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"*It is like he abandoned me in a war*" – A qualitative study of relationship distress in parents of children diagnosed with cancer

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ABSTRACT

Purpose: Up to 40 % of parents of children with cancer experience relationship distress; a significantly higher proportion compared to the general population. Despite this elevated risk, there are few in-depth qualitative studies investigating relationship distress in the paediatric oncology context. Therefore, this study aimed to explore how parents of children with cancer experience relationship distress to thereby generate an in-depth understanding of the phenomenon.

Method: A sample of 25 parents (17 mothers, 8 fathers) who had experienced relationship distress related to their child's cancer participated in semi-structured interviews exploring relationship dynamics, communication, conflict management, and relational changes following the child's diagnosis. The interviews were audio-recorded, transcribed verbatim, and analysed using inductive content analysis.

Results: Three categories and nine subcategories were identified. In addition to these, one overarching theme emerged. The first category 'Pressure on the relationship', illustrated factors that placed strain on the couple relationship. The second category 'When unity fails' included parents' experiences of challenges in dealing with the situation together as a couple. The third category 'Fractured togetherness' highlighted relationship deterioration as a result of the cancer experience. The theme 'Fighting together, yet drifting apart' linked the categories by illustrating the process of experiencing joint hardships, of trying to manage these together, but ending up with a wounded relationship.

Conclusion: This study contributes with an in-depth understanding of relationship distress in parents of children with cancer. Thereby, it can contribute to the development of currently limited interventions to support parents' couple relationships in paediatric oncology care.

1. Introduction

In high-income countries, paediatric cancer is the second most common cause of death, after accidents, in children beyond infancy (Pritchard-Jones et al., 2013). Nevertheless, survival rates have increased dramatically over the past half-century, with 5-year estimated survival rates exceeding 80 % in many European countries (Gatta et al., 2014), reaching almost 86 % in Sweden (Lähteenmäki, P., n.d. Årsrapport 2023 Svenska Barncancerregistret). Despite increasing survival rates, childhood cancer still poses a serious threat to children's lives and entails a range of emotional and social challenges for children and their families. For parents, this means having to adjust to a new, disruptive, chaotic and often uncontrollable situation, including hospitalization of their child, social isolation due to risk of infection, not being able to attend labour work, and at the same time, having to cope with the threat to the child's life (Carlsson et al., 2019; Lewandowska, 2021). Furthermore, depending on the child's diagnosis, the treatment trajectory may span over several years, involving numerous acute and chronic stressors over a long period of time (Lewandowska, 2021). Consistent with this, previous research has shown that parents are at risk of developing

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psychological distress, such as anxiety, depression, post-traumatic stress symptoms, and somatization symptoms (Burns et al., 2018; Ljungman et al., 2014, 2015; Wikman et al., 2022), persisting up to several years after the end of the child's treatment (Ljungman et al., 2014, 2015). Notably, psychological distress in parents has been associated with negative outcomes in the child such as psychological distress, internalising and externalising symptoms, post-traumatic stress symptoms, and social competence problems up to 7 years after the cancer diagnosis (Bakula et al., 2019; Sultan et al., 2016).

In addition to affecting individual psychological health, the challenges related to paediatric cancer may affect the parents' couple relationship. Previous studies have described this negative impact using various overlapping terms including; marital distress, relationship dissatisfaction, partnership dissatisfaction, poor relationship quality, and poor relationship adjustment. Henceforth, the overarching term "relationship distress" will be used to describe negative impact on romantic couple relationships. Relationship distress encompasses multiple aspects of impaired couple relationship functioning, including negative thoughts, emotions, and behaviours, low relationship satisfaction, difficulty adjusting to one another, and frequent conflicts (Doss et al., 2022; Jaremka et al., 2020). Relationship distress is common among parents of children with cancer, with up to 40 % reporting difficulties (Wiener et al., 2017). At diagnosis, levels of distress are significantly higher than in a general European population (Gajda et al., 2024), and such difficulties often persist for years after diagnosis (Burns et al., 2018). Previous research indicates that relationship distress in this population may involve challenges in communication, cooperation, and decision-making (Holm et al., 2024; Hooghe et al., 2020; Van Schoors et al., 2017), alongside emotional strain in terms of loneliness, anger, and tension (Van Schoors et al., 2017), as well as reduced intimacy (Van Schoors et al., 2017). In addition to the suffering that relationship distress implies in itself, it has been associated with a negative impact on the mental health of the parents, as well as on other members of the family (Chiang and Bai, 2022). Importantly, it has been shown that relationship distress in parents following their child's cancer diagnosis increases the risk of both emotional and behavioural problems in their child (Alba-Suarez et al., 2021).

An important concept used in the previous literature to explain relationship distress in times of stress is dyadic coping (Bodenmann, 1995). This concept refers to a dynamic, interdependent process of coping with stress in which partners serve as the primary source of practical and emotional support for each other, thereby facilitating shared regulation of emotions (Falconier and Kuhn, 2019). In parents of children with cancer, dyadic coping has been identified as an important aspect related to relationship distress, where well-functioning dyadic coping is associated with better individual adjustment and improved relationship outcomes, while dysfunctional dyadic coping is linked to heightened distress (Van Schoors et al., 2019).

Relationship distress among parents of children diagnosed with cancer has previously primarily been studied through quantitative methods, while there has been a lack of qualitative in-depth studies investigating this issue in the context of childhood cancer. A deeper understanding of relationship distress in this specific context is essential for the development of effective and targeted couple-based support tailored to this population, which may also promote the wellbeing of the entire family system. Therefore, this study aims to explore how parents of children with cancer experience relationship distress to thereby generate an in-depth understanding of the phenomenon.

2. Methods

2.1. Design

This qualitative study was based on semi-structured interviews with parents of children diagnosed with cancer who experience relationship distress related to their child's cancer. The study adhered to the consolidated criteria for reporting qualitative research (COREQ) (Tong et al., 2007). All data were handled in accordance with the General Data Protection Regulation. Ethical approval was granted by the Swedish Ethical Review Authority (Approval number: 2023-04023-01).

2.2. Procedure

Participants were recruited via advertisements on social media and patient organizations, as well as referrals from clinical contacts, from November 2023 to March 2024. In addition, snowball sampling, whereby participants informed their partners about the study, was used to facilitate the inclusion of fathers. Participants were recruited until the authors determined that the sample had sufficient information power to address the study aim (Malterud et al., 2016). Throughout the interview process, AK and LL engaged in continuous discussions to evaluate the richness of the experiences described by the participants, and the richness of the data, with particular efforts made to ensure that fathers' perspectives were included, as well as parents of children at different ages, different diagnoses, time from diagnosis, and a representation of children who had died from their disease. Potential participants were given information about the project, and were assessed for eligibility via telephone. To be eligible for inclusion, participants had to be a parent of a child diagnosed with cancer (age <19 years at diagnosis) within the past 10 years, be in a relationship at the time of their child's cancer diagnosis, experiencing/experienced relationship distress due to the child's cancer, and be fluent in Swedish or English. Participants meeting these criteria completed a digital informed consent form and were scheduled for individual interviews via telephone (n = 23) or video conference (n = 2) based on participant preferences. The interviews followed a semi-structured interview guide (see supplementary material) which gathered sample characteristics and explored the key areas: relationship dynamics, communication, conflict management, and relational changes in-depth following the child's diagnosis. Questions regarding support needs were also included; however, the results will be presented elsewhere. The guide was developed by LL and AW, drawing on their extensive research experience with the population. All interviews were conducted individually by AK (female research assistant with an MSc in psychology), supervised by LL (female associate professor and licensed psychologist). The authors most involved in the analysis (AK, LL) share cultural and professional perspectives since both are Swedish women with backgrounds in psychology. The co-authors represent the academic fields of paediatrics, care science (including palliative care), psychology and gender studies, bringing clinical expertise as a medical doctor, registered nurses, licensed psychologists, and licensed psychotherapists. The interviews lasted on average approximately 1 h (range 32–92 min). The interviews were then audio-recorded and transcribed verbatim by a professional transcriber. Participants received a digital gift card worth 400 SEK (approximately 40 USD) following their participation. All translations of quotes into English were carried out jointly by bilingual authors AK and LL.

2.3. Data analysis

The interview transcripts were analysed individually using inductive qualitative content analysis, following the approach of Graneheim and Lundman, to identify common patterns of meaning in the interview material (Graneheim and Lundman, 2004). The software NVivo 14 (Lumivero, 2023) was used to facilitate the data analysis. The first step of the analysis involved repeatedly reading the transcripts until the essence of the content was understood (AK, LL). Subsequently, meaning units relevant to the research question were identified and assigned a descriptive code, defining the content of each unit (AK, LL). Thereafter, each code was sorted into different subcategories, labelling the underlying meaning of the data (AK, LL). These subcategories were then further abstracted into a more limited number of categories, mapping connections across subcategories (AK, LL). In the final step of the

analysis, the categories were abstracted into an overarching theme reflecting the latent content of the results (AK, LL). The theme served to synthesize and interpret patterns across all categories. Examples from the analysis process are shown in Table 1, with a more detailed version provided in Table S1 in the supplementary material. Throughout the analysis process, any uncertainties were discussed by several authors (AK, LL, AW, and RS; all with previous experience of conducting research with qualitative analysis) until consensus was reached. To validate the findings, member checking was conducted with a reference group of parents of children diagnosed with cancer separate from the sample, consisting of 8 parents (6 mothers and 2 fathers). The final results were agreed upon by all authors of the study.

3. Results

3.1. Participants

A total of 28 parents expressed an interest in participating in the study. Out of these, two parents were found not to fulfil inclusion criteria (n = 1 child not diagnosed with cancer and n = 1 no experience of relationship distress). One was not reachable after inclusion. Seven fathers were recruited through partner referrals. The final sample consisted of 25 parents (17 mothers and 8 fathers) of 18 children diagnosed with cancer, including two children who had died from the disease. While all participants were in a relationship at the time of their child's diagnosis, by the time of the study some couples had divorced or separated, and in those cases were interviewed about their previous experiences of relationship distress related to their child's disease. Participants mean age was 40.3 years, a majority cohabited with their partner, had more than one child, and were caring for a child currently undergoing cancer treatment. Sample characteristics and information about the child's cancer are presented in Table 2.

3.2. Content analysis

The content analysis resulted in one overarching theme, three categories, and nine sub-categories (see Fig. 1), which are described in detail below.

3.2.1. Fighting together, yet drifting apart

The overarching theme, 'Fighting together, yet drifting apart', captured an interrelation, a temporal or possibly causal process, that linked the three categories together. In the first category 'Pressure on the relationship', aspects that placed strain to the relationship were identified. The second category 'When unity fails' included ways that the couple had failed to manage this strain in an adaptive and collaborative manner. The third category 'Fractured togetherness' included the profound disconnection and relationship distress that parents due to these processes had developed. The theme thereby illustrates a link between these, i.e., the process of experiencing joint hardships, of trying to manage these together, but ending up with a wounded relationship.

3.2.2. Pressure on the relationship

This category encompassed the aspects related to the context of being a parent of a child diagnosed with cancer that put strain on the couple relationship. It included three subcategories: 'Distressing emotions', 'Separation and isolation', and 'Parenting above all'.

3.2.2.1. Distressing emotions. Parents described a range of distressing emotions related to the constant exposure to low-intensity stress, as well as to high-intensity acute stressors in medical emergency situations, which were described by parents as profoundly exhausting and as having a negative impact on the couple relationship. As a consequence of this, parents described impaired general emotional capacity, decreased tolerance towards their partner, and loss of love in the relationship.

> *"You were constantly tired, you'd become a bit short-tempered, kind of irritable. / … / We both (my wife and I) became, well, more or less depressed, you could say, and ended up wearing each other down. / … / It became a vicious cycle that slowly but surely spiralled downward."* – Father #25

Parents described how the emotional distress and exhaustion negatively impacted their ability to interact as a couple, and described it as reducing their empathy towards their partner, and diminishing the positive interactions and efforts they made for each other. Overall, parents expressed how distressing emotions such as fear, anger and sadness related to the child's cancer affected the joy they could experience within their relationships.

3.2.2.2. Separation and isolation. Parents described how almost all aspects of their daily life were affected by the demanding management of the child's cancer treatment, which also implied reduced time available for contact, communication and interaction with their partner, and almost no time together without the child being present. The need for one parent to be at the hospital over long periods of time, while the other stayed at home with siblings created a physical distance between the

Table 1
Example of the analysis process.

Meaning unit	Condensed meaning unit	Code	Subcategory	Category	Theme
"We've … we've, uh, we've been parents so much that we've lost … uh, this relationship, uh, between us. We've … it's taken … the parenting role has taken over. It's been more about just surviving. Yes. Mm." – Mother #1	We have been parents so much that we have lost the relationship between us. The parenting role has taken over. It's been more about just surviving.	We have been parents focusing on survival so much that we lost our relationship.	Parenting above all	Pressure on the relationship	Fighting together, yet drifting apart
"Yes. I also felt quite criticized (by the partner) for being too worried and too negative and so on./ … /Uh, and that probably resulted in that I did not want to say anything to him, because I felt that he … criticized what I thought or felt, that it was not right to feel as I did." - Mother #18	I felt criticized (by the partner) for being too worried and too negative. That resulted in that I did not want to say anything to him, because I felt that he criticized what I thought or felt, that it was not right to feel as I did.	I felt criticized (by partner) for being too worried and negative, which resulted in that I did not share my thoughts or feelings.	Managing new emotions together	When unity fails	Fighting together, yet drifting apart
"We're not as good at compromising anymore or seeing the bigger picture, and that leads to unnecessary conflicts. And that's taken a toll on both of us, sometimes we can't agree on anything at all." – Father #3	We are not as good at compromising or seeing the bigger picture anymore, which leads to unnecessary conflicts. Sometimes we cannot agree on anything. The conflicts have taken a toll on both of us.	We are not as good at compromising or seeing the bigger picture anymore, which leads to unnecessary conflicts. Sometimes we cannot agree on anything, which has taken a toll on both of us.	Conflicts	Fractured togetherness	Fighting together, yet drifting apart

Table 2
Sample characteristics.

Parents of children diagnosed with cancer (n = 25)	n(%) or Mean[SD]
Parents	
Mother	17(68)
Father	8(32)
Age	40.3 [6.7]
Swedish speaking	25(100)
Marital status	
Married/Living together	22(88)
Divorced/Living separately	3(12)
Relationship duration in years	13.9[6.4]
Number of children	
1	7(28)
2	10(40)
3	7(28)
4	1(4)
Parents of children deceased from cancer	2 (8)
Educational level	
High school	3(12)
College/University	19(76)
Vocational education	3(12)
Occupation	
Working full-time	7(28)
Working part-time	10(40)
Sick leave	5(20)
Care of a sick child leave (VAB)[a]	10(40)
Self-reported mental health disorder prior to the child's cancer diagnosis	
No	13(52)
Yes[b]	12(48)
Depression	7(28)
Anxiety	7(28)
Stress/Burnout	2(8)
Post-traumatic Stress Disorder	1(4)
Suicidal ideation	1(4)
Eating disorder	1(4)
Addiction	1(4)
Self-reported mental health disorder after the child's cancer diagnosis	
No	9(36)
Yes[b]	16(64)
Depression	9(36)
Anxiety	10(40)
Stress/Burnout	5(20)
Post-traumatic Stress Disorder	3(12)
Children diagnosed with cancer (n=18)	**n(%) or Mean [SD]**
Gender	
Girl	11(61)
Boy	7(39)
Years since cancer diagnosis	2.67 [1.88]
Status of cancer treatment	
Ongoing cancer treatment	11(61)
Completed cancer treatment	5(28)
Deceased from cancer	2(11)
Years since end of treatment	1.20[0.45]
Years since death	3.50[2.12]
Paediatric cancer diagnosis	
Leukaemia	7(39)
Brain tumour	5(28)
Solid tumours	5(28)
Lymphoma	1(6)
Child's age at diagnosis	4.75[4.22]
Type of cancer treatment[b]	
Chemotherapy	16(89)
Radiotherapy therapy	5(28)
Surgery	8 (44)
Stem cell transplantation	2(11)
Immunotherapy	1(6)
Spread or relapse of cancer	6(33)

[a] VAB is a provision in Sweden's social insurance system that allows parents to take economically compensated leave from work to care for a sick child.
[b] Multiple response alternatives possible.

parents.

> *"So, for most of the time, we (my husband and I) mainly just met at the hospital door to switch shifts. And then the other would go home to the sibling. / … / We haven't really seen each other much, uh, due to the cancer, for an extended period."* - Mother #20

This separation was described as a barrier hindering the couple from maintaining their couple relationship. Conversely, parents also expressed how being isolated together could be negative for their relationship. Parents described that being confined to the home at all times to care for the child, with minimal social contact with the outside world due to the risk of infection, put a massive strain on the relationship. Thus, the demands placed on family life and daily routines by the management of the child's cancer, included aspects that parents described created enormous pressure on the couple relationship as well.

3.2.2.3. Parenting above all. Parents described themselves and their partner having been consumed by the only thing that mattered: curing their child's cancer. As a result, parents described a shift in priorities, with the child's needs becoming paramount, and the couple relationship being put aside.

> *"[Child's name] is the first priority all the time, the other children are the second priority, oneself is the third priority, and the relationship has been the fourth priority. / … / [laughs slightly] it's not surprising that it's not so good afterwards."* – Father #25

Parents described how their identity during their child's cancer treatment, consisted to 99.9 percent of being a parent. This change in focus was expressed as necessary for the child's survival, including managing the logistics of the child's medical care and supporting the child emotionally through cancer treatment. In line with this however, parents expressed placing their couple relationship on hold, since that was considered less important than the child's needs. In hindsight, parents acknowledged the toll this shift of focus had taken on their couple relationship.

3.2.3. When unity fails

This category described how parents handled the challenges of the situation of parenting a child with cancer as a couple. It contained the following three subcategories: 'Emerging differences', 'Abandonment', 'Managing new emotions together'.

3.2.3.1. Emerging differences. Parents described how they had reacted to and dealt with the child's cancer in different ways, which in turn had become problematic for them in order to manage the crisis as a couple. Some described the differences as unforeseen responses emerging from the new situation they found themselves in, for example as a desire to escape and shut down or an urge to be with the child all the time. Others described that the situation intensified previously apparent differences in personality traits between partners in areas such as the tendency to worry, emotional stability, rationality, and optimism. Parents expressed that these differences had been standing in the way for mutual support and care for one another.

> *"It has been discussions like, 'Well, what if *child's name* dies.' And then my response has kind of been, 'But no doctor has said that. Uh, so why are you thinking about this?' / … / And then it has become friction and silence. / … / It has been this clash between the emotional and the rational. Where my strategy has kind of been to stick more to the rational from the doctors."* – Father #22

These differences in how to handle the current situation made it more difficult for parents to understand each other, to help each other out, and to work together as a team.

3.2.3.2. Abandonment. Parents expressed a lack of support from their

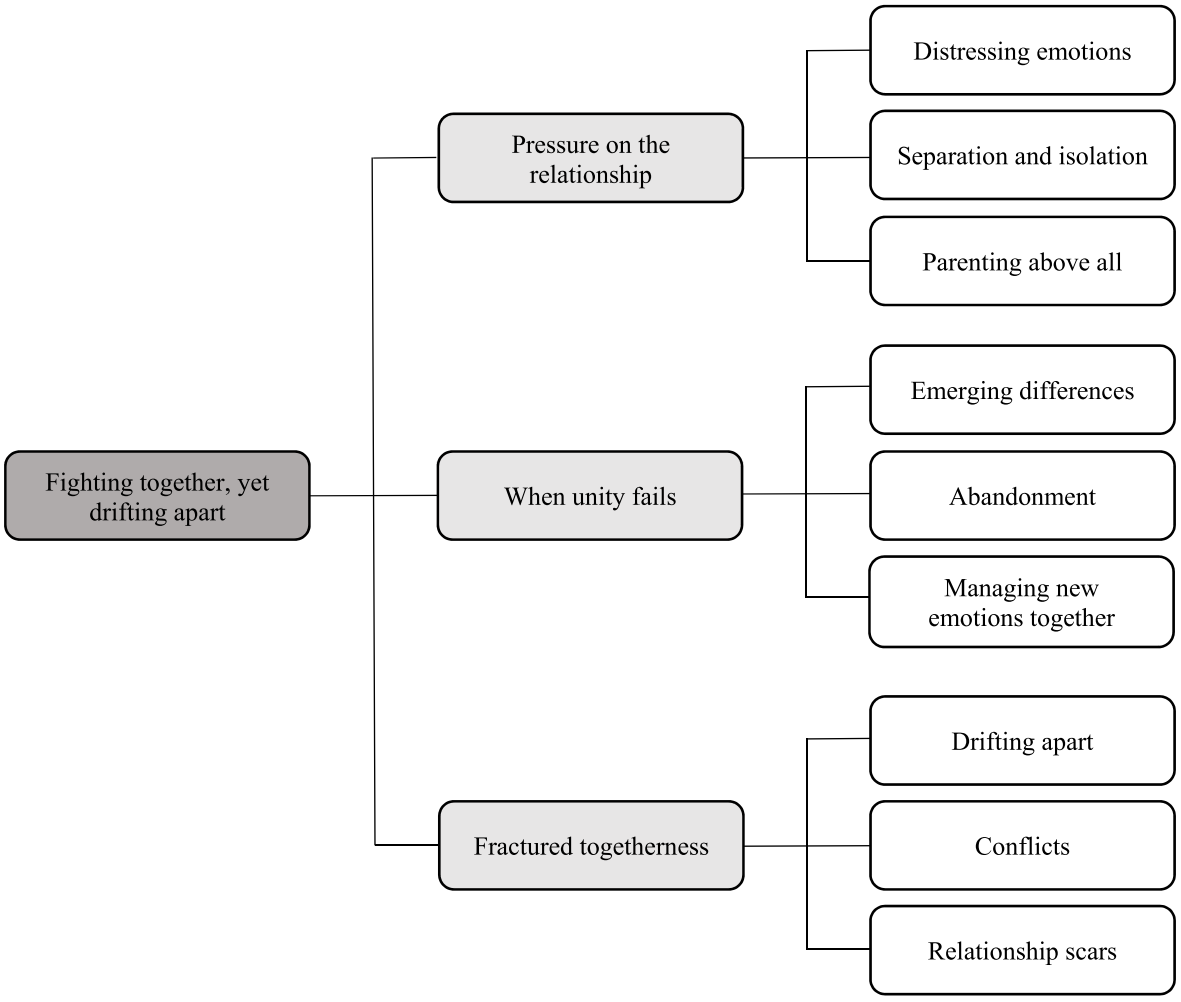

Fig. 1. Overview of the result from the content analysis; theme (dark grey), categories (light grey) and sub-categories (white).

partner, both practically and emotionally, following the child's cancer diagnosis. This subcategory was however almost exclusively expressed by the mothers in the study. Mothers described being left alone with all the practical concerns of everyday life and of the child's cancer treatment, which created a demanding situation where the partner's help was much needed but not received. Additionally, mothers described not being able to turn to their partner with their emotional needs due to experiencing inadequate support. This created feelings of being diminished, rejected, not understood, disappointed, and lonely, rather than comforted.

> *"I don't feel … seen, heard, or validated. I get so disappointed and angry that when you're going through, well, maybe one of the hardest things in life, the other person isn't there [starts sobbing]. Even in the toughest moments you can't support each other."* - Mother #19

This emotional and practical abandonment was described as weakening the emotional bond in the couple. Parents expressed some understanding towards their partner for not having provided them with support, such as it being a consequence of not fully understanding each other's needs in the demanding situation; the strain on their own mental health, or having to focus on and prioritizing the child's needs. Still, the abandonment from the partner was perceived as detrimental to the relationship since it was experienced at a time when they needed each other the most.

3.2.3.3. Managing new emotions together. Parents experienced not being able to communicate with each other and connect over their emotional reactions to the child's cancer, which in turn made it difficult to handle the crisis together as a couple. They experienced that they had to make room in the couple for only one partner to react emotionally at the time; if both parties had faced their fears and worries together, it would have been too emotionally difficult to handle.

> *"It's strange to think about it in hindsight; maybe we (my husband and I) should have tried to face it together (the fear and worry). But I think it became so incredibly difficult to do that, because it got so hard. Eh, and then there would be no one giving any hope, if we were to face it together."* - Mother #8

Parents described taking turns to express emotions within the relationship to be able to manage the situation. This could be by one partner setting their emotions aside to support the other by "keeping it together", being positive and "strong", or through a pattern of taking turns in "crashing emotionally" and "pulling it together". This pattern of switching roles when the emotional and practical burden became too hard to handle for the supporting partner, was described as necessary by parents in order to manage the situation. Still, parents were not able to handle the emotions together. Moreover, they described concern for their partner as a factor standing in the way of connection.

3.2.4. Fractured togetherness

This category described negative changes within the couple relationship occurring as a consequence of parenting a child with cancer. The following subcategories were included: 'Drifting apart', 'Conflicts', and 'Relationship scars'.

3.2.4.1. Drifting apart. Parents described that they had experienced an increased distance in the relationship over time; both on an emotional and physical level. Parents themselves perceived this distance as stemming from the experiences related to the child's cancer. The emotional gap between partners was described by the parents as devastating, and was associated with feelings of being invisible to their partner and with loneliness in the relationship.

> *"Uh, I try to hug him sometimes, but he doesn't hug back. / … / I think it's also about closeness; it's about looking at each other when you talk and, you know, a lot of it doesn't need to be physical. But I feel like I'm becoming increasingly invisible at home. No, it's really hard, truly."* – Mother #17

For some, the emotional distance ultimately created a situation where the partners lived completely separate lives in a shared home, staying in the relationship for the sake of the children. Parents explained that living parallel lives during their child's illness hindered their ability to reconnect following the child's treatment or death, as the experience led them to 'grow apart' and evolve in different directions. In some cases, parents described that the lack of intimacy even had resulted in a breakup or divorce from their partner. Parents described this as a consequence of them not being able to handle the crisis together, or that the crisis had shown to them that they were too different from each other to remain in a couple relationship. It was also described by parents that the emotional detachment further impacted sexual desire towards the partner. Combined with reduced libido due to fatigue, stress, worry, and grief, this had resulted in a negative effect on physical intimacy, including decreased frequency of having sex, kissing, hugging, touching, and even making eye contact. A great grief was expressed among parents due to having lost the connection with their partner.

3.2.4.2. Conflicts. Increased levels of friction in the couple relationship were described by parents, resulting in higher frequency and magnitude of conflicts concerning trivialities. Conflicts with the partner concerning the ill child and the cancer treatment were described as those most critical and unsolvable within the couple relationship. Parents described how the increased frequency of conflicts drained valuable energy, which in turn led to even more conflicts. The conflicts concerned several areas, including difficulties compromising, different priorities within the couple, mental health struggles, and a loss of respect for the partner due to perceived poor coping skills.

> *"There can be discussions, both about, uh, [Child's name] and her illness, but also about minor things that normally wouldn't matter in everyday life. / … / It (the child's cancer) affects the tone of the discussions, small things become blown out of proportion. It's not normal."* - Father #6

On the other hand, some parents also described a decrease in conflict frequency. This was also experienced as negative for the relationship, since it stemmed from being too exhausted to argue, in combination with the increased distance within the couple, which resulted in diminished connection and engagement within the couple relationship. Moreover, the conflicts that were described were unresolved to a greater extent and involved more serious topics than, for example, discussions about household chores.

3.2.4.3. Relationship scars. Parents expressed that the challenges during their child's cancer had deeply wounded their couple relationship, which was described by some as irreparable. Parents further explained that this was a result of the experience of being left alone when they needed their partner most.

> *"No, after that, I didn't want anything to do with him. He let me down completely. It's like he abandoned me in a war. And it's his child too."* – Mother #9

Moreover, partners described that their affectionate feelings toward the partner had become replaced by feelings of disappointment, hopelessness, sadness, discomfort, anger, and cold-heartedness. Some even described feelings of hatred towards their partner after the child's death, making it impossible to share a life together. Some parents also described how merely looking at their partner became a painful reminder of the shared cancer experience. While some parents described having managed to keep the basis of love somewhat intact, the passionate love had deteriorated due to experiencing so much anger and contempt towards the partner during the time of the child's cancer. The cancer experience had, in different ways, created lasting wounds in the parents' relationship which were described as difficult, or even impossible, to heal.

4. Discussion

This study aimed to explore relationship distress in the context of childhood cancer to generate an in-depth understanding of the phenomenon. The results revealed three categories, nine subcategories, and one overarching theme that illustrate the process of experiencing joint hardship, of trying to manage this together, but ending up with a wounded relationship.

The theme 'Fighting together, yet drifting apart' illustrates parents' experiences of the process of development of relationship distress in the context of childhood cancer. This theme can be placed in relation to general stress-coping models described in the literature (e.g., Bodenmann, 1995), whereby stressors lead to negative health effects through mechanisms of dysfunctional coping strategies. Previous results in the childhood cancer context also give some support to the occurrence of such a process, since it has been shown that parents of children with cancer who report negative dyadic coping within the relationship report higher levels of relationship distress (Van Schoors et al., 2019). It is important to highlight that since the present study is of a qualitative nature, causal or developmental pathways have not been investigated per se. Still, our results suggest potential mechanisms that could be involved in the development of relationship distress in parents of children diagnosed with cancer, and point to the specific nature of these. It is up to future studies to determine directional pathways, and to investigate if the potential mechanisms suggested by our results can be addressed by support interventions to reduce the development of relationship distress.

The first category, 'Pressure on the relationship', described different aspects related to the child's cancer that contributed to stress particularly on the couple relationship. The results in this category align with previous research which has reported that distressing emotions, geographical distance, lack of time for each other, and a shift of focus towards survival of the child negatively affect parents' couple relationship following a child's cancer diagnosis (Da Silva et al., 2010; de Arruda-Colli et al., 2018; Holm et al., 2024; Hooghe et al., 2020; Silva-Rodrigues et al., 2016). Our findings support these results and add a qualitative depth to *how* these factors challenge the relationship functioning. The stressors described in this category can be understood as conditions that challenge the couple's attachment system. Attachment theory (Bowlby, 1982; Hazan and Shaver, 1987) emphasizes that partners rely on each other for emotional security during times of distress. When geographical distance, lack of time, or an overwhelming focus on the child's survival reduce this availability, attachment needs risk remaining unmet. Such dynamics set the stage for relational strain, which in our material is further elaborated in the categories 'When unity fails' and 'Fractured togetherness'. Moreover, our study point to that parents experience being isolated together as an enormous pressure to the relationship. A similar finding has been observed among couples during lockdowns imposed by the COVID-19 pandemic (Ahuja and Khurana, 2021), where lower relationship satisfaction, intimacy, and passion within the relationships were reported due to being isolated together. Lastly, the results show that even though putting the needs of the child above all it is an inevitable part of parenting a child with

cancer, in hindsight, parents wish that they had not put their relationship entirely 'on hold' during the time of the child's illness since it made reconnecting with each other again very difficult. The results thereby point to the importance of supporting parent's couple relationship also at earlies stages in the child's disease trajectory in order to prevent relationship distress in the longer term.

The second category, 'When unity fails', illustrates how parents described having navigated the cancer experience as a couple. The results included experiencing emerging differences within the couples, perceived abandonment by the partner, and managing new emotions together. Parents' unforeseen different reactions to their child's cancer can be understood through the concept of evolutionarily rooted threat responses, specifically the fight, flight, or freeze responses (Kozlowska et al., 2015). This reaction to threat may manifest different in different people as heightened protectiveness, irritability, withdrawal, or even emotional shutdown. Parents described that reacting different from their partner had made it difficult to understand each other, and to work together as a team in a situation where mutual support was needed. By providing parents with information about normal threat responses, an increased understanding and ability to receive and give support to each other could possibly be obtained. The subcategories identified in this category all described different aspects of disruptive dyadic coping; 'Emerging differences', 'Abandonment', 'Managing new emotions together'. Since a well-functioning dyadic coping has been shown to be crucial for both individual and relationship outcomes in parents when facing childhood cancer (Van Schoors et al., 2019), these potential aspects of dysfunctional dyadic coping in parents of children with cancer who experience relationship distress should be brought attention. This is particularly important since research has shown that regulating emotions together as a couple is more effective in reducing stress than regulating emotions individually (Levy-Gigi and Shamay-Tsoory, 2017), that joint emotion regulation contributes to emotional stability for both partners (Butler and Randall, 2013), and that it plays an important role in the management of trauma-related experiences (Johnson, 2002). The failed joint emotion regulation may thereby also diminish parents' ability to regulate their own emotions, at a time when they experience a high degree of stress and distressing emotions. Taken together, these perspectives highlight the importance of examining the intricate dynamics between individual and dyadic emotion regulation in the development of relationship distress in the context of childhood cancer. This should be examined further in future studies**,** nevertheless, our results point to the potential benefit of addressing disruptive dyadic coping mechanisms, as outlined by results in this category, in support interventions for parents of children diagnosed with cancer.

It should be brought to attention that the subcategory 'Abandonment' in the second category, which described lack of support from one's partner, mainly was expressed by mothers. From the perspective of social role theory (Eagly and Wood, 2012), such patterns can be understood as reflecting socially constructed expectations that women should assume the nurturing role, while men are positioned as secondary caregivers. Previous studies show that there tends to be a shift towards more traditional parenting roles among parents of children with cancer (Clarke et al., 2009; Gibbins et al., 2012) and, in line with this, that healthcare staff often treat mothers of children with cancer as the primary caregivers (Hjelmstedt et al., 2021). Being the primary caregiver of a severely ill child is a very stressful event that can be expected to elicit a higher need for support from their partner. Importantly, our results should be interpreted within the Swedish cultural context, where gender equality is relatively highly valued which may contribute to mothers having higher expectations of partner support. Our findings, and previous research, however highlight the importance of awareness of gender roles and of equality in healthcare to better support families.

The third category 'Fractured togetherness', described aspects of relationship deterioration following the child's cancer, including drifting apart, experiencing increased levels of conflict, and the occurrence of 'emotional relationship scars'. Previous studies have reported similar tendencies in couples coping with childhood cancer including increased levels of conflicts and a tendency to drift apart (Da Silva et al., 2010; Long and Marsland, 2011; Van Schoors et al., 2017; Wiener et al., 2017). From a theoretical perspective, such relational strain may be understood as a consequence of attachment disruption. According to attachment theory (Bowlby, 1982; Hazan and Shaver, 1987), unmet attachment needs during times of stress can lead to emotional scars, withdrawal and escalating conflict between partners. Lasting emotional scars have previously been reported by parents in relation to traumatic events during their child's disease trajectory (Banienė and Žemaitienė, 2020; Carlsson et al., 2019); however, this study suggests the impact of such emotional scars also on the parents' couple relationship. These could be understood as a form of 'relationship scars'. In sum, our findings suggest that relationship distress in the paediatric cancer context, in contrast to relationship distress described in the general literature, appears to be more closely associated with the experience of trauma. Development and maintenance of trauma related symptoms has been described in the context of parenting a child with cancer previously (Ljungman et al., 2018), and our study expands this understanding by suggesting that this not solely is confined to the individual parent, but also have considerable implications for the couple relationship. Drawing on these results, parents of children with cancer who experience relationship distress may benefit from trauma-focused couples' therapy or interventions such as Emotionally Focused Couples Therapy (EFT) (Johnson, 2019) which emphasizes enhancement of the attachment bond between partners, of increasing emotion regulation, and of targeting distressing memories of having not been validated or seen by ones partner. Our results suggest that if interventions focus on reducing disruptive factors described in the first category, and focus on improving dyadic coping to enable unity as identified in the second category, the aspects of relationship distress described in the last category might possibly be prevented. It is up to future intervention research to determine if this suggestion holds true. While our study focused on parents who experience relationship distress following their child's cancer diagnosis, it is important to acknowledge that not all parents develop such difficulties. Thus, to fully understand relationship function in the aftermath of childhood cancer, protective factors among parents of children who do not develop relationship distress could also be investigated in future studies.

4.1. *Strengths and limitations*

Methodological considerations should be acknowledged when interpreting the results of the present study. To enable parents to speak freely about their relationship, individual interviews were conducted. However, since approximately half the sample consisted of parents of the same child, certain shared experiences may appear more prominent in the data than they are in the population. Nonetheless, the qualitative approach values each account as meaningful in its own right, with the aim of exploring diverse aspects of relationship distress in the context of childhood cancer, rather than quantifying them. Furthermore, sample homogeneity (e.g. Swedish speaking, highly educated, heterosexual mothers) limits the transferability of the findings. A more diverse sample reflecting fathers' perspectives to a greater extent, various cultural backgrounds, LGBTQIA + relationships involving non-cisgender identities, and families with low socio-economic status could have provided a broader perspective in the understanding of how parents experience relationship distress in this context. Given that cultural and gender norms shape relationship dynamics and may influence relationship distress, future research should examine more diverse samples in this context. Moreover, since relationship distress is relatively common among couples, it is possible that some of the difficulties expressed may have arisen in combination with factors other than the child's cancer, for instance, research has shown that parenthood in itself may contribute to relationship distress in couples (Doss et al., 2009). Nevertheless, similar to this population, parents of children diagnosed with other physical or psychological conditions have shown increased levels of relationship

distress (Gau et al., 2012; Wiener et al., 2023). Future studies could expand our findings to such populations, to investigate if similar factors and mechanisms are involved and of relevance to support interventions.

Recruiting fathers through their partner may have influenced the findings due to shared experiences within couples. However, this approach was essential to enable representation of fathers' perspectives, which previous studies in this population have struggled to represent. This study also included a representation of parental experiences of different cancer diagnoses and treatments, various stages of the cancer trajectory, a wide age range both in parents and their children at diagnosis, all of which strengthen the study. The sample further included bereaved parents, which enriches the study by capturing perspectives of relationship distress among these particularly vulnerable parents. Still, future research should further explore the challenges faced by bereaved parents to gain a deeper understanding of relationship distress in this specific context, including both the experiences of having a severely ill child, the death of the child, and managing bereavement. Furthermore, only including parents who experience relationship distress related to their child's cancer enabled a focus on this specific phenomenon, importantly however, many couples adapt well to their child's cancer and our results should not be transferred to couples who do not develop relationship distress following their child's cancer (Van Schoors et al., 2017). Additionally, preconceptions are always important to consider in qualitative analyses. The authors most involved in the analysis (AK,LL) share cultural and professional perspectives, which should be considered in relation to the transferability of the findings. To address this, the research team, engaged in ongoing reflexive dialogue throughout the process of analysing the results. To further enhance the trustworthiness of the results, findings were cross-checked with a patient group, who provided critical feedback on whether our interpretations resonated with lived experiences. In addition, all authors from interdisciplinary fields, with extensive expertise in qualitative methodology and clinical practice were involved in all stages of the study, strengthening the credibility of the results.

5. Conclusions

In conclusion, this study contributes with an in-depth understanding of relationship distress in parents of children with cancer by illustrating the process of experiencing joint hardships, of trying to manage these together, and sometimes ending up with a wounded relationship. The results can contribute to the development of targeted couple support interventions for this population, which may be beneficial for parents as individuals, as a couple, and potentially for the whole family.

CRediT authorship contribution statement

Astrid Kuylenstierna: Writing – review & editing, Writing – original draft, Visualization, Validation, Software, Project administration, Methodology, Investigation, Formal analysis, Conceptualization. **Pia Enebrink:** Writing – review & editing, Validation, Conceptualization. **Ulrika Kreicbergs:** Writing – review & editing, Validation, Conceptualization. **Gustaf Ljungman:** Writing – review & editing, Validation, Conceptualization. **Malin Lövgren:** Writing – review & editing, Validation, Conceptualization. **Renita Sörensdotter:** Writing – review & editing, Validation, Conceptualization. **Anna Wikman:** Writing – review & editing, Validation, Methodology, Conceptualization. **Lisa Ljungman:** Writing – review & editing, Writing – original draft, Validation, Supervision, Methodology, Investigation, Funding acquisition, Formal analysis, Conceptualization.

Declaration of competing interest

None declared.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ejon.2025.103064.

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