Parenting a child with cancer and maintaining a healthy couple relationship: Findings from the Family Talk Intervention

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Abstract

Background: Despite the challenges that caring for a child with cancer brings for parents, little knowledge is available concerning the effects on the parents' couple relationship. Furthermore, few interventions have been designed to support parents in their couple relationship. The aim of this paper was, therefore, to explore parents' experiences of their couple relationship while having a dependent child with cancer and the support they received from a family-based intervention, the Family Talk Intervention (FTI).

Methods: Data for this paper were taken from semi-structured interviews performed in a pilot study of the FTI in the context of pediatric oncology. In total, 22 couples were interviewed after participating in the FTI. The interviews were transcribed and analyzed using qualitative content analysis.

Results: Parents described how maintaining a couple relationship while living with childhood cancer could be very challenging and was not given the highest priority. The FTI was considered a way of providing important support to the couple and a chance for them to sit down together and listen to each other's perspectives on the situation. Parents described that the FTI had helped them gain an increased mutual understanding, sometimes also helping them to realize that they needed more extensive professional support in their relationship.

Conclusions: Living with childhood cancer and upholding a healthy couple relationship is challenging for parents. The FTI has the potential to support couples, mainly by providing opportunities for parents to communicate with each other. However, some couples may be in need of a tailored clinical intervention.

KEYWORDS
childhood cancer, parents, psycho-educational, relationship, support

1 INTRODUCTION

Having a child with cancer has been described as affecting the functioning of an entire family.1 Previous research shows that a high proportion of parents of children with cancer report distress, such as anxiety, post-traumatic stress symptoms, worry, and nervousness.2,3 The burden of care often places a strain on the well-being of parents, and, accordingly, an increased risk of psychotropic medication use has been reported, especially among mothers.4,5 In addition, having a child with cancer may negatively impact levels of income and employment status, which can put further strain on the family.6 Childhood cancer has not been associated with an increased risk of separation or divorce...
among parents. Still, the experience of parenting a child with cancer can be described as an exceptional situation for the whole family, with a likely impact on the couple relationship, for example, by changing the way parents talk to each other or by making sexuality and intimacy difficult. Parents may also struggle to give each other support in the distressing situation. A large study of parents of children with cancer showed that the majority report unmet informational, psychological, and emotional needs, which indicates that these individuals do not receive adequate support from their partners or the healthcare system.

Despite these results, in-depth knowledge about the effects of a child with cancer on the parents’ relationship is lacking. Few interventions have been designed to support parents, and it is important to determine how best to deliver effective interventions in the context of childhood cancer. Providing families with such interventions is important as a supportive relationship between parents, and adequate family functioning, have been associated with better adjustment to the illness.

A family-based intervention that has shown positive effects for both parents and children is the Family Talk Intervention (FTI) (also called Beardslee’s Family Intervention), originally developed for use in a psychiatric context. The primary goals of the FTI are to facilitate family communication about illness-related subjects, support parenting, and make the children’s needs visible. As these goals match the needs of families living with a child with cancer, the FTI has been pilot-tested in the context of pediatric oncology, with results showing that it can provide support for the entire family. Research about if and how the FTI can support the couple relationship is, however, lacking. Such knowledge could also guide healthcare professionals in the process of implementing tailored support to parents. Hence, the aim of this paper was to explore the experiences of the couple relationship among parents with a dependent child with cancer and the support they received from the FTI.

2 METHODS

2.1 Design

This study was based on interviews with dyads of parents who had participated in a pilot study of the FTI in pediatric oncology.

The FTI has been thoroughly described earlier, so an abbreviated explanation is presented in this paper. It is manual-based and led by FTI-trained interventionists (in this paper two experienced medical social workers). The FTI entails six meetings, with 1–2-week intervals between meetings. Meetings 1–2 (M1–2) include only the parent(s) and focus on their experiences of the situation, as well as the consequences of the diagnosis for each family member. The parent(s) formulate their goals for the intervention. M3 is held separately with each child. It focuses on the child’s life situation and the interventionists identify protective factors (e.g., well-functioning school) and risk factors (e.g., poor social network) from the child’s narrative. M4 includes the parent(s) and focuses on planning the family meeting. M5 is the family meeting and consists of questions and issues raised earlier by the family members. This can be seen as a starting point for communication within the family. M6 is a follow-up with all family members. The meeting is guided by the family members’ needs; extra meetings can also be offered, if necessary (Meetings 7–11) (Figure 1).

2.2 Study population

Recruitment to the FTI pilot study took place between September 2018 and August 2019. Families were considered eligible if they had a child being cared for at a Swedish pediatric oncology center. Families with at least one dependent child aged between 6 and 19 years (the ill child or their healthy sibling(s)) were invited to participate in the FTI when 2–3 months had passed since diagnosis or relapse (n = 61). Families were given the opportunity to define which family members they wanted to participate in the FTI, including step-parents and other nonbiological family members. Of 61 invited families, 27 gave their consent to participate. A child in one of the 27 families died before the FTI could be started. Consequently, 26 families started the FTI. Of the 26 families, 23 included parents in a relationship, either with the other parent or in another romantic relationship. Of these parental couples, 22 consented to participate in the semi-structured interview.

The goals which were formulated by the parents before the intervention were mainly related to the need for better family cohesion and communication, and for tools to support and help the children (unpublished manuscript). When participating in the FTI, most of the parents also requested an extra parental session due to the need for more support.

2.3 Data collection

In conjunction with the end of the FTI, the parents were invited to be interviewed by a researcher (the children’s experiences are reported elsewhere). The primary focus of the interviews was the parents’ experiences of taking part in the FTI, and parents were initially asked to freely describe their overall experience of the FTI. They were then asked to focus on their experiences of each of the meetings. Probing questions were asked by the interviewer. The interviews were performed by Malin Lövgren and a PhD student. The interviews were conducted in the families’ home (n = 20), at the hospital (n = 1), or by video conference (n = 1). All but one of the 22 couples were interviewed together.

2.4 Data analysis

For the current study, the interviews were analyzed with a focus on experiences of the couple relationship, and whether the FTI had any influence on this. Conventional content analysis was used based on Hsieh and Shannon’s approach. The authors Lisa Ljungman, Maja Holm, and Tina Lundberg were responsible for extracting meaning units from the interviews, that is, units of text corresponding to the
study purpose. Maja Holm and Tina Lundberg then separately coded the meaning units. To increase the trustworthiness of the results, the two sets of codes were compared. Through informal discussions and reflections between the two authors, a high degree of similarity was found, and the few inconsistencies were discussed until consensus was reached. The codes were then refined and Maja Holm initiated a search for similarities, differences, and patterns. Maja Holm and Tina Lundberg then compared and clustered the findings to create primary categories. In the last step of the analysis, the categories were discussed and refined into the final results, which were agreed upon by all the authors. The analysis is illustrated more closely in Table 1.

2.5 | Ethical considerations

The study received ethical approval from the Regional Ethical Review Board in Stockholm (Dnr 2018/250-31/2 and 2018/1852-32) and is registered at ClinicalTrials.gov (Identifier NCT03650530).

3 | RESULTS

3.1 | Participants

All couples (n = 22) consisted of one man and one woman. Their mean age was 42.0 (SD = 6.0) years (Table 2). Four couples consisted of one step-parent and one biological parent of the child with cancer.

The content analysis resulted in four categories: experiencing an unprecedented and overwhelming situation; living separate lives but being reconnected through the FTI; finding ways to understand and to be understood; and seeking ways to manage problems.

3.2 | Experiencing an unprecedented and overwhelming situation

In this category, parents described the struggle of being a parent of a child with cancer. Focus was primarily on parenting the ill child and the tasks related to his or her treatments and medical visits. Parents also described the need to care for siblings while simultaneously having to manage household chores and paid employment. This meant that the parents had little time or energy left to spend on maintaining the couple relationship.

Participating in the FTI was deemed positive by the parents and experienced as providing important support in their difficult situation. The parents described how it had helped them to bring structure into their everyday life as a couple, for example, working more closely together regarding chores in the home and in relation to the ill child and siblings. These changes in turn had strengthened the couple relationship. In the FTI sessions, parents described feeling seen and acknowledged in their struggles by the interventionists, both as a family and as a couple. Furthermore, parents were grateful that the interventionists had extensive knowledge about the context of childhood cancer and understood the special circumstances they were living under, something they felt they would not encounter within general healthcare. They described that as the interventionists had met other parents in their situation, they could provide a sense of confirmation and normalization of the challenges that the parents faced, which was reassuring by the parents as a couple.

"No, I was told ... we were told that we weren’t alone and that ... Yes, it’s more men who react. It is often the men [in the relationship] who crash... so we understood what she meant. Yes, it was so nice to hear that you weren’t alone in the world. Because that’s exactly how you felt, completely alone."
### TABLE 1  
Process of analysis.

<table>
<thead>
<tr>
<th>Meaning unit</th>
<th>Condensed meaning unit</th>
<th>Code</th>
<th>Final category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, because I can’t really manage to care about you (laughing) in the same way I did before, perhaps.</td>
<td>No energy to focus on partner</td>
<td>Relationship deprioritized</td>
<td>Experiencing an unprecedented and overwhelming situation</td>
</tr>
<tr>
<td>Perhaps not so much what others said, but rather how you are yourself. That it became very clear, like... no, but that I have a hard time letting go of this, like that I fix everything and I keep control of everything. Because I suppose that is what contributes to X [my husband]. not taking much responsibility for the children or does things with them, because I’m always doing it. So it became very clear, I haven’t seen that that’s the way it is.</td>
<td>She will fix things and keep control, her husband will stand back</td>
<td>Not working together</td>
<td>Living separate lives but being reconnected through the FTI</td>
</tr>
<tr>
<td>We weren’t just talking about brain tumor. We talked about so incredibly... Communication or communication problems between different family members and... so, there was an overall perspective. And then there is so much, that you can help each other, and... yes, I don’t feel like you do: “Well, then you X, may help Y to try to understand?” Do you understand?</td>
<td>Family Talk Intervention (FTI) was not just talk about the tumor, but communication/communication problems in the family and between parents</td>
<td>Increased understanding for each other</td>
<td>Finding ways to understand and to be understood</td>
</tr>
<tr>
<td>Before X became sick, we were thinking like: “Yes, well now we have to go to couple therapy a few times.” Again, as we did a few years ago, to try to handle the status [of our relationship]. That would be a good thing. And we probably have... it became like we... it was confirmed anyway, when we talked with them, that: “Yes, it’s a good thing to make time for.”</td>
<td>FTI provided confirmation about their need for couple therapy</td>
<td>Need for further support</td>
<td>Seeking ways to manage problems</td>
</tr>
</tbody>
</table>

### 3.3  Living separate lives but being reconnected through the FTI

Parents described life with a child with cancer as a situation where they lived together, but had limited opportunities for interaction and/or different approaches to the situation. The lack of interaction was related to the situation where one parent cared for the child, at the hospital or at home, while the other parent had to work. However, the couples were also separated by different priorities. Mothers described devoting most of their time and effort to fighting the child’s cancer, while fathers focused to a greater extent on maintaining a normal family life and continuing with paid work. Mothers expressed a sense of frustration with fathers whose priorities they felt were wrong. Meanwhile, fathers described feeling abandoned by their wives in the relationship, as illustrated by one man:

“She’s not coming back, and time is passing. She’s not coming back to our marriage, she’s just not there. And as time goes by, the harder it gets, because it’s been such a long time since I really saw her, so to speak.”

Participating in the FTI was described by the parents as an important opportunity to reconnect with each other. During the sessions, the parents sat down face to face, whether they had time or not, and talked to each other. They had to pause and reflect on their situation, which was necessary. The FTI also revealed important insights into family roles that needed to change. This was expressed by one mother who described herself as the leader of the family, the one who planned things for the ill child and their siblings, and had control over most things. Through participation in the FTI, the father realized that his partner needed support and the mother had understood that she had to relinquish some control. Parents also appreciated that the interventionists had encouraged them to focus on their relationship, do things together, and show each other affection during the difficult times.
TABLE 2 Characteristics of the couples.

<table>
<thead>
<tr>
<th></th>
<th>Number of participants, n = 44</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of couples</td>
<td>22 (representing 21 children)</td>
</tr>
<tr>
<td>Gender, n (%)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>22 (50)</td>
</tr>
<tr>
<td>Female</td>
<td>22 (50)</td>
</tr>
<tr>
<td>Age in years</td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>42.0 (6.0)</td>
</tr>
<tr>
<td>Min–Max</td>
<td>36–63</td>
</tr>
<tr>
<td>Education level, n (%)</td>
<td></td>
</tr>
<tr>
<td>Secondary school</td>
<td>12 (27)</td>
</tr>
<tr>
<td>University</td>
<td>31 (71)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (2)</td>
</tr>
<tr>
<td>Occupation, n (%)</td>
<td></td>
</tr>
<tr>
<td>Paid work</td>
<td>38 (86)</td>
</tr>
<tr>
<td>Compensated by State to care for sick child</td>
<td>3 (7)</td>
</tr>
<tr>
<td>Other</td>
<td>3 (7)</td>
</tr>
<tr>
<td>Number of children (including patient), n (%)</td>
<td></td>
</tr>
<tr>
<td>1 Child</td>
<td>1 (5)</td>
</tr>
<tr>
<td>2 Children</td>
<td>11 (50)</td>
</tr>
<tr>
<td>3 Children</td>
<td>10 (45)</td>
</tr>
<tr>
<td>Age of children in years</td>
<td></td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>10.0 (2.0)</td>
</tr>
<tr>
<td>Min–Max</td>
<td>1–24</td>
</tr>
<tr>
<td>Diagnosis of patient, n (%)</td>
<td></td>
</tr>
<tr>
<td>Central nervous system tumor</td>
<td>9 (43)</td>
</tr>
<tr>
<td>Leukemia</td>
<td>4 (19)</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>3 (14)</td>
</tr>
<tr>
<td>Other</td>
<td>5 (24)</td>
</tr>
</tbody>
</table>

3.4 Finding ways to understand and to be understood

Parents described that their communication with their partner had been challenged in several ways after the child's cancer diagnosis. First, parents described how they found it difficult to talk about their situation when the child/children were around, and that it was hard to find time to have conversations while taking care of the sick child. Second, parents described wanting to protect each other from bad news regarding their child's cancer.

“Yes, no, but I didn’t tell you anything. I was... I played the hobby researcher and had much more information than you did, and I didn’t give it to you since I wanted to protect you...”

Researching the disease on the internet could lead to information that made them feel uncomfortable, but rather than seeking comfort from their partner, parents described keeping this to themselves. Lastly, parents raised questions about whether their partner really understood the seriousness of the child’s condition, which was described as hard to talk about.

Parents expressed how difficulties with communication were addressed by the FTI. By participating in the FTI, the parents had discovered things that helped them understand each other better, giving them insight and empathy for their partner. The risk of misunderstandings was reduced during in-depth discussions in the sessions. Some couples felt that they had become more sensitive to their partner's needs and wishes after participating in the intervention, and accepted that the situation affected them differently.

“Yes, but I think it’s because I understand my partner a bit more and, yes, your situation and... it is talked about a bit more in these conversations because my partner also has a medical diagnosis and is on part-time sick leave right now.”

Parents also described how the presence of a third party (the interventionist) was sometimes a key to opening conversations about issues they had previously avoided. More uniquely, one of the couples also described that the interventionists had provided confirmation that the parents communicated well, which was perceived as validating and supportive.

3.5 Seeking ways to manage problems

For some parents, earlier problems in their relationship had accelerated with their child's illness. The family spent a lot of time at home together, with fewer social activities, which could be frustrating. Parents also reported that their own or their partner's fatigue could cause irritation and sometimes lead to conflicts. They described how seeing one's partner looking sad or depressed was troubling as they were unable to give support. Arguments about how to behave around the child with cancer also influenced the parents' relationship; for example, parents described having differing opinions regarding how to manage aggression in the child.

“If I’m talking to our son about something and he swears or thinks something is wrong, then I try to be calm, but then you come in and raise your voice in the middle of it all, which ruins everything I’ve been trying to do, and he goes away and is angry, and slams the door. Then... I get really angry with you.”

It was explained that participating in the FTI had given an opportunity for the couple to reflect on their relationship and their individual contributions to the problems. However, it was also described that once the FTI was finished, everything returned to normal again.
Nevertheless, there were also couples who described continuing with scheduled reflections and discussions of their feelings.

“But it’s like this, once a week or so, you do some kind of check-in or you maybe, yeah get together and talk to someone at breakfast or at the weekend or whatever, it doesn’t have to take that long either. So it’s a way to just check out the situation a bit more, something like that.”

Some parents stressed that the FTI provided support in their relationship, but that the sessions also made them realize that they might need more extensive professional support to solve their problems. In some cases, the FTI had guided them to attend couple therapy, but others also expressed the need for other kinds of support, such as group sessions with other parents of children with cancer. It was however also described that even though the couple needed further help, the treatment for their child was their first priority.

4 | DISCUSSION

This study explored couple relationship experiences among parents having a dependent child with cancer and whether the FTI could provide support for parents in their relationship.

The results showed that maintaining a couple relationship while living with a child with cancer can be very challenging. In the category *Experiencing an unprecedented and overwhelming situation*, it was described by participants that their role as parents had become more prominent than their role as a couple after the child had been diagnosed with cancer, and that this had impacted the relationship negatively. Previous research has shown that up to 40% of parents of children with cancer experience marital distress; however, the divorce rate is not increased in this population.²² Our results can be seen in light of this; family members become more dependent on each other from negative information regarding the child’s disease. Future studies should examine the adequate level of joint coping required to manage distress related to the child’s cancer.

Parents expressed how being able to sit down and talk during the FTI was meaningful and a way of resolving misunderstandings. Having the opportunity to discuss the situation with someone outside the family had helped parents solve problems and find an acceptable level of intimacy and communication. Although not the primary goal of the FTI, the sessions could be viewed as a way for parents to stay connected, something that parents going through a child’s cancer trajectory have stressed as important.²⁶ Listening to each other, as done in the FTI, can thereby strengthen not only family cohesion, but also the parents’ couple relationship. It could also have possible benefits for the ill child, as support from the parents is associated with improved child adjustment.²⁸ and it would seem plausible to assume that when parents are supported as a couple, they could also provide better support for the child.

For some parents, the FTI confirmed, or helped them realize, that they needed further support as a couple, as described in the category *Seeking ways to manage problems*. However, parents also emphasized the importance of the extensive knowledge about childhood cancer that the interventionists had, which would not be found elsewhere. This highlights the need for a specific couple intervention directed at parents in childhood cancer care, which is in line with research suggesting development of targeted interventions guided by dyadic coping strategies to improve parents’ ability to support one another by working together, learning to recognize the other’s emotional needs, and sharing responsibilities when facing the challenges of caring for a child with cancer.²⁷

Strengths of this study include that it is one of the few to investigate the situation for couples living with a child with cancer. The interviews were done in dyads, which gave the parents a chance to develop each other’s stories. The study also includes a varied sample, including step-parents and parents of different age and sex, which strengthens the data quality. Further, it also describes the value of a family-centered intervention to the parents’ relationship, something that has been studied even less. However, it should be stressed that the
interviews were not primarily conducted with the purpose of exploring the situation for the couples. Also, it should be acknowledged that as the interviews were carried out after participation in the FTI, data were provided in a context where parents had been given previous opportunities to reflect upon the functioning of their relationship.

Of 61 eligible families, 27 gave their consent to participate. This rather low acceptance rate should be considered; however, similar rates have been observed in other intervention studies in the context of advanced pediatric illness. Still, it raises questions of which family system tumors was also observed (Table 2), which could imply that this was a group with an increased need for support. Furthermore, it should also be underlined that all the families in this study had problems they wanted help with through FTI, which could be a factor that motivated them to participate. Taking these aspects into concern, we believe that the results of this study can be transferred to couples living with a child with cancer who experience a need for support, and who are willing to reserve time to participate in an intervention.

In conclusion, the FTI has the potential to support parents of children with cancer by providing opportunities for couples to sit down and communicate with each other, and to also have contact with interventionists with extensive knowledge about the context of childhood cancer. Still, for some couples further support in their relationship seems to be required, which indicates a need for a tailored intervention for these couples.

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CONFLICT OF INTEREST STATEMENT
The authors declare they have no conflicts of interest.

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