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BMJ Open Returning to daily life: a qualitative interview study on parents of childhood cancer survivors in Germany

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ABSTRACT

Objectives To investigate experiences of parents of paediatric cancer survivors in cancer-related changes in the parents' daily life (work life, family life, partner relationship and social life) during and after intensive cancer treatment and to examine the reintegration process with its impeding and facilitating factors.

Design The design of this cross-sectional study involves a qualitative content analysis of semistructured interviews.

Setting Participants were consecutively recruited in clinical settings throughout Germany.

Participants Forty-nine parents (59% female) of 31 cancer survivors (aged 0–17 at diagnosis of leukaemia or central nervous system tumour) were interviewed approximately 16–24 months after the end of intensive cancer treatment (eg, chemotherapy).

Results During treatment, more than 70% of parents reported difficulties reconciling paid work, household and family responsibilities and caring for the ill child. Couples spent little time with each other and approximately 25% reported dispute and burden. Many parents did not have enough energy for pursuing any hobbies during treatment. However, over the long term, being faced with the child's disease also led to strengthened relationships, new priorities, improved communication, increased mutual trust and greater appreciation for daily life. Supportive social networks (family/friends/employers), a strong partner relationship prior to the diagnosis and the use of psychosocial services (eg, family-oriented rehabilitation) had a positive impact. At the time of the interview, most families had adapted well. However, reintegration took time and some parents lacked the energy required to continue life as they did before the diagnosis.

Conclusions Even though most parents successfully readjusted to a new 'normality', reintegrating into daily life after paediatric cancer treatment remains difficult. Professional psychosocial support could help families with the reintegration process. Lastly, clinical staff (eg, physicians, psychologists, social workers) should bear in mind that the burden of parents does not automatically end with the end of intensive cancer treatment.

INTRODUCTION

In 2017, more than 2200 children under 18 years of age were diagnosed with cancer in Germany.¹ In the last decades, improved diagnostics and treatment methods have led to

Strengths and limitations of this study

- We interviewed parents of childhood cancer survivors throughout Germany and reached an adequate sample size, including both the mother's and the father's perspective.
- In this interview study, we identified specific strains and needs of parents of childhood cancer survivors. Thus, the results may help to develop or to optimise support services that help parents with the re-entry into 'normal' life after the end of cancer treatment.
- A selection bias, especially in regards to the level of education, employment status, relationship status, mental stability and sufficient German language skills, cannot be ruled out, since the consecutive sampling did not allow for a non-responder analysis.
- It is possible that the retrospective design of the study affected the parental report of their experiences during their child's cancer treatment.

increased survival rates from 65% in the 1980s to approximately 80% nowadays, resulting in a growing population of childhood cancer survivors.² Yet, the end of cancer treatment does not necessarily seem to determine the end of illness-related burden in parents of childhood cancer survivors.^{3–4} Even years after diagnosis, some parents report clinically relevant mental distress levels.^{4–5} However, childhood cancer can also result in positive changes in parents (eg, appreciation of life), often described as 'post-traumatic growth'.^{4,6,7}

Following the diagnosis of childhood cancer, some parents reduce their work time, take sick leave or even resign or lose their jobs to care for the paediatric patient and for the patient's siblings.^{8–10} Mothers seem to be more likely to reduce working hours or to stop working.^{10–12} These changes can also lead to financial problems after the child's diagnosis.¹⁰ Years after treatment, several parents still work less than before the cancer diagnosis.^{12–14} Family life can be negatively affected as well, for example, due to separation during hospital stays or less attention for

healthy siblings.^{9 13 15 16} Family members have to adapt to new roles and responsibilities after the diagnosis.¹⁵ In the long term, families also report positive changes in family life, especially with regard to family closeness, cohesion and appreciation.^{9 13 15 17–19} Notably, many parents focus on the family and the family home rather than pursuing social activities, which might lead to social isolation during cancer treatment and after. Study results reveal that the child's cancer disease can also affect the partner relationship. Some parents experienced more closeness in their relationship,^{15 19} while others reported marital tensions and in some cases separation.^{9 15 19} According to a recent systematic review, most couples successfully master the crisis of childhood cancer.²⁰

In conclusion, the literature shows that childhood cancer and its treatment lead to long-term changes in the lives of parents of paediatric cancer survivors.^{21 22} The transition back to normality after the end of treatment is often a major challenge and thus requires intensive psychosocial aftercare for the entire family. Hence, the family-oriented rehabilitation programme (FOR), a 4-week inpatient rehabilitation concept in Germany, routinely includes all family members.^{23 24} Previous research mostly focused on the time from the diagnosis to the end of the cancer treatment. Many studies included a broad, heterogeneous sample of parents regarding the time since diagnosis. Not much is known about reintegration processes of parents into daily life directly after the end of the treatment. In this interview study, we have investigated parental experiences in cancer-related changes in their daily life during and in particular after intensive cancer treatment. Furthermore, we have examined the reintegration process together with the impeding as well as facilitating factors. We interviewed parents of survivors of leukaemia or central nervous system (CNS) tumour, the most frequent childhood cancers in Germany,¹ approximately 16–24 months after the end of intensive cancer treatment to answer the following questions:

1. Which cancer-related changes in their daily life (work, family life, partner relationship and social life) do parents of childhood cancer survivors experience during intensive cancer treatment and thereafter?
2. Which factors impede or facilitate reintegration into daily life after end of treatment? How do rehabilitation programmes influence reintegration and psychosocial outcomes?
3. How do parents experience the reintegration process and how do they feel about their current situation?

METHODS AND ANALYSIS

Design

This qualitative interview study is part of a prospective observational study with a longitudinal mixed-methods design.²⁵ The study protocol was published elsewhere.²⁵ In this interview study, we investigated the reintegration process of parents and children. The following analyses focus on the parents' daily life. The interview guideline

is provided in online supplementary appendix A. The reporting of this article follows the Consolidated Criteria for Reporting Qualitative Research.²⁶

Participants

Inclusion and exclusion criteria

Interviews were conducted with parents or other caregivers approximately 16–24 months after the end of their child's intensive cancer treatment. The children were up to the age of 17 at the time of their diagnosis (leukaemia or CNS tumour). Exclusion criteria constituted refusal of participation, serious physical and/or mental burden (applicable if the interview would be unduly burdensome), cognitive limitations and insufficient German language skills. Inclusion and exclusion criteria were assessed by the study registries and the healthcare providers in the clinics.

Sampling and sample size

Parents were recruited via two different approaches. First, we recruited parents who had already participated in the quantitative part of our prospective observational study.²⁵ Families received information letters and consent forms to participate in an interview with the final set of questionnaires. Second, we recruited families via the International HIT-MED Registry (I-HIT-MED; ClinicalTrials.gov Identifier: NCT02417324) and the Cooperative Study Group for Childhood Acute Lymphoblastic Leukemia (COALL) study (COALL 08–09; ClinicalTrials.gov Identifier: NCT01228331). They identified potentially eligible patients who received aftercare at the same site as the research institute. When attending their next follow-up appointment, the physician informed the parents about the study and gave them written information and consent forms. We approached a consecutive sample of the first 25 families that agreed to participate in the interview study and continued recruiting until no new themes occurred in the interviews and until data saturation was reached.²⁷

Data collection and analysis

Research team and reflexivity

The authors MLP and LI conducted the interviews. Both interviewers are female researchers, graduated psychologists and experienced in conducting qualitative studies.

Procedure

We conducted semistructured qualitative telephone interviews with one interviewer and one interviewed parent. Face-to-face interviews were offered to participants from the Hamburg region. In the beginning, the interviewer provided background information on the research project, data protection and organisational matters. We also assessed sociodemographic and medical characteristics. The interview guideline was pilot tested in the first interview and was only slightly adapted afterwards. Hence, we included the pilot interview in the data analyses. At the end of the semistructured interview, the parents were encouraged to add further experiences or thoughts. Field notes were taken during and after the interview.

Data analysis

The audio files were transcribed verbatim using the Simple transcription system²⁸ and the f4transkript software V.4.2 (www.audiotranskription.de). The transcripts were not returned to the parents for comments or corrections. The interviews were analysed using the methodical approach of qualitative content analysis.²⁹ MLP and LI generated categories both deductively (based on the interview guideline and on theoretical considerations) and inductively (from the transcripts) using the qualitative data analysis software MAXQDA V.10. A coding guideline with all category labels, category definitions, necessary coding rules and anchor samples is provided in online supplementary appendix B. MLP coded all interviews with this coding system and LI coded 20 interviews to enhance reliability. The intercoder agreement was 85%. Interviews of mothers and fathers of the same child were analysed separately. Sociodemographic and medical characteristics were analysed descriptively with the software IBM SPSS Statistics V.25. Additionally, we conducted an exploratory subgroup analysis on differences between the experiences of parents of CNS tumour and leukaemia survivors. We compared the codings in every category systematically between the diagnosis groups.

Patient and public involvement

Childhood cancer patients and their families were involved in our research project by participating in our pilot study.^{30 31} The results of the pilot study had a crucial impact on our choice of research questions, outcome measures and instruments for this prospective observational study. Furthermore, the participants of the pilot study were asked to provide information on missing topics and to add further considerations that were implemented in our interview guideline.

RESULTS

We have reported our results under four main areas of daily life: Work life, family life, partner relationship and social life. Within each area we have specified changes, barriers and facilitators (including the impact of rehabilitation measures) as well as the reintegration process and satisfaction with current daily life.

Sample characteristics

Information letters were sent to 113 families that had participated in the quantitative study.²⁵ Further information letters were issued by the cooperating study centres. The number of informed parents in this second recruitment approach is unclear. In total, 35 families returned the signed consent form. Interviews were conducted with 29 mothers and 20 fathers from 31 families. Parents from four families had dropped out due to incomplete contact data (n=1) or because no interview appointment could be arranged (n=3). One interview was conducted face to face. The average interview length was 43 min (range: 20–112 min). **Tables 1 and 2** provide an overview of the sociodemographic and medical data of parents and patients.

Work life

Changes

In more than half of the families, the child's disease led to sick leave for at least one parent during treatment. Thirty-five per cent of the parents reduced their working hours, terminated their job or chose a career change with better working conditions. Two parents lost their jobs.

I was fired because my bosses weren't really patient anymore because, well, the sickness is lasting so long and for a long time I have been just not as resilient as others. (Father of a toddler)

Furthermore, many parents described that the family took priority over work and that they handled difficulties at work more calmly. While more than 20% of the parents reported that working gave them a sense of normality, others reported lower productivity and loss of concentration.

I'm not that tough anymore. I have to save my energy. Therefore, you have to slow down a bit with regard to your career. (Mother of a school-aged child)

Four parents also reported financial difficulties.

Barriers and facilitators

The most important facilitating factors for parents' work life were support by the extended family and friends as well as support by employers.

My parents, who are both retired, live really close to us, just around the corner. And without them I wouldn't be able to be back at work again. (Mother of a school-aged child)

More than 40% of the parents that participated in a FOR reported that the programme had helped them to acquire greater resilience and energy. Other reported positive factors encompassed flexible working hours, support by the health insurance (eg, nursing service), maternity/paternity leave or being a homemaker as well as self-employment. Negative factors that influenced work life included a young age of the children, shift work and a long commuting distance.

Reintegration process and current daily life

For many parents, the occupational reintegration gradually took place after the end of the intensive cancer treatment or after a FOR. Fifteen per cent of the employed fathers and 91% of the employed mothers were working part time at the time of the interview. Only one mother was seeking employment. Most parents expressed a rather positive attitude towards their current work situation. Many parents appreciated flexible working hours and part-time work, because the child that was diagnosed with cancer still required extra care and follow-up visits in the clinic.

My priorities are definitely private. [...] I went down to 30 hours because I just hadn't had the time at

Table 1 Sociodemographic data of 49 parents from 31 families

Sociodemographic data (parents)	Total (n=49)		Fathers (n=20)		Mothers (n=29)	
	n	%	n	%	n	%
Age in years (mean, SD/range)	42.6	7.1/ 26–65	43.4	5.9/ 31–52	42.0	7.9/ 26–65
Familial situation						
Permanent relationship*	44	91.7	18	94.7	26	89.7
Living with the partner*	43	90.0	18	94.7	25	86.2
Family living situation*						
Living with the other parent and the child/children	42	87.5	18	94.7	24	82.8
Living only with the child/children	5	10.4	1	5.3	4	13.8
Patchwork family	1	2.1	0	0	1	3.5
Education						
>10 years	34	69.4	14	70.0	20	69.0
≤10 years	15	30.6	6	30.0	9	31.0
Employment status						
Gainfully employed	42	85.7	20	100	22	75.9
Full time	19	45.2	17	85.0	2	9.1
Part time	23	54.8	3	15.0	20	90.9
Not gainfully employed	7	14.3	0	0	7	24.1
Homemakers	3	42.9	0	0	3	42.9
Maternity/paternity leave	3	42.9	0	0	3	42.9
Seeking employment	1	14.3	0	0	1	14.3
Child's cancer diagnosis						
CNS tumour	15	30.6	6	30.0	9	31.0
Leukaemia	34	69.4	14	70.0	20	69.0

*Missing value of one father.
CNS, central nervous system.

home. And that's more important to me. (Father of a toddler)

Family life Changes

Especially during the inpatient cancer treatment, more than 70% of the parents struggled with the difficulties of dealing with everyday life (eg, work, household, disease management, childcare). Almost one-third of the parents reported that a new allocation of responsibilities became necessary.

We had to organise ourselves even more. Who takes care when and for which child, who goes to the hospital, who goes to work? Without the support of our social network, grandparents, friends and so on we wouldn't have managed the situation. (Mother of a school-aged child)

Sixteen of 26 families with more than one child reported that siblings received less attention from their parents, which made many parents feel guilty.

You always can intend not to forget your second child in such situations but it's hard to put into practice, because even if you're playing with your second child while the other child is in hospital, you always have something on your mind. [...] Then you hear about other mothers, who are in the same situation. Sitting in bed at nighttime crying and don't know how to fix it. (Mother of a toddler)

However, many parents also mentioned positive changes, such as strengthened family relationships and a shift of priorities towards the family being most important.

Barriers and facilitators

Support by the extended family, especially the grandparents, and friends was an important resource (eg, childcare, grocery shopping).

My husband had to go to work, I was in the hospital and grandma did everything she could to make sure the children were cared for. (Mother of a school-aged child)

Table 2 Sociodemographic and medical data of the 31 paediatric cancer patients

Sociodemographic and medical data (paediatric cancer patient)	Total (n=31)		Boys (n=19)		Girls (n=12)	
	Mean	SD/range	Mean	SD/range	Mean	SD/range
Age at time of interview in years	9.0	4.7/3–20	9.3	5.1/3–20	8.4	4.2/3–18
Age at time of diagnosis in years	5.5	4.5/0–17	6.1	5.3/0–17	4.6	2.8/1–9
	n	%	n	%	n	%
Number of siblings						
0	5	16.1	3	15.8	2	16.7
1–2	23	74.2	15	78.9	8	66.7
>2	3	9.7	1	5.3	2	16.7
Cancer diagnosis						
CNS tumour	9	29.0	5	26.3	4	33.3
Leukaemia	22	71.0	14	73.7	8	66.7
Maintenance treatment at time of the interview						
Yes	4	12.9	2	10.5	2	16.7
No	27	87.1	17	89.5	10	83.3
Rehabilitation use						
Yes	30	96.8	18	94.7	12	100
No	1	3.2	1	5.3	0	0
Inpatient rehabilitation						
Family-oriented rehabilitation	28	93.3	16	88.9	12	100
Rehabilitation for adolescents	2	6.7	2	11.1	0	0

CNS, central nervous system.

Twenty-two of 28 families that participated in a FOR described a positive influence of the programme on their family life (eg, spending time together, coping with family problems). Other factors that affected family life positively were the siblings, the use of other psychosocial support services, a clinic in near vicinity and financial security. However, parental fear of progression impeded a carefree, 'normal' family life.

You don't have cancer and then at some point you are healthy again and everything is good. I think it's just a very formative experience you can only process it but you can't just shake it off. And it also shapes the whole environment somehow. [...] That is very formative, also for families. (Mother of a toddler)

So the point is, you're always afraid there's going to be something like that again and the fear pops up with every small matter. In these cases, rational mechanisms fail. So that's affecting me quite a lot now. (Mother of a school-aged child)

Furthermore, parents reported that additional burden such as house construction, physical impairment of the survivor, risk of infection and further medical issues in the family impaired family life.

Reintegration process and current daily life

After the end of the intensive cancer treatment, some families still had to deal with physical or psychosocial

long-term consequences of the disease that affected their family life negatively. However, at the time of the interview, many parents pointed out positive aspects of current family life (eg, greater appreciation of daily life).

Looking back, I would say our family life became even better. We came closer together. (Mother of a school-aged child)

Partner relationship Changes

Approximately 40% of the parents described positive changes in their relationship such as improved communication, increased trust and a strengthened bond. However, approximately half of the parents also stated negative changes. During the intensive cancer treatment, the patient required 24 hours care and in many families, the parents only met in the clinic during certain treatment phases.

It has been a massive burden and we took turns looking after this child 24/7. So we weren't even husband and wife anymore. We basically saw each other when we handed over the child, where we talked about what has happened and so on. So when I was at home, my wife was at the hospital and when my wife was at home, I was at the hospital. (Father of a school-aged child)

Dispute and burden during and after the treatment phase was mentioned by approximately one quarter of the parents. In one family, the parents separated during the treatment period.

Barriers and facilitators

Parents reported that the quality of the relationship prior to the diagnosis crucially influenced the relationship during and after treatment. Existing problems exacerbated, whereas a strong relationship served as a resource. Grandparents covering responsibilities in the childcare enabled parents to spend time together. Almost 30% of the interviewed parents who had participated in a FOR described the programme as helpful for their relationship (eg, use of couple therapy during the FOR, discovering new hobbies together as a couple). The relationship was described as an enormous resource during and after cancer treatment by almost 70% of the parents who lived in a relationship.

I was somehow the tower of strength. When the recurrence came, all were in tears and somebody had to say “Everything will be alright” although you might also need mental support. But then you had to find the strength to console. (Father of a toddler)

Single parents lacked the mutual support by a partner.

You’re lonely from time to time. Always to have to be self-motivated is kind of hard. I suppose it’s easier together. (Mother of a school-aged child)

Reintegration process and current daily life

Even though the relationship of some parents remained strained, most couples reported to be satisfied with their relationship and spent time together in a more conscious and appreciative way. Looking ahead, they felt strengthened, since they went through the child’s cancer treatment together.

I think our relationship has intensified. Together we have overcome a major crisis. This has strengthened our trust in each other and also the bond between us. (Father of a toddler)

Social life

Changes

Social isolation and withdrawal during their child’s cancer treatment was reported by almost 30% of the parents. Reasons were for example, limited time or energy.

But there was no way to even think about having a hobby. There’s no time for that at all. So if I pursued a hobby at that time, it was getting some sleep. [...] I’ll just say, that was the only thing worth striving for. Giving your body a break to regain strength. (Mother of an adolescent child)

Few parents engaged in hobbies (eg, sports) for relaxation or distraction purposes during treatment. One quarter of the parents mentioned that friendships ended and

one-third of the parents made new friends and deepened existing friendships.

We have fewer friends since then, but deeper and by far less superficial contacts. (Father of a toddler)

Around 65% of the parents described the contact to other affected parents who shared their situation as helpful. Some parents who lacked this contact, due to living far away from each other, wished for more exchange.

[...] where you don’t have to restrict yourself while talking. Well, you can mention radiotherapy without shocking others. More like “Ok, well, how was it for you?”. That is already a big relief. (Mother of a toddler)

Barriers and facilitators

More than 60% of the parents who participated in a FOR reported a positive impact on their social life (eg, getting in contact with other affected families, new input for leisure activities and self-care). Additionally, more than half of the parents reported support and understanding of family and friends as a facilitating factor. Single parents, shift workers and families with a physically burdened child struggled most with social activities since they only had little time available.

Reintegration process and current daily life

While some parents reintegrated quickly into their daily social life after the end of treatment, the reintegration process for others took months or years.

It took me a long time to have the energy to say ‘I’m meeting someone now’. You have to become active again. I still suffer from chronic exhaustion in such things. (Mother of a school-aged child)

Step by step, most parents reintegrated into their social life and (re)gained the ability to self-care. However, when weighting up time with the family or time alone or with friends many parents focused more on the family than before the cancer diagnosis.

Explorative subgroup analysis

The results of our explorative subgroup analysis revealed only minor differences between parents of CNS tumour and leukaemia survivors: The risk of infection seems to be more restrictive in families of leukaemia survivors, especially with regard to family and social activities (eg, going swimming, having visitors).

DISCUSSION

In our interview study, parents of childhood cancer survivors reported various positive and negative cancer-related changes in their daily life. We also identified factors that impeded or facilitated reintegration retrospectively and investigated the parents’ satisfaction with their current daily life.

Return to daily life

In many cases, the childhood cancer disease caused long-term changes on the parents' work life, especially in mothers. Some parents did not return to work as they did before the disease, because the children still needed special support or because of new priorities. Parents benefited particularly from supportive employers and flexible working time models. Family friendly working environments are therefore especially important for parents of seriously ill children.¹⁴

The childhood cancer diagnosis affected the entire family system and led to various changes in daily family life. The most frequently reported changes were organisational challenges, new task allocations within the family and siblings drifting out of focus. Yet, positive changes were mentioned, such as a strengthened relationship and family resilience. At the time of the interview, parental fear of progression still burdened the family life of some parents.

Most parents adapted well to cancer-related changes in their partner relationship and reported a strengthened bond. A recent large-scale study which investigated the relationship status and quality of parents of long-term childhood cancer survivors found an increased dependency within the partner relationship in terms of solving problems together and having a particularly close relationship.³² Our qualitative results show that these effects already occur in an early stage of survivorship.

Even after the end of treatment, some parents remained in their family for the time being and reported a recovery time of several months until the strength and desire for social and leisure activities returned. Social isolation of parents of children with cancer during treatment has already been described in earlier studies.^{8 13} Our study shows that this social isolation can also last beyond the end of treatment.

Clinical implications and future research

Even though not every family requires psychosocial support measures, support should be offered to every family that needs or requests professional help even after the end of treatment. Various psychosocial interventions for parents or the entire family have been described in earlier studies.²¹ However, the concept of an inpatient family-oriented rehabilitation programme for the entire family is only implemented in Germany.²¹

When developing or optimising support services that help families with the re-entry into 'normal' life, fear of progression that impedes reintegration should be taken into account.³³ Furthermore, healthcare providers should identify families with specific support needs (eg, single parents or families without support from the extended family). Although the results of our explorative subgroup analysis revealed only minor differences between parents of CNS tumour and leukaemia survivors, different diagnosis groups can have specific psychosocial burdens (eg, impaired social functioning in brain tumour survivors).³⁴ A quantitative approach would allow for a systematic

analysis of psychosocial differences between leukaemia and CNS tumour survivors and their family members.

Furthermore, little is known about the reintegration into social life of affected parents, even though social contacts, positive activities and self-care are important resources. Social life could be an important protective factor and should therefore be further investigated.

Due to the rarity of childhood cancer, parents in our study often reported lacking contact to other affected families near their home and wished for more exchange. Support groups that are not connected to a specific place of residence, such as computer-based support groups,³⁵ are required.

Conclusion

Even though most families successfully (re)adjust to a new 'normality', (re)integrating into daily life after cancer treatment remains difficult. Professional psychosocial support can help families during treatment as well as thereafter. In our study, the FOR was considered particularly helpful. New programmes (eg, computer-mediated support groups, multimodal programmes) that help families with the reintegration into daily life should be developed and evaluated. Most importantly, healthcare professionals (eg, physicians, psychologists, social workers) should bear in mind that the burden of parents does not automatically end with the end of intensive cancer treatment.

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Contributors CB is the principal investigator of the study. CB and LI developed the study concept and the design. LI and MLP developed the study materials and MLP, LI, KAK, GE, SR and DK acquired the data. MLP and LI analysed and interpreted the data. MLP wrote the first draft of the manuscript. CB, LI, KAK, GE, SR, and DK revised the first draft critically for important intellectual content. All authors have revised the subsequent drafts critically, approved the final manuscript to be published and agreed to be accountable for all aspects of the work.

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