


ORIGINAL ARTICLE

Concerns experienced by parents of children treated for cancer: A qualitative study to inform adaptations to an internet-administered, low-intensity cognitive behavioral therapy intervention

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Abstract

Objective: Childhood cancer treatment completion is associated with mental health difficulties and negative socioeconomic consequences for parents. However, psychological support needs are often unmet. We developed an internet-administered, guided, low-intensity cognitive behavioral therapy-based self-help intervention (EJDeR) and examined feasibility and acceptability with a single-arm feasibility trial (ENGAGE). Results suggest EJDeR is acceptable, however, adherence, especially for fathers, could be improved. Following the Medical Research Council complex interventions framework, this study explores concerns experienced by parents actively seeking support related to their child's cancer who were recruited into ENGAGE to inform further adaptation of EJDeR.

Method: Seventy-three semi-structured interviews (26 fathers, 47 mothers) were conducted, with data analyzed using manifest content analysis.

Results: Analysis resulted in seven categories: (1) Feeling lost and lonely in life; (2) Low mood; (3) Parenting difficulties; (4) Productivity difficulties; (5) Relationship challenges; (6) Stress reactions; and (7) Worry. With the exception of subcategories *Afraid of not being a good parent*, *Cancer recurrence*, and *Child's development and future* a somewhat higher percentage of mothers than fathers mentioned all identified concerns.

Conclusion: Parents described experiencing a range of concerns after their child had completed cancer treatment. EJDeR will be adapted to address these concerns and include indirect intervention modules targeting concerns such as stress. Information to support parenting, relationships, finance, and employment difficulties, alongside signposting to inform help-seeking, will be included. Findings also suggest a need to improve the gender-sensitivity of EJDeR.

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KEYWORDS

adolescent, child, childhood cancer, intervention development, mental health, parenting, parenting concerns, parents, qualitative research

1 | BACKGROUND

Completion of childhood cancer treatment is a period of vulnerability for parents^{1,2} with most actively involved in the child's physical and psychosocial care related to the cancer years after treatment. After treatment, many parents adequately adjust and cope successfully with the transition,^{2,3} reporting positive changes such as post-traumatic growth⁴ and benefit finding (e.g., finding purpose in life and developing helpful coping strategies).⁵ Despite this, anxiety, depression, post-traumatic stress (PTSS),^{2,6–8} productivity losses,⁹ and restrictions on daily life¹⁰ are reported by a subgroup of parents. Parents also report unmet psychological support needs.¹¹ To address these needs, innovations to improve access to psychological support, such as low-intensity cognitive behavioral therapy (LICBT),¹² are being implemented worldwide.¹³ LICBT is delivered through self-help materials using various formats, including the internet.¹² Guided internet-administered cognitive behavioral therapy (supported by trained professionals) shows equivalent effects to face-to-face interventions in adult populations.¹⁴ To develop an internet-administered LICBT intervention to meet parents' psychological needs we adopted an iterative phased approach to intervention development, following the Medical Research Council (MRC) complex interventions framework.¹⁵ In Phase I, we co-created alongside four Parent Research Partners, the LICBT intervention EJDeR (internetbaserad självhjälp för föräldrar till barn som avslutat en behandling mot cancer).^{16–18} EJDeR targets symptoms of depression and generalized anxiety disorder (GAD) and includes four modules: psychoeducation, behavioral activation (BA), worry management (WM), and relapse prevention.¹⁸ In Phase II, we conducted a single-arm feasibility trial (ENGAGE)¹⁹ examining methodological uncertainties (e.g., recruitment), procedural uncertainties (e.g., data collection procedures), and clinical uncertainties (e.g., intervention adherence) to prepare for the design and conduct of a future pilot randomized controlled trial (RCT) and subsequent superiority RCT. An embedded semi-structured interview study explored: (1) parents' self-reported concerns at baseline; and (2) treatment expectations; intervention acceptability; and perceived impact of the intervention on difficulties and mechanisms of change at post-treatment.

While recruitment into ENGAGE exceeded expectations, fewer fathers (36%) than mothers (64%) were recruited. The minimum treatment dose is defined elsewhere,^{18,20} however parents were expected to adhere to at least one LICBT module (BA or WM). Overall, 77% of parents adhered to BA and 50% adhered to WM, with adherence to WM dropping to 42% for fathers.²⁰ Given adherence concerns, especially for fathers, adapting EJDeR before progressing to a future pilot RCT is warranted. Importantly, fathers and mothers may experience different concerns and needs. Mothers report more mental health difficulties than fathers after the end of

treatment^{2,7,8} and experience an increased risk of hospital contacts for psychiatric disorders compared to fathers.²¹ However, we have shown childhood cancer has a negative long-term effect on fathers' earnings, but a positive long-term effect on mothers' earnings, suggesting fathers and mothers may experience different concerns and needs at different times after end of treatment. We may need to consider such different concerns and needs when adapting EJDeR to improve relevance and acceptability, and potentially adherence, for both fathers and mothers.

While our previous research exploring parents' concerns^{22,23} informed the development of EJDeR,¹⁸ the concerns of parents who self-report a need for psychological support related to the child's cancer are not well described. Therefore, considering concerns of parents recruited into ENGAGE can help to further adapt EJDeR and improve relevancy. Following the MRC framework¹⁵ and guidance on developing complex interventions,²⁴ we aimed to use findings from semi-structured interviews at baseline, exploring parents' self-reported concerns, to inform further adaptation of EJDeR.

2 | METHODS

We conducted an embedded semi-structured interview study at baseline, exploring self-reported concerns experienced by parents recruited into ENGAGE prior to accessing EJDeR. Data was analyzed using manifest content analysis,²⁵ with the consolidated criteria for reporting qualitative research adopted.²⁶ Ethical approval was received from the Regional Ethical Review Board in Uppsala, Sweden (Dnr: 2017/527).

2.1 | Participant selection

Recruitment into ENGAGE took place between 03-07-2020 and 30-11-2020. Parents were recruited using two approaches: (1) personal identification numbers of children were provided by the Swedish Childhood Cancer Registry and linked to parents' names and addresses via NAVET, a Swedish population registry. Parents were invited in random blocks of 100 using postal study invitations; and (2) online advertisements on social media sites, websites, and newsletters of cancer organizations, and interest groups. Eligible participants were: parents of a child (0–18 years at cancer diagnosis) who completed treatment three months to five years previously; residing in Sweden; with internet access, a mobile phone, and Bank-ID (a Swedish authentication system); self-reporting a need for psychological support related to the child's cancer; and able to read and write Swedish. Exclusion criteria were: experiencing a severe and

enduring psychological disorder; substance misuse; currently attending psychotherapy; and acute suicidality.

Eighty-one parents consented to participate in ENGAGE, 76 completed an eligibility interview via the telephone, with one excluded (acutely suicidal), and 75 enrolled. One dropped out, with the remaining 74 (26 fathers, 48 mothers) invited to an optional semi-structured interview at baseline which was completed by all parents. One semi-structured interview was not recorded (technical failure), resulting in data for 73 parents, (26 fathers, 47 mothers) being reported. For a summary of participant flow, see Figure 1.

2.2 | Data collection and setting

Eligibility interviews via the telephone included modules of the Mini-International Neuropsychiatric Interview version 7.0.0 (M.I.N.I.) to assess psychiatric (mood and anxiety) disorders, drug and alcohol misuse, and suicidality. Data was also collected on parent and child sociodemographic and clinical characteristics. Interviews (see Supplementary File 1) were conducted by eight licensed psychologists with three to 30 years of clinical experience (two internal and six external to the research team), two interviewers

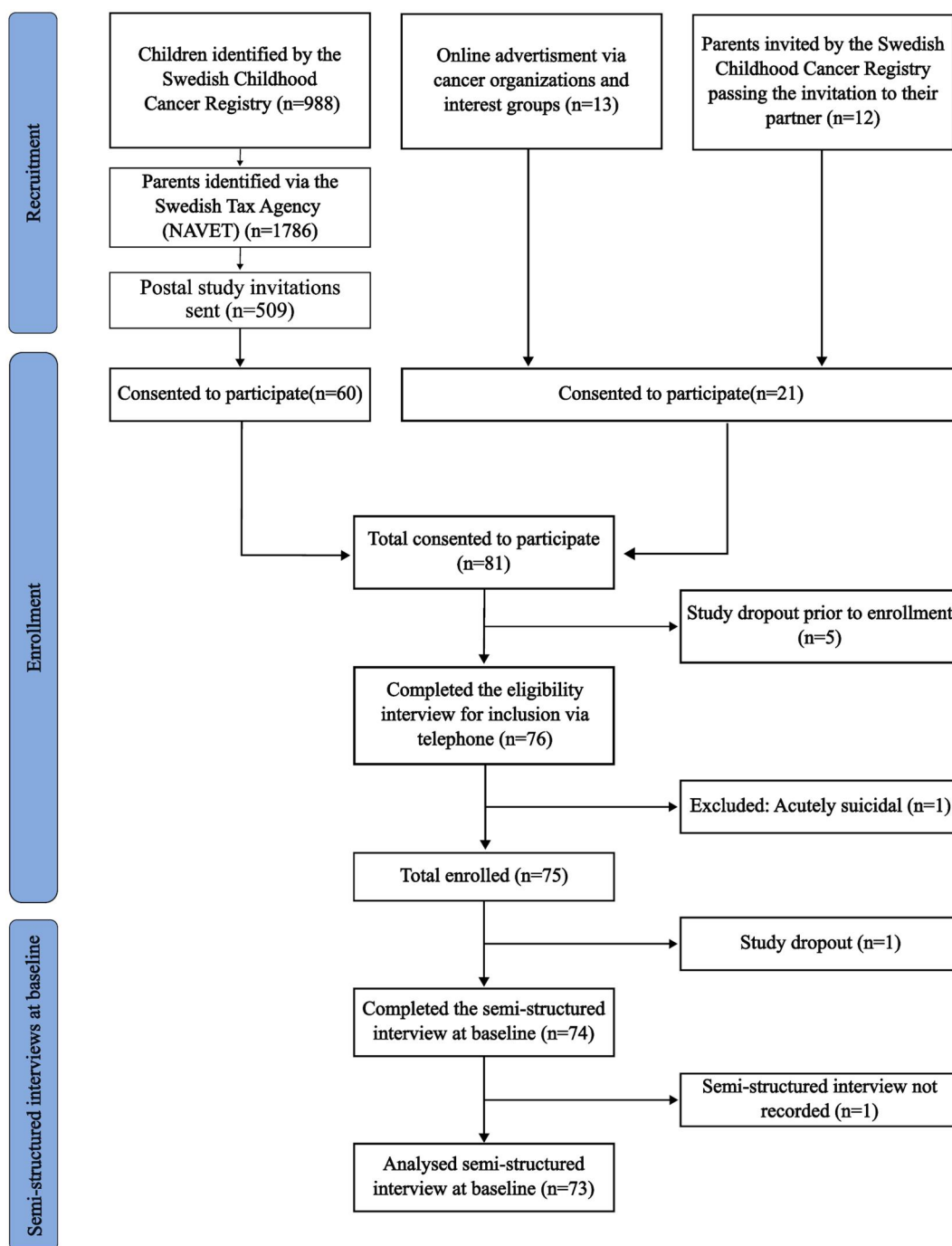


FIGURE 1 Flow chart of participants in the study.

had prior experience conducting semi-structured interviews. Interviewers conducted a median of nine interviews (range 1–23), lasting a mean of 37.5 (SD 10.9, range 17–67) minutes. Interviews were audio-recorded and transcribed verbatim in Swedish by a professional transcriber.

2.3 | Description of the sample

Baseline sociodemographic and clinical characteristics for parents and children are reported in Supplementary File 2 and 3. Parents ($n = 73$) had a mean age of 43 years, 36% were fathers, most had tertiary level education, were house owners, born in a Nordic country, and cohabited with a partner. One third reported at least one physical health problem, and 81% reported having experienced at least one traumatic/difficult life event, of which 47% were related to their child's cancer (54% of fathers; 43% of mothers). Overall, 50% of fathers and 66% of mothers fulfilled criteria for at least one past and/or present psychiatric disorder according to assessments with M.I.N.I. (Supplementary File 4).

2.4 | Data analysis

Manifest content analysis was used to analyze interview data,²⁵ with an illustration of the analysis process provided in Figure 2.

Authors LvE, JL, NL, CR, and ET read transcripts, coded meaning units, and created a preliminary codebook. Each interview was coded independently by at least two authors. New codes suggestions, coding variations, and unclear codes were discussed at

weekly workshops, with the codebook revised and interviews subsequently back-checked against the revised codebook. When all interviews were coded, meaning units were condensed and code content was checked against the interviews to ensure a credible foundation in data. Preliminary categorization of codes into categories and subcategories was performed with a low degree of interpretation by CR, JL, and NL. Category and subcategory descriptions in English were presented to authors LvE, PF, and JW for peer examination to further establish credibility and dependability of the analysis. Final category and subcategory revision was performed by JL. NVivo 1.5.1 was used to support the data analysis.

2.5 | Trustworthiness

Disconfirming cases were actively sought and reported. Aspects of pre-understanding were discussed during data analysis to facilitate confirmability. Credibility was enhanced using triangulation between authors, peer examination, and participant checking with three parents (two fathers and one mother). These parents expressed high recognition for concerns they had experienced, and found it plausible other parents could have experienced concerns described. When parents provided feedback that categories or subcategories were not clearly described, or missing information, feedback was checked against the interview data and content was revised when confirmed in the data. Participant checking did not change the number of categories or subcategories or core category content, but increased clarity and nuance to study findings.

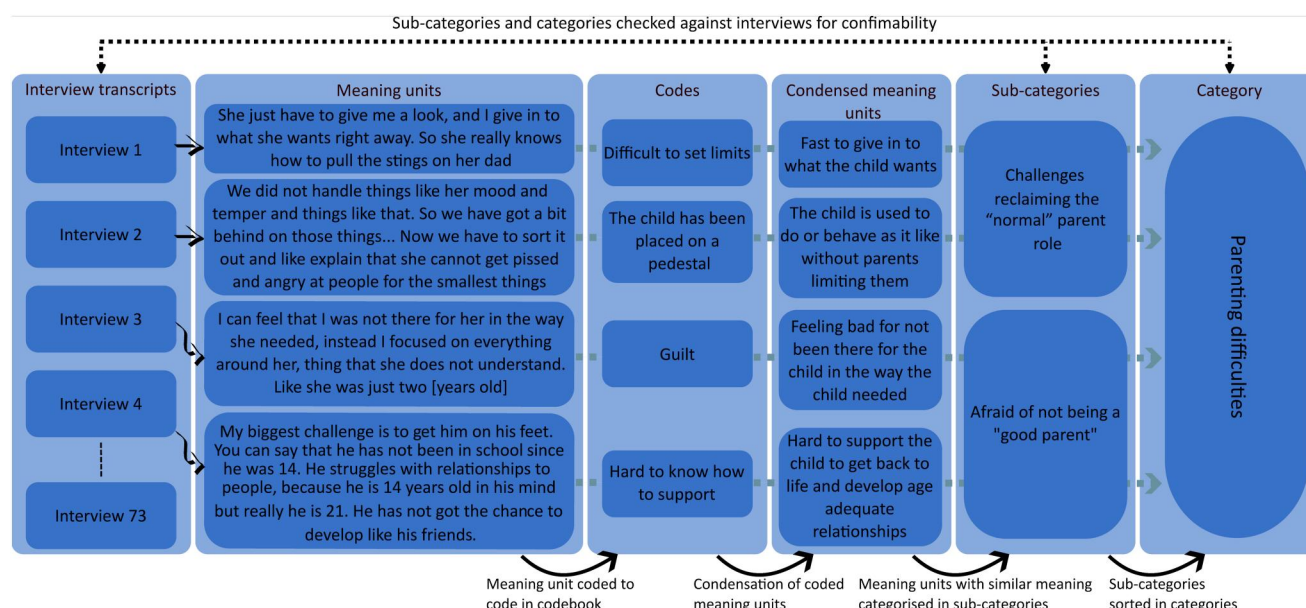


FIGURE 2 Illustration of an example of the analysis process. The dotted gray and the solid black arrows indicate the main direction of the analysis with an increased level of abstraction going from transcript to finalized categories. Dotted black arrows represent the iterative process ensuring confirmability in data.

3 | RESULTS

Analysis resulted in seven categories: (1) Feeling lost and lonely in life; (2) Low mood; (3) Parenting difficulties; (4) Productivity difficulties; (5) Relationship challenges; (6) Stress reactions; and (7) Worry. A category definition table is presented in Supplementary File 5. Illustrative quotations and counts are presented in Supplementary File 6. Illustrative quotations were translated from Swedish to English by research team members with Swedish as a first language and reviewed by an author with English as a first language and some Swedish knowledge. As a qualitative study, we did not compare and contrast concerns expressed by fathers and mothers. However, counts are provided for parents overall and separately for fathers and mothers to help locate potentially important patterns in the data and aid interpretation. We did not identify any distinct needs of fathers or mothers. Overall fathers and mothers expressed similar concerns, with a somewhat higher percentage of mothers mentioning all identified concerns, with the exception of *Afraid of not being a good parent*, *Cancer recurrence*, and *Child's development and future*.

3.1 | Feeling lost and lonely in life

Feelings of loneliness arose from perceiving that the cancer experience was not understood by others, including other parents. Sharing the cancer experience with others was difficult, contributing to feelings of loneliness which exacerbated feelings of helplessness and powerlessness when facing difficult life situations. Parents described that during the child's treatment all life goals centered around a treatment outcome, and after treatment ended, parents found it difficult to identify new goals.

3.2 | Low mood

Two subcategories describing concerns related to low mood were identified.

3.2.1 | Sadness and grief

Low mood was related to actual and/or perceived loss related to the cancer experience. Sadness and grief were experienced when parents were reminded of the cancer experience, for example, seeing scars or noticing the late effects of cancer and treatment. Parents also described sadness and grief due to "losing out" on positive life events, such as parental leave with other siblings.

3.2.2 | Depressive symptoms and rumination

Depressive symptoms and negative mood changes were described. Difficulties experiencing pleasure from previously enjoyed activities could result in withdrawal from activities, especially with others, and

contributed to feelings of not being "mentally present" in family life. Parents perceived difficulties such as comfort eating, gaining weight, and cognitive impairment as related to their low mood. Rumination about the child's cancer was mentioned, with intrusive thoughts about the cancer experience having negative impacts such as difficulties sleeping.

3.3 | Parenting difficulties

Four subcategories describing concerns related to parenting were identified.

3.3.1 | Challenges reclaiming the "normal" parent role

Parents described deviating from the "normal" parent role during cancer treatment, for example, placing increased attention on the child with cancer and engaging in an over-permissive parenting style. When parents attempted to return to a "normal" parent role, conflicts with the child arose. Consequently, behavioral boundaries were difficult to set and parents found themselves returning to parenting styles adopted during treatment.

Disconfirming cases: Some described the cancer experience led them to adopt a more relaxed parenting style which they did not want to change. Others found it easy to set boundaries, not wanting their child to become "spoiled" because of the cancer.

3.3.2 | Changes in family dynamics

The cancer experience not only changed the parent and child treated for cancer relationship, but also changed the entire family dynamics. During treatment, the health and wellbeing of the child with cancer dictated how the family operated, a pattern continuing after end of treatment. For children with severe late effects, the family needed to adapt to caring for a child with life-long needs. Parents described needing to put increased time and effort into planning life after cancer, with some children requiring additional support in school. Parents felt inadequate when struggling to find time and energy to support the child and other siblings. Parents also experienced difficulties becoming irritated, angry, and losing patience with their child (ren) more easily in response to normal child behavior.

Disconfirming cases: Some parents described the relationship to the child treated for cancer becoming stronger.

3.3.3 | Afraid of not being a "good parent"

Parents placed high expectations on themselves to be a "good parent" with an increased recognition of life being fragile and that "this life" was their only chance to be a "good parent". Parents hid emotions from their children to appear stable and described guilt for not having

detected the child's cancer earlier and/or having sought care more quickly. They expressed difficulties talking to their child about cancer and possible late effects and lacked understanding concerning how to support their child's social, and emotional developmental needs, for example, re-establishing peer contacts. Further, parents lacked knowledge to distinguish between age-appropriate development and developmental problems possibly linked to the cancer and treatment. A somewhat higher percentage of fathers mentioned concerns related to being afraid of not being a good parent.

3.3.4 | An urge to overprotect

Parents described a desire to protect their child from potential dangers and painful experiences. This could lead to parents preventing their child engaging in age-appropriate behaviors, such as walking to school on their own. Parents expressed a need to control all potential risks, especially regarding their child's health, and did not trust others, including the health care system, to provide their child adequate care.

3.4 | Productivity difficulties

Two subcategories describing concerns related to financial and employment productivity were identified.

3.4.1 | Personal finances

The cancer experience had negative impacts on parents' financial situation, forcing them to live on a lower income. Examples included no longer purchasing things for themselves, needing to use savings, and asking for financial help from others. Financial difficulties were particularly sensitive and complicated when the parent lived with a partner who was not the child's biological parent.

3.4.2 | Work life

Difficulties focusing on or performing at work were expressed. Parents described falling behind in their career and associating their workplace with their child's illness, which for some resulted in changing employment. Regretting returning to work too quickly and/or placing too high expectations on themselves regarding work performance upon returning to work was also voiced.

3.5 | Relationship challenges

Four subcategories describing concerns related to relationship difficulties were identified.

3.5.1 | Closest family

Relationships to closest family members had deteriorated in the shadow of the child's illness. For example, closest family members for example, partners were described as withdrawing, causing feelings of disappointment and isolation.

Disconfirming case: For some, the cancer experience had brought close family members tighter together.

3.5.2 | Wider family

Parents described wider family members, including their siblings and parents, as not understanding their situation. For example, while parents considered the cancer experience to be something they would live with for the rest of their life, wider family members saw it as a closed chapter, leading to parents not feeling understood.

Disconfirming case: Some described a closer relationship to one or a few specific persons, as a consequence of the child's cancer.

3.5.3 | Social network

Parents' social networks shrunk during the child's illness and they experienced difficulties re-establishing social contacts after treatment. Parents found it difficult to plan time with their wider social networks, feeling that they only had time for their children. Parents also described being too tired to keep in touch with friends. Fear of exposing the child to infections during periods of immunosuppression also negatively impacted their ability to socialize with others.

3.5.4 | Healthcare and other public organizations

While parents were satisfied with healthcare during treatment, this changed when the child was referred to primary healthcare, social services, and re-entered school after treatment. Parents described primary care, social services, and schools as not possessing adequate knowledge to take care of their child. Lack of trust resulted in parents perceiving a need to be extra vigilant when in contact with the healthcare system and other public authorities.

Disconfirming cases: Some described positive experiences with specific persons within healthcare and other public organizations.

3.6 | Stress reactions

Two subcategories describing concerns related to stress reactions were identified.

3.6.1 | Living in or reliving the past

Parents experienced traumatic stress symptoms, such as flashbacks and re-experiencing emotions felt during treatment, triggered by reminders of cancer, for example, hospital visits, scars, or seeing cancer related stories on social media or television. Parents tried to avoid thinking about the cancer experience, with one parent describing keeping memories and emotions in a "Pandora's box". Parents also described difficulties leaving the cancer experience behind them, either due to insufficient time passing since the treatment, or general difficulties adjusting to everyday life after treatment.

3.6.2 | The mind is in red alert

Parents considered themselves more sensitive to stress than before their child was ill. Intense stress reactions could be triggered by everyday situations for example, going shopping with their child(ren). Intense stress could lead to physical reactions such as headaches, muscle tension, and concentration difficulties, and panic attacks. Parents also experienced tiredness related to prolonged stress, describing feeling exhausted and "burnt-out".

3.7 | Worry

Three subcategories describing concerns related to worry were identified.

3.7.1 | Cancer recurrence

Hypothetical worry about cancer recurrence was described. This worry could be triggered by the child having common illness symptoms such as colds or headaches, or cancer specific situations such as hospital follow-up appointments. This worry was intrusive, persistent, and present years after treatment and sometimes extended to their own and/or siblings' health. A somewhat higher percentage of fathers mentioned concerns related to cancer recurrence.

3.7.2 | Child's development and future

Worries concerning their child's development and future were described, for example, in connection to coping in school or how late effects of cancer and treatment, such as infertility, may affect their child's future. A somewhat higher percentage of fathers than mothers mentioned concerns related to the child's development and future.

3.7.3 | Non-specific worry

Parents reported heightened feelings of worry and/or anxiety without being able to identify a reason. Although these worries were not

connected to cancer, they were described as emerging or increasing after the child became ill.

4 | DISCUSSION

Following the MRC framework¹⁵ and associated guidance on developing complex interventions,²⁴ we explored self-reported concerns experienced by parents recruited into the feasibility trial ENGAGE to inform further adaptations of EJDeR. Findings illustrate fathers and mothers experience concerns related to feeling lost and lonely in life, low mood, parenting difficulties, productivity difficulties, relationship challenges, stress reactions, and worry. A somewhat higher percentage of mothers mentioned concerns with the exception of *Afraid of not being a good parent*, *Cancer recurrence*, and *Child's development and future*. Concerns mentioned by a somewhat higher percentage of fathers may represent important areas to target in future iterations of EJDeR to improve fathers' adherence.

Parents described behaviors, cognitions, and emotions consistent with anxiety, depression, and stress. Difficulties with anxiety, depression, and stress have previously been reported^{2,6,7,21,22} and supports the decision to target depression and GAD in EJDeR. Parents also described concerns consistent with PTSS. Our previous research suggests a subgroup of parents experience clinically relevant levels of PTSS up to 5 years after treatment.^{2,8,27} Given a lack of evidence base for LICBT for post-traumatic stress disorder we decided not to target PTSS in EJDeR.¹⁸ However, results indicate a need to adapt EJDeR to help parents manage PTSS, for example, we will provide psychoeducation and techniques to strengthen resilience and coping strategies.²⁸ In addition, we will include indirect interventions²⁹ on concerns such as sleep and strategies to manage stress to further adapt content and increase relevance and acceptability for parents.

Parents also described concerns related to hypothetical future orientated worry, especially in relation to the cancer experience. This finding is supported by other research identifying parents experience concerns with hypothetical future-orientated worry,^{16,22,23} such as worry about cancer recurrence^{22,23} and the late effects of treatment.²³ Importantly, a somewhat higher percentage of fathers than mothers mentioned worries related to cancer recurrence and the child's development and future. Research suggests anxiety, and associated feelings of fear and powerlessness, conflict with traditional masculine norms and prevent help-seeking in men.³⁰ When men do seek help they can experience social and self-stigma resulting from transgressing these norms and may perceive themselves as a failure if unable to control their anxiety.³⁰ While EJDeR included WM strategies, given low adherence to WM, especially for fathers, coupled with a somewhat higher percentage of fathers than mothers reporting concerns related to worry, there is a need to focus on adapting WM to meet fathers' needs and improve fathers' adherence. For example, we will further co-create EJDeR with fathers to improve gender-sensitivity and focus on using language to destigmatize and normalize anxiety symptoms for fathers. In addition, we will further tailor the WM content to support parents overcome worries

specifically related to cancer recurrence and the child's development and future.

Parents described parenting difficulties, such as being over-protective and finding it difficult to set behavioral boundaries. This supports previous research suggesting childhood cancer survivors perceive their parents as more over-protective and less likely to adopt punishing parenting behavior than the general population.³¹ Lacking knowledge about the late effects of cancer and treatment were also described, a finding supported by research suggesting parents have unmet information needs regarding late effects and feel ill-prepared for life after cancer treatment.³² Importantly, a somewhat higher percentage of fathers mentioned being afraid of not being a good parent, which may have further implications for adapting EJDeR to meet fathers' needs. Wider research suggests fathers of children with life limiting conditions are excluded from participating in the child's care^{33,34} with information commonly provided to mothers, exacerbating feelings of exclusion.³³ In the present study, a slightly higher percentage of fathers expressed difficulties talking to their child about cancer and possible late effects and understanding how to support social and emotional developmental needs. Potentially, fathers' exclusion from the cancer experience may heighten concerns regarding their parenting ability and exacerbate feelings of helplessness.³⁴ For future adaptations of EJDeR, we will provide information and provide information to signpost parents to appropriate support services for parenting difficulties.

Relationship challenges and a perceived lack of social support were also identified as concerns, resulting in parents feeling abandoned and not understood. Relationship strains, resulting in conflicts and disengagement from social activities have been reported elsewhere for parents of children treated for cancer.²¹ While parents find seeking social support difficult, social support is associated with improved wellbeing among parents of children with cancer.³⁵ As such, findings suggest parents need support navigating relationship difficulties and seeking social support. Results also suggest some parents experience financial difficulties, which is particularly important given previous research suggesting financial difficulties correlate with poor mental health during cancer treatment³⁶ and that parents would like support locating financial resources.³⁷ Future adaptations of EJDeR will include information and signposting for difficulties concerning relationships, finance, and employment.

4.1 | Study limitations

There was heterogeneity concerning length of time since completing cancer treatment. Given parental concerns may change during the post-cancer treatment trajectory, the transferability of findings may be limited. Transferability of findings may also be limited as parents were mainly born in a Nordic country, Swedish-speaking, mothers, with a high level of education, and parents currently experiencing a severe and enduring psychological disorder and/or attending psychotherapy were excluded. Parents were not required to meet diagnosis for major depressive disorder or GAD, and results may not

be transferable to clinically depressed or anxious parents. While sample size justification in qualitative health research is an area of debate,³⁸ the current study may be conceptualized as a large interview study,³⁸ which can lead to failures in capturing important complexities and nuances within the data.³⁹ However, given the broad aim of this study, a large sample size may be considered necessary to capture data to achieve sufficient information power.⁴⁰

Despite these limitations, strengths include the use of independent coders, data analysis workshops, peer review, participant checking, and disconfirming case analysis which strengthen the credibility and confirmability of findings.²⁶

4.2 | Clinical implications

Findings illustrate that parents of children treated for cancer experience a range of concerns and can be helpful for health and social care professionals working with families after cancer treatment to understand parents' complex life situation. Concerns identified underscore the need to establish guidelines for the provision of psychosocial support to parents throughout the post-cancer treatment trajectory and for several years after end of treatment. Results also indicate a need for health and social care professionals involved in the long-term provision of follow-up care to families to consider the gender-sensitivity of support provided to meet the needs of both fathers and mothers.

5 | CONCLUSIONS

By following the MRC Framework¹⁵ and complex intervention development guidelines²⁴ we successfully identified ways to adapt EJDeR to improve relevance and acceptability. Results from post-treatment semi-structured interviews (reported elsewhere) will be used to inform further adaptations. Adaptations will be co-created alongside four Parent Research Partners in accordance with results from the present study and post-treatment semi-structured interviews to prepare for the design and conduct of a future pilot RCT and subsequent superiority RCT of EJDeR.

AUTHOR CONTRIBUTIONS

Author contributions are written in accordance with the CRediT statement: **Johan Lundgren**: Validation; formal analysis; data curation; writing – original draft; writing – review and editing; visualization; supervision. **Ella Thiblin**: Validation; formal analysis; investigation; data curation; writing – review and editing. **Nina Lutvica**: Validation; formal analysis; investigation; data curation; writing – review and editing. **Christina Reuther**: Validation; formal analysis; investigation; data curation; writing – review and editing. **Paul Farrand**: Formal analysis; writing – review and editing. **Joanne Woodford**: Methodology; formal analysis; writing – original draft; writing – review and editing; supervision; project administration. **Louise von Essen**: Conceptualization; methodology; formal analysis;

resources; writing – original draft; writing – review and editing; supervision; project administration; funding acquisition.

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CONFLICTS OF INTEREST

The author declares that there is no conflict of interest that could be perceived as prejudicing the impartiality of the research reported.

DATA AVAILABILITY STATEMENT

Due to the nature of this research, participants were not asked to share their data publicly, so supporting data is not available.

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SUPPORTING INFORMATION

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