

"The child is our focus"

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“The child is our focus”: On couple issues in child oncology treatment

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Abstract

Objective: This study explored the perspectives of child oncology professionals and parents about the attention professionals should give to the parent couple relationship during treatment of the child.

Methods: We employed a qualitative research design, framed within the approach of consensual qualitative research (CQR), gathering data from four focus groups with 20 professionals and from nine in-depth interviews with 16 parents. Thematic analysis of the focus group and interview data was done with MaxQda software, using two coders and member checks to strengthen confidence in the analysis.

Findings: Both professionals and parents talked about an elevated tension in the partner relationship during oncology treatment of the child. However, explicit attention to the partner relationship in this context felt inappropriate to professionals and parents. All emphasized the importance of the professional helpers' openness to conversation and an attuned response to the parental couple relationship.

Conclusion: During treatment, the child is the primary focus for parents and professionals. The parents' focus on supporting their child makes talking about their own emotions or about issues in the partner relationship potentially disruptive and unhelpful. Therefore, it is crucial for professionals to support the parents in their parents' role, but with an openness to converse about issues in the partner relationship at the moments when these issues might threaten their focus on the child.

KEYWORDS

cancer, child, communication, couple communication, couples, interpersonal relationships, parents, pediatric oncology, qualitative research

1 | INTRODUCTION

A child's cancer diagnosis and oncological treatment have significant impact on the child's parents.¹⁻⁴ Reviews^{5,6} focusing on the effect of childhood cancer on the parents' marital satisfaction found both positive and negative changes. A growing body of literature emphasizes the importance of assessing relationship quality as part of routine psychological care throughout the treatment trajectory.^{5,7,8} Moreover, some argue for identifying parents at risk and implementing interventions aimed at strengthening the marital relationship of the parents.^{5,9-11}

Such a psychosocial focus on the parents' marital relationship is not well established in routine pediatric care. Although one review concluded that health providers recognize emotional distress, they feel unable to address psychosocial issues due to lack of time, lack of confidence in their own skills, and the perception that parents prioritize child physical care over parental psychosocial care.¹¹ That review went on to say that “for patients and their families the main issue was that the healthcare system was focused on physical care with little opportunity to talk about psychosocial concerns.”¹¹ But do parents and professionals who work with them say that parents want such talk?

To our knowledge, no qualitative research has been done to explore the views of parents and professionals concerning attention given to the parent couple relationship while their child is in oncology treatment. In our study, we inquired with both parents and professionals about their views concerning attention to parent couple relationships during this time.

2 | METHODS

2.1 | Design

We conducted four focus groups with professionals, one at each of the four child oncology departments in Flanders (the Dutch-speaking part of Belgium). In addition, nine interviews with 16 parents whose child was in cancer treatment were conducted. We combined what started out as two independent studies because both projects were looking at the same phenomena. Combining them gave us the perspectives of the parents and the professionals in a single analysis and report. Both focus groups and interviews were audio and videotaped. Our research can be framed within the approach of consensual qualitative research (CQR).¹² CQR is an integrative approach to qualitative research, based on the idea that doing research is teamwork and that analyses should be checked by independent external auditors who have the task of challenging interpretations and checking if these interpretations are sufficiently grounded in the data. All couples provided informed consent, and the research protocol for studying couples and professionals was approved by the Medical Ethics Commission of Leuven University (B322201627096).

2.1.1 | Focus groups with the professionals

In Flanders, there are four child oncology departments (in Leuven, Brussels, Ghent, and Antwerp). At each of these departments, a focus group was organized with professionals. Inclusion criteria were being close to the families and having a minimum of 5 years of experience in child oncology. In total seven psychologists and 13 nurses participated (Table 1). All but one were women. Each focus group was conducted at the professionals' workplace, and lasted between 1 and 1.5 hours. Beforehand, the professionals were provided with a document with three fictional cases in which professionals encounter marital communication difficulties or conflicts between partners during their stay in the hospital. At the start of each focus group, these cases were discussed by the participants, with only minimal structuring by the researchers (first and third authors). Examples of questions asked by the researcher are as follows: "How do you understand parents not talking with you about emotional or relational difficulties?" and

TABLE 1 Professional participants

Focus Groups	Hospital	Psychologists	Nurses
1	University Hospital Leuven (L)	2	2
2	University Hospital Brussels (B)	2	2
3	University Hospital Ghent (G)	2	4
4	University Hospital Antwerp (A)	1	5

"How do you see your own task or engagement related to marital difficulties of the parents?"

2.1.2 | Parent interviews

Parents whose child was in cancer treatment at the child oncology department in Leuven were invited for an interview as a couple about their experiences. Recruitment for these interviews was done by the psychologists of the oncology department at the University Hospital in Leuven. They selectively invited Dutch-speaking couples (both biological parents of the child, living together) whose child was in active oncological treatment (at least 2 mo after a first diagnosis) and were considered to be willing to participate in the study. Between August 2015 and August 2016, eight couples were invited, and only two couples chose to participate. The other six couples considered an interview too exhausting in this time of treatment and did not see the value of this interview for their child. As recruitment turned out to be difficult, we decided to post an invitation on a Facebook page for parents whose child is in oncology treatment. One mother volunteered, and we interviewed her. Afterwards, we decided to collaborate with the child oncology department in Brussels and changed some of the inclusion criteria: We also invited parents whose child was not in active treatment and parents who were willing to participate individually. Over 15 months (Aug 2015-Oct 2016), sixteen parents participated, seven couples (interviewed together) and two mothers (Table 2). The time since their child's diagnosis ranged from 2 months to three and a half years. For half of them, treatment was still going on, the others were in a period where their child needed to go only for checkups. Diagnoses included brain tumors, leukemia, bone tumor, and Langerhans cell histiocytosis (LCH). The ages of the children were between 9 months and 15 years. Most parents had other children besides the one that was in treatment. The interviews were planned at the time and place of their choice (eight interviews at their homes, one in the hospital) and lasted between 1 and 2 hours. Open-ended questions were posed related to the conversations with health care professionals at the hospital about themselves and their partner relationship. Examples include "How was it for you to talk with the professionals about your emotions or your partner relationship?" and "Can you help us understand why you say you sometimes preferred not to talk about it with them?"

2.2 | Analysis

Qualitative thematic analyses were done separately on the transcripts of the focus groups and interviews. The interviews and focus groups were transcribed in Dutch and were inductively coded. The first author was the main researcher and primary data analyst for the interviews, the third author for the focus groups. Statements and sentences that seemed essential, revealing, and/or surprising were identified and marked. Subsequently, a thematic coding was done by grouping codes into clusters around similar and interrelated ideas or concepts using MaxQda software Version 2.¹³ Descriptive themes were identified using line-by-line coding and the constant comparison method, assessing meaning units and themes for similarities and differences.^{14,15} This resulted in a hierarchical coding structure with themes and subthemes reflecting the meaning structures in the

TABLE 2 Parent participants

Interview	Hospital	Date Diagnosis	Date Interview	Treatment Phase	Interviewed Together/Alone	Type of Cancer
1	Leuven	May 2015	Sept 2015	Active treatment	Together	Bone tumor
2	Leuven	May 2015	Oct 2015	Active treatment	Together	Bone tumor
3	Leuven	February 2007	July 2016	Checkups	Alone	Leukemia
4	Brussels	June 2016	Aug 2016	Active treatment	Alone	Leukemia
5	Brussels	April 2015	Aug 2016	Checkups	Together	Brain tumor
6	Leuven	April 2015	Sept 2016	Active treatment	Together	LCH
7	Leuven	February 2014	Oct 2016	Checkups	Together	Leukemia
8	Brussels	May 2015	Oct 2016	Checkups	Together	Brain tumor
9	Brussels	Sept 2013	Oct 2016	Checkups	Together	Leukemia

Abbreviation: LCH, Langerhans cell histiocytosis.

transcripts related to the conversation between parents and professionals about the couple relationship.

Credibility and trustworthiness of these analyses were verified by an extensive auditing process.^{12,16} For the analysis of the focus groups, three independent auditors (an experienced psychologist and family therapist, an experienced psychologist working in palliative care, and the fourth author) gave feedback about the overall theme structure for coherence/consistency and elegance/nonredundancy. All meaning units were audited for their fit into the theme to which they were assigned. This feedback was then used to modify the theme structure and was subsequently returned to the auditors, until consensus about the report was reached. To check the trustworthiness, a second meeting was done with three psychologists of the focus groups. All themes were discussed and agreed upon as fitting what they encounter in their practice.

3 | RESULTS

In the focus groups of professionals, as well as in the interviews with parents, two main themes stood out with respect to the partner relationship. First, explicit attention to the partner relationship in this context feels inappropriate, as the child is their primary focus now. Second, there should be offered an attuned response to the partner relationship.

3.1 | “The child is our primary focus now”

The professionals in this study expressed how their professional commitment and engagement always needs to be associated with the well-being of the child. For that reason, emotional difficulties in the partner relationship are beyond their mandate, focus, and skills.

FG A:

- Nurse 1: I think we mainly look at the relationship with the child.
 Nurse 2: mainly the child, we don't look at the relationship between the partners. Is there an effect on the child? Is the child burdened by it? Not the couple.

Moreover, the professionals assume this is also the case for the parents. Indeed, the parents in our interviews stated that in a child oncology department with professionals specialized in childcare, the

focus is on the child. All are there because of the child, and they do not expect any offer of psychological treatment for themselves or their partner relationship.

Mother 5: I think that they are there for (the child), and of course that's logical, it's a child department, That's the most important.

Mother 9: I did not expect them asking how we were doing, because they are child psychologists, they are there for the patients.

The professionals in our focus groups saw most parents trying to keep their heads up, to survive and stay strong for their child. This often includes that parents do not give priority to their own emotions. Sometimes, talking about their own emotions or difficulties in the partner relationship can make things worse at a time they need to be stable and function for the sake of their child.

FG B:

Psychologist: Sharing emotions is a nice basic assumption, but it needs to be helpful. If, because of that, he (father) can't function anymore at a time where he feels he needs to function, than that's not good.

Similarly, all parents in our interviews emphasized that they would find it inappropriate to receive too much attention from the professionals to their emotions or partner relationship. In these circumstances, they feel they need to put their own emotions “on hold” to be able to stay focused and strong for their child.

Mother 8: If they would have invited us for a conversation, in another room, about ourselves, No, that would not be the right moment! ... I wouldn't have wanted to talk about myself at that time.

Both professionals and parents recognized that the hospital setting is not inviting and appropriate for emotional conversations about their own emotional status. During the time in the hospital, all parents want to be with their child as much as possible. They do not want to cry in front of their child or be invited to another room away from the child. If the tension between partners becomes high, and a

professional is in the room, often the only “way out” is the hallway, which of course is not suitable for a conversation.

Moreover, as the professionals reported in the focus groups, it is also a matter of time. Often, there are other pressing practical, medical, and organizational issues that need their attention. Although some might like it to be different, often, there is just no time for longer conversations with the parents.

In the interviews with the parents, this observation, that the professionals did not have the time for longer conversations, was a recurrent theme. Although some of them missed having somewhat more time with the professionals, they also largely appreciated their efforts.

Father 2: The nurses and psychologists here, they all work very hard, but they are shorthanded, even at a department for child oncology.

For some parents, the time schedules at the hospital are inconvenient. Many parents, especially fathers, can only visit in the evenings, when the psychologists are not present. In addition, they all mention the discontinuity in care, having many professionals coming in at different times.

3.2 | “An attuned response to the partner relationship”

The professionals in our focus groups emphasized the importance of a safe environment for the parents in which they try to embody openness for conversation in case the parents would want to talk. Rather than initiating conversations, they observe and try to trust the process and the coping abilities of the parents and support the things that may come up.

FG B:

Psy 1: I think it's about creating the space for a good balance in those things, and leaving parents in their strength, ... but always creating the space to share difficult emotions.

Psy 2: I agree, it's up to the parents to ask for a conversation, but we need to create the space to make that possible.

FG G:

Nurse: Sometimes they just want to ventilate some of their emotions, and then we just offer a listening ear. Sometimes just a few words is enough for them to pick up their strength again and go on.

In the interviews with the parents, trust in the availability of the professionals in case they need it is one of the main themes. They had the feeling that the professionals kept an eye on them. All parents said that there was little or no conversation about themselves or how their partner relationship became tense in this context, but they felt trustful that there would be an openness to have a conversation about it if they would need it.

Sometimes, emotions spill over or relationship issues surfaced. Then, the professionals (mainly psychologists) see it as their duty to respond in a way that helps parents to go on and focus on their child

again. They listen and try to frame relational tensions as normal in this stressful time.

Parents talked about moments during treatment that it was just not feasible to put their emotions on hold. Sometimes their emotions overflowed, or issues in the partner relationship demanded their attention. At these moments, they were very appreciative of those professionals who noticed and took the time to listen to them. Importantly, these moments needed to feel attuned to their own process, at the time when they needed it, and in a way that felt spontaneous.

Interviewer: Would it be of extra value to you if the psychologists would invite you as a couple and explore how things are going for you, as a couple?

Mother 4: Yes, I think so, but maybe not like an appointment, but rather as a spontaneous act. You are sitting there and you start to talk ... If you need it, you can go to them, or they come and sit with you.

In these moments, they do not want to deepen or reflect on their emotions, but instead need a supportive and encouraging response to enable them to go on and focus on their child.

Some parents indicated that it would be of value for them to get the explicit offer of a psychologist to be available for them, as adults and as a couple, in case they need it. Finally, many parents noted that they might need attention from professionals for their partner relationship when treatment ends. The partners for whom this was already the case admitted that their partner relationship needed some kind of rebuilding after a long time of inattention.

4 | DISCUSSION

The impact of childhood cancer on parents and their marital relationship is evident, and some studies have advocated for an enhanced attention for it in routine pediatric care.⁵⁻¹¹ In our research, we aimed for a better understanding of the perspectives and experiences of parents and professionals at child oncology departments related to the attention given to parents and their marital relationship.

Most importantly, we found that attention to the partner relationship during treatment of the child is not a priority. Everyone has a similar focus: the child's illness and medical treatment. For professionals, the main task and mandate concerns the child's illness, and for parents, the child is their dominant focus. Therefore, everything else, including the emotions of the parents and any difficulties in the couple relationship, are put on hold. The marital relationship loses its importance,¹⁷ as one is a parent all the time.⁷ As the parents in our interviews reported, talking about the partner relationship could distract them and undermine their focus on the child. Accordingly, professionals are very careful not to destabilize the parents, who are trying to survive and stay strong for their child. Moreover, in this setting where medical care is prioritized, people feel that there is little or no room, nor time, for conversations about side issues like marital difficulties.

Notwithstanding what they see as the inappropriateness of an explicit attention to the partner relationship during the child's treatment, professionals and parents also acknowledge the elevated

tension in partner relationships during the child's treatment. Consequently, our findings point to the need for a more complex approach related to the attention given to the parents and their relationship. The analysis of all four focus groups with the professionals showed some kind of implicit working model they employ in their approach toward the parents and potential partner relationship tensions. Most importantly, their efforts concentrate on creating a safe environment for the child and the parents, in which they try to embody openness for conversation, in case the parents would want to talk. Rather than initiating conversations, they accept, observe, and support the things that may come up. Therefore, they try to trust in the process and the coping abilities of the parents. This can be understood using ideas of containment as a working model. This concept of containment was introduced in psychoanalysis¹⁸ and implies the creation of a safe ground, from where the client can maintain strength, and grow. When emotions of the parents or relationship issues surface and might threaten the child, there is a need for an attuned response. Similarly, Davies and colleagues¹⁹ conclude that best practices in psychosocial care for parents of children with life-threatening conditions are composed of the ability to attune to what is present at the time. An important aspect of this attunement involves timing and spontaneity.

5 | STUDY LIMITATIONS

Through the difficult participant recruitment, possibly, our sample of parents was biased. Since the parents we interviewed were selected by hospital staff, it is possible that the staff chose parents who seemed to accept the limited attention staff was able and inclined to give to the parental relationship. Interestingly, the difficult participant recruitment did not only represent a limitation. It can also be seen as a validation for our findings. The parents who did not want to participate were asked for their reasons not to participate. Interestingly, the reasons they gave were similar to the meanings we found for not giving attention to the partner relationship. They wrote things like "the interview is not in the immediate interest of the treatment of our child," "talking about the partner relationship could be too disturbing in this time of survival in which we need to stay strong for our child," or, most frequently expressed, "there is no time to arrange a couple interview as we want at least one of us to be with the child."

6 | CLINICAL IMPLICATIONS

In light of our findings, it is useful to reconsider the recommendations for professionals to include interventions aimed at the partner relationship during pediatric oncology treatment. Our study points to the complexity inherent in the attention given to the parents and their partner relationship in this time, with a focus on attunement. Consequently, we might wonder about the impact of, for example, the setting aside of a private parent "lounge" that is better suited for private, informal contacts between parents and professionals. Or, as some parents mentioned the fact that there were only child psychologists, how it would be different for professionals and parents if—instead of only child psychologists—there were also adult psychologists at the department who were exclusively available for the

parents? Extending their attention to the broader system around the child can be challenging for professionals. As it is often difficult to assess the dividing line between focus on the child and focus on the relationship of the parents, they struggle with their position and mandate. Also, some reported that they felt wary of creating even more tension in the couple. But what if professionals were more trained in giving attention to couple issues? Possibly not much would change for some parents, because the child's illness so captures the situation. However, there might be parents who would be quite responsive to the availability of resources for helping with couple issues. In addition, the parents in our study, those for whom active treatment had ended, pointed to the value of psychosocial care once they were back home with the child. Perhaps, more attention for the parents and their partner relationship is needed in preparation for the transition to the end of treatment in the hospital.²⁰

7 | FUTURE RESEARCH

Future research could aim to explore what happens when there are dedicated couple and family therapists available to work with parents of child patients. Perhaps what we report in this paper is driven in part by the constellation of what kind of professional help is available to parents. There also seems to be a need for research exploring how what goes on or does not go on between parents affects a child cancer patient physically and psychologically, both in the moment and in the long run. Even with the focus on the child, we need to know more about what is happening to the child when, for example, parents bicker, communicate poorly, seem not to be talking with each other, or have long-standing difficulties. We also need to develop a broader cultural perspective on what the issues are regarding parent couples in cases of pediatric cancer in disparate cultures. How much of what we report here is about Flemish culture and how much is it about child oncology treatment and couple relationships everywhere in the world? Our study does not compare cultures, so it does not allow for any statements regarding the specific influence of culture.

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CONFLICTS OF INTEREST

We have no conflict of interest.

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