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To understand the experiences, needs, and preferences for supportive care, among children and adolescents (0–19 years) diagnosed with cancer: a systematic review of qualitative studies.

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Abstract:

Purpose: To understand the experiences, needs, and preferences for supportive care, among children and adolescents (0 – 19 years) diagnosed with cancer.

Methods: A qualitative systematic review has been reported according to PRISMA guidelines. A comprehensive search was conducted across multiple databases (APA PsycINFO, CINAHL, and Medline) and citation searches. Studies were screened according to pre-determined inclusion and exclusion criteria. Methodological quality was evaluated. Findings were extracted in relation to the context of interest of experiences, needs, and preferences of supportive care. Each finding was accompanied by a qualitative verbatim illustration representing the participant's voice.

Results: 4,449 publications were screened and 44 studies were included. Cancer populations represented in the included studies included lymphoma, leukaemia, brain cancer, sarcomas, and neuroblastoma. Two overarching synthesised findings were identified as 1) Coping, caring relationships, communication, and impact of the clinical environment, and 2) Experiences of isolation, fear of the unknown, restricted information, and changing self. Children and adolescents articulated that cancer care would be enhanced by developing a sense of control over their body and healthcare, being involved in communication and shared decision-making, and ensuring the clinical environment is age-appropriate. Many experienced a sense of disconnection from the rest of the world (including peers, school, and experiences of prejudice and bullying), and a lack of tailored support and information were identified as key unmet care needs that require further intervention.

Conclusions: Children and adolescent who are diagnosed with cancer are a unique and understudied group in oncological survivorship research, with the slowest progress in improvement of care over time. This review will facilitate the development of future interventions and promote the importance of tailored support for children and adolescents at all stages of the cancer journey.

Implications for Cancer Survivors: Children and adolescents continue to experience a range of difficulties despite routine contact with cancer healthcare professionals. Children and adolescents should be carefully assessed about their individual circumstances and preferences for support given the clear implications from this review that "one size" does not fit all.

Introduction

Globally, it is estimated that 400,000 children aged 0-19 will be diagnosed with cancer annually [1]. Through the advancement of cancer research and modern medical treatments survival rates are high at 80% in high-income countries, but many children and adolescents develop significant negative long-lasting holistic health impacts into adult survivorship.[2] A diagnosis of cancer in childhood and adolescence creates a profound sense of stress,[3] and paediatric cancer treatments can last for months or years. The most common cancers diagnosed in this patient population include brain tumours, leukaemia, sarcomas, lymphomas, and cancers of the central nervous system.[4] Many children and adolescents affected by cancer experience profound distress and challenges daily, which include managing the disease and coping with aggressive treatment regimes, understanding their condition, with fear of cancer progression or recurrence.[5-7]

There have been several systematic reviews conducted to understand various health impacts among children, adolescents, and young adults affected by cancer; however, there are several limitations with extant reviews. Firstly, several of these reviews are now clinically outdated by the limits of when the literature searches were conducted < 8 years,[5,7] and <12 years.[6] With the latest advancements in treatments and the emergence of newer supportive care models for this population, an up-to-date contemporary critical synthesis of the evidence is needed. Moreover, existing systematic reviews explored experiences of supportive care for adolescents and young adults (15 – 25 years of age),[6] (15 – 30 years old),[7] (15 – 39 years),[8] (15 – 24 years) [9] which are not reflective of children and adolescents aged (0 – 19 years of age).[1] Other related systematic reviews have identified quantitative coping measures for children,[10] the quantitative prevalence of psychiatric disorders in adolescent cancer survivors,[3] and quantitative social support outcomes in children and adolescents.[11] Other reviews have explored various impacts on family caregivers of adolescents and young adult cancer survivors,[12-14] mothers,[15] and fathers [16] with children diagnosed with cancer, and parental distress.[17] However, there remains an important evidence gap to provide a voice to children and adolescents specifically those aged 0 - 19 years old affected by cancer. It is timely to critically synthesise all existing contemporary qualitative research to specifically understand and identify what are their current experiences of supportive care and what supports are perceived to be beneficial in this vulnerable patient group. [18]

Supportive care is an umbrella term used to describe the necessary cancer services for those affected by cancer to meet their individual person-centred emotional, physical, spiritual, social, informational, and practical needs during diagnosis, treatments, and all follow-up phases in the cancer care continuum.[18] Given the reported unmet needs of children and adolescents affected by cancer it is critically important to synthesise all recent evidence to identify experiences of care in young people's own words. This systematic review aimed to inform holistic rehabilitation person-centred models of care for children and adolescents affected by cancer in their own words. This systematic review of qualitative studies aimed to understand the experiences, needs, and preferences for care, among children and adolescents (0 – 19 years) diagnosed with cancer.

Method

Design: A systematic review [19] of qualitative studies followed the Joanna Briggs Institute (JBI) methodology for meta-aggregation.[20] This systematic review has been reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRIMSA) guidelines, see **Supplementary File 1**.[21]

Pre-eligibility screening criteria

Types of studies

Inclusion criteria

- Studies exploring experiences, needs, and preferences for supportive care [18] in participants (0 – 19 years old) when they were diagnosed with cancer. Participants >19 years old were included in studies only if they were diagnosed with cancer when they were 0-19 years old. Supportive care was defined as a person-centered approach to the provision of the necessary services for those living with or affected by cancer. This approach aims to meet their informational, spiritual, psychological, social, or physical needs during diagnosis, treatment or follow-up phases, including issues of health promotion and prevention, survivorship, palliation, and bereavement.[18]
- All children and adolescents (0 – 19 years of age) who were diagnosis of cancer irrespective of stage, cancer type, or treatment.
- This review only included studies published in the English language.
- Qualitative studies only irrespective of research design.

Exclusion criteria

- All quantitative studies, mixed methods studies, conference abstracts, commentaries, editorials, or studies that did not provide data to address the research question.

Search strategy

The APA PsycINFO, CINAHL, and Medline databases, were searched via the EBSCOhost interface on the 19th of July 2022. To capture all contemporary evidence the databases were searched from 2011 given treatment advances and modern treatments now available compared to 20 – 40 years ago.[2] Relevant systematic reviews were scrutinised for potentially relevant studies for screening. The search architecture was designed by an expert librarian, utilising the efficient search method for systematic reviews developed at Erasmus Medical Centre.[22] Search filters adapted from the CADTH Search filters database [https://searchfilters.cadth.ca/] were applied to retrieve all qualitative studies. Citation management was conducted using Endnote software. The search used a combination of keywords and subject headings to increase the sensitivity and inclusiveness of the searches and capture the "Sample" – children and adolescents affected by cancer and "Phenomenon of Interest" – experiences, needs, and preferences for supportive care. See **Supplementary Table 2** for the full record of database searches.

Study Selection

Following the search, all identified citations were imported into Covidence systematic review software where duplicate records were removed. All remaining publications were screened according to the pre-determined inclusion and exclusion criteria. Titles and abstracts were screened by two reviewers (CP, MC), with any conflicts resolved by discussion. The full texts of selected studies were retrieved and assessed in detail against the inclusion criteria by two reviewers (CP, MB). Full-text studies that did not meet the inclusion criteria were excluded, and reasons for the exclusion were provided, see **Supplementary Table 3** for a full reference list of excluded studies**.** The study selection process was described using the PRISMA flow diagram.[21]

Methodological Quality Assessment

Methodological quality for all included full-text studies was evaluated using the JBI Critical Appraisal Checklist for Qualitative Research.[23] This 10-item Critical Appraisal Checklist assessed for congruity between the stated philosophical position, methodology, research question, data analysis, and interpretation of results. Each question was rated individually as either "yes", "no", or "unclear". All studies were included regardless of the results of the quality appraisal to enable a comprehensive overview of the current state of the evidence, results for the quality assessment were cross-checked by four reviewers (CP, MM, RB, MT).

Data extraction

The data extracted from each study included the author's details, country, year, phenomena of interest, participant clinical and demographic characteristics, and major findings relevant to the research question. Findings were extracted from each study and organised into a data extraction table that was piloted on several studies first and agreed upon by the review team. Each finding comprised a qualitative theme supported by a qualitative verbatim illustration of participant (children and adolescents) voices. A finding was considered as a theme or subthemes related to the context of interest of experiences, needs, and preferences of supportive care. The findings were given a classification as either unequivocal (findings linked to an illustration that is beyond reasonable doubt and not open to challenge), credible (findings that lack clear association with the data and are open to challenge), or unsupported (findings that are not supported by the data).[20] The conqual ratings of “unequivocal”, “credible”, or “unsupported” were independently checked by two reviewers and consensus reached by discussion. Only unequivocal or credible findings were included in the meta-aggregation in line with the JBI method.[20] All unsupported findings were excluded from the data synthesis. For studies where they included very small infants (<1 years old) parent interviews were conducted in a small number of studies, and were not included as this review as only extracted findings and illustrations directly from children were extracted.

Data synthesis

Unequivocal and credible findings across the included studies were given labels and synthesised into categories based on similar meanings and themes. The identified categories had at least two findings and were subsequently developed into synthesized findings following careful and repeated assessment of the extracted data with consensus reached first among two reviewers (CP, MB) and then consensus reached among all reviewers (CP, MM, PK, RB, MT, MC). The synthesis of each category produced a single comprehensive description related to experiences, needs, and preferences for supportive care among children and adolescents. The data synthesis involved three steps in this process. The data extraction (findings and illustrative quotes) from the main findings of the original studies were extracted in tabular format. Then the findings and associated illustrative quotes were grouped based on similar meanings. The final step in the meta-aggregation synthesis involved the generation of categories and the final synthesised findings reviewing conclusions with primary sources. This process in the data synthesis was conducted by one reviewer (CP) and quality was checked by (MB) and agreement by all review authors. Any disagreements were resolved by discussion.

Findings

Of the 4,449 publications screened, a total of 94 full-text publications (inclusive of 13 publications identified from citation searching) were assessed for inclusion. Fifty publications were excluded for reasons, see **Figure 1,** and **Supplementary Table 3.** A total of 44 publications were included, and represented a range of countries namely: Jordan,[24] Singapore,[25] USA,[26-33] Demark,[34,35] Australia,[36-38] Italy,[39,40] UK,[41-45] Sweden,[46-50] Spain,[51,52] Turkey,[53] Canada,[54-59] Brazil,[60,61] Norway,[62] Iran,[63-65] Israel,[66] and Belgium.[67] The sample sizes ranged from 5 to 70 participants, with a total of 837 children and adolescents' voices represented. There were 395 females and 344 males, and several studies did not report on the sex of the participants. [40,42,50,64,65] Most studies did not include very young infants, most of the studies represented school-age children and adolescents. Furthermore, the majority of the participants were currently receiving active cancer treatment,[5,24,25,29,31,33,35,39,41,42,45,47-49,51-53,55,60,61,63,66] mixed sample of completed or actively receiving cancer treatment,[26,28,36,38,40,44,50,57-59] and completed treatment and into survivorship.[27,30,32,34,37,43,56,62,64,65,67] None studies represented children and adolescents at end-of-life. Most cancer populations represented lymphoma, leukaemia, brain cancer, sarcomas, and neuroblastoma with a range of cancer treatments see **Table 1.** The methodological quality assessment of the included studies is presented in **Table 2.**

A total of 254 unequivocal and credible findings were extracted from the 44 included studies (see **Supplementary Table 4** for extracted findings). There were only four findings which were unsupported in two studies.[31,48] Two main synthesised findings emerged related to 1) Coping, caring relationships, communication, and impact of the clinical environment, and 2) Experiences of isolation, fear of the unknown, restricted information, and changing self, see **Table 3** for overview.

Coping, caring relationships, communication, and impact of the clinical environment

Coping, control, and forward transitions in life

Children and adolescents clearly articulated the need to develop a range of coping strategies and the central importance of hope,[26,56] maintaining a positive outlook,[35,40,42,48,56] gratitude,[30] personal growth,[30,40] and giving something back through fundraising.[56] Children found it helpful to talk about their experiences,[29] express their thought processes through expressive writing at school,[27] or keep a journal [29] to cope with life. Other children used problem-solving behaviours to cope with unpleasant treatment smells, for example, placing a small piece of chocolate directly under their noses.[48] Children also expressed that they found it very helpful to think about something fun [48,58] and laugh,[56] play games or paint,[29,61] watch television,[29] go to sleep,[29] listen or play music,[38] read or having their parents read them a story,[29,61] or having a stuffed toy nearby to cuddle when they were distressed in hospital, during procedures and treatments.[48] For some children and adolescents, they found a profound sense of peace and comfort in God expressing that they felt Him very present.[30,42,61,63] Some children and adolescents felt it was God who gave them the greatest strength and helped them through their experiences.[60,61]

"I believe, because when I go to church it seems that God speaks to me. Then I have more faith, because I know God is with me. To finish this treatment, I went to church, prayed and thank God everything is right." [61] (page 146)

" … I think hope is one of the most important things to have during treatment. That's what gets you through those really hard days, and there are going to be a lot of really hard days." [26] (page 586).

Gaining a sense of control was clearly expressed by young people with cancer across several qualitative studies.[40,44,47,48,63] Children reported that they wanted to be in control of their pain so they independently applied anaesthetic cream at home before going into the hospital to reduce discomfort.[47] Other children kept control by telling nurses to warm their cold hands up first before touching them,[47,49] keeping authority that no one was to move their nasogastric tubes (NG),[47] also maintained responsibility for pushing their medicines down their NG tubes,[47] and other children only wanted their mum to apply tape to their bodies, not nursing or medical staff,[47] and finally, when to play games or not.[47]

Children found it helpful when there was less pressure or conflict to eat,[36] and making healthier food choices,[29] and getting physical conditioning back.[35,56] Children valued having good support structures for rehabilitation to support self-management [33,40,44,55,56,61,64] to build independence and resilience strategies,[30,40,43] which was particularly relevant for teenagers [30,32,40,44] to coping in returning back to normal life. Children and teenagers emphasised that it was not a transition into survivorship,[32] but rather a helpful milestone to get back to 'normal',[32,60] returning to daily routines such as getting back to school, sports, and friends.[60]

"It wasn't transition because it was kind of like the same thing I had been doing before and so I didn't feel like I had to transition back into my life. I feel like that would be weird. And so it was just kind of like stepping back into the story for a little bit." [32] *(page 135)*

However, some children and adolescents used avoidance to cope and did not want to engage with talking to the doctors, and often were happy for those discussions to remain completely between their parents and the medical team, which was also viewed as helpful coping.[36]

"I don't really talk to the doctors, mum talks to the doctors. I don't like talking to the doctors just

because it reminds me of what I'm actually doing here … I don't even like hearing the name of the chemo's now because like they just make you feel bad." [36] *(page 149)*

Caring, honest relationships with continuity

Children and adolescents valued caring and honest relationships [39,41] to meet their emotional needs. It was clear across several of the studies that having the unconditional support of parents, [28,30,33,42,43,45,48,53,56,59] nurses,[30,33,42,46,48] and friends [32,33,35,44,47,48,53,59] was crucial to their emotional well-being. Children also expressed the need for caring practices [48,49,53,65] with continuity of clinical staff involved in their care [48] and treating them like a healthy person.[53]

"I want healthcare professionals to treat me as though I am a healthy person. I don't like to feel like only a patient. If health professionals want to heal children, they have to love children and be tolerant of them … because I need love, compassion, and a smiling face." [53] *(page 3475)*

" … whenever you need me (nurse) just to talk, I will be there for you." [42] *(page 34)*

"She (the nurse) is terrific and crazy. I love it." [49] *(page 27)*

"She (nurse) wasn't the one I knew." [48] *(page 10)*

Children and adolescents also spoke about relationships with the family becoming closer [25,28,30,45,53,56] and being able to discern who their real friends were through keeping regular contact and checking in with them [28,53,55] that brought a sense of normality.[32,44,55,65,67]

"It definitely shows you who your true friends really are, and who you know is willing to make that extra step to 'I wanna come see you, when can I come see you'."[28]*(page 558)*

Often, children spoke about how mothers helped them through very difficult times, communicated for them, and asked the right questions to the medical team.[45,59,65]

Clinical Environment

Children and adolescents expressed that it was important to them that the clinical environment had to have fun activities for them to do,[42,52] the option of a playroom [38,53] and enjoyable and nutritious hospital food to eat.[53,61] When they were undergoing radiotherapy they valued having distractions and liked listening to music, reading a story, or watching a film.[48]They wanted the clinical environment to be bright and colourful (the curtains and walls) with bright rainbows to positively energise young children.[53] For adolescents they preferred more plain designs and consideration of physical space and designative units for them.[52,53] Children and adolescents wanted to have access to videogames, Guitar Hero [38] or a PlayStation [28,61] in hospital to help them stay connected to their friends.

"Definitely videogames. Like even in the hospital, we brought a Play Station from home, and I was able to stay connected every day." [28] (page 558)

Younger children need preparation through play and toys to adjust to the hospital environment, procedures, and treatments.[43] It was also really important that the clinical staff maintained a quiet environment at night to help children have a good quality sleep.[53] Where possible, children valued having their clinical care delivered at home to maintain closeness to family and friends [55] and liked the use of clinical mobile applications on their phones. [50,54]

Tailored information and communication

Across several of the studies children and adolescents had a desire for specific, individualised, easy-to-understand and trust-worthy information about their disease, treatment, side-effects, and self-management.[45,48,50,52,55,58,64,66] For some children they expressed that the more members of their clinical team talked to them the better they knew and felt.[33,45,52,63]

"I knew what was going to happen so that was reassuring. The doctor was really good at telling me everything so I felt ok." [45] *(page 9)*

"About the treatments, I know it's chemo, that it destroys the healthy cells as well, and that it has side effects: hair loss, nausea, loss of taste." [66] *(page 4)*

"Don't sugarcoat it … and be real, real up front with me. That's what I want." [33] *(page 4422)*

It was important that both their parents and members of their clinical team were honest and told the truth to them.[66] For teenagers, they wanted tailored information about the late effects of cancer treatments, such as co-morbidities and impacts on fertility and body image.[58] Teenagers especially valued information sharing and communication to be provided in a peer-to-peer setting,[59] particularly for discussing issues around sexuality,[58,66] as it was viewed as being less awkward than discussing this with adults.[58]

Experiences of isolation, fear of the unknown, restricted information, and changing self

Isolation, changing routines and relationships

Many children and adolescents spoke about the profound sense of isolation [28-30,45,46,48,51,60] created due to the hospital environment. Only one study [63] was conducted with children and adolescents during the COVID-19 pandemic which also impacted the sense of loneliness and changing routines. Many young people reported that they stayed in a single room, with limited opportunities to communicate with the outside world,[28-30,45,46,48,51,59] and with no place to play.[24,46] There was also a lack of support to adjust to the changing dynamics in relationships among friends and family members that were frequently experienced.[25,28-30,46,51,59] Children and adolescents also spoke about their worry about their family members' emotions.[45,65]

"Because I didn't see them (friends) for about a whole year... a lot of my relationships kinda broke off..." [25] *(page 538)*

"My father, every time ... very pestering to me ... every time, every hour, message me, call me, then, like, I don't have space." [25] *(page 538)*

"Well, I miss my Dad and my little brother. I miss my little dog. I've got a little dog and I taught him to play. It makes me really sad." [51] *(page 4)*

There were also concerns about the perceptions of others [27,28,30,34] and being identified as a 'cancer patient' and some instances of bullying.[34]

"They are making 'rules' about me that are not correct. For example, my teachers and classmates say that I cannot play soccer or 'you are not allowed to hit and tackle him – after all, he can die of it." [34] *(page 719)*

"No one would share my table. They said I could transmit the cancer to them. When I finally returned to school, I was all alone. In the break, some girls called me 'cancer bitch'. I wish my teacher had done something." [34] *(page 720)*

The Changing Self

Many children and adolescents grapple with the emotional physical and changing self. Children and adolescents also spoke about their emotional response to cancer and its associated treatments. They spoke about feeling angry, depressed, sad, frustrated, scared, ashamed, and embarrassed, often because they were not able to do the things, they used to do.[25,29,39,45,48,51,56,64] The impact of physical symptoms was distressing for children and adolescents and commonly reported symptoms included: pain, nausea and vomiting, tiredness, difficulties swallowing, reduced appetite, chemotherapy-induced alopecia, headaches, and dizziness.[25,29,44,47,48,51,56,60,61,64] They reported difficulties in managing hair loss, changes in body shape (either weight gain or weight loss), medical device attachments on their bodies, changes in skin colour, new prostheses, body scars, and struggling to speak and hear [24,30,34,43,44,47,48,51,56] which made them feel like a stranger in their skin.[30,44,46,47,51]

> *"The hair loss [pause] I am a girl and I liked my hair. Without hair, I feel that I am like a boy and I do not know how my friends will respond when they see me like this [without hair]. They [friends] will not like it [my new look]."* [24]*(page 3)*

> *"It is like a fucking freak show! We have gastric tubes and are bald, wearing hats everywhere. We are getting used to it, but I clearly understand that our friends react and stay away from us."* [34] *(page 718)*

Children and adolescents also expressed the need for improved support given concerns that they were failing academically, [25,28,56,62] due to prolonged absence [65] and struggled with concentration.[30,56,62] Children valued academic community support during treatment phases.[52,55]

> *"I have missed about a year and a few months' worth of school, which is why this year I'm kinda scrambling to catch up with everything."* [25]*(page 538)*

> *"I don't understand anything in school (cries)."* [62] *(page 6)*

Fearing the unknown

It was evident that children and adolescents feared the unknown. In particular, this fear was expressed related to clinical procedures and their risks, fear of death, dying, and relapse, future fertility concerns, and no longer being able to see their loved ones.[24,29,30,32,37,44,45,48,51,53,60,61,65]

“. . . I’m scared of not seeing my family, and staying in the grave alone. I thought about death when I was very tired, when I was admitted to the ICU. I even told my mum, if I died, to bury me near the house because I’m afraid to be alone.”[24] *(page 5)*

“After ending chemotherapy, I don't menstruate anymore, and then it occurs irregularly. This creates some worries about having babies or marriage in the future. I believe that if the issues about marriage and having baby are explained to the patients or their families, or if they receive a consultation, their worries are eliminated.” [65] *(page 215)*

Children also expressed fear of the unknown when they felt powerless in the clinical environment and interactions with clinical members of staff.[39,47,48,53]

“*Tell me … ask ME if it's OK to lift up my t-shirt.”* [47] *(page 40)*

“From the start, I refused up until the end. It was Friday, the first Friday, so I refused to go. But I was simply forced.” [48] *(page 5)*

Issues with restricted information and decision-making

Children and adolescents reported problems with restricted information [45,58,64-66] and truth-telling conversations.[31,41,66] However, what was also apparent was that information-sharing must be tailored to each child or adolescent given the dynamic nature of individual preferences and needs.[31,61,66] It was important for parents and members of the clinical team to have an awareness of when children and adolescents wanted to have a say and when they did not want to have a say [32,33,61,66] and when they wanted information and when they did not.[32,33,61,66]

“I was a bit mad when they told me I had cancer. They didn’t tell me because like when they said, ‘Chemotherapy,’ I knew that I had cancer. They didn’t want to tell me, or because to them it would make me really upset because my Mum didn’t think I knew what chemotherapy meant.” [41] *(page 150)*

“And he [the doctor] I mean, I remember talking to him, and he gave it to me straight really, and he said listen, ‘Yeah this could happen … I mean we could say one in a million and you could be that

one'. So the number really doesn't do a whole lot. It is just a number and doesn't mean anything to me." [32] *(page 135)*

"There are kids that may be scared by it (the information) and kids for whom it is a relief. For me, it's a kind of relief. At first, I thought you could die of it, but my condition was not bad. You can take care of yourself and stay alive. [My] parents explained it and it was reassuring." [66] *(page 5)*

Discussion

The aim of this qualitative systematic review was to understand, from a young person's perspective what supports, and coping strategies are beneficial when they are affected by cancer, alongside their experiences of unmet supportive care needs to fill the gap in the extant literature. By looking at the issues from both sides (i.e., what works and what needs more work), clinicians are in a better position to be able to continue the good work they are doing and look at ways to fill the gaps identified by children and adolescents affected by cancer. The level of evidence (see Supplementary Table 4) for most of the findings in the review was considered "unequivocal", with some consider "credible" and a handful considered "unsupported". To the best of our knowledge, this is the most comprehensive qualitative systematic review conducted among children and adolescents (0-19 years) to represent their current experiences. The review represented children of school age and adolescents, and there was little representation from infants. For example, the younger children (1-3 years old) were noted to be generally be not interested in interacting with the interviewer, assuming a more watchful role.[46] Future studies should consider age-appropriate methods of data collection tailored to the age ranges inclusive of 0-19 years old.[68]

The overarching theme of the findings can be viewed as young people needing an age-appropriate level of agency and autonomy, including being listened to as to what they perceive they need to progress through their treatment journey. This finding was evidenced when it was working well (e.g., having their developmental needs met) [48] and when things were not working well (e.g., not being consulted about their bodies).[45,47-49] Young people reported that having a sense of control over their bodies and treatment, having caring relationships, appropriate information about their treatment and consequences, and age-appropriate environments when undergoing treatment, were helpful. Whereas a sense of disconnection from the rest of the world (including peers, school, and experiences of prejudice and bullying), and a lack of support and information were identified as key unmet care needs which requires further intervention. Given the profound multi-dimensional impacts on children and adolescents diagnosed with cancer future targeted holistic models of multidisciplinary rehabilitation care is needed.

In keeping with a previous qualitative systematic review [6] conducted over 12 years ago (representative of 15-25 years old), our findings indicate that children and young adults survivors are continuing to experience many challenges throughout the cancer care trajectory and identify many unmet needs into survivorship that have remained unchanged over time. However, our review has provided valuable new insights to improve the care provided to this cohort and critical insights to alleviate the burdens of care and ensuring optimal patient outcomes by capturing the supports and coping strategies which have been perceived to be helpful. Future planning of interventions to address the various needs and taking into consideration these important views are essential for improving outcomes for these patients. Recent evidence [3] has shown that many adolescent survivors of cancer are at high risk for developing clinically significant symptoms of anxiety, depression and post-traumatic stress disorder. Therefore, careful co-designed, aged appropriate, and holistically targeted interventions that promote 'wellness' [18] are considered crucial in this vulnerable patient cohort. Working with children and adolescents in clinical settings will require establishing children-adolescent-friendly ways of discussing their concerns, expressing their needs following their cancer diagnosis, and reflecting back on it. A one-size-fits-all approach is not suitable for this population given the unique findings reported in this systematic review. Depending on the unique characteristics of the child or adolescent, stage of the cancer and treatments, the support requirements will vary considerably from one young person to the next. Children and adolescents should be carefully assessed in relation to their own individual circumstances and preferences for support at all stages of the cancer journey as part of their routine standard of care.

Of note, most of the studies found were representative of children and adolescents in high-income countries.[69] Nine out of ten children and adolescent cancers are diagnosed in low-to-middle-income countries and this observation underscores that they are grossly underrepresented in this systematic review.

Limitations and Implications for Cancer Survivorship

This qualitative systematic review presented some methodological issues, and limitations which also pertain to the field of survivorship at large. The small sample sizes, grouping of all cancer types and treatments, and grouping of children and adolescents together is perhaps partially explained by the overall low number of cancer cases in this age range. In this qualitative systematic review, the variability across these considerations was still very large within the included studies. Additionally, we were interested in the survivorship issues across the whole cancer care continuum, but we were unable to discern nuanced differences over time due to the limitations of the reported data within each individual study and lack of longitudinal study designs. Furthermore, there was no study which explored experienced among children and adolescents at end-of-life. The qualitative systematic review was carried out with methodological rigor, including reporting adherence to the PRISMA guidelines. This review followed JBI qualitative meta-aggregation methodology [20] and was able to create overall synthesised statements in the form of recommendations to guide practitioners and policy makers in future planning of child and adolescents cancer services and interventions. There are several limitations to point out. Firstly, the possibility that relevant papers might have been missed should not be excluded despite employing a deliberately inclusive search strategy across multiple databases and having an expert systematic review librarian designing and conducting the search. Secondly, the exclusion of non-English language studies may have resulted in publication bias. Finally, it was not possible to draw any conclusions in relation to differences in experiences sensitive to those receiving active treatment versus those who were not, sex, cancer, treatment types, and specific ages, due to the dearth of studies in this area examining these particular differences. Despite these limitations, this qualitative systematic review synthesized the evidence pertaining from a young person's perspective on what supports, and coping strategies were beneficial, alongside their experiences of unmet supportive care needs. This review will facilitate the development of interventions and promote the importance of strong support for children and adolescents at all stages of the cancer journey.

Conclusion

Children and adolescent cancer survivors are a unique and understudied group in oncological survivorship research, with the slowest progress in improvement of care over time. Helpful supports were identified as having a sense of control over their bodies and treatment, having caring relationships, appropriate information about their treatment and consequences, being listened to, and age-appropriate environments when undergoing treatment. Many experienced a sense of disconnection from the rest of the world (including peers, school, and experiences of prejudice and bullying), and a lack of tailored support and information were identified as key unmet care needs which requires further intervention. Children and adolescents should be carefully assessed in relation to their own individual circumstances and preferences for support at all stages of the cancer care continuum as part of their routine standard of care.

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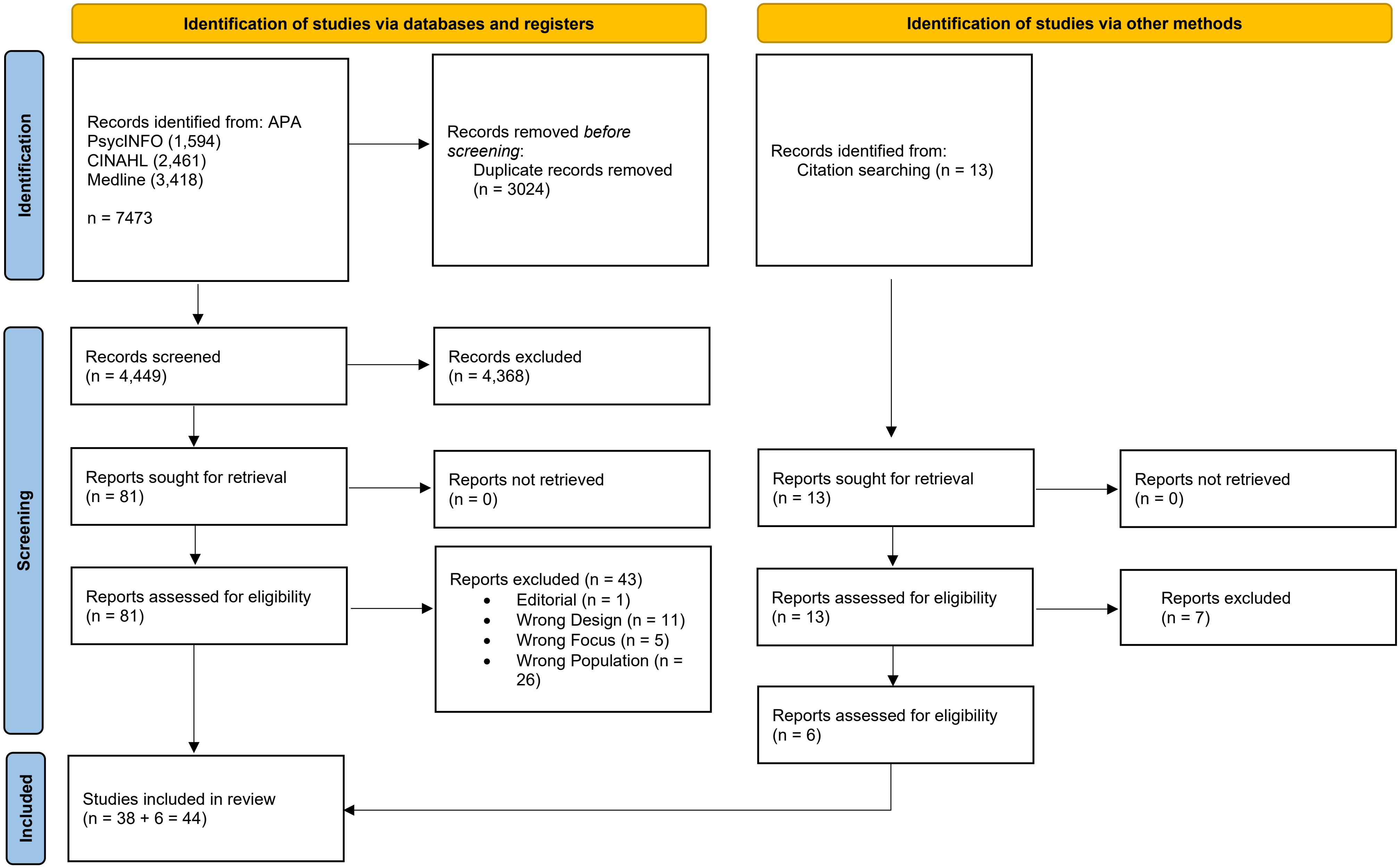

Figure 1. PRISMA Flow Diagram

Table 1: Characteristics of the Included Studies

Study and country	Methodology	Phenomena of interest	Setting/context/ culture	Participant characteristics and sample size	Description of main findings
Al Omari & Wynaden (2014) Jordan	Semi-structured interviews. Interpretive Phenomenological Analysis (IPA).	To explore the psychosocial lived experience of adolescents with haematological malignancies.	Two hospitals in Jordan.	14 participants Age: 13-17 years Cancer: Hodgkin lymphoma (5), non-Hodgkin lymphoma (3), leukaemia (6). Treatment: Chemotherapy (14). Gender: Female (5), Male (9)	Three themes emerged: 1. Being in hospital: When participants were hospitalised, they were removed from family and friends and prevented from engaging in their normal daily routine. 2. The changing self: As participants' illness progressed it led them to have negative feelings and experiences about themselves, exacerbated by their developmental stage – a period heavily focused on identity, peer group interactions, and physical and emotional achievements. **3.** Fearing the unknown: Participants were not prepared for the side effects of chemotherapy, or the invasive diagnostic tests or treatments conducted on them. They also began to come to the realisation that they may die sooner than they had previously expected.
Ang et al. (2018) Singapore	Semi-structured interviews. Phenomenology	To explore the experiences of adolescents living with cancer	Paediatric oncology ward in a Singapore hospital	10 participants Age: 10 – 18 years Cancer: mixed Treatment: Not reported Gender: Female (6), Male (4)	Four major themes emerged: 1. experience of physical symptoms, 2. emotional response to their condition, 3. changes in social dynamics; and 4. falling behind in academics
Bennett et al. (2022) USA	Semi-structured interviews. Phenomenology	To explore experiences with hope by adolescents and young adults who had advanced cancer.	A non-profit organisation supporting the online AYA cancer community.	15 participants Age: 12–21 years Cancer: Hematologic (12); Non-Hematologic (3) Treatment: Not specified. Completed treatments (60%), or actively receiving treatments (40%). Gender: Female (12); Male (3)	Main theme: Transitions of Hope. Participants described differences in their hope before and after experiencing cancer. Participants who experienced a relapse reported their past experiences helped them build hope during their relapse. Participants described a new sense of purpose after experiencing cancer, such as starting a non-profit organisation, giving back to others, doing "what I'm passionate about", and honouring the legacies of others.
Barnett, et al (2014) USA	Semi-structured interviews. Grounded theory.	Understanding cancer-related disclosures among adolescents and young adults.	Memorial Sloan Kettering Cancer Center (MSKCC) and who lived within one hour of MSKCC.	26 participants Age: 15–25 years old at participation (SD 2.8), 14–21 years old at diagnosis Cancer: Leukaemia (3), Lymphomas (8), Neuroblastoma (2), Other (6), Sarcomas (5), Thyroid (2)	Disclosure emerged as a nuanced and complex process. ''It depends'' decision-making processes were most frequently endorsed, consistent with the developmental complexities of this age group. It reflected the importance of peers and social interactions as variables that influence disclosure. In the context of AYA cancer survivorship, understanding ways in which disclosure may bolster or hinder social support can assist survivors, clinicians, and families in navigating survivorship.

				Treatment: Chemotherapy (18), Radiation (11), Surgery (17), Multi-modal treatment (17) Gender: Female (16), Male (10)	
Carlsen & Christensen (2020) Denmark	Semi-structured interviews and focus groups. Ethnographic methods and grounded theory.	Understand the challenges experienced by childhood cancer patients with peers during and after treatment.	Children affiliated with a paediatric oncology unit in Denmark.	70 participants Age: 3-17 years old Cancer: Leukaemia (32), lymphoma (9), brain tumours (11), others (19). Treatment: Completed within the past 2 years: Treatment type not specified. Gender: Female (36), Male (34)	Childhood cancer patients experience two types of exclusion: 1) unavoidable diagnosis-related exclusion; and 2) person-based exclusion from teachers, peers, and peers' parents. Person-based exclusion was manifested through the perceived insecurity of peers, misconceptions, and bullying. The impact and degree of these interactions partly depend on the patients' social affiliation before cancer.
Cohen et al (2017) Australia	Semi-structured interviews. Content analysis.	Exploring perspectives regarding enteral nutrition in paediatric oncology	Kids Cancer Centre, Sydney Children's Hospital.	10 participants Age: 9 (SD 5) Cancer: ALL (9), AML (3), Wzilms' tumour (3), Brain tumour (8), Neuroblastoma (2), Other (5) Treatment: Treatment type not specified Gender: Female (17), Male (13)	The present study showed that parents/patients and health-care workers could all see the positive and negative aspects of enteral nutrition, as well as the management of enteral nutrition, similarly. Discordant views between the patients/parents and healthcare workers appeared around the decision-making process and when information was provided on the use of enteral nutrition.
Corsano et al. (2015) Italy	Semi-structured interviews. Analysed "speaking about an emotional experience" method.	To explore the emotional events experienced by children specifically with nurses and doctors.	Paediatric haematology and oncology ward of a Hospital in Northern Italy.	27 participants Age: 6 – 15 years old Cancer: Haematological malignancies (15), solid tumours (4), blood disorders (8) Treatment: Not reported Gender: Female (15), Male (12)	The findings identified a relationship between hospitalised children and healthcare professionals has an emotional significance for children and this emerged especially for happiness.
Coyne et al (2016) Ireland	Semi-structured interviews. Constructivist grounded theory method.	Examined participants' views on children's participation in information-sharing and communication interactions.	A 32-bed children's cancer unit that is the principal treatment centre for all children with cancer in Southern Ireland	20 participants Age: 7 – 16 years old Cancer: Leukaemia (6), cancers of central nervous system (4), kidney (1), sarcomas (5), Lymphomas (4) Treatment: Not reported Gender: Female (9), Male (11)	Children trusted their parents to share information and valued their parents' role as interpreters of information, advocates, and communication buffers. This study adds important insights into the complexities of information-sharing in triadic encounters.

Darby et al (2014) England	Semi-structured interviews. Phenomenology	To identify the spiritual and religious needs of young people with cancer.	Birmingham Children's Hospital	9 participants Age: 11-16 years old Cancer: Not specified Treatment: Receiving treatment for > 4 weeks and < 2 years. Type of treatment not reported. Gender: Not reported	Spiritual needs were classified under personal issues, relationships and attitudes, and environment. Religious needs were identified as hope, resilience, ritual, connection, use of language, and world view.
Darcy et al. (2014) Sweden	Semi-structured interviews. Content analysis.	To explore the impact of cancer on everyday life for children with cancer.	Paediatric oncology unit in Southern Sweden	13 participants Age: 1 – 6 years old Cancer: lymphocytic leukaemia (8), myeloid leukaemia (1), Wilms tumour, rhabdomyosarcoma (2), brain (1), missing (1) Treatment: newly diagnosed Gender: Female (9), Male (4)	The child and his/her everyday life were suddenly unfamiliar, resulting in the child feeling like a stranger. The child's self-image, energy levels, and independence were suddenly and unexpectedly changed. Life at home and the home itself changed to accommodate the demands of the illness. The child wants to be seen as a competent individual requiring information and participation in care.
Darcy et al. (2019) Sweden	Longitudinal, semi-structured interviews. inductive interview. Content analysis.	To describe the young child's experiences of living an everyday life with cancer, over 3 years from diagnosis.	Paediatric Oncology Centre in the West of Sweden	13 participants Age: 1 – 8 years Cancer: leukaemia (9), brain (4) Treatment: on treatment (13) not specified. Gender: Female (9), Male (4)	The main finding describes the child living with cancer over the three-year trajectory as different than before, different than peers, and actively striving to make sense of the world. Young children with cancer actively strive to understand their illness, participate in care, and live an ordinary everyday life- but with ongoing feelings of social isolation and loneliness.
Ellis et al. (2016) Australia	Semi-structured interviews. Thematic analysis	To describe fertility concerns among child and adolescent cancer survivors and their parents	Sydney Children's Hospital	19 participants Age: 7 – 17 years (time of diagnosis), 12 – 20 years (time of interview) Cancer: Mixed Cancer Treatment: Not reported. Gender: Female (6), Male (13)	Themes included: • distress regarding potential infertility • the effect of infertility on future relationships • self-esteem, and miscommunications/confusion about fertility status • access to fertility testing; and • preservation options.
Engvall et al (2016) Sweden	Semi-structured interviews. Content analysis.	To describe children's experiences of preparing for and undergoing radiotherapy	Paediatric Oncology Centres in Sweden	13 participants Age: 5 – 15 years Cancer: lymphatic leukaemia (1), brain (8), sarcoma (3), neuroblastoma (1) Treatment: mixed Gender: Female (7), Male (6)	The main findings were that radiotherapy includes struggle with emotions and is perceived as "tough and tiring but it works". Although the children described facilitating and comforting measures taken by staff and parents, there were still several elements that caused distress for the children.
Enskär et al. (2020)	Semi-structured interviews.	To describe experiences that young children with	Paediatric oncology centre in the west of Sweden	25 participants Age: 1 - 6 years	The results of this study show that nurses' caring practices in caring for young children with cancer and their parents have some similarities across the different phases of the child's cancer trajectory. But they also show a lot of

Sweden	Content analysis.	cancer and their parents had with nurses		Cancer: leukaemia (17), brain/ solid tumours (8) Treatment: Active or maintenance Gender: Female (15), Male (10)	specific differences over time. Therefore, nurses need to plan caring practices accordingly, throughout the entire illness trajectory.
Fladeboe et al. (2021) USA	Semi-structured interviews. Content analysis.	To describe relationships with healthy peers during the 1st year postdiagnosis.	A children's hospital in the Pacific Northwest United States.	14 participants Age: 12-17 (SD=1.8) Cancer: Leukaemia (6), Lymphoma (5), Sarcoma, (2), CNS-tumour (1) Treatment: Not reported Gender: Female (9), Male (5)	Adolescents perceived friendships became less close since their cancer diagnosis, but cancer had strengthened at least some of their friendships by demonstrating how much they and their friends cared about each other. Adolescents re-evaluated friendships recognising which were most valuable, and experienced shifts in friend networks, finding their closest friends were not the same people as before diagnosis. Adolescents discussed the importance of talking to friends often. Communication efforts were critical for maintaining their friendships.
Gibbs et al (2022) UK	Semi-structured interviews. Thematic analysis	To understand the experiences of living with an artificial eye in children with retinoblastoma	Single tertiary hospital centre in England	7 participants Age: 4 months to 5 years Cancer: retinoblastoma Treatment: surgery and all have an artificial eye Gender: Female (2), Male (5)	The perspectives of children were: a) the importance of preparation and play; b) positive reinforcement and hospital support; c) support and openness at home; and d) the importance of good school planning. Two overarching themes related to parent and child adaptation were also identified.
Gibson et al (2016) UK	Virtual ethnography online, a participant–observation approach using computer-mediated communications as the data source	To describe young people's cancer experience	Online website: JTV Cancer Support (JTV; https://jtvcancersupport.com/)	18 participants Age: 11–25 years Cancer: Brain (3), Lymphoma (3), Leukaemia (5), Sarcoma (5) Unknown/carcinoma (2) Treatment: Not reported Gender: Female (11), Male (7)	Young people strive towards normality and create a new normal, even where uncertainty prevails. Strategies young people use to gain mastery over their illness and the types of stories they choose to tell provide the focus of the main narrative. Social Media sites can be examined as a source of data, to supplement or instead of more traditional routes of data collection known to be practically challenging with this population.
Gomex-Gamboa et al. (2022) Spain	Semi-structured interviews. Phenomenology	To explore the experience of hospitalisation among children and adolescents.	Paediatric oncology unit in Barcelona	7 participants Age: 9-18 years Cancer: Acute lymphoblastic leukaemia (7) Treatment: Not reported. Gender: Female (3), Male (4)	The children and adolescents considered that it was normal to feel afraid when in-patient treatment was required. For children and adolescents with cancer, the fear of hospital is related to being separated from family and friends in what is experienced as a hostile environment. Needle procedures are associated with pain, illness, and dying and participants related their fear of hospital to the pain that is inherent to needle procedures. Children wanted nurses to allow them to express their feelings, and to be honest if a procedure was likely to be painful.
Gurcan & Turan (2021) Turkey	Semi-structured interviews. Watson's Theory of Human Caring provided a framework for the development of themes	Expectations of children with cancer about the healing care environment during hospitalisation based	Haematology and oncology clinic at University Hospital.	12 participants Age: 10 – 17 years Cancer: lymphoma (5), leukaemia (5), sarcoma (2)	Revealed children's need for humanistic, compassionate, honest, and problem-focused care. Need for improvements in the physical environment. Felt lonely and needed social support from their family, peers, and society.

		on Watson's Theory of Human Caring		Treatment: Stayed in hospital for treatment and diagnosed 2+ months prior Gender: Female (7), Male (5)	
Hildenbrand et al. (2011) USA	Study semi-structured interviews. Thematic	To explore common cancer-related stressors for children with cancer	Paediatric cancer centre in the North Eastern region of the USA	15 participants Age: 6 - 12 years Cancer: leukaemia (4), brain (4), lymphoma (3), neuroblastoma (2), sarcomas (2) Treatment: Currently undergoing treatment Gender: Female (7), Males (8)	Distress experienced by children during cancer treatment was associated with treatment rather than the cancer itself. Coping strategies included the following: • cognitive restructuring • relaxation • practical strategies • seeking social support • emotional expression Distraction was the only avoidant coping strategy.
Jibb et al. (2022) Canada	Semi-structured Interviews. Inductive thematic analysis	Examine the views of children (family carers and clinicians) to improve home-based paediatric cancer care delivery.	Oncology Division Children's Hospital Eastern Ontario Canada	13 participants Age: 7 - 18 years Cancer: adrenal carcinoma (1), ALL (4), not reported (1), CNS tumour (1), lymphoma (5), osteosarcoma (1) Treatment: Receiving home-based care Gender: Female (6), Male (7)	Value of home-based care: • child health advantages • family social advantages • family financial advantages • health centre • system advantages Home-based cancer care challenges: • informational • cancer treatment and care • material • psychosocial Solutions to facilitate quality home-based care: • Informational • cancer treatment and care • material • psychosocial
Jibb et al. (2018) Canada	Semi-structured telephone interviews. Content analysis.	To identify perceptions of adolescents with real-time pain management smartphone app.	Two haematology/oncology divisions at Canadian paediatric tertiary care centres.	20 participants Age: 12 – 18 years Cancer: Acute lymphoblastic leukaemia (7), Lymphoma (5), Colon (2), Acute myeloid leukaemia (1), Langerhans cell histiocytosis (1), Ovarian (1), Lung (1), Ewing sarcoma (1), Germ cell tumour (1) Treatment: Not reported Gender: Female (9), Male (11)	Adolescents with cancer generally liked the Pain Squad+ smartphone-based real-time pain self-management app and considered it helpful. They found the app was easy to use and understand, supported the self-care of pain, and simplified patient-provider communication. They liked the capacity of the app to support pain treatment via the advice provided (especially when they were outside the hospital), pain self-monitoring, and facilitation of communication with health care providers. Challenges adolescents experienced with the app suggested that real-time symptom assessment questionnaires should be brief and notifications directing patients to interact with apps should be minimised.

Jones et al. (2011) USA	Semi-structured interview. Constant comparative analysis	To understand the experiences of adolescent cancer survivors with a particular focus on identity, health promotion, and meaning-making.	Dell Children's Medical Centre Central Texas USA	12 participants Age: 12 – 21 years (cancer diagnosis before 18) Cancer: Not reported. Treatment: post-treatment at the time of study. Gender: Female (7), Male (5)	Adolescent survivors might experience an identity paradox when making the transition to 'survivor' which can contribute to their sense of isolation and risk of health-detracting behaviours. Health promotion, prevention, and supportive programs need to be developed for healthcare professionals to address the isolation and identify transition needs of adolescent cancer survivors. Finding meaning: • appreciation • personal growth Identity paradox: • cancer identity • survivor identity Need to belong: • isolation • importance of family and friends and the health care providers • lack of support as a survivor
Kelly et al. (2016) USA	Semi-structured interview. Constant comparative analysis	To identify treatment decision-making preferences and experiences.	Middle Atlantic Children's cancer	29 participants Age: 9 – 17 years Cancer: Leukaemia and lymphoma (15), CNS (7), solid tumour (7) Treatment: Not reported Gender: Female (14), Male (15)	Having a Say – preferences ranged from not wanting to hear information at this time to being included in treatment discussion, to choosing a treatment option. Children reported both positive and negative effects of being involved (or not) in treatment discussions as they preferred. Children's preferences assumed the presence and involvement of their parents and doctors. Illness conditions (e.g., stage of treatment, symptom distress) informed child communication preferences more so than the child's age.
Lombardo et al. (2011) Brazil	Semi-structured interview. Social phenomenology	To explore experiences among adolescents during chemotherapeutic drug therapy	Chemotherapy Unit of the Clinical Hospital of the Faculty of Medicine of Botucatu	7 participants Age: 11 – 18 years Cancer: leukaemia/lymphoma (4), astrocytoma (1), osteosarcoma (1), Wilms tumour (1) Treatment: Not reported Gender: Female (6), Male (1)	Their discourses: • Impact of the disease on their lives • The discomfort of treatment • Coping strategies and Projection to the future without the disease. The statements of the adolescents revealed that the experience with the chemotherapeutic treatment affects several possibilities of being in the world with the other.
Lopez et al. (2014) USA	Semi-structured interviews. Analysed using immersion/crystallisation approach and cross-case analysis strategies	Examine the perspectives of adolescent survivors of childhood cancers during the transition to early survivorship.	Paediatric oncology outpatient clinic at an urban hospital in the Mid-Atlantic region USA	8 participants Age: 12 – 16 years Cancer: leukaemia (5), lymphoma (3) Treatment: Chemotherapy (4), Chemotherapy and Radiotherapy (3), Chemotherapy and bone marrow transplant (1) Gender: Female (3), Male (5)	Adolescent survivors perceived that their lives changed after treatment completion. But they did not define this time as a 'transition'. They identified re-engagement in activities and improvements in or absences of negative residual effects of treatment as indicators of returning to normalcy. The presence of residual effects restricted adolescent's participation in desired activities and reminded them that the impact of cancer and treatment extended beyond treatment completion. Adolescents varied in their perceived need for transitional care.

Macartney et al. (2014) Canada	Semi-structured interviews. Content analysis	To explore the symptom experience, and coping strategies, among children after treatment for brain cancer.	Paediatric hospital in Ontario Canada	12 participants Age: 9 – 18 years Cancer: Brain Treatment: surgery (3), surgery and chemotherapy (2), surgery and radiotherapy (2), chemotherapy and radiotherapy (1), surgery, radiotherapy, and chemotherapy (4) Gender: Female (6), Male (6)	Children described symptoms including feeling tired, pain, headaches, emotional problems, difficulty thinking and remembering, problems with sleep, physical problems, and weight changes. Symptoms interfered with physical activity, keeping up with school, maintaining appearances, and communication. Coping strategies included reconditioning, taking breaks, taking medication, challenging themselves, volunteering, maintaining friendships, laughing, and using aids.
Mant et al. (2019) UK	Semi-structured interviews. Interpretative phenomenological analysis	To explore and understand the feelings of children with cancer with the hope of improving communication and supports	Tertiary oncology department United Kingdom	6 participants Age: 8 – 12 years Cancer: lymphoma (2), leukaemia (3), astrocytoma (1) Treatment: Not reported Gender: Female (4), Male (2)	Children expressed that they felt shocked and scared, chemo is an awful thing, and the need to have someone to talk to, more information, and family are vital.
Mellblom et al. (2017) Norway	Video recorded consultations between paediatric oncologists and adolescent survivors.	Identifying negative emotions expressed during follow-up consultations with adolescent survivors of childhood cancers	Oslo University Hospital	66 participants Age: 12 – 20 years (aged at diagnosis 0-16 years) Cancer: leukaemia (47), lymphoma (14); *received stem cell transplant for benign disorder (5) Treatment: Stem-cell transplant preceded by high-dose chemotherapy treatment Gender: Female (45), Male (21)	Negative emotions were most commonly associated with late effects such as fatigue, psychosocial distress, pain, and treatment-related effects on physical appearance.
Mirlashari et al. (2021) Iran	Semi-structured interviews. Thematic analysis.	Investigate the perspectives of children with cancer and their families, in the era of the COVID-19 pandemic.	Central Paediatrics Hospital in Tehran, Iran	18 participants Age: 2 - 14 years Cancer: Acute lymphoblastic leukaemia (13) Acute myeloid leukaemia (1) Ewing's sarcoma (2) Lymphoma (2) Treatment: Not reported Gender: Female (14), Male (4)	Children and their families felt threatened by the uncertainties of living with cancer during the COVID-19 pandemic but developed strategies to deal with the fear of COVID-19. For children and families, being together is an essential need. Restrictions on person-to-person interaction enforced during the pandemic particularly concerned the children. Restrictions on interaction with broader society also left children feeling restless, lonely, and bored. Pandemic rules and restrictions imposed on the children, the lack of attention to the children's needs, and confusion and difficulty in implementing the instructions led to extra stress and worries. Due to COVID-19 children and families require more support and attention from healthcare workers, including effective and empathetic communication.
Miralles et al. (2016)	Semi-structured interview.	To identify the needs of hospitalised	Hospitals Toledo and Madrid	8 participants Age: 15 – 19 years	The lack of variety and availability of educational activities and leisure and the subsequent changes in the individual's physical, social, and cultural

Spain	Constant comparative analysis	adolescents with cancer about the performance of meaningful activities		Cancer: lymphoma (2), leukaemia (2), bone tumour (1), Ewing's sarcoma (2), medulloblastoma (1) Treatment: bone marrow transplant (2), Chemotherapy (3), No active treatment (3) Gender: Female (3), Male (5)	environments could cause situations of occupational deprivation and also affect the health and quality of life of the individuals.
O'Callaghan et al. (2011) Australia	Semi-structured interviews. Grounded theory and observation of children's music behaviours.	To examine paediatric cancer patients and their parents' perspectives about music and music therapy's role in the children's lives.	Paediatric Integrated Cancer Service (3-hospital partnership) in Melbourne, Victoria.	26 participants Age: 3 - 14 years Cancer: Leukaemias (18), neuronal (6), non-neuronal (3) solid tumours, and lymphomas (2). Treatment: Chemotherapy (29), surgery (6), radiotherapy (10), bone marrow transplant (3), not currently receiving treatment (8). Gender: Female (7), Male (19)	Children's adverse cancer experiences are often alleviated by music usage. Broader family, social, and electronic musical interactions also promote children's resilience and "normal" development. Music therapy and associated programs often, but not always, alleviate children's distress. Positive effects may carry over into children's home lives and vicariously support families.
Schwart-Attias et al. (2021) Israel	Semi-structured interviews. Content analysis	To identify adolescents with cancer need trustworthy information	Tertiary paediatric medical centre in Central Israel	19 participants Age: 8 – 18 years Cancer: Mixed Treatment: Not reported Gender: Female (9), Male (10)	Adolescents know quite a lot about the course of their disease and the information they lack is mainly aetiological. The participants reported a lack of knowledge concerning sexuality and a sense of discomfort talking about it, leaving them with open questions. They all claimed that it is important to tell the truth: "Even if the truth is difficult, it is important to tell it." The participants reported that information can be scary, so it must be structured and adapted to the age and emotional readiness of the individual.
Sposito et al. (2015) Brazil	Semi-structured interviews using puppets, to represent the children. Inductive content analysis.	To identify and understand the coping strategies used by hospitalised children with cancer undergoing chemotherapy.	Paediatric oncology ward at a public teaching hospital in Sao Paulo Brazil.	10 participants Age: 7 - 12 years Cancer: Osteosarcoma (3), Acute lymphoid leukaemia (2), non-Hodgkin's lymphoma (2), Ewing's sarcoma (1), Rhabdomyosarcoma (1), Medulloblastoma (1). Treatment: Chemotherapy (10) Gender: Female (5), Male (5)	Children with cancer undergoing chemotherapy need to cope with hospitalisations, pain, medication side effects, idle time, and uncertainty regarding the success of treatment. These challenges motivated children to develop their coping strategies, which were effective while undergoing chemotherapy.
Stinson et al. (2015) Canada	Semi-structured interviews. Thematic analysis.	To explore the impact of cancer on romantic relations among adolescents	Large metropolitan tertiary paediatric haematology/oncology care centre	20 participants Age: 12 – 17 years Cancer: Mixed Treatment: Mixed Gender: Female (11), Male (9)	Qualitative analysis revealed main themes for adolescents and parents related to: 1) romantic relationships (opinions on the importance of dating in the context of cancer, expectations that cancer will impact future relationships, dating as a source of moral support, and limited opportunities to engage with partners);

					2) sexual relationships (thoughts related to the impact of cancer on future sexual relationships); 3) fertility (initiating treatment as a primary concern and fear of infertility and perceived consequences); and 4) care recommendations (access to knowledge and support through adolescent-friendly and accessible means).
Stinson et al. (2012) Canada	Semi-structured interviews. Thematic analysis.	To explore the self-management needs of adolescents with cancer	Large tertiary-care oncology centre	29 participants Age: 12 -18 years Cancer: Mixed Treatment: mixed Gender: Female (15), Male 14	Four major themes, which captured the self-management needs of AWC, emerged from the data. These themes were: 1) disease knowledge and cancer care skills; 2) knowledge and skills to support effective transition to adult healthcare; 3) delivery of AWC-accessible healthcare services; and 4) supports for the adolescent with cancer.
Thorsteinsson et al. (2017) Demark	Semi-structured interviews. Analysis strategy of systematic text condensation	To identify rehabilitation needs of functional, cognitive, emotional, social, and physiological among young people with cancer.	Department of Paediatrics and Adolescent Medicine, Copenhagen University Hospital	13 participants Age: 8 – 16 years Cancer: Not reported. Treatment: Chemotherapy Gender: Female (6), Male (7)	The qualitative analysis showed that children's motivations for engaging in the physical activity program during intensive medical treatment was primarily influenced by: a) opportunity for physical activity with a classmate; b) participation in group physical activity sessions; c) support from significant others; and d) improvement of physical well-being. Main barriers included: a) poor physical well-being; b) compliance with medical procedures and being treated in protective isolation; and c) limited physical activity facilities
Valizadeh et al. (2019a) Iran	Semi-structured interviews. Content analysis	Investigate adolescent cancer survivors' experiences of supportive care needs.	Paediatric hospitals and cancer care centres.	49 participants Age: 11 – 19 years Cancer: solid tumours, leukaemia or lymphoma, and brain tumours (no further information reported) Treatment: Not reported. Gender: Not reported.	Many of the participants expressed a need for empathic care. They highlighted that family tension, isolation from friends and the community due to lingering side effects of treatment, and inadequate communication with healthcare providers during follow-up care can hurt the mental health of cancer survivors. Adolescent cancer survivors frequently mentioned that their families provided physical and financial support, but psychological support often received less attention or consideration.
Valizadeh et al. (2019b) Iran	Semi-structured interviews. Content analysis	Explore the perception of adolescent cancer survivors self-care needs	Children Teaching Hospitals in Tabriz City of Iran	19 participants Age: 11 – 19 years Cancer: solid tumours, leukaemia or lymphoma, and brain tumours (no further information reported) Treatment: Not reported. Gender: Not reported.	Content analysis revealed nine subcategories: 1) nutritional protection; 2) prevention from infection; 3) prevention from physical damage; 4) control over cancer recurrence; 5) informational needs; 6) pain management; 7) releasing positive thoughts; 8) continuing routine life;, and

					9) family protection. The first six subthemes were related to protection against physical distress, and the final three ones were related to protection against psychological distress. These two categories form one theme: “protective self-care need” as an essential self-care need in adolescent cancer survivors
Vanclooster et al. (2020) Belgium	Semi-structured interviews. Content analysis	To describe experiences of childhood brain tumour survivors and key figures in their environment regarding school life during the period of reintegration into school.	Two academic hospitals in Flanders, Belgium (Brussels and Gent)	5 participants Age: 7-10 (SD) not reported Cancer: Pilocytic astrocytoma (1), Anaplastic ependymoma, (1), Medulloblastoma (2), Low-grade glioma (1). Treatment: Surgery (1), Surgery and radiotherapy (1), Surgery, radiotherapy and chemotherapy (2), Surgery and chemotherapy, (1). Gender: Female (2), Male (3)	Positive experiences regarding social participation were associated with care and assistance from peers, as well as with peers’ familiarity with the child’s condition. Classmates gave children compliments, and offered practical support. The child’s age could have an (indirect) effect on reintegration into school with a higher age associated with a less smooth return. The older the children were, the more study material they had missed to keep up with peers, and the more psychosocial issues seemed to prevail. Some of them experienced pressure to perform due to high learning objectives and upcoming study choices, in addition to the age-specific challenges of upcoming adolescence.
Veneroni et al. (2015) Italy	Not reported.	Evaluate the effectiveness of creative projects and laboratories to help young patients express their thoughts and feelings	Paediatric Oncology Unit of the Istituto Nazionale Tumori in Milan	24 participants Age: 15 – 20 years Cancer: Not reported. Treatment: Not reported. Gender: Not reported.	The fashion project proved a fundamental resource in helping the young patients involved regain a positive self-image and the feeling that they could act, both on themselves and in their relations with others. It enabled them to construct or reconstruct their individuality: through fashion, they could find fulfilment and beauty. They were no longer on the side-lines of what was happening in the world; they became creators of new trends, an inspiration for others. While fashion represents inventing beauty, for our young cancer patients, it proved to be a way of inventing themselves and life.
Weaver et al. (2015) USA	Semi-structured interviews. Content analysis	Explore factors influencing decisional preferences in treatment and information access from adolescent perspectives	Treatment centres in Memphis, Tn, and Washington	40 participants Age: 12 – 18 years Cancer: Not reported Treatment: Active treatment (no further information reported) Gender: Female (16), Male (24)	Adolescents recognised that situational and social contexts might shift their preferred level of involvement in medical decisions. Although adolescents wanted to be involved in decisions, they also expressed an appreciation of family insight, parental presence, and clinician guidance.
Weidman et al. (2022) Canada	Semi-structured interviews. Thematic analysis.	To characterise peer support needs of adolescents with cancer during or shortly after treatment	Large urban Canadian children’s hospital	10 participants Age: 14 – 18 years Cancer: leukaemia/lymphoma (3), solid tumour (6), CNS (1) Treatment: Mixed Gender: Female (6), Male (4)	Three themes were apparent: 1. cancer journey difficulties 2. current support system 3. peer support perspectives Participants felt incompletely understood by existing supports, lacked connection with other AWCs, and craved experiential information. Peer support

					interventions should be flexible, facilitate various interactions, and include social media.
Wiljen et al. (2022) Sweden	Focus groups and interviews. interpretive description technique	Identify the symptom-reporting needs of children with cancer and congenital heart defects that could be satisfied by using a mobile app.	Five different hospitals in Sweden	17 participants Age: 7 - >15 years Cancer: Mixed Treatment: Not reported Gender: Not reported	Participants stressed highlighting symptoms beyond pain; for example, anxiety or fear. Children expressed a wish to receive support for self-care; however, there seems to be a disparity between what children want and what healthcare professionals provide. Children also appreciated when the nurses provided emotional support and took time and stayed a little longer to talk about entertaining topics such as movies or books. Children wanted to feel safe and have a sense of control over the situation. When they knew what to expect, children could handle their treatment-related procedures better. Healthcare professionals felt they were able to listen to the child's needs and wishes and, thereby, provide appropriate help.

Table 2 Quality appraisal of primary studies

Qualitative Study	1	2	3	4	5	6	7	8	9	10
Al Omari & Wynaden 2014	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Ang et al. 2018	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Bennett et al. 2022	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes
Barnett, et al 2014	Yes	Yes	Yes	Yes	Yes	No	No	Yes	No	Yes
Carlsen & Christensen 2020	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Cohen et al 2017	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Corsano et al. 2015	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Coyne et al 2016	Yes	Yes	yes	Yes	Yes	No	No	Yes	Yes	Yes
Darby et al 2014	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Darcy et al. 2014	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Darcy et al. 2019	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Ellis et al. 2016	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Engvall et al 2016	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Enskär et al. 2020	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Fladeboe et al. 2021	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Gibbs et al 2022	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Gibson et al 2016	Yes	Yes	No	unclear	unclear	No	Yes	unclear	Yes	unclear
Gomex-Gamboa et al. 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Gurcan & Turan 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hildenbrand et al 2011	Yes	Yes	Yes	Yes	Yes	No	No	Yes	No	Yes
Jibb et al. 2018	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes

Jibb et al. 2022	Yes	Yes	Yes	No	Yes	No	No	Unsure	Yes	Yes
Jones et al. 2011	Yes	Yes	Yes	No	Yes	No	No	No	Yes	Yes
Kelly et al. 2016	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Lombardo et al. 2011	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Lopez et al. 2014	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Macartney et al. 2014	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Mant et al. 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Mellblom et al.2017	Yes	Yes	Yes	Yes	Yes	No	No	No	No	Yes
Mirlashari et al. 2020	Yes	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	Yes
Miralles et al.2016	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
O'Callaghan et al. 2011	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Schwart-Attias et al. 2021	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Sposito et al. 2015	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Unclear	Yes
Stinson et al. 2015	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Stinson et al. 2012	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Thorsteinsson et al. 2017	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Valizadeh et al. 2019a	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Valizadeh et al. 2019b	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Vanclooster et al. 2020	Yes	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	Yes
Veneroni et al. 2015	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Weaver et al. 2015	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Weidman et al. 2022	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes
Wiljen et al. 2022	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes

Item number checklist key*: 1 Is there congruity between the stated philosophical perspective and the research methodology?; 2 Is there congruity between the research methodology and the research question or objectives?; 3 Is there congruity between the research methodology and the methods used to collect data?; 4 Is there congruity between the research methodology and the representation

and analysis of data?; 5 Is there congruity between the research methodology and the interpretation of results?; 6 Is there a statement locating the researcher culturally or theoretically?; 7 Is the influence of the researcher on the research, and vice-versa, addressed?; 8 Are participants, and their voices, adequately represented?; 9 Is the research ethical according to current criteria for recent studies, and is there evidence of ethical approval by an appropriate body?; 10 Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

1	Yes
2	No
3	Unclear

Table 3. Synthesised Findings

Findings	Categories	Synthesised Finding
F8, F9, F10, F12, F17, F22, F25, F27, F37, F38, F39, F42, F52, F56, F57, F64, F81, F82, F83, F86, F106, F107, F208, F114, F115, F116, F117, F118, F119, F120, F122, F121, F123, F124, F125, F127, F141, F142, F143, F144, F146, F162, F166, F168, F169, F176, F177, F183, F194, F195, F197, F198, F199, F206, F209, F216, F224, F227 F236, F237	Coping strategies gaining control, forward transitions	**Coping, caring relationships, communication, and impact of the clinical environment** Children and adolescents affected by cancer self-identified a range of coping strategies and behaviours that helped them to deal with the distress caused by cancer and its associated treatments. Gaining a sense of control was important and children and adolescents achieved this through various behaviours. It was centrally important for their emotional well-being that caring relationships with their parents, clinical team, and friends were present through the good and bad cancer experiences. Children and adolescents found it helpful to have tailored information to understand their disease, treatments, and side effects, and to support their self-management. Having a positive clinical environment that was aesthetically pleasing with fun activities to do was also critical.
F18, F21, F24, F25, F30, F44, F58, F59, F62, F63, F65, F67, F68, F69, F75, F76, F80, F92, F94, F95 F100, F101, F102, F108, F129, F145, F167, F178, F179, F221, F225, F228, F233, F235, F245, F246, F247, F54, F77, F102	Caring and honest relationships with continuity	
F26, F55, F70, F78, F99, F96, F97, F98, F110, F112, F113, F185, F186, F189, F190, F192, F196, F200, F207, F208, F217, F222, F223, F250,	Clinical Environment	
F61, F111, F175, F187, F191, F201, F202, F204, F212, F213, F218, F219, F220, F229, F231, F240, F244, F249 F251, F252, F253, F254, F210, F211	Tailored information and communication	
F1, F6, F29, F40, F41, F47, F60, F66, F72, F73, F89, F105, F128, F130, F139, F174, F180, F184, F234, F246, F248, F11, F14, F15, F16, F74, F127	Isolation, changing relationships and routines	**Experiences of isolation, fear of the unknown, restricted information, and changing self** Children and adolescents expressed a profound sense of isolation due to a disconnect from the outside world. There was a lack of support to help them adjust to new routines and changes in relationships. Some children experienced bullying in the school environment with a lack of support to keep up with their academic studies. They grappled with their changing self and experienced fear of the unknown. Some children and adolescents also experienced restricted information, and not being involved in decision-making.
F2, F13, F28, F31, F32, F33, F34, F43, F50, F51, F84, F85, F126, F158, F160, F161, F165, F170, F193 F4, F43, F53, F85, F90, F103, F140, F147,F151, F152, F155, F156, F157, F163, F164, F206, F232 F5, F19, F20, F49, F90, F104, F153, F172, F173, F233, F7, F71, F109, F126, , F154, F159, F181, F188, F230	The changing self	
F3, F20, F36, F45, F46, F49, F53, F86, F87, F89, F91, F93, F126, F139, F148, F171, F182, F209, F88, F104, F226	Fearing the unknown	
F23, F131, F133, F134, F135, F136, F137, F138, F149, F150, F175, F181, F202, F203, F204, F205, F214, F215, F226, F231, F238, F239, F241	Issues with restricted information and decision-making	

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Page 1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Page 1
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Page 2 - 3
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Page 3
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Page 3
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Page 4
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Page 4
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Page 4
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Page 4 -5
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Page 5
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	5
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Page 4 -5
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	NA
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Page 5 -6
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	Page 5 -6
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	NA
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	NA
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	NA
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	NA
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	NA
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	NA

PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Figure 1
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Figure 1
Study characteristics	17	Cite each included study and present its characteristics.	Table 1
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	NA
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	NA
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	NA
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	NA
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	NA
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	NA
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	NA
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	Table 2
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Page 13 -14
	23b	Discuss any limitations of the evidence included in the review.	Page 13 -15
	23c	Discuss any limitations of the review processes used.	Page 14 - 15
	23d	Discuss implications of the results for practice, policy, and future research.	Page 14 - 15
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Page 3
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Page 3
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	NA
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Title page
Competing interests	26	Declare any competing interests of review authors.	Title page
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Supplementary Tables

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

Supplementary Material

Supplement 2 – Search strategy

Three databases were searched on 19 July 2022 to identify relevant studies. These were APA PsycINFO, CINAHL, and Medline, all searched via the EBSCOhost interface. A limiter was applied to each database to retrieve studies published only from 2011 onwards and another limiter applied for studies published in English. Searches returned a total of 7,473 results. Search terms and number of search results by database:

APA PsycINFO (1,594)

(((TI (adenocarcinoma* OR cancer* OR carcinoma* OR malignan* OR neoplasm* OR oncolog* OR sarcoma* OR tumo#r*) OR AB (adenocarcinoma* OR cancer* OR carcinoma* OR malignan* OR neoplasm* OR oncolog* OR sarcoma* OR tumo#r*)) AND (TI ((bereavement OR caregiver* OR cognitive OR decision* OR “daily-living” OR diet* OR emotion* OR employment OR “end-of-life” OR exercis* OR existential OR family OR fear OR financial OR “health care” OR hospice OR “housekeeping” OR information* OR interperson* OR intima* OR isolat* OR lonel* OR “mental health” OR nutrition* OR pain OR “palliative care” OR partner* OR “patient-clinician” OR physical OR practical OR psychological OR psychosocial OR sadness OR social OR spiritual OR spous* OR “terminal care” OR transition*) N6 (need* OR support*)) OR AB ((bereavement OR caregiver* OR cognitive OR decision* OR “daily-living” OR diet* OR emotion* OR employment OR “end-of-life” OR exercis* OR existential OR family OR fear OR financial OR “health care” OR hospice OR “housekeeping” OR information* OR interperson* OR intima* OR isolat* OR lonel* OR “mental health” OR nutrition* OR pain OR “palliative care” OR partner* OR “patient-clinician” OR physical OR practical OR psychological OR psychosocial OR sadness OR social OR spiritual OR spous* OR “terminal care” OR transition*) N6 (need* OR support*))) AND (TI (adolescen* OR carer* OR child* OR parent* OR "young adult*" OR "young people" OR "young person" OR youth*) OR AB (adolescen* OR carer* OR child* OR parent* OR "young adult*" OR "young people" OR "young person" OR youth*)))) NOT MR systematic review

CINAHL (2,461)

(((TI (adenocarcinoma* OR cancer* OR carcinoma* OR malignan* OR neoplasm* OR oncolog* OR sarcoma* OR tumo#r*) OR AB (adenocarcinoma* OR cancer* OR carcinoma* OR malignan* OR neoplasm* OR oncolog* OR sarcoma* OR tumo#r*)) AND (TI ((bereavement OR caregiver* OR cognitive OR decision* OR “daily-living” OR diet* OR emotion* OR employment OR “end-of-life” OR exercis* OR existential OR family OR fear OR financial OR “health care” OR hospice OR “housekeeping” OR information* OR interperson* OR intima* OR isolat* OR lonel* OR “mental health” OR nutrition* OR pain OR “palliative care” OR partner* OR “patient-clinician” OR physical OR practical OR psychological OR psychosocial OR sadness OR social OR spiritual OR spous* OR “terminal care” OR transition*) N6 (need* OR support*)) OR AB ((bereavement OR caregiver* OR cognitive OR decision* OR “daily-living” OR diet* OR emotion* OR employment OR “end-of-life” OR exercis* OR existential OR family OR fear OR financial OR “health care” OR hospice OR “housekeeping” OR information* OR interperson* OR intima* OR isolat* OR lonel* OR “mental health” OR nutrition* OR pain OR “palliative care” OR partner* OR “patient-clinician” OR physical OR practical OR psychological OR psychosocial OR sadness OR social OR spiritual OR spous* OR “terminal care” OR transition*) N6 (need* OR support*))) AND (TI (adolescen* OR carer* OR child* OR parent* OR "young adult*" OR "young people" OR "young person" OR youth*) OR AB (adolescen* OR carer* OR child* OR parent* OR "young adult*" OR "young people" OR "young person" OR youth*)))) NOT PT review NOT PT systematic review

Medline (3,418)

(((TI (adenocarcinoma* OR cancer* OR carcinoma* OR malignan* OR neoplasm* OR oncolog* OR sarcoma* OR tumo#r*) OR AB (adenocarcinoma* OR cancer* OR carcinoma* OR malignan* OR neoplasm* OR oncolog* OR sarcoma* OR tumo#r*)) AND (TI ((bereavement OR caregiver* OR cognitive OR decision* OR “daily-living” OR diet* OR emotion* OR employment OR “end-of-life” OR exercis* OR existential OR family OR fear OR financial OR “health care” OR hospice OR “housekeeping” OR information* OR interperson* OR intima* OR isolat* OR lonel* OR “mental health” OR nutrition* OR pain OR “palliative care” OR partner* OR “patient-clinician” OR physical OR practical OR psychological OR psychosocial OR sadness OR social OR spiritual OR spous* OR “terminal care” OR transition*) N6 (need* OR support*)) OR AB ((bereavement OR caregiver* OR cognitive OR decision* OR “daily-living” OR diet* OR emotion* OR employment OR “end-of-life” OR exercis* OR existential OR family OR fear OR financial OR “health care” OR hospice OR “housekeeping” OR information* OR interperson* OR intima* OR isolat* OR lonel* OR “mental health” OR nutrition* OR pain OR “palliative care” OR partner* OR “patient-clinician” OR physical OR practical OR psychological OR psychosocial OR sadness OR social OR spiritual OR spous* OR “terminal care” OR transition*) N6 (need* OR support*))) AND (TI (adolescen* OR carer* OR child* OR parent* OR "young adult*" OR "young people" OR "young person" OR youth*) OR AB (adolescen* OR carer* OR child* OR parent* OR "young adult*" OR "young people" OR "young person" OR youth*)))) NOT PT review NOT PT systematic review

Supplementary Table 3: Full reference list of excluded studies

Author	Title	Reason for exclusion
Albers et al. 2022	Discussing Sexual Health with Adolescent and Young Adults with Cancer: A Qualitative Study Among Healthcare Providers	Wrong population
Agnew et al. 2020	The experience of fatherhood following childhood cancer survival	Wrong population
Avoine-Blondin et al. 2017	Identifying domains of quality of life in children with cancer undergoing palliative care: A qualitative study with professionals	Wrong population
Azizi et al. 2012	Determining, Ranking and Comparing Treatment Stressors in Children and Adolescents with Cancer in Tehran	Wrong design
Barrett et al. 2019	Enduring psychological impact of childhood cancer on survivors and their families in Ireland: A national qualitative study	Wrong population
Belpame et al. 2020	Coping Strategies of Adolescent and Young Adult Survivors of Childhood Cancer	Wrong population
Boles and Winsor 2019	"My School Is Where My Friends Are": Interpreting the Drawings of Children With Cancer	Wrong design
Brage et al. 2017	An ethnographic exploration of the delivery of psychosocial care to children with cancer in Argentina	Wrong population
Bultas et al. 2017	Art Making From the HEART	Wrong design
Check et al. 2017	Concerns underlying treatment preferences of advanced cancer patients with children	Wrong population
Cheng et al. 2022	Perceptions of Infertility Risk Among Chinese Parents of Children with Cancer: A Qualitative Study	Wrong population
Clerici et al. 2021	Illusionist techniques as a complement to psychological support for children with cancer	Wrong focus
Darcy et al.2020	The development of the clinical assessment tool "Health and Everyday Functioning in Young Children with Cancer"	Wrong design
Darbyshire et al. 2012	Supporting bereaved parents: a phenomenological study of a telephone intervention programme in a paediatric oncology unit	Wrong population
Darabos et al. 2021	Cancer-Related Decision-Making Among Adolescents, Young Adults, Caregivers, and Oncology Providers	Wrong design
David et al. 2012	A small scale, qualitative focus group to investigate the psychosocial support needs of teenage young adult cancer patients undergoing radiotherapy in Wales	Wrong population age (18 – 24 years) (hand citation searching)
Fern et al 2013	The art of age-appropriate care: reflecting on a conceptual model of the cancer experience for teenagers and young adults	Wrong population age (13 – 25 years) (hand citation searching)
Firth et al. 2013	Views of Childhood Cancer Survivors and Their Families on the Provision and Format of a Treatment Summary	Wrong focus
Ferraz de Arruda-Colli et al. 2018	In good times and in bad: What strengthens or challenges a parental relationship during a child's cancer trajectory?	Wrong population
Gaggiotti et al. 2019	"What shall I do when I grow up?" Adolescents with cancer on the Youth Project in Milan play with their imagination and photography	Wrong design
Gibson et al. 2010	Children and young people's experiences of cancer care: A qualitative research study using participatory methods	Did not meet year of inclusion (hand citation searching)
Gibson et al. 2013	Young people describe their prediagnosis cancer experience	Wrong population age (18 – 24 years)

		(hand citation searching)
Gray et al. 2018	Balancing Hope and Risk Among Adolescent and Young Adult Cancer Patients with Late-Stage Cancer: A Qualitative Interview Study	Wrong population age (18 – 39 years) (hand citation searching)
Hendriks et al. 2021	The long shadow of childhood cancer: a qualitative study on insurance hardship among survivors of childhood cancer	Wrong population
Henry et al. 2014	The development and evaluation of a holistic needs assessment and care planning learning package targeted at cancer nurses in the UK	Wrong design
Hershberger et al. 2012	The decision-making process of young adult women with cancer who considered fertility cryopreservation	Wrong population age (mean age 24 years) (hand citation searching)
Jibb et al. 2014	A Smartphone-Based Pain Management App for Adolescents With Cancer: Establishing System Requirements and a Pain Care Algorithm Based on Literature Review, Interviews, and Consensus	Wrong focus
Luckett et al. 2022	Patient and carer experiences of pain care in an Australian regional comprehensive cancer care setting: A qualitative study	Wrong population
Kenney et al. 2021	End of life communication among caregivers of children with cancer: A qualitative approach to understanding support desired by families	Wrong population
Karst et al. 2018	Assessment of end-of-treatment transition needs for pediatric cancer and hematopoietic stem cell transplant patients and their families	Wrong design
McErlean 2022	Planetary health, carbon zero healthcare and cancer nursing	Editorial
Murphy et al. 2012	Using a Patient-Centered Approach to Develop a Fertility preservation Brochure for Pediatric Oncology Patients: A Pilot Study	Wrong population
Nandakumar et al. 2018	Attitudes and experiences of childhood cancer survivors transitioning from pediatric care to adult care	Wrong population
Nightingale et al. 2021	Financial burden for caregivers of adolescents and young adults with cancer	Wrong population
Norgate et al. 2011	Children memories for events relating to treatment for eye cancer: Influence of age and loss of eye	Wrong population
Nilsson et al. 2022	Visualizing the Invisible—The Needs and Wishes of Childhood Cancer Survivors for Digitally Mediated Emotional Peer Support	Wrong population
Patterson et al. 2012	The unmet needs of emerging adults with a cancer diagnosis: a qualitative study	Wrong population age (20 – 25 years) (hand citation searching)
Sadak et al. 2017	Identifying metrics of success for transitional care practices in childhood cancer survivorship: A qualitative study of survivorship providers	Wrong populations
Sadruddin et al. 2013	Understanding the perceptions of children battling cancer about self and others through drawing	Wrong design
Sariman et al. 2022	The Experiences of Young People Living With Cancer in Regional and Remote Australia: A Qualitative Study	Wrong populations
Slater et al. 2020	Telling the Story of Childhood Cancer—The Experience of Families After Treatment	Wrong design (no children's perspectives)
Sighorelli et al. 2018	The Role of Primary Care Physicians in Childhood Cancer Survivorship Care: Multiperspective Interviews	Wrong population

Sinclair et al. 2021	Compassion in pediatric oncology: A patient, parent and healthcare provider empirical model	Wrong focus
Smits-Seemann et al. 2017	A Qualitative Inquiry of Childhood and Adolescent Cancer Survivors' Perspectives of Independence	Wrong population
Smith et al. 2018	'I know I'm not invincible': An interpretative phenomenological analysis of thyroid cancer in young people	Wrong population
Testoni et al. 2020	Can desire and wellbeing be promoted in adolescents and young adults affected by cancer? Phtotherapy as a mirror that increases resilience	Wrong focus
Tsimicalis et al. 2018	The Impact of a Childhood Cancer Diagnosis on the Children and Siblings' School Attendance, Performance, and Activities: A Qualitative Descriptive Study	Wrong population
Wakefield et al. 2005	Accommodation in pediatric oncology: parental experiences, preferences and unmet needs	Wrong population
Weidman et al. 2022	Peer Support Needs of Adolescents with Cancer in Pediatrics: A Canadian Mixed Methods Study	Wrong design
Zanatta et al. 2021	Children and adolescents with cancer: vulnerabilities and implications on the right to health	Wrong population

Supplementary Table 4. Qualitative Findings

Author	Finding	Illustration	Level of evidence			Finding No.
			Unequivocal	Credible	Unsupported	
Al Omari et al. 2023	Being in Hospital	I like my school and considered it as my second home . . . I used to spend seven to eight hours every day at school. In school, I played some games with my friends like hide [and] seek and the circle game. I used to play with them for hours and I used to study with my friends every day. Now I cannot do any of these things and I constrained between four walls . . . I am very stress in this place and we do not have facilities to communicate and study with our friends and there is no place to play. (page 2) I do not like hospital . . . I do not like the routine [in the hospital]. The most annoying things are the doctors . . . Doctors came and woke me up for weight measurements in the morning, after that they woke up me for my temperature then for medical rounds or in the evening for another temperature reading (page 3) Here [in the hospital] I feel bored because I'm isolated in the room. I cannot get out; there is nobody to visit me [friends]. They [doctors and nurses] did not allow my friends to visit me. A person should be able to go out, walk and have fun. (Participant 2, Interview 1). Hospitalisation deprived the adolescents with HMs from being with their family members and friends, which increase the illness severity. (page 3)	X			1
	The changing self	I used to not wear a Hijab before my sickness but now I wear it all the time. Sometimes I was wearing a pyjama, blouse, and jeans while making my rounds to see my friends. . . . My hair was long and I was pretty, not like now. I do not have any hair and my shape has changed. I was beautiful [before I became ill]. . . . Compared to what I looked like before I am not that beautiful. (page 3) The hair loss [pause] I am a girl and I liked my hair. Without hair, I feel that I am like a boy and I do not know how my friends will respond when they see me like this [without hair].They [friends] will not like it [my new look]. (page 3) I told them [people in the chat room] yes [I have cancer], so they would leave me and go far away from me. I don't know why, and they called me cancer boy. In particular, a girl who I knew before [I got sick] she disturbed me with this title. . . . I went to her house [on the internet] and shouting that all people have cancer, not just me. She said to me Don't talk to me. At that time I thought very seriously about leaving everyone [to isolate myself]. (page 4) I expect that the students will ask me why I have been absent from school. This is an expectation, so I don't care about the answer. [Pause] I will answer that I was sick without telling them my real diagnosis. I don't want to tell them; even on the internet when I connect with my friends, they ask me What's wrong with you? I just tell them that I'm tired. . . . We have a girl in school who had a brother who was sick with this disease. Just imagine, when her brother had this disease, the girls kept away from her, they were scared of the infection! You feel that people will keep away from you, so why should I put myself in the same situation? (page 4)	X			2

Supplementary Table 4. Qualitative Findings

	Fearing the unknown	. . . Then they [the doctor] told me that they wanted to take a bone marrow biopsy, but I told them that I would not let them take it, because I knew nothing about it and I was afraid. [Pause] I fear pain and fear of becoming paralysed, but at the end, some other patients convinced me to do it. (page 4) No, no one told me that the bone marrow aspiration would be painful, but I became afraid of the bone marrow biopsies until the last one when they told me that they would anesthetise me. . . . They anaesthetised me, so I felt no pain (page 4) . . . Yes, everyone thinks about death. . . . One in my circumstances and my situation thinks about death. After I got cancer, in the early stages, I did not know what the nature of my sickness was and no one tell me, but when I saw people and they began to tell me unpleasant stories about cancer, and I saw people die, the idea of death became dominant in my life, cancer is a killer. (page 4) . . . I'm scared of not seeing my family, and staying in the grave alone. I thought about death when I was very tired, when I was admitted to the ICU. I even told my mum, if I died, to bury me near the house because I'm afraid to be alone. (page 5)	X			3
Ang et al. 2018	Experience of physical symptoms	(Chemotherapy caused) ... like, my whole body, (I) think, muscle pain and joint pain. Invasive procedures such as setting plugs on the legs... is quite painful ... I also had to do, er, the biopsy and the bone marrow aspiration without sedation ...I think I fainted halfway through, uh (page 537) ‘‘I will vomit a lot in the middle of the night’’ and that ‘‘(I) don’t really have the appetite to eat, even if it’s [the food is] nice (page 537) Once I start(ed) receiving the injections, then the lethargy sets in ... When I feel weak, I, like, don’t really have the energy and mood to do anything ... Doing things that I normally can do easily is a bit difficult (page 537) Side effects also include changes in physical appearance such as ‘‘the moon face ... the loss of hair ... then, the cheeks a bit fatter’ (page 537)	x			4
	Emotional response to their condition	When they were initially diagnosed with cancer, one of them felt ‘‘a little bit more depressed than now’ (page 537) Another felt ‘‘sad and frustrated because, like, I can’t do all the things I used to do in the past (page 537) You will get used to it ...I was also quite scared at first, ah (page 537) I feel scared because I, like, have the fear of dying ... cause I’m not ready (page 537) I’ve gone through that whole, like, really depressed stage of life ...I kinda know how my friends feel at some point in time ...I have certainly become a bit more respectful of people ... cause, like, you cannot really tell what someone is going through until you gone through yourself (page 537)	x			5

		I (am) still, like, worried, la. Like go (to) school, go bald or go like this or go, like, wear wig ... But then, if I wear wig, also it will be obvious that I wear wig (page 537)				
	Changes in social dynamics	There's age limit here, right? Twelve and below cannot come. They [my siblings] haven't (reached) 12 yet so they cannot come ... (page 538) Both of them (my parents) will always see me at the same time ... I feel like the family relationship is getting closer... because they want me to feel happy (page 538) Because I didn't see them for about a whole year... a lot of my relationships kinda broke off... (page 538) My father, every time ... very pestering me ... every time, every hour, message me, call me, then, like, I don't have space (page 538) Making friends was also hard, as explained by one of the adolescents, ''Most of them are babies, there are not much people at the same age (page 538)	x			6
	Falling behind academically	I (am) actually sec four (last year of high school) this year, then I have my ''O'' Level (high school leaving examination) ... I actually can go and do my ''O'' level and go to, like, poly (polytechnic)... but, now (I) cannot ... Last Friday, when I just got admitted, they (my classmates) graduated. Then I feel like, oh my god, I am going to miss that (page 538) I'm, like, worried if I can catch up with all the work that they have done ...It's possible that if I can't catch up, I have to retain ... All my friends are going to be in sec four ...I don't want to get left out ... . (page 538) 'I have missed about a year and a few months' worth of school, which is why this year I'm kinda scrambling to catch up with everything ..(page 538)	x			7
Bennett et al., 2022	Hope before cancer	Before cancer, I didn't think much about hope. There were situations in which I was hopeful, but I didn't comprehend the full meaning of the word hope until I was diagnosed with cancer. (page 585) . .before, it was something I never really needed to have. Hope wasn't something I really thought about, but once I was in treatment, I really had to find a lot of it. (page 585) Before cancer, my feelings about hope were pretty vague. I don't think it played any special role in my life, similar to what an ordinary person who's never been through something super traumatic feels. It was more like I hope I finish this assignment on time kind of thing, very low-tier. (page 585) I feel like before cancer the role of hope in my life was vague. I just hoped I would be able to do what I wanted in life and be successful. (page 585) I wasn't as hopeful then, and always thought It will get better when ___ happens, etc. I lived day to day, not really hopeful for the future, but waiting for better days, but not expecting them to happen.	X			8

Supplementary Table 4. Qualitative Findings

	Levels of hope during cancer	I had to hope my treatments were effective and know that I was given the best shot to be cancer-free. Part of my hope was knowing if the cancer returned, I could go through treatment again. I think hope is one of the most important things to have during treatment. That's what gets you through those really hard days, and there are going to be a lot of really hard days. (page 586) I do believe that there are a lot of types of hope: There's school hope in the sense that you hope for school success; there's life hope in the sense that you hope for life or career success, and then there's another stage of life hope – hoping that someone's going to live. They're all used for different purposes, depending on what's going on in the world around you. The smaller levels of hope that get you through the day are used more often than those bigger levels of hope when someone's ill, and you're using every ounce of hope you can muster in the anticipation that they will get better. (page 586) Once the pandemic hit, everything I was planning was again out of my control. I lost a lot of hope during the pandemic, things weren't going my way. (page 586) It's been hard to stay hopeful during the pandemic, especially because my friends and I had just gotten out of treatment. I felt like I had just got my life back together and felt for the first time like a real teenager doing teenager things. (page 586)	X			9
	A new purpose; hope after experiencing cancer	...compelled me to focus my goals on helping other people who have it. I really wanted to make a difference for others, give back, spread awareness about cancer, and give hope to others. (page 586) After finishing treatment hope inspired me to give back to others, do what I'm passionate about, and be grateful for every moment- not just the big ones. Thinking about the friends that I made who didn't survive cancer, and how I'm going to live for them keeps me hopeful and inspired for the future. Hope makes me work harder to make sure my future is what I want. (page 586) I bring my light and energy to others. I've been in situations like this before when I think 'This sucks', but later on it's going to get better. I try to get it in my mind that I'll think back about this situation and realize it isn't as big a pain as I thought it was, and realize it's gonna be OK. (page 586) My value of what a problem or an inconvenience is has definitely changed. I've started looking at things differently compared to the things people complain about on social media kind, and feel like. . . 'ughh, you're seriously complaining about this right now?' Cancer definitely put things into perspective, and gave me a new value and appreciation for health. (page 586)	X			10
Barnett et al. 2014	Perceptions of others' responses	I don't want to say I'm a cancer survivor; it'll depress everyone. (page 126) My friends hear me talk about it. I could talk about it with them. But I talk about it with them for a reason, because they don't look at me like, ''Oh, you poor thing. (page 126)	x			11

	Method of disclosure	It's such a big part of my life and had such an impact on me that I do like talking about it. I'm very flattered when people ask me about it or want to talk to me about it. (page 126) In my [psychology] essay the goal is to explain how life is not life after cancer; it's more like life with cancer. Just because the disease isn't there you're still living the cancer lifestyle to some extent. (page 126) I've been more willing to volunteer and get other people involved. It's time to do it back for everyone else. I got to keep going. I met new people that way and I don't really talk to people about what happened but at those points I really wanted people to understand. (page 126)				12
Carlsen & Christensen 2020	Perceived insecurity of peers	It is like a fucking freak show! We have gastric tubes and are bald, wearing hats everywhere. We are getting used to it, but I clearly understand that our friends react and stay away from us (page 718) You are pretty much white as a sheet, and then you were bald too… (hesitating) and you could see the bones and all kind of stuff. They were afraid of me. (page 718)	x			13
	Misconceptions	Do not treat me like glass! There are stories about what I can and cannot do, yet they are not correct. If I am in class, I am okay (page 719) They are making 'rules' about me that are not correct. For example, my teachers and classmates say that I cannot play soccer or 'you are not allowed to hit and tackle him – after all, he can die of it (page 719) I think they did it to show consideration for me. I had a gastric tube and could not eat, so they stopped inviting me. I think they wanted to avoid me feeling embarrassed. But I ended up all alone (page 719)	x			14
	Bullying	Imagine two of your classmates crawling on their knees and pushing their bellies forward so that they become fat and are talking stupid. And then you realize that it is you they are making fun of because you have gained some weight and changed appearance. (page 719) Pinch the other children when we are eating. But I only do it to the children who tease me. They make a mockery of me because I cannot walk. They are playing a game where they are walking strange and saying, 'I'm Peter'. So, I pinch them (page 719) No one would share my table. They said I could transmit the cancer to them. When I finally returned to school, I was all alone. In the break, some girls called me 'cancer bitch'. I wish my teacher had done something. (page 720)	x			15
	Change in social affiliation post-diagnosis	I am kind of a nerd (laughing). I do not care what other people think. I had two good friends – and I still have them (page 721) First, my friends said they would support me no matter what. We just started drinking, not me – I'm on a fucking cure. They don't invite me to the parties, and now I am the boring guy. I could not graduate and be there with my mates. I missed all the fun parts. Instead, I got my	x			16

Supplementary Table 4. Qualitative Findings

		preliminarymarks transferred but then my so-called friends called me a 'flop' and said I was cheating. My life and status changed completely (page 721) Suddenly I was excited and received messages from all sorts of people I never hung out with before. I was so overwhelmed and thought they meant it. But after some weeks, it stopped again (page 721)				
Cohen et al., 2017	Less pressure on the child to eat/less conflict	'When I found out about it I felt a huge amount of relief that I wouldn't have to struggle with trying to eat (page 480)	x			17
Corsano et al. 2015	Emotional antecedents	I celebrated my birthday in the hospital and they (the nurses) sang happy birthday, I got a Barbie and a pair of pajamas with a penguin (page 87) When the care and hospitalization will be finished, and I will speak with the doctors in the room, and they finally say that I can go home. (page 88) I always talked and played with them, I never felt sad, there is not a sad time. (page 88)	x			18
	Emotional and medical terms	Medical terms: the children mentioned: lumbar injection, needle aspiration, anesthesia, sleeping pills. (page 88) Emotional terms: angry, sad, frightened, happy, ashamed, embarrassed. (page 88)		x		19
	Behavioural reactions	When I have to have an injection, I feel very angry. I cannot sit quietly, four people have to hold me still (page 89) I went away because I was frightened (page 89)	x			20
Coyne et al. 2016	Maintaining an open and honest approach	They're really good at that. They've never spoken to Mam and Dad on their own. There's always like the three of us. They make sure everyone is included with me. They make sure I understand everything and they ask me before they leave do I understand everything and do I have anything to ask . . .when like he's talking straight to you, you know that there's nothing hidden or anything, that he's telling you everything (page 145) If there's anything I don't understand I just ask and they just tell me. Yeah, they always let me give my opinion and they always take notice of it (page 146) No the doctors kind of mentioned it, and then other. . like you know nurses would say in passing. You kind of find bits out over time. The longer you're here the more you find out (page 148) They do explain everything to you. I prefer them to tell me. Like when I was first starting out they just told my parents just because it was scary the first time I was in here. But they tell me everything now (page 148)	x			21

	Maintaining hope and spirit	I don't really talk to the doctors, Mum talks to the doctors. I don't like talking to the doctors just because it reminds me of what I'm actually doing here. . just want it over and done with, as fast as possible. I don't even like hearing the name of the chemo's now because like they just make you feel bad (page 149) If it's something bad I don't want to hear about it (page 149)	x			22
	Managing restricted information-sharing	I was a bit mad when they told me I had cancer. They didn't tell me because like when they said, 'Chemotherapy,' I knew that I had cancer. They didn't want to tell me, or because to them it would make me really upset because my Mum didn't think I knew what chemotherapy meant (page 150)	x			23
Darby et al. 2014	Personal issues	Starting treatment was hard for my family but 'I was okay due to her easy personality (page 34)		x		24
	Relationships and attitude	You'll all have your weepy days, there's no point in being negative about it. A positive outlook will get you through it. (page 34) They used to whenever you need me (nurse) just to talk, I will be there for you (page 34)	x			25
	Environment	brilliant, it's a lovely place, loads of things to do, could not be improved (page 34)	x			26
	Religious needs of young people	I'm not like massively religious – I do believe in God and everything. I suppose it's like he does everything for a reason. (page 35) I think some people could be angry with their God… but I would say I was – you know I mean bad things always have to happen, don't they? (page 35)	x			27
Darcy et al. 2014	Feeling like a stranger	Child: We had to buy that buggy. Interviewer: Why? Child: For me to sit in I can't walk anymore Interviewer: Why not? Child: My legs are too strange it was different before. (page 449)	x			28
	Feeling isolated	Used to have a best friend … now we never can play (page 449)				29
	Feeling powerless	Mother: Some nurses are better than others at keeping her calm. It's their way I like way of being. She has had times she has said ''I want to go to hospital to meet X.'' Child: I like X.		x		30

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Darcy et al. 2019	Feeling like a stranger	Now I get help from my Mummy to do pretty much everything, (before) I did it all myself (page 39) Tape on my cheek … nobody allowed touch (page 39)	x			31
	Sometimes feeling the same	She had tubes and stuff and no hair, she looked sad (page 39)		x		32
	Feeling almost normal	Look at me, I'm almost like a real child again (page 40) Mummy, Mummy, it feels almost like I'm well, like I was before I got this illness (page 40)	x			33
	Aware that body is different	I have thousands of scars now … one here, one here, one here, see? no one else in my class has these (page 40) They can cycle and I can't cycle - I`ve been sick you see (page 40) Next week I start cortisone treatment again, I'll be a real witch for a while (page 40)	x			34
	Living in the shadow of illness	I'm going to school soon … Mum is going to the parent-teacher meeting with Dad, both of them so that the school knows I have a port here (page 40) Sometimes I want to be sick again … I miss the nurses and I miss the presents (page 40)	x			35
	Feeling powerless	Tell me … ask ME if it's OK to lift up my t-shirt (page 40)	x			36
	Experiencing the need for control	Put it on at home (anesthetic cream) … so that it won't hurt, put on the tape myself (page 41) Get good medicine in here (CVC) …to fight the bad guys in my blood (page 41) Have to take tests and stuff.. because that's good … so that I'll get better and that … so that those mean cells won't … I don't want them in my body. Stupid cells! Get out! (page 41)	x			37
	Feeling secure and in control	I'm not sick, I have leukemia (page 41) So I said to the nurse, don't you touch me with your cold hands, warm them up first (page 41) No, no, that (NGtube) belongs to me and it's to stay right here (page 41) Mummy is the only one on this ward who knows where the tape sits best– I want her to do it (page 41)	x			38
	A continuing need for control	decide which finger to stick and what number to count to. I get to press the button on the lift too – don't I Mummy? (page 41)	x			39

		push my own medicines down this nose tube with this (syringe) … Mummy is allowed watch me (page 41)				
	Feeling isolated	Always played with my best friend before, now we never play (page 41) I can't go (to preschool), I just have fever all the time (page 41) wonder what they are doing at preschool – do you think they think about me? (page 41)	x			40
	Feeling left out	wish I was well and could play again (page 41)	x			41
	Feeling lonely	My teacher actually said she misses me (page 41) I'm the one who decides, and today don't want to play that game (page 41)	x			42
	Not the same as others	They play chasing but my legs get tired (page 42) (My friends) go to swimming classes … I want to swim too (page 41)	x			43
	Learning to be a social being	go to football after school … and I go swimming too (page 42) have a best friend now (page 42)	x			44
Ellis et al. 2016	Uncertainty and impact on future relationships	Probably my main concern is, when I decide to have a child, whether I can have one. I've already started having problems - I wasn't ovulating and stuff like that (page 351) They did freeze a lot but I don't know - it could be a bit weird for your future wife. It'd be a bit of a hard subject to explain if I am [infertile (page 351)	x			45
	Communication and information	I asked if there is a test they can just do to see if you can have kids. [Mum] said there's nothing really. I'd kind of like to know at least one way or the other (page 351) I don't know what's going on but after my surgery, the surgeon told me I've still got my right ovary. And then [the oncologist] told me that I don't have it in anymore, which made me a bit upset and angry. (page 351)	x			46
Engvall et al. 2016	Positive and negative experiences with hospital stays and practical arrangements	School feels normal. . . and my friends know everything [about my illness] (page 5) oh, that's the time to wait, like, a lot of it. If you've decided to meet some doctor, uh, and then you have to sit in the waiting room for, like, four hours (page 5) It's quite a long way from home. . . you can't see your siblings so often. . . (page 5)	x			47
	Age-appropriate information, communication, and	No, there was nobody telling about it (page 5) The thing was, I didn't know that much (page 5)	x			48

	guidance to various degrees	Eh, no, not–not the first time. . . I didn't have my eye on the mask, either, so I didn't know. (page 5)				
	Struggle with emotions	No, I was mostly afraid (page 5) We tried to do the radiation therapy when I was awake, but. . . it got too lonely in the room when they [the parents] had to go out. It felt nice to sleep (page 5) From the start, I refused up until the end. It was Friday, the first Friday, so I refused to go. But I was simply forced (page 5)	x			49
	Disliking and accepting the mask, the dot tattoo, and the machine	Then it was also a little tough when the mask was fixed, because it sat really hard, that mask (page 6) It's big. . . and then it spins around and makes sounds, it rumbles (page 6) So. . . I got a goddamned mask like this. . . uh, then I had to have radiation while in it. That was worse. A mask, but it's. . . like when you're stuck in. . . it's tight at first (page 6) was nervous about the tattooing but then I saw that they were barely there (page 6)	x			50
	Finding the right position and remaining motionless	That was probably the hardest. . . lying still. . . it itches [when you're supposed to lie still] (page 6) So it's so hard to lie still with your legs (page 5)	x			51
	Disliking the sensations	Things I react to that I don't think are all that cool, is that it smells really bad. . . it smells like iron. I smell it every time. . . and there was a blue light, and then there was that sound. It sounded like something tooting. . . and then it finished, that thing with the light. That's nice (page 5)	x			52
	Suffering physical and psychological problems to various extents	My throat's really fragile. . . I can't swallow. . . So I don't have a big appetite and I don't each much at all. I try. Most of it's difficult (page 7) I had radiation on my back first, because I was having chemotherapy at the same time as I was having radiation first. Because I have tumors that don't respond to treatment. When I had to start radiation on my head. Because then it felt like it hadn't helped anything. . . I also think it's tough because I have these record doses (page 7) Now it feels really nice that the radiation will soon be over (page 7) Oh, then in two weeks the MR will x-ray again and see if it's helped anything. If it, like, hasn't disappeared down there where it's sitting, it can't be irradiated any more. That's a little scary, because, like, then you die. Nothing can be done about it, either. It feels screwed up (page 7)	x			53
	Appreciating small gifts	Today I got three things (0203B7); one girl described getting a dress (page 7)	x			54

Supplementary Table 4. Qualitative Findings

	Using a suitable media distraction	The younger children described the distractions they preferred during radiotherapy: some liked listening to music, reading a story, or watching a film.		x		55
	Using problem-solving activities	To get rid of this smell. . . we usually put a bit of chocolate in front of my nose [laughs] so it smells a bit like chocolate and I get to eat it when I'm done, so that's why I think it's such a good idea [laughs]. . . it doesn't help, but it's good [laughs] (page 7) once I did it twice in one day. . . that was because I wanted to take a day off because I was going away [brief pause] on a class trip (page 7)	x			56
	Using strategies to deal with emotions	I think about something fun, about graffiti and ice hockey (page 7) My stuffed toy can stay in the same room, near me. . . I talk with them. . . my stuffed toy doesn't get scared (page 7) Like, take it one day at a time and count, now one day is gone (page 7)	x			57
	Wanting parents close by before, during, and after treatment	They just have to leave me for a bit, then they'll come (page 7) They [the parents] are entirely outside, but there is a wall between (page 7)	x			58
	Seeking support from parents, staff and peers	There was another boy also, who was also getting radiation to his head, which removed a brain tumor, just like me. We meet at breakfast, at lunch, and at dinner and I've asked him. . . if he also noticed this light and smells, but he noticed the light sometimes he says, but not any smells. . . very different (page 7)	x			59
	Desire for facilitating routines and suitable equipment	time for preparing prior to irradiation and radiation time should be shortened: I think it's tough that it [the radiation] takes so long (page 7)	x			60
	Desire for specific, individualized, and easy-to-understand information	It sounds scarier than it is. You think it's Star Wars. . . I don't know about this. . . radiation (page 9) If you're getting radiation to the face, it could be good to know there will be a bad smell or. . . a bad taste, oh. A little of that, practical (page 9) Talking to the speakers, that helped a lot. Because then you're prepared. . .. Otherwise it's like a surprise, you're lying there and suddenly it just starts the radiation (page 9)	x			61
	Desire to choose the kind of distraction preferred	The young children wanted to decide themselves what kind of distraction they wanted during the treatment			x	

Supplementary Table 4. Qualitative Findings

	Desire for gifts as encouragement	The younger children liked to receive small gifts as encouragement and looked forward to post-treatment			x	
	Desire for sympathetic staff and continuity	She wasn't the one I knew (page 10) One of the older boys thought it was very good to have continuity among the staff and to meet the same person each time: I think you should continue with that (page 10)	x			62
	Desire for peers to talk to	Among the older children, one of the boys described it being nice to have peers to talk to who understand exactly what radiotherapy is like.			x	
Enskar et al. 2020	Caring practices at diagnosis and induction therapy	At this point, children now have quite extensive experience about many procedures, they also have wishes and demands about how things are to be carried out: I don't like it, but I'm used to it—I've had it so many times before and now it's just the last medicine left and then it's time to take it away for good (page 26)		x		63
	Do not assume anything (knowing)	So I said to the nurse, don't you touch me with your cold hands, warm them up first . . . You warm your finger first, on a heating pad (page 26)	x			64
	Highlight positive experiences and happy moments (maintaining belief).	She (the nurse) is terrific and crazy. I love it (page 27)		x		65
Fladeboe et al. (2021)	Shifting relationships	We like talk and stuff, but it's not—we're not as close as we used to be before I like left for a while'' (page 557)	x			66
	Bringing us closer	Yeah, it did [change], but not in a bad way, you know what I mean? Like, it changed to a good way, cause we, like, care more about each other (page 558)	x			67
	Finding my real friends	It definitely shows you who your true friends really are. And who you know is willing to make that extra step to 'I wanna come see you, when can I come see you'. And there's the friends where it's like, 'Oh man, sorry, that sucks, hope you get better'. Which is, it's nice, but the people that make the extra effort to come down here and see me are the people that really stick out and are the people I can really tell care about me and my health (page 558)	x			68
	staying connected	Like, trying to keep up with communication really helps with staying closer with people (page 558)	x			69
	Connecting with technology	Definitely videogames. Like even in the hospital, we brought a Play Station from home, and I was able to stay connected every day (page 558)	x			70

Supplementary Table 4. Qualitative Findings

	Staying updated	‘‘They try to keep me updated on how school is going. Like, you know, and all the drama (page 558) Not generally, it [cancer] doesn’t come up that much, unless I’m like going to the hospital for a bunch of reasons (page 558)	x			71
	Being far away	I would say just not being at school and being so far away is definitely the hardest part. And so, for the people that I used to go to school with every single day and now I don’t go to school with. I miss my friends (page 559)	x			72
	Being restricted	Um, mostly just having everything have to be within my own time frame. Like after chemo, there would be days where I wouldn’t be able to go and see more than two people. so I wouldn’t be able to go to a party or like, go to a group and hang out. Yeah, not being able to be on their time. made it hard (page 559)	x			73
	Making them uncomfortable	Some people are really uncomfortable talking to me. I think just me having cancer, in general, makes things uncomfortable for them, which I can kind of understand. But it’s like, when I try to interact with them, they have a hard time interacting with me. And I would say that’s the majority. (page 559)	x			74
	Being there for me	And so, he came down. He drove all the way and showed up, and he was there for like eight hours with me while I was in the ICU. and especially in that moment when I was in this state of, ‘I’m in the ICU, I’m having like three surgeries in a row, I’m diagnosed with cancer, how can it get worse?’ And he just being there kind of lifted a little bit of the weight off (page 560)	x			75
	Checking in on me	If we’re like talking more, like, if we’re messaging more that would probably make me think they’re actually thinking about me here rather than never saying anything (page 560)	x			76
	Giving me gifts	Receiving the gift baskets from them, that kind of helped me know that they’re still thinking about me and they hadn’t, like, forgotten about me or anything (page 560)	x			77
Gibbs et al. 2022	The importance of preparation and play programs.	The children valued having specialist equipment and toys that they were able to relate to, such as Dino the Dinosaur and Ellie the Elephant (page 259)		x		78
	Positive reinforcement and hospital support	At the retinoblastoma treatment center, the children and families were offered an opportunity to attend Eye Club, which is a hospital support program focusing on patient-led teaching of the removal and insertion of the artificial eye and provides a support group for siblings and parents. (page 259)		x		79

	Support and openness at home	it is mainly my Mum and Dad who are there and who help me (page 260)	x			80
	The importance of good school support	The children talked about challenges that they directly faced at school such as concerns regarding their eye falling out, when to clean it, who to go to if something happened with their prosthesis, and discussions within their peer group (page 260)		x		81
	Increasing independence	The focus on developing independence in the school setting was particularly relevant for older children (page 260)		x		82
	Developing resilience strategies	Some of these were practical in relation to adapting to the loss of their visual field and/or depth perception and the implications this may have on choice of activity engagement.		x		83
	Changes to self-image and peer interactions.	The triggers for these moments varied but could be associated with life transitions such as a new activity being incorporated into the child's life, or in relation to developing self-awareness and relationships such as a peer at school making a comment about the prosthesis. (page 260)		x		84
Gibson et al. (2016)	Treatment and un-relenting side-effects	I'm so tired and I don't know why…this is not a normal tired, it's something to do with the treatment [radiotherapy]. It feels like chemo-tired but on a lesser scale. It's not as bad…nowhere near as bad as chemo tiredness, which is interesting…not nice…no energy' (page 1319) 'Celebrate your baldness, make it your fashion statement… I wanted to take control and didn't want to find hair on my pillow, and I wanted to say OK cancer you can't control me' (page 1319)	x			85
	Rehabilitation and getting on with life	especially when you are a teenager… you don't want your parents there all the time and you do need friends to be normal with (page 1320) I feel the cancer has taken control of my life, no longer feel I can do things for myself, like go down in the morning to make myself a cup of tea without having someone to help me (page 1320)	x			86
	Relapse and facing more treatment	Uncertainty shadowed remission for some young people. For those who relapsed, some expressed anger as they felt they had kept their side of the deal and were back at square one, their body having let them down.		x		87
	Coming to terms with dying	For patients with a terminal diagnosis nearing the last few weeks of life, an attempt to retain a sense of normality often featured— this included everyday things (school and examinations) and goals (holiday planning) but as a mechanism to come to terms with their imminent death.		x		88
Gomez-Gamboa et al. 2022	It's normal to feel afraid when being treated in hospital	I've always been someone who is really afraid of hospitals. (page 4) The other boy, he seems calm, but suddenly you hear him crying. You feel sad for him, but then you say to yourself: Well, it's normal. It's only normal in a hospital (page 4)	x			89

		He was crying and saying Mum, I don't want to go there (page 4) You lose a sense of connection to the outside world: fresh air, the warmth of the sun, going for a walk …. (page 4) Well, I miss my Dad and my little brother. I miss my little dog. I've got a little dog and I taught him to play. It makes me really sad (page 4)				
	Needle procedures are associated with pain, illness, and dying	When I was ill here, and they had to put a catheter in, I hated it because they just couldn't find a vein. I remember once they tried six times and it wouldn't go in. It usually hurts a lot. The catheter is usually only good for three or four days because the vein tends to swell up and they have to change it (page 4) Yes, but when they put a tube in I cry because it usually hurts a lot. (page 5) With the EMLA® you don't notice any pain with the port-a-cath (page 5) think it's 100% psychological. That's the bad thing, that it's psychological (page 5)	x			90
	Difficulty of expressing the suffering that is experienced in hospital	She doesn't have a problem. It doesn't hurt and she'll say: 'Why are the children screaming? What's wrong?' She never complains that it hurts. My daughter isn't anxious (page 5) It'd be nice if the nurses didn't just talk to each other but also asked me things. (page 5) Being in a hospital where they tell you the truth, that's really important for how you feel. Not being in a hospital where they don't tell you anything …. For example, if it's going to hurt, then you want them to tell you. But they tell you it won't and then it does really hurt. (page 5)	x			91
Gurcan & Turan 2021	Healing care behaviours	I want healthcare professionals to treat me as though I am a healthy person. I don't like to feel like only a patient. If health professionals want to heal children, they have to love children and be tolerant of them, then they should be nurses and doctors [looking angry]. Because I need love, compassion, and a smiling face. (page 3475) Most nurses approach me in a polite and friendly way [smiling]. Nurses should be friendly not only to me but also to my family. They should never argue with my mother [shaking head]. (page 3477)	x			92
	Honesty and a trusting care relationship	If healthcare professionals want me to accept all treatments, they should tell me what they tell my parents. I want to know everything about my illness, even if it is negative. Maybe I will be upset, but when I think that something is being hidden from me, I feel terrible [raising hands (page 4377) Healthcare staff should explain and inform the children more. They talk in detail with the parents but less with the children. I want the nurses to give me information about the procedure. Instead of saying It won't hurt at all, I wish nurses would say It'll hurt a little before they try not to hurt as much as they can. If I know the facts, I will be better prepared [shrugging shoulders]. During the procedure, maybe I will scream and cry less [looking sad]. (page 3477)	x			93

	Seeking problem-focused care	I want them to solve my problems quickly. I don't want to be delayed when I have pain or nausea. I think that there are personal differences among healthcare professionals. Some of them come immediately when I call; some come later [frowning]. There should be harmony within the health team (page 3477)	x			94
	Optimal practice skills of the nurse	I want the vascular access to be successful the first time. My vein is thin so it can be damaged during catheter insertion [looking at her arms and pointing at her veins]. The damaged vein cannot be used until it heals and it is sore a lot. I do not want to be exposed to a central venous catheter because of the high risk of infection. (page 3478)	x			95
	Hospital patient room and clinic design	Because this is a children's clinic, it would be better if the walls and curtains were more colourful [looking and pointing at curtain and walls]. Pictures of the rainbow and the sky would be nice to positively energize us [smiling]. Rooms should be designed according to the age of the patients. Young children should be placed in more colourful and decorated rooms; adolescents should be placed in simpler rooms (page 3478).	x			96
	Fun activities in hospital	There are no activities for me to have a fun time in the hospital. I need to engage in different fun activities in order to forget that I am in the hospital and not think about my illness [looking down for a while and remaining quiet]. There should be a separate room for individual activities and games in the hospital (page 3478)	x			97
	The environment for quality sleep	Healthcare staff should not speak loudly among themselves at night. They don't sleep, but we do [frowning]. I need a quiet environment for quality sleep at night. When I cannot sleep at night, I sleep during the day, which negatively affects my life (page 3478)	x			98
	Pleasure in nourishment	Since I do not like hospital meals, I cannot eat the food they offer. My parents always buy food from outside. Buying food from outside is very expensive [raising hands]. I wish delicious meals were made in the hospital because I have to be fed to be able to heal. (page 3478)	x			99
	The presence and love of family	Since my family is always with me, I don't feel alone in the hospital [smiling]. My family gets and buys what I want. Their approach to me is very loving and positive. I am very happy with my family. They try to protect me. I need their presence and help. (page 3478)	x			100
	Relations with peers	My friends at school send their videos to me. They send gifts [smiling]. They support me to continue studying. My friends make me feel worthy and like I have a simple and temporary illness. Instead of talking to my friends about my illness, I want to talk about other topics as if everything is normal (page 3479)	x			101
	Seeking support from society	Surprise gifts are distributed to children in this clinic. It makes me so happy [smiling]. In addition, some chemotherapy drugs are expensive. People in a good financial situation can support families here (page 3479)	x			102

		I feel lonely and isolated in the hospital. I need people outside to visit me. It makes me happy to see different people, not only for gifts but also smiling faces [looking sad]. (page 3479)				
Hildenbrand et al. 2011	Cancer treatment and side effects	It's kind of scary when I have to get my port needle in. . . . Even though it's numb, I still don't like it. (page 347) It's kind of hard to sleep because sometimes when I lay down and close my eyes I feel a little dizzy . . . it's hard and since I have an IV and I'm getting fluids, I have to go to the bathroom, so I feel like I have to wake up and start all over again, and I get a little dizzy and nauseous all over again. (page 347)	x			103
	Distressing emotional reactions	[Finding out I had cancer] was just really, really scary for me. . . . I kind of didn't know what was going to happen next. (page 347) [When I found out I had cancer] I wasn't sure if I was going to survive and I wasn't sure what was going to happen, and I was really afraid of my hair falling out. (page 348)	x			104
	Disruption in daily routines and activities	[The hard part of finding out I had cancer was] that I had to stay up here and I barely got to see my family. (page 348) I don't like to go to the hospital so much. . . . I [am] missing my school things . . . like art and music. (page 348)	x			105
	Approach coping strategies	I think . . . I'm going to get rid of it and it's going to go by and I'm young, so it's not like I am going to live with it for . . . the rest of my life. . I still have friends and they are still going to think that I am who I am. . . . Even though I don't have hair and I have cancer, [if] I just don't think of it as cancer and don't react to it that much, then my friends won't either. (page 349) [To help me deal with my cancer, I] eat healthier . . . . It gives me more energy. (page 349) [To cope with my cancer and cancer treatment, I] try and make as many people come visit me as I can. (page 349) [I] take a nap . . . play games and paint [to help myself feel better]. (page 349) I usually write in a journal [when I'm upset about my cancer or treatment]. (page 349)	x			106
	Avoidance coping strategies	[I] find a distraction like watching TV . . . going to sleep . . . or listening to my mother read to me [to make my cancer easier to deal with]. (page 349)	x			107
Jibb et al. 2022	Family social health advantages	I can go out and hang out with my friends which makes me seem a lot more normal. Not like, 'Oh, there's something wrong with me.' I just come in occasionally for treatments (page 5)	x			108
	Child health	Oh, and my home teacher, because I have a home instruction teacher. So she's able to come at home and that's a lot better than having to come to the hospital (page 7)	x			109

	Family social health	Getting cancer care at home is easier for like if I have a friend over…I wouldn't want to have a friend over at the hospital whereas at home it's a lot better (page 7)	x			110
	Informational	Yeah, it was a bit difficult at the beginning because the homecare nurses are used to dealing with adults and so they had to get used to like dealing with kids (page 7) So [the hospital and homecare agencies] just need to communicate a bit more. Like sometimes [the homecare nurses] would come over and ask us what to do. I have no idea. I'd just say, 'You guys do your thing, you know (page 8)	x			111
MJibb et al. 2018	General impressions (phone app)	It's really appealing to the eye. The color, the theme is good. The font. And it's not really that hard to understand. The vocabulary is really straightforward and all of the things on it, like you know, the multiple-choice questions and the [visual analog scale] sliders are really easy to use. And for cons? Don't really think I can really think of any. (page 4)	x			112
	Usability	It was really easy. It was very straightforward. It wasn't really complicated. It was just like simplified so it was easy to use for little kids (page 4) I'm used to that stuff so it made it easy. (page 4) It was really straightforward. I think all the questions were worded well so you could like understand what they were getting at (page 4) It was good because it was really fast and easy (page 4)	x			113
	Pain self-management advice	I thought the pain help ideas were really awesome. When they suggested like different things that you could do? Those were really helpful. And they had some [pieces of pain management advice] where they would suggest like relaxation and breathing, and how do I do that. And then you click on it and there is someone talking to you, walking you through it. Like how to relax. So that's helpful because someone can tell you to relax, but you can just be sitting there like, I don't know how. (page 4) I think overall it was good. Probably one of my favorite parts of it was that you could do the 8 questions in the middle (short-form pain assessment). That helps a lot. (page 4) There was stuff you could try at home and like do yourself. So I liked that (page 4)	x			114
	Challenges	It was okay and too much. Because sometimes people don't want to like keep...um...doing the same thing over again...22 questions every time (page 4) Even if I did do my case (pain assessment), it would still just keep on giving notifications. And I know that after you say, yes to the case, (the app will) follow up (on the severity of pain one hour later). But even if I would do the follow-ups, it would just keep on giving more and more (notifications). (page 5)	x			115

		Sometimes it was hard for me to do it. Like 2 or 3 times I couldn’t (use the app), because like as soon as I clicked on the app, the screen would just go white. (page 5) I think it was a problem with my version [of the app] but I wasn’t getting any reminders (to complete pain assessments)...So I set up just a regular alarm on the clock the phone has itself (page 6)				
	Self-management support	Yeah because being like an out-patient, you’re not at the hospital all the time. And you don’t want to call the doctor every time you have something as simple as a stomach ache when you know you got tips from the app to help. (page 6) Yeah especially because it really helps me to track my pain and remember everything (page 6) Some of the questions were things that I didn’t really consider when I was thinking about my pain. So (Pain Squad+) helped with (recognizing how pain) affected me and all that (page 6) I think when I had a problem at home, like experiencing some kind of pain, after inputting it into the app and coming back to the hospital, talking to my doctor was easier (page 6)	x			
	Nurse interactions	I liked that when you answer questions if you go higher (in pain intensity rating), a nurse actually calls you and like asks about your pain. It’s actually a good thing because like if you actually have pain and you don’t know what to do, she can help you. (page 6) The part where you get the advice from the nurse was good but then sometimes I would just miss her if I was out or my phone was on silent. So, it might be better if she left you a (text) message so that you could check what she was telling you to do (page 6)				116
	Impact on daily activities	Oh, it was good, it was good. It didn’t really take that much time and effort (page 6)	x			117
	Recommended usage	Yeah, I didn’t really have pain all of the time. So, I think [the number of notifications] just wasn’t for me, but I’m sure for someone who’s going through the pain it’s going to be really helpful (page 6) Like it got a little tiring sometimes. Because especially there are days I didn’t feel any problems, like have any problems, and I felt less inclined to actually finish the surveys (page 6)	x			118
	Recommendations for improvement	I think if there were more ways to help you manage your pain added on, then it would be more helpful (page 6) Um, maybe like something a little more than just like how you level up (by completing pain assessments and management advice). Just...more to do with that. A little more interactive kind of thing...like even more, fun (page 6) Umm, I think probably like uh a few videos from actual professionals, healthcare professionals, like doctors. Or like maybe like, err therapists, like massage therapists. If there was like maybe,	x			119

		for example like a massage therapist showing someone how to relieve pain in a certain area. (page 6)				
	General impressions and specific likes	And I don't know, I really liked...I just liked the app. I liked being able to record my pain, like without just writing it down in like a journal or something you know? I really liked how they gave me suggestions for like what I could do. I just liked it all, overall. (page 7) I liked the questionnaires at the beginning and the end. Just to like compare sort of how you're doing before and after (page 7)	x			120
	Motivation for participation	I just liked, you know, contributing to the development of this app. It will be a huge help to other little kids going through cancer. (page 7) Yeah, but it was pretty cool. It made you sort of want to do it more. Okay, I've got to do this because I want to get the next level. (page 7)	x			121
	Challenge	Half the time, I wouldn't even hear it because it would be in a different room or something and I just totally forget about it. If (Pain Squad+) was on my actual cell phone I probably would have done it more. But it wasn't on my actual phone that I have on me all the time. (page 7)	x			122
Jones et al. 2011	Finding meaning	I had time to think about everything that I was doing because I had to be alone a lot, and I got a lot of time for introspection, and then I realized that I probably wasn't doing things the right way, so I just changed. (page 1035) One of my old friends died, so it kind of makes me wonder why God took her life and not mine. (page 1035)	x			123
	Appreciation	It's made me appreciate things I guess others take for granted, like family and friends. (page 1035) It's taught me to appreciate life more. (page 1035)	x			124
	Personal growth	It's given me a drive for what I want to do. Now, I want to do something with my life and become more successful. Before I had cancer, I never thought that could do that, because it takes a lot of hard work and stuff, but now I'm taking advanced classes and trying to get an education. (page 1035) My career goals have changed. Now, I want to go to art school and be a designer. I also want to keep people informed about cancer. I want to inform them through my photography. I want to show children going through chemo [chemotherapy] as happy like I have seen them. (page 1035) Having cancer changed me for the better, because when, before I got diagnosed I was kind of a brat and complained a lot, and didn't really know how to be a good person. And then afterward I realized that the stuff that I was doing wasn't right, and I changed. I also became friendlier. I had a hot temper before, but now I'm just like cool with everything. I'm just glad to be alive, basically. (page 1035)	x			125

	Cancer identity	can’t play in sports. I can’t be out in the heat too long or I’ll have a heat stroke, so cancer kind of put a damper on my life. Because when I was younger I liked to play sports. I liked to be a part of everything. I can’t really be out in the heat anymore, or I will get really overheated and have to go the hospital. (page 1036) Due to some of the meds [medications], my running initially was impeded because of the neurological side effects like in my foot. I can’t bend my foot all the way up, so it is hard to run or do something like that. (page 1036) actually took growth hormones for two years. I was like, maybe 4’9 or so, and now I’m 5’2, because I took those shots, and then you know they just started wearing off. I could have been maybe 5’4 with the shots. If I’d never even gotten sick again, I would have been like 5’8 actually, which is a lot better. (page 1036) think my chemo messed up some stuff. I have trouble in math, and I didn’t use to before the chemo, and they said that it might be a side effect. Also, it’s pretty hard for me to concentrate in class sometimes because I just can’t wrap my mind around it (page 1036) worry all the time about getting sick again. That feeling is always going to be there; it will never go away (page 1036)	x			126
	Survivor identity	have started taking cooking classes that are really fun. Also, I have recently started this whole art thing, ’cause I want to go to art school and stuff (page 1036) have started going to [the park] on the weekends to play Frisbee and football and stuff. I have branched out, and become sportier, I guess. (page 1036) joined lacrosse and I’ve been playing that for three years now, and it’s helped me meet a lot of new people (page 1037) I don’t feel uncomfortable telling people that I had cancer, but I noticed that they kind of feel uncomfortable hearing it sometimes. So the hardest thing for me is when I meet someone new, trying to bring it up and say, Oh yeah, I had cancer. It’s like you always get so many different reactions, but most of them are, Oh, I don’t know if I want to talk about this with you. I have met people and brought it up right away, and they don’t really want to talk to me anymore. (page 1037)	x			127
	Isolation	I don’t talk to anyone. I go in my room and I watch TV, and I just stay there (page 1037) Well, I’m in the process of getting counseling. But I don’t really feel comfortable talking freely about myself because I don’t really get—like myself, so I’m not sure if I’m going to get it, because I’m just not comfortable talking to people anymore (page 1037) gave up on fitting in. That was part of the whole cancer thing, was I gave up on caring about people—like what they think about me, at least (page 1037)	x			128

	The importance of family, friends, and the health care team	I got really close with my mom through that whole ordeal, and she quit her job to help me. And it was, I'd say really like a blessing, 'cause if I didn't have anyone, I don't know if I could have survived it. (page 1037) My mom was there for me and my brother. My mom was there to comfort me, and she was always there for me in the hospital, and my brother, he was a lot like my best friend, too. We played and stuff. (page 1037) They always made sure that I had someone to talk to if I had any problems, and when it got really hard, they were always just there for me. They didn't have to say anything. I just knew that they were there, and I could talk to them whenever I wanted. (page 1037) The nurses did help a lot. We made friends because we'd see them a lot. And we got really close. They were just really warm and friendly, and they'd always make sure that I was comfortable, even if they were drawing blood. I liked the doctors, too. They kind of connected with me on a personal level, and I thought that was really cool (page 1038)	x			129
	Lack of support as a survivor	I have no one to go with me. All my friends are either—they don't want to go out and actually have people see them exercising. I just want to go walk around the block a couple times, if you'll even do that. (page 1038) used to see them and talk to the nurses and doctors all the time. Now I rarely hear from them. Some I have not talked to since my treatment (page 1038)	x			130
Kelly et al. (2016)	Having a say, as I need at this time	'Having a Say' depicts child and adolescent illness and treatment communication preferences. (page 3)			x	
	What influences how much say I want to have	mean, if you're very sick or in a lot of pain, I don't really think – like, I didn't really think about who was going to make the decision or not. I would just want to get better (page 3) When asked about how much of a say they wanted, children responded it depends, underscoring the dynamic nature of their preference (page 3)	x			131
	Doing what is best for me	usually leave my decisions up to my mom and my doctors because I know they know best (page 3) …mom and dad know me pretty well and they know the stuff that I like a lot. If they're told that I'm not going to be able to do something that I really like, they know that I don't need to know that straight away because that's going to make me really sad and make this whole experience even harder (page 3)	x			132
	Getting what I need to know	…in the beginning, I didn't want a lot of information because I was confused (page 5) You want information but not a lot of information so you don't get scared or upset (page 5) …if I don't want this stuff [information and involvement in discussions and decisions], then I'll basically turn into a guinea pig. I won't be asked about my opinions. I want to be asked about	x			133

		what I think about the treatments. I want to have a say in my discussions… I still don't want a lot of information about my cancer and treatment. But at this point, I want to have a say and I want information and I want and I need all of this information to help me get better. Because even though I don't want to, I need to. (page 5)				
	Knowing when I can't or don't want to have a say (and when I can and want to have a say).	Because I'd have more say in it, but I don't really want that much say in it. I just want them to do whatever they think is right (page 5) Well, I know I don't like making big decisions, but I still like having a bit of a say in the matter (page 5) Like, if you're going through a lot of pain, like, how I got here, you wouldn't really be thinking about any of this (page 5) just want the doctors to help them get better and to help them get out of there (page 5)	x			134
	Thinking there is no decision to make	In the beginning, it was just what needed to be done (page 5)	x			135
	Have less say	Yes, because I really hated chemo and I really wanted to get over with it as fast as possible, but that would probably - looking at it now - not be the right decision if I were to completely choose… That was from my perspective when I was just really sick…. But looking at it now, yes, I would much rather have them make the decision because they'd be at the point of view that I'm at now. (page 5) because they're going to give me a treatment that they know is going to work best for my body so there's no point in me telling them what treatment I want to get (page 5)	x			136
	Have more say	talked to my parents a lot while we were waiting … I think we all just agreed that the chemo was better (page 6) Well, during getting chemo, Imake a lot of decisions that I like having pills instead of…With my port access, I like them all setting it up beforehand and being able to just get it over … Then when I get my blood drawn, I like it taken from the same spot every time…(page 6)	x			137
	How having a say affects me	feel like my parents and the doctor know a lot more than I do about all of this (page 6) the doctors might do something wrong because no one is telling me what is going on (page 6)	x			138
Lombardo et al 2011	Impact of the disease on their life	[...] I stopped practicing a few things, handball [...]. Doing boxing, I stopped dancing [...](page 534) Soon after I discovered (the disease), I started to do everything, so the hospital became part of my life [...]. I went every day (Page 353) [...] at first I thought I was going to die [...] (page 353)	x			139

		I was afraid to leave the house [...], more afraid of catching something else, of becoming sick. Then I stayed locked inside the house (page 353) It started as a pain like a stiff neck and more lumps in the neck were appearing, then these lumps got smaller and disappeared, then I had a puncture done, this showed nothing, and next biopsy was carried out, I was hospitalized, and then biopsied and then came the result that it was Hodgkin's Lymphoma (page 353)				
	The discomfort of the treatment	In the first chemo, I thought I would die, I was debilitated from the surgery [...], I lost weight 15 Kg so I was really weak, I felt very sick in the first. (page 353) I started chemotherapy, it was difficult, I would feel really bad, it hurt my body a lot, my back (page 353) After two weeks, my hair began to fall out, then my father had to shave it anyway. In the beginning, I used a bonnet, but now I don't use it anymore, I don't care anymore (page 353) [...] the hair was the most difficult situation, not so much from vanity, but what people would think [...] (page 353) [...] I feel it is difficult (the treatment) because I'm bedridden, but now I have improved because I have gotten used to the medication and I'm going to be well (page 353)	x			140
	Coping strategies	At school, it was cool too because at the end of the year, when I started treatment, everyone in my class sent a letter, saying that I was not to give up and such, I thought it was very cool (page 356) Here everyone is great, the doctor, the nurse, whenever we need them, they are here (page 356) Here in chemo, I have no complaints; the people here put themselves in our place and end up seeing our needs and treating us well (page 356) [...] it was God who gave me great strength [...] that's why I was so calm. He helped me. (page 356)	x			141
	Projection into the future without the disease	Now I go to school, I have fun and play a lot at break time and lead a normal life (Page 356) Now I have gone back to do karate, to get the black belt. And in school, I'm in the 1st year of high school. I think about college, everything, I want to study medicine (page 356) [...] I do not care, no, I do not need to know what the others think, what I think is what is important [...]. So the treatment is difficult at first, but you have to think it is for you to get better, to heal. (page 356)	x			142
Lopez et al. (2014)	It's not a transition, let's get back to normal	Adolescents described this shift to early survivorship in a variety of ways, including: ''closing a chapter and moving on,'' ''moving on to the next stage,'' ''stepping back into the story or page of a book,'' and ''continuation of the journey.'' (page 135)	x			143

		It wasn't transition because it was kind of like the same thing I had been doing before and so I didn't feel like I had to transition back into my life. I feel like that would be weird. And so. it was just kind of like stepping back into, the story for a little bit, like stepping back into like the page of a book or something (page 135)				
	My approach to life after treatment	I think um it was probably the majority of just taking it as it comes really. I think that describes me better. I mean I thought about it a little bit. But I mean I don't know it wasn't on my mind too much. I thought a lot about the day that I would get out. I thought about that day and that was always sort of I'd focus on that. But I mean I had never really thought too far past that and stuff. So I mean it was just a lot of you know taking it as it comes and stuff like that. (page 135)	x			144
	Signs that I'm making my way back to normal	I was so excited. I was like, ''Yes, I can finally like walk down to my friend's house and like see her.'' Like 'cause I used to like live there and I then like I had, like every day after school we'd like go over there and do homework together. And so it was nice to be able to go back to them. Like we studied for finals together and things like that like we used to. And so it was I don't know it was like a big sigh of relief I guess. (page 135)	x			145
	Feeling more comfortable with time	Now I think now it has been a year I'm more able to have that time in between to realize this still happens in real life, people still get tired, that doesn't mean that something is going wrong and things like that. (page 135)	x			146
	Signs that life is not back to normal just yet	I know I still missed a lot because although I was finished um like the treatments and stuff I still had to go for like PET scans and CT scans and all like the other tests after that and I was still like tired and stuff. So I still missed a lot of days like I never really got into a routine of going back to school like every single day for like a week straight (page 135)	x			147
	It is not the focus of life, but the idea of relapse is there	It's always. I wouldn't say it's a big worry or anything but sometimes thinking of what your symptoms were beforehand and if you start you know if you're just tired even though you know it's for a different reason you start thinking about that or something (page 135)	x			148
	My need for support and/or services	I didn't want to hear those. um, I guess I don't want to know like that I'm more likely to get this kind of cancer, I'm more likely to get that. I'd rather just live happily now and not have to think about like those things they would say. I guess that's why. yeah, they would just probably cause me to worry. Yeah, but I never wanted to hear like any side effects or any of that kind of stuff. (page 135)	x			149
	What my healthcare team told me	There were a couple doctors, and I think this is part of being a doctor for some people is they try to sugar coat things a little too much. And he [the doctor] I mean I remember talking to him and he gave it to me straight really and he said listen, ''Yeah this could happen,'' um he said, ''We don't I mean doctors in general we don't like to give a number um because it's just a number. I mean we could say one in a million and you could be that one. So the number really doesn't do a whole lot. It is just a number and doesn't mean anything.'' And he was honest he said, ''I mean	x			150

		yeah there's a chance this comes back, we've seen it before, um but on the flip side there's also a chance that it doesn't. That is the better chance right now.'' (page 135)				
Macartney et al. (2014)	Feeling tired	Well, like in gym, I can't do all the stuff that the other kids can do [because] I get tired more quickly. (page 393)	x			151
	Pain and headaches	The shunt, it hurts sometimes. It causes pain and, also, when you do a lot of effort, it can cause a headache. Like, if you're lifting something heavy, pushing a lot, or whatever, it starts to hurt. (page 393)	x			152
	Emotional problems	When you go through [treatment] like that, well, it makes you down, I guess, a little bit. I was also angry because of my right arm. (page 393) do worry when I come to the doctors. I think because I got so many needles, I was scared that the visits may be about needles, and I have to get one or something. I worry about not being on time, to something like school. And . . . I worry about . . . I think about . . . what if someone is mean to me at school today or something like that? (page 393)	x			153
	Hard to think or remember	I will tell my educational assistant that I have to go to the bathroom and we will be walking to the bathroom, and I will walk right into another classroom. She will be like, Where are you going? You said you had to go to the bathroom. Oops. (page 393)	x			154
	Sleep problems	Six children described difficulties falling asleep, waking up in the middle of the night, and having trouble falling back to sleep or simply not getting enough sleep.		x		155
	Physical problems	My right hand and my right leg . . . I can't pick things up like most people can. I can sometimes, but it takes me more time. I can't do the same things with other kids. I can't do sports like other kids. (page 393) I have had no vision in my left eye since I was I think, around 3 or 4 and, um, I got my cataract removed. . . . I gained back some vision, but not all (page 393)	x			156
	Weight changes	gained weight after surgery. They want me to lose weight; my mother does too. I eat a normal diet. My mom wants me to be active, which I am. (page 393)	x			157
	Doing physical activity	Um, my vision loss affects me for driving purposes. Because when I started driving with my G1 [learner permit], I steered more towards the right side because that is the side that I can see out of. . . In sports, I play baseball, I am a right-hand batter, and it affects me because I have to turn my whole head and not just like the side of my head or face like most people do. And then, for rugby, you can't see through mulls of people. (page 394)	x			158
	Keeping up at school	I was not able to go to school because I had so little energy. . . . I only started off with going half days because I would get so tired, and now we have worked up to full days. (page 394)	x			159

Supplementary Table 4. Qualitative Findings

	My appearance	They always say I'm a fatso, but now that has stopped because that was back in grade one and last year in grade two. . . . When I would touch them, they would have to touch somebody else or, if they don't, they get my cooties unless they have their fingers crossed (page 394)	x			160
	Hearing and speaking	I also developed aphasia, so I have difficulty reading and speaking. . . . Well, I don't think I talk as much as I used to. I'm more reserved. I have difficulty starting conversations . . . I have difficulty explaining things precisely. My parents keep telling me, You're not explaining it properly; you are just saying what you see in your head. I don't understand what they're trying to tell me (page 394)	x			161
	Get my conditioning back	I am trying to work up, I try to exercise more often and do sports. I'm trying different kinds of sports and outdoor stuff, so my energy is coming; it is better than it was before, a lot better, but [low energy] is still there. I am trying to get it back. . . . I'm trying to get my conditioning back. (page 394) Well, I would like to start hockey again next year. . . . I'm not sure if I am going to do a sport in the summer or not. Probably just road hockey with my friends and get more exercise because I haven't done much. (page 394)	x			162
	Take breaks	When I am walking, like around a store for a long time, I have to sit down because I get tired. (page 394)	x			163
	Take medications	Once a month or so [I get headaches]. I got one this morning because I was reading in the car. If it is at night . . . they will just go away as soon as I lie down, but they just last for a couple of hours. I usually take [ibuprofen]. (page 395)	x			164
	Challenge myself	I try to test out and challenge my vision in the left eye, as it is changing. And I, like, cover my right eye, so I don't always favor it. I just kind of do it off and on to see what I can see out of my bad eye. (page 395)	x			165
	Volunteer	And I did a brain tumor walk last year and my goal was 50 bucks. That is not very much. And, then, I ended up raising $583. . . . This year, I already got $200 in one week and a corporate sponsorship. So, really, it just keeps me going knowing that things are going to get better, not worse. And people are supporting you. (page 395)	x			166
	Keep up friendships	My family, they've been so supportive. That really helped me. I always knew there was always somebody there to help me. (page 395)	x			167
	Laugh	No one sees my shunt. I do not mind if people see it. They did not even know it is there. I like it because I gave it a name. I called it Bumpy. So, I had some fun with it. (page 395)	x			168

Supplementary Table 4. Qualitative Findings

		One girl mentioned the importance of her dad making jokes all the time to help her remain positive. Another girl made a joke about herself saying her blonde hair explained her forgetfulness (page 395)				
	Use aids	Sometimes I just forget to bring things like I will just forget to do something. . . . I write it down somewhere noticeable and I keep a calendar. My mom helps me to remember things as well. . . . I use my walker at school.	x			169
	Well-Being	have a good life. I am happy (page 395) Um, before, I guess, before my brain tumor started growing and stuff, I was, like, a little superstar athlete. . . . I was . . . doing quite well. I was, like, in U9, which was, like, the best hockey for initiation, and I was . . . scoring, and I was, like, really fit. Like, [I was] extremely fit. Now . . . [points to himself] . . . my chubbiness does affect my quality of life. . . . It's more or less, like, well, You were a really fit kid, and then you got a brain tumor, which made you chubby. So it's . . . yeah, I used to be like a superstar in like gym and . . . make all the teams. And, now, I'm not making much teams [laughs]. . . I think I have a good quality of life, although I won the bad luck lottery a couple of times. . . . I just think that everything is going to get better, and it has (page 395)	x			170
Mant et al. 2019	initially, I felt shocked and scared	was a bit like errrr because it was serious . . . I was making gulping noises because it was serious . . . I was nervous it was serious (page 8)	x			171
	Feeling shocked	was a bit shocked really when I first heard about it. I was shocked more than upset (page 8) I was in shock for quite a while . . . I felt numb (page 8) I couldn't take it all in . . . I just blocked out completely because I didn't want to hear it anymore (page 8)	x			172
	Feeling scared	was really scared about how I was going to feel. I was scared about what my treatment may do (page 8) What was going to happen and was treatment going to work? (page 8) was thinking will I be alright? . . . Will I die? (page 8) Happy that I knew what it was. No worry. No scared feelings. Mostly happiness. Really relieved hospitals look after you. Care for and look after me (page 8)	x			173
	chemo is an awful thing	They need to know about chemo - I am going to write this in big writing - not to make them scared - but because it makes you sick and it is an important part (page 8) Me stuck with my worst enemy (page 8)	x			174

Supplementary Table 4. Qualitative Findings

		It stops me. It is always slowing me down. I can't go to the park . . . There are so many things I'm not allowed . . . There is so much I can't do (page 8) It is important to know that you have to take medicines and that these are going to make you feel really poorly at times and sick (page 8)				
	Please talk to me – the more I know the better I feel	was not sure what was going to happen . . . I was scared about what was going to happen . . . it was just not knowing things (page 9) They (the nurses) are really kind and helpful . . . you can ask them anything (page 9) I knew what was going to happen so that was reassuring. The doctor was really good at telling me everything so I felt ok (page 9) It would have been better to know about it (Hickman line) sooner (page 9) '(I would be) doomed if I ask anymore . . . I wouldn't be allowed to know . . . no idea why theywon't let me know (page 9)	x			175
	I accepted treatment and quickly got used to it because I know I will get better	I got used to treatment very quickly (page 9) had to deal with things . . . I have to accept the treatment because I would not be able to make it without it (page 9) When you start it (chemotherapy) is not nice but when you get used to it it's not so bad. It happens very quickly - getting used to it. (page 9)	x			176
	I know I will be cured	It is leukaemia. That is what we call it. But you can treat this now (page 9) It's curable. Soon I will be having a body like everyone else (page 9) felt like it is good that it is going to get better and they can do something about it. I was glad he (the consultant) said that it made me feel safer (page 9)	x			177
	I need my family to be present	It really helped having my mum, my dad, and my mum's best friend with me . . . my mum was there to reassure me (page 9)	x			178
	I need my family to help with communication	At the end, they (the medical staff) would always ask me do you have any questions, and often I hadn't really been listening and taking it all in, so I would say no, and then Mum would tell me something later (page 9) asked Mum lots of questions. Sometimes I don't like to ask questions to staff. (I) usually just ask mum afterwards (page 9)	x			179
	I worry about my family's emotions	knew that it's bad 'cos of her (mother's) reactions and the way she is (page 9) was also thinking about my family and how they were going to manage . . . I thought it would be hard on them as well (page 9)	x			180

Mellblom et al. 2017	Associations between emotional concerns and late effects	I’m struggling with not having any energy (page 6) think that I soon… You have to hit the bottom before it can get better (page 6) I’m wondering, how long am I going to have this pain? (page 6) Do I grow, is my height normal? (page 6) I don’t understand anything in school (cries) (page 6)	x				181
Mirlashari et al. 2021	Exposed to an unknown and enormous threat (COVID-19)	have gotten used to cancer, I mean I know about it. However, corona is strange and unknown to me. So I am afraid of it more, and I am worried about getting the coronavirus. (page 27) I am afraid of the corona. I am afraid of getting infected because everyone who gets it will die. (page 27) The immune system of my child is weakened because of cancer. My child is at an increased risk of COVID-19. (page 27) At the beginning of the outbreak, we had trouble getting masks, gloves, and disinfectants because of the shortages and high costs. Because of the cancer treatment, my child needs these. (page 27)	x				182
	Developing strategies to address corona phobia.	I was constantly following the coronavirus news to get more information. (page 27) I was washing my hands constantly until my skin became dry. Whenever I touched anything, I washed my hands immediately because I was afraid of getting infected. (page 27) We were terrified and anxious, but when we all stayed at home, the chance of getting the infection was reduced, and our anxiety was minimized (page 27) Even talking about corona is scary. I do not talk about it, and I do not listen to the news to make myself less worried. (page 27) We try to follow hygiene principles and teach our children how and when to use a mask or wash their hands. (page 27) In coordination with the doctor, we made the treatment program more compact and changed it to outpatient treatment. (page 27) It is stressful for me that children with cancer are at increased risk of Coronavirus infection. However, when praying to God, I feel calm. (page 27)	x				183
	Left alone at emotional distances	has been about two months since my father avoided close contact with me so that I do not get corona. We cannot communicate with our relatives. Corona has created a gap between our loved ones and us and reduced affections (page 27) My daughter is very dependent on her father. She misses him so much. (page 27)	x				184

		Since nurses and doctors are using masks and shields, the children and their mothers are not able to identify them. Wearing masks along with social distancing in the unit has led to severe communication problems and intensifies the feeling of loneliness and emotional distancing among the children and their families (page 27)				
	Sacrificing children and family's needs due to concentration on COVID-19 prevention.	To be allowed to enter the ward, the mother and child must take a Corona test, which is expensive (page 28) As before, there was no disinfectant in all rooms and inside the ward. If necessary, we should have asked the nurses to deliver us some disinfectant. (page 28)	x			185
	Confusion about issuing and implementing instructions.	Some people do not respect public health instructions in the community or the hospital. Some people do not fully follow the principles of personal hygiene and health advice. Some doctors were using full personal protective equipment at the hospital, but some others only wore masks (page 28) Mothers and children were not allowed to enter the cancer ward with their shoes and were required to use special slippers provided by the hospital. This is for our children's health, but why do they not observe this rule themselves and enter the wards with high heels? They are making it hard on us so that we do not carry corona to the ward. We do not even have the right to choose the right slippers for ourselves and our children, and we have to wear whatever they give us (page 28)	x			186
	Children and family expectations from medical staff and health system in the context of the COVID-19 pandemic.	These disinfectants are vital during the COVID-19 pandemic. When the pandemic is over, they no longer have value for us. We need these substances, and they should provide sufficient disinfectant for us. We are faced with different stresses. We do not want the medical staff to upset us and make the situation worse by creating such tensions (page 28) Nurses are more nervous than before and stay away from us. They do not spend enough time to answer our questions, and they just lead us to our rooms and tell us not to leave the room (page 28)	x			187
Miralles et al. 2016	Educational needs	During that time I did not go to class, I had help in the hospital and did not do bad. There were few hours, but I got on with it and then when I rejoined high school I did notice a change, because you feel it, you're at home, they go to your house when you want so you feel more comfortable. But, having to go to school at a certain time already forces you to catch the bus, you notice the difference (page 30)	x			188
	Leisure needs	You watch TV, which is all you can do (page 30)	x			189

		No, well. we also have Internet, that’s what we do the most, because then. there are board games, but the problems are that, or you play with your parents because the others are little children and nothing else you help in some activity, but, games for us, no (page 30)				
	Physical space of the rooms	Yes, I have had companions forever. Very bad, it’s a bit annoying (page 31) If you are alone you have enough privacy, but if you are with someone there are many things you have to restrain yourself a bit from doing (page 31) I’ve been with girls who were 8, 10, and even 3! There is a huge difference huge (page 31)	x			190
	Interaction with medical staff	The treatment provided by doctors is perfect, no doubt (page 31) Yes, everything you ask, they explain, they clarify (page 31) Yes, yes, the treatment is very good (page 31)	x			191
	Lack of specific care units for adolescents	Unfortunately, most hospitalized people are children (page 31) Because everyone else is a young child, nothing else (page 31) You’re surrounded by many children, there should be two sections, for the babies and for older kids, because, you know, there should be. be a ward in between, between young and old, and either they move you from a room with a baby or they put you with an 80-year-old man, and . that shouldn’t happen (page 31)	x			192
O’Callaghan et al. 2011	Music preferences, performances, dancing, and/or usages remain comparable or change with cancer diagnoses, treatments, and post treatment phases, possibly affected by music exposure in hospitals	It just stopped (clarinet playing)…because of the chemo it makes your fingers hard to play (page 784) From the songs that she’s learnt in the hospital, then she would…want to do it at home…. Old Macdonald, Twinkle Twinkle…and we would do all the actions and what I did was actually went out and bought the books and we did that at home so it was fabulous. (page 784)	x			193
	Liked music widely varied, and listening, playing instruments, karaoke, or emulating pop stars could distract, relax,	Sometimes when I’m really frustrated at the end of um lunchtime or playtime at school and the music gets on. I just dance to it and let the feelings go (page 784) It makes me feel good (playing drums)…and sweaty! (page 784)	x			194

	bring happiness, or frustrate (when cancer affected one's performance abilities).					
	Recorded music, music performing, and singing often, but not always, helps children sleep, experience symptom relief, and/or reduced distress associated with cancer experiences	We used to play the mouth organ to get her, to distract her to take her medicine…actually made her forget about me trying to stick a syringe in her mouth and she would drink her medicine. (page 784)	x			195
	Children are often musically engaged, at varying levels, with their families, people met in hospitals, and the wider world, including through the internet, sharing musical play, and concert going	The reason why I was into techno and all that was by a friend…and the reason why he's into some of my songs is by me…let's just say there's a song on Guitar Hero (electronic music game) like, What I've done, and then you just go on the internet, write it down, download it…. (page 784)	x			196
	The child's home life, social, and educational music background provides the foundation for music's help during cancer treatment and post-treatment, and hopes for their music futures, and normal musical development is	We used to put the headphones on my tummy when they were in there… she loved acca dacca! She used to jump around something shocking to ACDC…. We probably listen to music more now. Yeh, when she gets really stressed out or really worked up, when she can't sleep, or when she doesn't want to take her medications we probably use it as well. (page 784) play a bit of guitar that my next-door neighbor taught me a few years ago. Yeh, it's been good to enjoy a little bit of guitar and that…(but now) getting a bit tired…. I haven't played that much. (page 784)	x			197

	evident through their treatment					
	Music therapy, recorded music, music DVDs for radiation education, famous musicians, and/or concert opportunities often help children through aversive cancer experiences, and also extend the children's love of music	(Music therapist) recorded you playing the clarinet…there was a school performance and you were supposed to be playing the clarinet…you were neutropenic, but they actually played your CD at the school and they said all the class stood up and held hands on the stage… (page 784)	x			198
	Families and friends are helped by music therapy and radiotherapy DVD creation through discovering music's benefits and seeing children calm or happy	Mother (M) and Father (F) of 3-year-old girl F: We've bought a keyboard at home as a result of (music therapy)… M: When she stopped walking…and that was an encouragement for her to stand up and play the piano. Mother of 4-year-old boy If it wasn't for you guys…we would have gone nuts.		x		199
	Music therapy creates positive ambiance, which helps other patients and families	Doesn't take a brain surgeon really to chuck a few instruments into a room and let them have fun. (page 785)	x			200
Schwartz-Attias et al. 2021	The information that children and adolescents have about the disease, treatments, and side effects	I have acute leukemia, a blood cancer. A condition where T cells in the bone marrow remain young and divide quickly. They occupy the bone marrow and it keeps other cells from thriving (page 4) I know I have 17 treatments; then surgery and then 11 more treatments (page 4) About the treatments, I know it's chemo, that it destroys the healthy cells as well, and thatit has side effects: hair loss, nausea, loss of taste (page 4)	x			201
	Children and adolescents want to	When I arrived, they didn't explain to me about the disease. I wanted to know what was causing it (page 5)	x			202

	know more about the cause of illness and the treatments	I need to know what I'm going through. not just come to the hospital and get the treatment (page 5) [I'd like to know more about] the side effects [of] the medications. To know more about the treatment itself rather than the disease (page 5) I didn't know about Ifosphamide [Chemotherapy drug]. I had side effects, but I didn't know I would get so thin. I'd like to know that in advance. . . to know all the side effects (page 5) lack of knowledge concerning sexuality and intimate relationships given their illness, and their need for information and support: I would like to know what I am allowed, what I am not allowed to do (with my girlfriend) – I asked my mother and she didn't know. I would like to know more in terms of my relationship. What's allowed? It feels like I have no one to talk to about it. Although I would like to talk about it (page 5)				
	Some children and aolescents want to get any kind of information even if It Is intimidating, and some avoid It	How did the illness develop? How many cases are there worldwide (because it is rare) and what is the chance of recurrence? (page 5) There are kids that may be scared by it (the information) and kids for whom it is a relief. For me, it's a kind of relief. At first, I thought you could die of it, but my condition was not bad. You can take care of yourself and stay alive. [My] parents explained it and it was reassuring (page 5) I'm not interested in knowing more; I wouldn't want to know more; It's not urgent for me. I get along as it is; I don't have to [know]. For me, it's enough (page 5) On the other hand] it might be better not to know. Because sometimes when you know you're scared. And it can happen to you, just because of the thought about it. common side effects, but:: :. in spite of it, I prefer to know. I'd like to know more about what's going on (page 5)	x			203
	The opinions of children and adolescents about truth-telling	Why does the hair fall out? Why does the illness appear? And about the treatments and the pills. You need to say how long it will last; to tell children the truth from the beginning. (page 6) At first, they didn't tell me anything. I was told that this is a kind of flu. Then I was hospitalized. I saw different children. And I didn't understand what this had to do with the flu. I inquired about it in more depth – What flu? What type of the flu? I asked the other kids what they were sick with. They told me it was blood cancer. If I could turn time back I'd like you to tell me the truth (page 6) to know the truth, even if it is difficult to say; it is better [to hear it] directly than to seek the information from other sources. I searched the internet, Google. I don't think it's good to search on Google – most things are frustrating (page 6) only recently found out that there is such a form [informed consent] I would have felt more comfortable if they had shown it to me much earlier. I think every adolescent should insist on reading it (page 6) seek information from the doctors and nurses. I don't look for information on the internet because it's unreliable. It's better to ask people rather than a computer (page 6)	X			204

Sposito et al. 2014	Understanding the need for chemotherapy	It's to kill the cancer (page 146) Ah, it [chemotherapy] helps to kill the bacteria, right? (page 146) Understanding why I take chemo helps me not to complain about the treatment (page 146) Accept it because I know this treatment serves to kill the disease (page 146) Chemotherapy is needed to reduce the tumor. Despite the treatment being so bad, I keep taking chemo because I'm afraid of getting something much worse (page 146) The doctors talk to me, but when I don't understand, my mother explains it (page 146) The doctor explains each procedure that I have to undergo, everything that I have to go through. I prefer knowing what's going to happen so that I can prepare myself (page 146)	X				205
	Finding relief for the chemotherapy's side effects and pain	Ah, vomiting it's the worst side effect of the treatment. . . . My stomach starts to get upset, then my mouth waters, and then I know when I'm gonna throw up (page 146) Before, when I used to go with a cap [to school], it was kind of difficult because people are very prejudiced. Now that I've put on the wig it's nice! They say that it's pretty, that it matches my skin tone (page 146) Researcher: [W]hen you're in pain, what helps you to get through it? Participant: [I pray] 'Our Father' to God, and God helps me! (9-year-old child). And: Ah, I think distraction helps relieve the pain (page 146) The pain isn´t so bad. It hurts a little, but then I already know it hurts, so I do some massage (page 146)	x				206
	Seeking pleasure in nourishment	My fruit is all separated. They're all sterilized (page 147) do not like hospital food . . . ! Food from outside is much easier to eat (page 147)	x				207
	Engaging in entertaining activities and having fun	Ah, it's bad to stay in hospital because sometimes there is nothing to do (page 147) Ah, to keep myself busy, sometimes I read comics, I draw, I paint (page 147) Ah, the computer really helps to keep me close to other people, because I know people on the Internet, and then I can talk to more people (page 147)	x				208
	Keeping the hope of cure alive and finding support in religion	Sometimes I feel sad, but then I think that, if I want to get better, it's best to do the treatment correctly (page 147) I'm afraid of it [the tumor], I'm really scared that it will come back, right? That it will turn into something much worse (page 147)	x				209

Supplementary Table 4. Qualitative Findings

		I believe, because when I go to church it seems that God speaks to me. Then I have more faith because I know God is with me. To finish this treatment, I went to church, prayed, and thank God everything is right (page 147)				
Stinson et al. 2015	Themes related to fertility	‘Um, it’s definitely really important. I definitely always pictured myself as an adult, having kids. And I’d love to have kids and, umm, be able to raise them and stuff. So I think definitely I would do anything I could to protect my fertility because it’s important. (page 87)	x			210
	Themes related to sexual relationships	We’ll be dating before [sex] and I’ll probably tell him [I had cancer]. So he’ll know it’s nothing to feel uncomfortable about (page 87)	x			211
	Recommendations for care	It wasn’t a question of comfort [talking about fertility status with the healthcare team]. I don’t approach it any differently than any of the other potential long-term effects. I just want to know (page 87) Giving information about sexuality to teens. would just support the teens by telling them, ‘It doesn’t matter who you are, nobody’s perfect. There’s no normal thing. Be yourself because everyone else is taken.’ Um, tell them, ‘Once you get better, you can do anything you want and just go back to normal and be yourself. (page 87)	x			212
	Support through adolescent-friendly and accessible means.	Well, talking to someone your own age about it would really help, like, ‘Hello?’ it would! Just because you know that they’ve been through what you’ve been through, and they’re your age. They’re also like living it. It’s not like you’re asking an adult. And it’s less awkward because they’re not going to judge you really. (page 87) Well whenever I have a question that I don’t need to ask my nurse I would just go on a website and see all of the topics and click it and get the answers there (page 87)	x			213
Stinson et al. 2012	Working knowledge of the disease	Like umm, could the cancer spread and stuff, why do I need this particular test, and like umm, how will a surgery affect the rest of my life, and what could I do and could I not do because I had a choice between two surgeries, like questions of which one is better (281)	x			214
	Working knowledge of treatments, therapies, and procedures	It’s like, there are a whole lot of medications in me and I don’t know where they’re going, what they’re doing, how they gather, or how they help each other. (page 281) And it might not hurt to encourage other things, like meditation, or yoga, or deep breathing exercises. All of those other things that are used to manage anxiety and manage symptoms and pain control (page 281)	x			215
	Practical skills to manage the cancer	It would probably help kids if they didn’t like it and wanted to get past it faster, tips would be better. So like, they could keep themselves occupied and their minds off of it and stuff. So you’re not just sitting there just feeling it (page 281)	x			216

Supplementary Table 4. Qualitative Findings

	Knowledge of adult care and the transition process	Because kids need to know, you know, what am I suppose to be doing afterward, if God-forbid something was to happen to myself and your dad. Who is going to be the, you know, who is going to help you ask the right questions and make the right decisions and continue on? (page 281)	x			217
	Knowledge of late effects to support survivorship	Stuff to like help your body out, because it went all through these drugs and stuff and it can affect you in the long-run. Like, you might have troubles, heart troubles, liver troubles, all that kind of stuff (page 281) At this age, you're thinking about like going to university and stuff. So yeah, I think [survivorship] would be a good thing to talk about. Cause it's just looking forward into the future, what can you expect and stuff. As much information as possible about your future is always good (page 282)	x			218
	Up-to-date, trustworthy information delivered at opportune times	You never know what you are reading, something that was … modern five years ago may be different today … So you want to have a sense that people are updating it and reviewing it and I mean when I go to a website that's what I would look for (page 283)	x			219
	Body image and lifestyle information	Body image. Because I think body image is an issue for every adolescent regardless of whether you have a chronic or life-threatening illness. It's huge (page 283) How is it going to affect what they do every day—if they play sports, or if they like to party and drink, if they use marijuana? They want to know, alright, what is it going to do to me? How is it going to affect the way I live my life? (page 283)	x			220
	Connection with other adolescents	Well um, I have two really close friends that come and visit me most of the time. And then I have another best friend of mine that came quite a bit ago—and yeah, I'll probably have them over again because um, sometimes you just, sort of start to miss them	x			221
Thorsteinsson et al. 2017)	Ambassadors and group training	It affects] my mood. … I'm much happier when they're here (page 5) That way…we can motivate each other, right? If there's someone here that you really get along with…then you can…do push-ups…. Come on, darn it! You can do the last one! I just did it [said in a pressing tone of voice] and this way ….they motivate you…or alternatively you can motivate yourself, right (page 5) Yeah, it was definitely more fun and easier to train when my ambassador was with me (page 5) also think it was really fun at the group training sessions with ambassadors, especially the physiological testing. It was actually really fun—we made it into a small competition (page 5) …it's always fun to train with others who you get along with…people who you know…just like last time when we trained…it was cool that we were able to sit and do those exercises together. I thought that was really cool (page 5)	x			222

		Because it [training] makes the day go faster. The main thing when you have cancer is to get rid of it right away…and fast! You don't feel like having long, boring days and feeling bad (page 5)				
	Significant others and daily routines and habits	Because it wouldn't be the same. I wouldn't be forced like I am when you [the exercise psychologist] come every day. When you're forced to do it, it's easier to get started (page 5) It's easier when you are dragged out of bed [by the exercise psychologist] and told, Now, get going (page 5) Yeah, and it turned out to be a good thing anyway…Yeah, [it's because] you don't have the strength… you're tired or not feeling well enough but when you are pushed to do it, it turns out to be okay anyway. That's because you're just happy to be able to train. At least that's how I see it. So, it's always nice to be able to train even when you don't feel up to it at the beginning (page 5) That was real fun, actually. I certainly got a lot from it. I think it was interesting to see that you could actually improve [your physical well-being, fitness] during cancer treatment (page 5)	x			223
	Physical and psychological wellbeing	feel happy but also really tired. Your legs hurt the next day… Well, you feel happy that you could do it… that you did something that day…that you can still do something physical (page 6) Because once you actually start training…you begin to think… about all the good it's doing and you feel happier and forget about that medicine you were given that makes you so bad… I think that training puts you in a better mood… (page 6) still, you could keep your spirits up when you do exercises… I think you get in a better mood when doing physical training (page 6) I think that's really cool. I really mean it. And then there's the fact that you get a break from your parents, especially when you're a teenager…when you're trying to separate yourself a bit from them…but then all of a sudden, you're shoved back into that little room with them again. It's really great to be able to get out of bed and move around a little and not just lie belly up staring at the ceiling. It's cool…socially I really like it (page 6)	x			224
Valizadeh et al. 2019a	Empathic care	My family supports me, but they usually pay attention to my diet and they are not aware that I am annoyed in front of my friends and relatives because of my sickness, and they don't support me at all in this case. (page 215) Sometimes, doctors don't listen to the patient at all or don't spend enough time for follow-up visits and talking to the patient. Actually, not all doctors are like that; some others do everything for the patient to get better (page 215) One year after ending my treatment, I returned to school, but all of my friends had left there, so I sometimes miss them a lot (page 215)	x			225

Supplementary Table 4. Qualitative Findings

	Information about the survival period	Neither the doctors nor the nurses gave us nutritional or educational consultations about how to care for myself at home. When we refer to the clinic and show the tests, the doctor says: It's ok. Then he examines me, but he doesn't explain the tests or drugs. (page 215) After ending chemotherapy, I don't menstruate anymore, and then it occurs irregularly. This creates some worries about having babies or marriage in the future. I believe that if the issues about marriage and having baby are explained to the patients or their families, or if they receive a consultation, their worries are eliminated (page 215)	x			226
	Instrumental support	have to travel to another city for my doctor's visit. I'm on the way for some hours. When it's my turn, it's almost dark, and we can't return to our town. If there were places or vehicles for commuting allocated for the patients who go to other cities for follow-up care, it would be better. (216) I can't walk properly because of an osteosarcoma operation on my foot, and it sometimes aches. I know that I won't be able to do hard jobs. I believe that if organizations support me financially and occupationally, I can pay medical care expenses independently. (page 216) My eyesight has decreased because of the brain tumor. The school principal told my mother to take me to the blind students' school. Since they didn't have such facilities in their typical school, they couldn't teach me. If it were possible for my teacher to write on the board with bigger font size, or use a tablet, laptop, or magnifier, there wouldn't be any problem. (page 216)	x			227
	Cooperation in care	My mother always reminds me the times of my drugs or manages my visits with the doctor. If they give the order to have a test or sonography, I always do them with my mom or my aunt (page 216) Because of physical and movement restrictions resulting from the illness, my mother has to help me in doing daily work, such as taking a bath or (helping me with) my personal hygiene. When I go out, one of the family members, for example, my sister, accompanies me because my mother always worries that when I am out alone, I may fall down (page 216)	x			228
Valizadeh et al. 2019b	Nutritional protection	should not use processed foods and eat fruits and vegetables that are organic, but many of the foodstuffs that we use are hormonal. Finding the local type of these foods is difficult for my parents, nobody informed us about how to get them and if we find them, sometimes their prices are so high that my family cannot afford it (page 75)	x			229
	Prevention from infection	Even though take care of my health, I always get sick more than my classmates, especially in the cold season, I am usually absent in school because of frequent colds or I have to be away from my classmates and definitely use mask (page 75)	x			230
	Informational needs	Neither the doctors nor the nurses gave us nutritional or educational consultation about receive care at home. When we refer to the clinic and show the tests, doctor says: it's ok. Then he examines me, but he doesn't explain the tests or medicines. I and my parents got some	x			231

		experiences and also asked others for some information; for example, what activities I can do, what foods are good for me or what are the symptoms of disease recurrence (page 76)				
	Pain management	After the treatment ended, my pains decreased but they never disappeared. Sometimes that I do more activities, they get worse. Therefore, I need to take a rest and not to think about my pain (page 76)	x			232
	Protection from psychological distress	I'm always upset when my family or other people talking about my disease. I do not want to remember the hard days of treatment or think about my illness. I may take a trip with my friends, or communicate with friends who have more optimistic point of view towards life (page 76)	x			233
	Family protection	My family is always anxious about my coughs. They count them, they ask me why I'm coughing more today! My parents' sadness makes me sad too, so I sometimes hide my physical symptoms, just not to make them worried (page 76)	x			234
Vanclooster et al. 2021	Activities and participation	Everyone at school was very kind to me after I returned. Just being in the classroom was nice, even when I could not pay attention (page 2615)	x			235
	Environmental factors	know that I will have to work harder to succeed, it will become more difficult. We (parents and child) have already talked a lot about it, which study I will have to choose (page 2615)	x			236
Veneroni et al. 2015	What the patients had to say	This was a creative way to go beyond the limits that have been imposed on us by the doctors and our parents. We created something beautiful, and not only for ourselves but for others too… (page 628) Behind every item of clothing, there was a choice, an act of self-determination against everything that had been done to my body (page 628) realized that I didn't need to feel ashamed of having no hair, that I didn't need to be afraid of looking at myself in the mirror. I realized that I look good even like this (page 628) Many people ask me how I managed to be so strong. The answer is simple: I had no choice. But B. Live helped me to see that I had to resist, I had to fight, solid as a rock and as proud as a lioness. Before there was an abyss all around me, and especially inside me. Now I am a warrior. (page 628) For me, 'B.Live' is a way to make everyone else understand that cancer can't stop you and that you can still do everything other people do. You can even do more (page 629)	x			237
Weaver et al. 2015	Behaviors (decision-making)	Reading consents to me (page 4421) Tell me what they [parents] think is best (page 4421)	x			238

		Ask me separate from the medical team so we can discuss as a family before decisions (page 4421)				
	Attitudes (decision-making)	Remind me sometimes it's ultimately my decision what we do, whether it's like a medicine choice given to us and the doctor doesn't just say, well we have to do it like this. And that's really enough support for me, I guess. I kind of have been wanting, wanting me to kind of grow up like that, to grow up to make my own decisions (page 4421)	x			239
	Learning (decision-making)	Explain things to me before. Explain them to me early and explaining well. You know, so I can understand. Understanding is important to me (page 4421)	x			240
	Legacy (decision-making)	It actually helps me that she [mom] is involved because it takes off the weight I have to carry (page 4421)	x			241
	Facing forward (communication)	Face me. Then my parents maybe have a reminder, oh, maybe it is our son's decision or at least his body, even if we are the ones who sign the papers. (page 4422) Look at us when you are talking. Not to our parents. Look at us. We are your patients. They ain't wearing the gown that opens in the back (page 4422)	x			242
	Listening to language (communication)	Well, like, they just come in and like talk to me a normal person. That just makes me kind of comfortable with them . . . Avoid doctor talk or using real official doctor tone or doctor voice. Just come in to talk to me like, just, like friends, or something. Like, I know it when I see it and I hear it in their voice (page 4422)	x			243
	Advocating for honesty (communication)	Don't sugarcoat it (page 4422) And be real, real up front with me. That's what I want (page 4422)	x			244
	Giving encouragement and respect while granting hope	Tell me you're going to have my back through the whole thing (page 4422) More encouragement because it is hard (page 4422)	x			245
Weidman et al. 2022	Cancer journey difficulties	There is a barrier... a lot of the things I would express and [my mom and my boyfriend] just can't understand... it's not their fault, but I do crave talking, to talk to someone that has been through what I have been through as well. (page 435) My friends... they don't understand what I'm going through. Like, they can see it, but they've never experienced it, so they can't really relate to what I'm going through (page 435)	x			246
	Current support system	have a good support network. Like my mom is a good support, my friends (page 435)	x			247

		Definitely just talking and just chatting, I would say. There is nothing... you know... more they could do. But just talking and then... just spilling your feelings... having them replying back. I found it helpful (page 435)				
	Perspectives on peer support	Well, [existing programs] and stuff, like everyone, is kind of younger than me, so I can't really talk to them about what I'm going through (page 435)	x			248
Wiljén et al. 2022	Significant standpoints to address	Self-care strategies are needed to help children cope: Not meeting friends and not even doing...video games make them feel sick. That's it. And some of them feel ill as long as the therapy lasts. (page 9)	x			249
	Need for an easy tool to assess symptoms and facilitate communication	It would be easier, instead of talking all the time, you could just show them (page 9) If you have a bad day, then you may not want someone to ask how you feel. Then you can write it in the app. That would be a smart thing (page 9)	x			250
	Mapping the journey to facilitate recall	It would have been good to have a positive thing so that you can see that sometimes you feel well, so you can see which days during the week are the better ones (page 9)	x			251
	Different perspectives on provided and perceived support	It helps you to say how you feel, and the tips on what you can do to lessen the pain or lessen the nausea; it's good to get help with that because sometimes it feels like nothing works. But if you have tips, maybe you will find one that works for you (page 10) This app could make Mum and Dad stop asking how I feel all the time; instead, I can go in here and press from time to time how I feel, so they can see (page 10)	x			252
	Mapping the journey to facilitate recall	You can see what's going on and that the doctor can put in, yes, but around this time I'll come in and talk to you, and around this time you'll change the infusion (drip) or something (page 11) Friends ask day in, day out, day in, day out. And it's really hard because it's so hard to explain (page 11)	x			253
	Design of the mock-up	I think it's very nicely laid out and looks good etc. It's not too difficult for five-year-olds and not too childish then for those who are older (page 11)	x			254