoham V, Mueser KT, Daiuto AD, Stickle TR. Empirically supported couple and family interventions for marital distress and adult mental health problems. *J Consult Clin Psychol*. 1998;66(1):53–88.
32. Schulz MS, Pruett MK, Kerig PK, Parke RD eds. *Strengthening Couple Relationships for Optimal Child Development: Lessons from Research and Intervention*. Washington, DC: American Psychological Association; 2010.
33. Stehl ML, Kazak AE, Alderfer MA, et al. Conducting a randomized clinical trial of a psychological intervention for parents/caregivers of children with cancer shortly after diagnosis. *J Pediatr Psychol*. 2009;34(8):803–816.
34. Spanier GB. Measuring dyadic adjustment: New scales for assessing the quality of marriage and similar dyads. *J Marriage Fam*. 1976;38(1):15–28.
35. Spanier G, Filsinger E. *The Dyadic Adjustment Scale, in Marriage and Family Assessment*. Filsinger E, ed. Beverly Hills, CA: Sage; 1983.
36. Cutrona CE. Ratings of social support by adolescents and adult informants: Degree of correspondence and prediction of depressive symptoms. *J Pers Soc Psychol*. 1989;57(4):723–730.
37. Cutrona CE, Russell DW. The provisions of social relationships and adaptation to stress. In: Jones WH, Perlman D, eds. *Advances in Personal Relationships*. Vol 1. Greenwich, CT: JAI Press; 1987:37–67.
38. Bonner MJ, Hardy KK, Guill AB, McLaughlin C, Schweitzer H, Carter K. Development and validation of the parent experience of child illness. *J Pediatr Psychol*. 2006;31(3):310–321.
39. Bonner MJ, Hardy KK, Willard VW, Hutchinson KC, Guill B. Further validation of the Parent Experience of Child Illness (PECI) scale. *Child Health Care*. 2008;37(2):145–157.
40. Hutchinson KC, Willard VW, Hardy KK, Bonner MJ. Adjustment of caregivers of pediatric patients with brain tumors: A cross-sectional analysis. *Psychooncology*. 2009;18(5):515–523.
41. Hardy KK, Bonner MJ, Masi R, Hutchinson KC, Willard VW, Rosoff PM. Psychosocial functioning in parents of adult survivors of childhood cancer. *J Pediatr Hematol Oncol*. 2008;30(2):153–159.
42. Storch EA, Lehmkuhl H, Pence SL, Geffken GR, Ricketts E, Storch JF, Murphy TK. Parental experiences of having a child with obsessive-compulsive disorder: Associations with clinical characteristics and caregiver adjustment. *J Child Fam Stud*. 2009;18(3):249–258.
43. Williams NA, Parra GR, Elkin TD. Subjective distress and emotional resources in parents of children with food allergy. *Child Health Care*. 2009;38(3):213–227.
44. Tedeschi RG, Calhoun LG. The Posttraumatic Growth Inventory: Measuring the positive legacy of trauma. *J Trauma Stress*. 1996;9(3):455–471.
45. Best M, Streisand R, Catania L, Kazak AE. Parental distress during pediatric leukemia and posttraumatic stress symptoms (PTSS) after treatment ends. *J Pediatr Psychol*. 2001;26(5):299–307.
46. Rini C, Manne S, DuHamel KN, et al. Mothers' perceptions of benefit following pediatric stem cell transplantation: A longitudinal investigation of the roles of optimism, medical risk, and sociodemographic resources. *Ann Behav Med*. 2004;28(2):132–141.
47. Frank SJ, Olmsted CL, Wagner AE, Laub CC. Child illness, the parenting alliance, and parenting stress. *J Pediatr Psychol*. 1991;16(3):361–371.
48. Floyd FJ, Gilliom LA, Costigan CL. Marriage and the parenting alliance: Longitudinal prediction of change in parenting perceptions and behaviors. *Child Dev*. 1998;69(5):1461–1479.
49. Thompson RJ Jr, Gil KM, Burbach DJ, Keith BR, Kinney TR. Psychological adjustment of mothers of children and adolescents with sickle cell disease: The role of stress, coping methods, and family functioning. *J Pediatr Psychol*. 1993;18(5):549–559.
50. Nguyen TD, Attkisson CC, Stegner BL. Assessment of patient satisfaction: Development and refinement of a service evaluation questionnaire. *Eval Program Plann*. 1983;6(3–4):299–313.
51. Baucom DH, Porter LS, Kirby JS, et al. A couple-based intervention for female breast cancer. *Psychooncology*. 2009;18(3):276–283.
52. Porter LS, Keefe FJ, Baucom DH, et al. Partner-assisted emotional disclosure for patients with gastrointestinal cancer: Results from a randomized controlled trial. *Cancer*. 2009;115(18 suppl):4326–4338.

53. Whitehead AL, Sully BG, Campbell MJ. Pilot and feasibility studies: Is there a difference from each other and from a randomised controlled trial? *Contemp Clin Trials*. 2014;38(1):130–133.
54. Kraemer HC, Mintz J, Noda A, Tinklenberg J, Yesavage JA. Caution regarding the use of pilot studies to guide power calculations for study proposals. *Arch Gen Psychiatry*. 2006;63(5):484–489.
55. Eldridge SM, Lancaster GA, Campbell MJ, et al. Defining feasibility and pilot studies in preparation for randomised controlled trials: Development of a conceptual framework. *PLoS One*. 2016;11(3):e0150205.
56. Porter LS, Keefe FJ, Baucom DH, Olsen M, Zafar SY, Uronis H. A randomized pilot trial of a videoconference couples communication intervention for advanced GI cancer. *Psychooncology*. 2017;26(7):1027–1035.
57. Reese JB, Porter LS, Regan KR. A randomized pilot trial of a telephone-based couples intervention for physical intimacy and sexual concerns in colorectal cancer. *Psychooncology*. 2014;23(9):1005–1013.
58. Porter LS, Keefe FJ, Garst J, et al. Caregiver-assisted coping skills training for lung cancer: Results of a randomized clinical trial. *J Pain Symptom Manage*. 2011;41(1):1–13.