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### **An indepth qualitative study**

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*Published in:*  
Psycho-Oncology

*DOI:*  
[10.1002/pon.5480](https://doi.org/10.1002/pon.5480)  
[10.1002/pon.5480](https://doi.org/10.1002/pon.5480)

*Publication date:*  
2020

*Document version*  
Early version, also known as pre-print

*Citation for published version (APA):*  
Andrés-Jensen, L., Larsen, H. B., Johansen, C., Frandsen, T. L., Schmiegelow, K., & Wahlberg, A. (2020). Everyday life challenges among adolescent and young adult survivors of childhood acute lymphoblastic leukemia: An indepth qualitative study. *Psycho-Oncology*, 29(10), 1630-1637. <https://doi.org/10.1002/pon.5480>, <https://doi.org/10.1002/pon.5480>

## **Everyday life challenges among adolescent and young adult survivors of childhood acute lymphoblastic leukemia: an in-depth qualitative study.**

**Running title:** Everyday life challenges among AYA survivors of childhood ALL

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**Abstract:** 246

**Main text:** 4200 (Excluding abstract, title page, conflicts of interests, data declaration statement and references)

**Tables:** 0

**Figures:** 0

**References:** 38

**Supporting information:** 5

## **ABSTRACT**

### **Objective**

As survival rates increase, growing numbers of childhood acute lymphoblastic leukemia (ALL) survivors are at risk of somatic and psychosocial late effects. Adolescent and young adult (AYA) survivors represent a distinct and vulnerable group. This study aimed to explore how AYA survivors of childhood ALL experience everyday life after cancer while adjusting to the potential impact of prior disease and treatment.

### **Methods**

Semi-structured interviews were carried out with survivors aged 15–22 years. Criterion-based homogenous purposive sampling was used to identify similarities within the group. Data were analyzed using an inductive, thematic approach.

### **Results**

Data saturation occurred after 18 interviews. Identified themes included the post-chemo body, negotiating identities, and disruption. More than 80% reported physical or cognitive late effects, but survivors adapted to these and had a positive view on own health. However, a co-existing experience of frailty persisted. Social disruption during treatment had negative impact of social relations even years following cure. Identity issues revolved around the paradox of seeking recognition for their cancer-related experiences, while also wanting to be treated like everyone else. Some participants aged 18–22 experienced delayed reactions and a new, but unmet, need to process the past.

### **Conclusions**

AYA survivors of childhood ALL adapt well to their new life situations, but many experience ongoing cancer-related disruptions and not being fully understood. We suggest exploration and verbalization of these issues alongside somatic follow-up around the age of 16–18 years to support the AYA survivors during their transition into adulthood.

## 1. INTRODUCTION

Survival rates among children with acute lymphoblastic leukemia (ALL), the most common childhood cancer, have increased dramatically from less than 10% in the 1960s to above 90% in developed countries today.<sup>1,2</sup> The growing number of survivors emphasizes a need for evaluating persisting treatment-related physical and psychosocial effects, and how survivors experience and adapt to these. Cure for ALL depends on intensive, prolonged (two to three years) chemotherapy. However, the price includes acute toxicities (causing 40% of deaths during treatment<sup>3</sup>), and chronic or late-occurring morbidity affecting at least 50% of survivors.<sup>4,5</sup> This collective survivor morbidity is significantly increased compared to that of matched controls.<sup>6</sup> Furthermore, the excessive morbidity seems to increase with survival time, exceeding the expected age-related morbidity rate.<sup>6</sup> Treatment strategies have been modified (e.g. omission of cranial irradiation<sup>7</sup>) to lessen this burden, resulting in changing patterns of late effects.<sup>8,9</sup> Most prevalent physical late effects among survivors treated with contemporary protocols include endocrine system disorders, musculoskeletal conditions, neuropathy, neurocognitive impairments and cardiovascular disease, while the prevalence of treatment-related cancers, reproductive system disorders and immunological disease among survivors have decreased.<sup>5,9,10</sup> Despite temporal changes, the overall number of health conditions per individual childhood ALL survivor is still double the number identified in community controls.<sup>9</sup>

Besides therapy-related physical burdens, patients experience abrupt discontinuation of their everyday lives when frequently disconnected from their homes, family, friends and school for weeks to months while admitted for intensive therapy or supportive care. These long-lasting interruptions in daily life may have life-long psychosocial and socioeconomic consequences.<sup>11,12</sup> Consequently, rehabilitation efforts are increasingly being initiated in pediatric oncology wards to support patients' transition back into daily routines as early as possible.<sup>13</sup> Adolescent and young adult (AYA) survivors represent a distinct and vulnerable subgroup, characterized by rapid biological and psychosocial identity-forming changes that mark the passage from childhood to independent adult life. These developmental processes are disrupted in AYA ALL patients and survivors<sup>14</sup> and, in addition, AYA survivors face increased risk for unmet survivorship needs when transitioning from pediatric- to adult centered care.<sup>15,16</sup> The impact of physical and psychosocial effects is often quantified with standardized health-related quality of life (HRQL)-instruments, and scores are generally lower among childhood ALL survivors compared to healthy peers.<sup>17</sup> These measures are valuable for comparing results across subgroups and temporal periods, however, they might be limited in capturing the issues most important to the survivors in question.<sup>18-21</sup>

As we sought a deeper understanding of possible AYA ALL survivorship challenges, we turned to qualitative methodologies.<sup>22</sup> A review of PubMed-indexed qualitative studies among survivors of childhood cancer revealed that very few focused entirely on ALL survivors and none of these explored more general aspects of everyday life among AYA childhood ALL survivors (supporting information S1). Accordingly, we aimed to explore how AYA survivors of childhood ALL experience everyday life while reflecting on and adjusting to the impact of prior disease and treatment. Our focus was on physical and cognitive function; emotional wellbeing; social relations; and inner motivations.

Identification of unacknowledged survivorship issues within this specific group can potentially facilitate improved follow-up strategies, better tailored to the needs of AYA ALL survivors.

## **2. METHODS**

### **2.1 Study design**

We used a qualitative, semi-structured interview design. The study was conducted and reported according to the consolidated criteria for reporting qualitative research (COREQ) guidelines<sup>23</sup>, was performed according to the Declaration of Helsinki, and was approved by The Danish National Committee of Health Research Ethics (H-18035090) and The Danish Data Protection Agency (VD-2019-5019).

### **2.2 Participants**

We used criterion-based purposive sampling to recruit a homogenous sample of survivors.<sup>24</sup> Inclusion criteria were: i) childhood ALL survivors treated in Denmark according to the Nordic Society of Pediatric Haematology and Oncology (NOPHO) ALL2008 protocol<sup>2</sup> (used at all treatment centers during 2008-2018), ii)  $\geq 1$  year from therapy completion, and iii) aged 15–22 at time of recruitment and interview. Exclusion criteria were: i) severe psychiatric or cognitive conditions hindering participation in an interview, and ii) non-fluent in spoken Danish. Eligible survivors were identified using the National NOPHO treatment database. Treating physicians screened for eligibility and extracted treatment data from medical charts. Parents were approached if participant age was  $< 18$  years. Informed written consent was provided by all participants. Recruitment continued until data saturation, meaning that no new themes were identified.<sup>25</sup>

### **2.3 Semi-structured interviews**

Aspects of everyday life was schematized using a semi-structured interview guide exploring survivor experiences within the domains: physical and cognitive function; emotional wellbeing; social relations; and inner motivations (S2). Participants were encouraged to tell their story as they wished, however a series of prompting questions were picked from to stimulate reflections within the focus areas of the study. Interviews were performed between June 2018 – January 2019 at an undisturbed location of the participant's choice (two at the pediatric research department, all others in the homes of participants). Interviews lasted 45–90 minutes. Parents were present during three interviews. Interviews were performed by LAJ and AW in four cases and by LAJ in the remaining 14 cases. All interviews were recorded and transcribed verbatim by trained research assistants.

### **2.4 Data analysis**

Inductive, thematic analysis was performed according to the multistep process, suggested by Braun and Clarke.<sup>26</sup> This included: 1) reading and re-reading interviews followed by meetings to discuss initial ideas, 2) line-by-line data-driven coding, 3) individual sorting of codes, identification of themes and meetings to compare and discuss these, 4) review of themes at the level of coding extracts and in relation to the entire data set (securing internal homogeneity and external heterogeneity), and 5) final definition and naming of themes. Data were organized and coded manually by LAJ and AW and using NVivo 12 software by LAJ. The final selection of key themes was agreed upon by all authors.

### 3. RESULTS.

#### 3.1 Participants

A total of 53 survivors fulfilled the inclusion criteria. One was excluded due to a diagnosis of severe infantile autism and two were lost to follow-up. Ten participants declined participation in interviews but consented to use of treatment data. Data saturation occurred after 18 interviews and recruitment was discontinued. Mean age of participants was 19.1 years (range 15.3–22.7 years) and mean time since diagnosis was 7.5 years (range 4.2–10.0 years). Those who declined were significantly younger than participants at both time of the study (mean age 17.1 years (range 15.4–20.3),  $p=0.015$ ) and time of diagnosis (mean age 9.3 years (range 6.0–12.9) versus 11.6 years (range 5.5–15.1),  $p=0.038$ ), however comparable with regards to sex, leukemia therapy, and follow-up time. Demographic details are provided in S3.

Nine of the ten who declined were aged < 18 years and according to parents the reason was that “[she/he] *wants to forget and be like everyone else*”. We did not have ethical approval to investigate this further.

#### 3.2 Main themes

Three main themes were identified: 1) My post-chemo body, 2) Negotiating identities, and 3) Disruption. Themes, subthemes and representative quotes are provided in S4.

##### 3.2.1 My post-chemo body

###### Living with late effects

Survivors were asked to describe somatic and cognitive effects relating to previous leukemia and/or therapy. Only three survivors (17%) reported not having late effects, while the rest reported a variety of late effects including severe and disabling conditions such as osteonecrosis, reduced lung function and chronic pain (S4). The negative impact of these was recognized by survivors, who described how their current capacity had been reduced compared to before leukemia, limiting participation in peer activities. However, most survivors also described a conscious decision to accept and adapt to their current state, e.g. by replacing sports with e-sports, which “*is also becoming a kind of sport today*” (P2). Some even expressed feeling lucky, that the price of survival had not been higher, albeit with underlying ambiguities:

*“I realize that it sounds kind of depressing when I mention that I have osteonecrosis, asthma and this and that, but it doesn’t take up so much space anymore. It’s not something that I want to perceive as negative. It’s simply a part of my body now, it’s just the way it is (...) I think many others have had more late effects than me. That’s why I feel lucky. I do. For sure.”(P4)*

###### A different kind of healthy

Reflecting on their own health status and how they positioned themselves in relation to the concepts of being healthy or ill today, most survivors described feeling completely healthy and that the transition from illness coincided with leukemia therapy completion. A few explained that this transition had occurred at a later point in time, e.g. when

fatigue had subsided or after surgery for treatment-induced osteonecrosis. Survivors with persisting, severe morbidities (e.g. significantly reduced lung function), equally reported feeling healthy. When then asked to compare themselves with their pre-leukemia self or with peers, the majority reported inferior health to both. However, even in this context, survivors insisted they were healthy, implying that late effects such as chronic lung disease, hormone replacement or disabling osteonecrosis were somehow not perceived as illnesses:

*“I would say that I am healthy. I just have some issues that make things a bit difficult, for example my hip and my lungs. They are the biggest problem right now. On a scale from 1-10, my health is around 4-5.”(P3)*

### My fragile body

Most survivors described how chemotherapy had “*crushed*”, “*damaged*” and “*destroyed*” their body and organs, leaving them fragile.

*“The body received a lot of poison, right? (...) So, I’m guessing that inside, the body is still a bit – it’s not so well. I don’t know...”(P3)*

This fragility was interpreted by many as leading to both a “*greater risk of becoming ill than [their] friends*”, which prompted them to lead a healthy lifestyle, which meant eating nutritious, organic food and abstaining from smoking, alcohol, lotions with parabens, and sun- or microwave rays. Some also explained having reduced physical resistance to injuries, leading them to be cautious when performing physical activities or even abstaining completely from physical activity such as running due to a fear of falling.

Experiencing common bodily sensations, such as minor pains or passing discomforts, could lead to anxiety and fear of illness (cancer or other diseases). While some had developed conscious strategies to subdue this, e.g. by distracting themselves or rationalizing with their parents, others persistently sought a doctor’s opinion before feeling reassured.

*“It’s in the back of my mind, that, if I feel pain somewhere, it could be something. (...) Not so much cancer! But almost anything else. (...) It’s calming to be checked by a doctor, who can tell you that everything is fine – also on the inside.”(P10)*

When asked about the origin of their ideas of frailty, disease, causality and risk-adaptive patterns, most survivors were unsure, and did not recall them stemming from health care professionals or self-educational activities, but rather from inner intuitions and self-drawn conclusions.

### **3.2.2 Negotiating identities**

#### Internal versus external identity

The experience of having leukemia and receiving prolonged therapy was perceived as a life-changing event, now

integrated as part of the surviving self. Cancer was not described as a definite event to reflect upon, but as an accepted phantom presence in survivors' lived lives. This changed identity was reported by survivors regardless of having visible late effects (e.g. physical scarring, inability to participate in sports, reduced attendance in school), invisible late effects (e.g. pain or fatigue) or no apparent physical or functional late effects at all.

*"I'm a healthy cancer patient. I mean, you're always – even though you're not... (...) I think about the cancer pretty much every day. (...) It's always there. And that is okay."(P1)*

Survivors shared the experience that their surroundings, i.e. family members, friends and society, treated the cancer experience as a problem now solved. They found this external anticipation of normalization difficult and conflicting with their internal identity.

*"It has been hard to feel that people are pulling away from something that has impacted so profoundly on my life, that I have had to fight against, and that they can just almost walk away from it, closing their eyes."(P14)*

The divergence between internal and external identities was paralleled by another paradox; the inner paradox of wanting to be recognized for their survivor status while also wanting to be treated like everyone else:

*"Well, when I reflect on it, I think it is an important part of me, but I don't want people to think that it is."(P5)*

This paradox was especially apparent in the context of forming new relationships. Survivors described being unsure of when, how and if they should share their cancer history, as sharing was necessary for developing more profound friendships, however at the same time it put them at risk of being alienated.

*"I often wonder 'should I say it' or 'when should I say it' and 'how important is it' and so on. Because in some ways, it's something you want people to know, because it's so important – or well, it's not so important, but at least it's a big part of who I am now. But it's really difficult to figure out when to tell people, and it's quite individual how they react to being told."(P3)*

This ambiguity was expressed across all participant ages, however less pronounced among the youngest participants, who seemed to focus primarily on looking ahead.

### No-one asks

Most survivors (except for some of the youngest) expressed an unfulfilled wish to talk about past and present cancer-related experiences with close friends and relatives, and they missed being asked.

*"Well, no-one asks me about it. I wouldn't mind talking about it, but yeah...they don't really think about it...about how it has been (...) It's okay not to talk about it all the time, it's not part of my*

*everyday life anymore, but it would be nice if they knew more about it, or that we could talk about it (...) I have no idea how to tell them. I guess it's just me who still thinks about it."*(P16)

In addition, survivors would themselves refrain from initiating (or revisiting) conversations on the issue, due to previous experiences of limited resonance.

*"Sometimes I've told friends, and they're like 'oh okay, we didn't know', ... and they might cry and stuff. But then they don't think more of it. They don't mention it again after I have told them once. (...) I think it's strange. I would have asked more about it, I think."*(P5)

Or because they simply did not want to burden the listener.

*"I try to minimize talking about it, because I feel it gets a little tiresome for people sometimes. They think like "oh, this again" and my father doesn't like to talk about it. At least that's the impression he gives me."*(P3)

### **3.2.3 Disruption**

#### Social disruption

Cancer-related disruption of everyday life was mainly described as disruption of social (peer and family relations) and educational life. Most expressed contentment with educational catch-up and family relations today, however social disruption impacted still. Absence from school and missing friends during peripubertal age was described as a critical and negative experience, resulting in an experience of developmental discrepancy. Some had been able to maintain friendships, easing their reintegration to everyday life. However, many expressed that friendships were lost during the treatment period and that return to normal everyday life had been difficult since everyone else had changed and moved on. Some had managed to catch up, but others had eventually pursued new social circles and/or schools.

*"Yes, um, it was quite difficult. (...) It was exactly around the time where - when you are twelve years old, it has a lot to do with identity (...). It was a really frustrating time, and I just wished and hoped so much that I had gotten it [cancer] earlier if I was to have it at all. (...) Yes, it was just really tough not being a part of all those changes that my friends went through."*(P11)

The experience of social discrepancy persisted in present life among some who described feeling both more and less mature than peers resulting in both experienced and formal distancing. Some described an ongoing lack of inclusion in certain characteristic adolescent social activities such as parties, which could result in the experience of isolation.

*"It was during that time they started throwing lots of parties. It's during the summer months that I feel most... when the others, almost the entire class, have lots of parties and such. That's when I don't have much to do."* (P18)

On the other hand, several survivors explained how parties, alcohol and superficial social relations did not interest them, while acknowledging that they probably differed from their peers in this way.

### Delayed disruption

The youngest participants (aged 15–17) focused primarily on present life and on leaving the cancer experience behind. The slightly older survivors (aged 18–22), however, explained that, while needing a break from everything cancer-related during adolescence and the first years following cure, thoughts on the issue were now reemerging, accompanied by a gradual realization of how serious their condition had been.

*" I've thought about it more as I have become older. When I was younger, I didn't want it to take up so much space. When I was done with chemo and was still on pills, people kept treating me like a sick person and I didn't want that. Because I didn't feel sick that way. And I didn't remember or understand so much of what had happened. Now, gradually over the years, I have been told what happened. Now I understand."(P3)*

These reflections resulted in a renewed wish to talk about and process their past, however as everyone around them seemed to have moved on, and since many survivors no longer attended follow-up clinics, they did not know where to turn with this.

## **4. DISCUSSION**

In this qualitative study exploring everyday life experiences of 18 AYA survivors of childhood ALL, the dominant themes revolved around successful adaption to life with late effects, a shift in the perception of own health alongside an increased body awareness, long-lasting impacts on peer relationships, contrasts between own and surrounding perceptions of survivorship identity, and an unmet need to process these issues, perhaps most pronounced among those in young adulthood.

Eighty-three percent reported having physical and/or cognitive late effects, of which many were associated with bodily discomfort and/or limiting participation in peer activities. Rather than denying these late effects, survivors seemed to accept and adapt to them as part of their "new" body and self. Survivors perceived themselves as healthy overall (despite even severe late effects), leaving the impression that "healthy" was defined as the absence of leukemia, demonstrating the subjectivity in perceptions of illness and health and the dynamic self-regulation that survivors perform over time.<sup>27</sup> Treatment-related and medically termed disease did not translate into illness among survivors who adhered to a different, internal survivor logic, illustrating also the contrast between health as evaluated at the individual, psychological level and health as defined within cultural and societal structures. Paradoxically, the general positive view upon own health was accompanied by an increased body awareness and the perception of having a fragile (or rather, *frail*) body. While motivating health-promoting behaviors in some, it led to an unwarranted reduction in physical activity in others, potentially compromising health. In addition, enhanced body awareness facilitated worry about disease in some, further compromising health-related quality of life. The contrast between a cognitive perception of good health on the one hand, and an emotionally driven perception of frailty on the other, can be conceptualized using the Leventhal common-sense model of self-regulation<sup>27</sup>, which describes how health-related stimuli (internal or external) lead to cognitive and emotional representations of danger, each guiding the actions taken

to cope with this danger and/or fear. In the context of ALL survivors, the cognitive and emotional path seem to co-exist and relate back to the prior cancer experience. Identification and awareness of these patterns may aid the survivor in choosing appropriate coping strategies in present life.

As pointed out by others, the concepts of illness and health are insufficient for cancer survivors to identify with, as they identify with a third concept, coined by some as *permanent survival*<sup>28</sup> or, in this study, as being a “*healthy cancer patient*”. In this context, survivorship encompasses the evolution following cure while framing a “new normal” existence, differing from that of “pre-cancer normal”, which has been biographically disrupted by the cancer experience.<sup>29</sup> Biographical disruption, conceptualized by Bury to describe experiences of living with chronic disease, includes 1) disruption of behaviors and assumptions regarding the past, present and future which are taken for granted, 2) a fundamental re-thinking of the person’s own concept of self and their relationships, 3) increased body awareness and related concerns, and 4) mobilization of resources and coping strategies as a response<sup>30</sup>. This concept has also proved useful to describe experiences during different stages of adult cancer including survivorship<sup>31</sup>. As participants in this study seemed to likewise describe an ongoing or intermittent disruption of inner anticipations regarding own health, physical capacity, identity, and social relations, we suggest that Bury’s concept is also helpful for understanding the cancer-related disruption experienced among AYA survivors of childhood ALL.

Social interruption and insufficient reintegration were described by survivors as significant challenges, impacting on everyday life even years after cancer cure. Obvious childhood ALL factors affecting social relations include the life-threatening disease itself, aggressive therapy, and severe adverse effects. However, the *duration*, characteristic for ALL regimens, represents an additional, independent factor contributing to the type of biographical disruption occurring in lives of ALL patients and substantially compromising both preservation and development of social relations. This may be experienced as particularly devastating during peripubertal age.

The identity conflict between wanting to be treated like everyone else while seeking to be understood and recognized for what they have overcome is consistent with findings from previous AYA cancer survivor studies.<sup>32,33</sup> Cancer survival as an interim state between illness and health, pre-cancer normal and new normal, is related to the anthropological concept of liminality, described as a passage “*through a cultural realm that has few or none of the attributes of the past or coming state*”, and characterized by loss of status, marginality and ambiguity<sup>34</sup>. Liminality has been used to describe survivorship following adult cancers<sup>35</sup>, and we suggest that it also applies to survivorship issues experienced by AYA survivors of childhood ALL. The experienced lack of interest and resonance from their surroundings could also be explained in part by a possible societal misconception that cancer (for those who survive) is a passing difficulty, ultimately yielding opportunities for positive transformation and growth. Such a perception imposes the risk of suppressing less socially accepted emotions of anger and disappointment, potentially hindering the likelihood of survivors feeling understood and receiving the kind of attention sought.<sup>36</sup>

Cancer-related disruption may reappear in different stages of survivorship as survivors transition through liminality towards a new normal<sup>37</sup>, and as the survivor, like everyone else, faces the characteristics of different life stages. Young adult survivors expressed a recurring inner disruption as they experienced a cognitive maturation resulting in new

reflections regarding the past and its impact on present life. A qualitative study among young adult lymphoma survivors reported similar findings.<sup>38</sup> This gradual realization and the renewed, but unmet, need to process this, may be characteristic for AYA survivors of childhood cancer and suggest a focus area in follow-up care to be improved.

#### **4.1 Clinical implications**

An active exploration and identification of survivors' perception of own health, body, and related behavioral patterns may enable a more directed and thus improved consultation between health care provider and survivors, e.g. when informing about risks, or in guiding survivors to abandon self-perceived fragility, while maintaining a positive view of own health and capacity. Articulation of the paradoxes concerning concepts of illness, cure, and survivorship identity can facilitate awareness of own preferences, aiding communication to and from family and peers, ultimately promoting mutual understanding.

#### **4.2 Limitations.**

Participants aged  $\geq 18$  years dominated our sample. Results may therefore reflect young adult survivors more than the adolescent. The 36% who declined participation could represent distinct aspects of AYA ALL survivorship, not revealed in this study. Exploration of survivorship issues among young adolescents (including barriers to participating in survivorship research) is of interest.

#### **4.3 Conclusion and future directions**

Our study is among few to provide insight into survivorship challenges as experienced by AYA survivors of ALL. Survivors adapted well to even severe late effects and maintained an overall positive view of own health, however a co-existing increased body awareness and self-perceived frailty led to self-limiting behavior and concerns of disease. Long-lasting interruption of social relations during peripubertal **age** had negative social implications even years following cure. Cancer-related biographical disruption had forever changed survivors' internal identity, and this contrasted with expectations of **pre-cancer** normality perceived from their surroundings. Late adolescent and young adult survivors experienced a gradual realization and a renewed but unmet need to process past and present cancer-related experiences. We suggest that systematic consultations addressing these issues alongside somatic concerns be offered to all AYA survivors thereby supporting them through survivorship challenges when transitioning into adulthood.

#### **Acknowledgements**

We wish to thank participants for their shared experiences.

The study was supported by the Danish Childhood Cancer Foundation and the Danish Cancer Society.

Ayo Wahlberg acknowledges the European Research Council (grant no. ERC-2014-STG-639275-VITAL).

#### **Conflicts of interest**

The authors declare no conflicts of interest

#### **Data availability statement**

All data supporting the findings of this study are available from the corresponding author upon reasonable request.

## REFERENCES

1. Hunger SP, Mullighan CG. Acute Lymphoblastic Leukemia in Children. *N. Engl. J. Med.* 2015;373(16):1541–1552.
2. Toft N, Birgens H, Abrahamsson J, et al. Results of NOPHO ALL2008 treatment for patients 1-45 years with acute lymphoblastic leukemia. *Leukemia.* 2017;32(3)(August):606–615.
3. Lund B, Åsberg A, Heyman M, et al. Risk factors for treatment related mortality in childhood acute lymphoblastic leukaemia. *Pediatr. Blood Cancer.* 2011;56(4):551–559.
4. Robison LL. Late effects of acute lymphoblastic leukemia therapy in patients diagnosed at 0-20 years of age. *Hematology Am. Soc. Hematol. Educ. Program.* 2011;2011:238–42.
5. Mody R, Li S, Dover DC, et al. Twenty-five – year follow-up among survivors of childhood acute lymphoblastic leukemia : a report from the Childhood Cancer Survivor Study. *Blood.* 2016;111(12):5515–5524.
6. Bhakta N, Liu Q, Ness KK, et al. The cumulative burden of surviving childhood cancer: an initial report from the St Jude Lifetime Cohort Study (SJLIFE). *Lancet.* 2017;390(10112):2569–2582.
7. Vora A, Andreano A, Pui CH, et al. Influence of Cranial Radiotherapy on Outcome in Children With Acute Lymphoblastic Leukemia Treated With Contemporary Therapy. *J. Clin. Oncol.* 2016;34(9):919–926.
8. Armstrong GT, Liu Q, Yasui Y, et al. Late mortality among 5-year survivors of childhood cancer: a summary from the Childhood Cancer Survivor Study. *J. Clin. Oncol.* 2009;27(14):2328–38.
9. Mulrooney DA, Hyun G, Ness KK, et al. The changing burden of long-term health outcomes in survivors of childhood acute lymphoblastic leukaemia: a retrospective analysis of the St Jude Lifetime Cohort Study. *Lancet Haematol.* 2019;6(6):e306–e316.
10. Jacola LM, Edelstein K, Liu W, et al. Cognitive, behaviour, and academic functioning in adolescent and young adult survivors of childhood acute lymphoblastic leukaemia: a report from the Childhood Cancer Survivor Study. *The Lancet Psychiatry.* 2016;3(10):965–972.
11. Mitby PA, Robison LL, Whitton JA, et al. Utilization of special education services and educational attainment among long-term survivors of childhood cancer. *Cancer.* 2003;97(4):1115–1126.
12. Lund LW, Winther JF, Dalton SO, et al. Hospital contact for mental disorders in survivors of childhood cancer and their siblings in denmark: A population-based cohort study. *Lancet Oncol.* 2013;14(10):971–980.
13. Thorsteinsson T, Helms AS, Adamsen L, et al. Study protocol: Rehabilitation including social and physical activity and education in children and teenagers with cancer (RESPECT). *BMC Cancer.* 2013;13:1.
14. Barr RD, Ferrari A, Ries L, Whelan J, Bleyer WA. Cancer in Adolescents and Young Adults. *JAMA Pediatr.*

- 2016;170(5):495.
15. Psihogios AM, Schwartz LA, Deatrick JA, et al. Preferences for cancer survivorship care among adolescents and young adults who experienced healthcare transitions and their parents. *J. Cancer Surviv.* 2019;13(4):620–631.
  16. Nathan PC, Hayes-Lattin B, Sisler JJ, Hudson MM. Critical issues in transition and survivorship for adolescents and young adults with cancers. *Cancer.* 2011;117(SUPPL. 10):2335–2341.
  17. Vetsch J, Wakefield CE, Robertson EG, et al. Health-related quality of life of survivors of childhood acute lymphoblastic leukemia: a systematic review. *Qual. Life Res.* 2018;27(6):1431–1443.
  18. Anthony SJ, Selkirk E, Sung L, et al. Quality of life of pediatric oncology patients: Do patient-reported outcome instruments measure what matters to patients? *Qual. Life Res.* 2016;26(2):273–281.
  19. Brown MC, Pearce MS, Bailey S, Skinner R. The long-term psychosocial impact of cancer: The views of young adult survivors of childhood cancer. *Eur. J. Cancer Care (Engl).* 2016;25(3):428–439.
  20. Nightingale CL, Quinn GP, Shenkman EA, et al. Health-Related Quality of Life of Young Adult Survivors of Childhood Cancer: A Review of Qualitative Studies. *J. Adolesc. Young Adult Oncol.* 2011;1(3):124–132.
  21. Gwendolin P. Q, Huan I-C, Murphy D, Zidonik-Eddelton K, Krull KR. Missing content from health-related quality of life instruments: interviews with young adult survivors of childhood cancer. *Qual. Life Res.* 2013;22(1):111–118.
  22. Malterud K, Horton R, Sassower R, et al. The art and science of clinical knowledge: evidence beyond measures and numbers. *Lancet.* 2001;358(9279):397–400.
  23. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int. J. Qual. Heal. Care.* 2007;19(6):349–357.
  24. Palinkas LA, Horwitz SM, Green CA, et al. Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. *Adm. Policy Ment. Heal. Ment. Heal. Serv. Res.* 2015;42(5):533–544.
  25. Moser A, Korstjens I. Series: Practical guidance to qualitative research. Part 3: Sampling, data collection and analysis. *Eur. J. Gen. Pract.* 2018;24(1):9–18.
  26. Braun V, Clarke V. Using thematic analysis in psychology. *Qual. Res. Psychol.* 2006;3(2):77–101.
  27. Friedman HS. Oxford Handbook of Health and Psychology. Oxford University Press; 2013.
  28. Mullan F. Seasons of Survival: Reflections of a Physician with Cancer. *N. Engl. J. Med.* 1985;July:1985.
  29. Balmer C, Griffiths F, Dunn J. A ‘new normal’: Exploring the disruption of a poor prognostic cancer diagnosis using interviews and participant-produced photographs. *Heal. (United Kingdom).* 2015;19(5):451–472.
  30. Bury M. Chronic illness as biographical disruption. *Sociol. Health Illn.* 1982;4(2):167–182.

31. Hubbard G, Forbat L. Cancer as biographical disruption: Constructions of living with cancer. *Support. Care Cancer*. 2012;20(9):2033–2040.
32. Cameron N, Ross K, Baken D, Bimler D. The Psychosocial Interactions of Adolescent and Young Adult Cancer Survivors and the Possible Relationship With Their Development. *Cancer Nurs*. 2019;00(0):1.
33. Victorson D, Garcia SF, Sanford S, et al. A Qualitative Focus Group Study to Illuminate the Lived Emotional and Social Impacts of Cancer and Its Treatment on Young Adults. *J. Adolesc. Young Adult Oncol*. 2019;8(6):649–659.
34. Turner VW. *The Ritual Process: Structure and Anti-Structure*. Chicago: Aldine Publishing Company; 1969.
35. Blows E, Bird L, Seymour J, Cox K. Liminality as a framework for understanding the experience of cancer survivorship: A literature review. *J. Adv. Nurs*. 2012;68(10):2155–2164.
36. Sulik G. What cancer survivorship means. *Virtual Mentor*. 2013;15(8):697–703.
37. Monaghan LF, Gabe J. Chronic illness as biographical contingency? Young people's experiences of asthma. *Sociol. Heal. Illn*. 2015;37(8):1236–1253.
38. Lie HC, Loge JH, Fosså SD, et al. Providing information about late effects after childhood cancer: Lymphoma survivors' preferences for what, how and when. *Patient Educ. Couns*. 2015;98(5):604–611.