



Prepared for survivorship? Multidisciplinary healthcare professionals' experiences with adolescents' transition off cancer treatment: A focus group study

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ABSTRACT

Purpose: Research indicates that re-entering everyday life after completed cancer treatment can be challenging for adolescents, and knowledge about how healthcare professionals prepare them is scarce. This study explored (a) healthcare professionals' experiences with adolescents with cancer transitioning off active cancer treatment; and (b) what healthcare professionals' do to prepare adolescents and their families for this transition; and c) their ideas to improve current practice.

Methods: We conducted 8 focus-group interviews with 56 multidisciplinary healthcare professionals working in paediatric oncology settings across Norway. The sample consisted of nurses, physicians, social workers, psychologists, physiotherapists, a nutritionist, a dentist, a teacher and a music therapist. Inductive thematic analyses was used.

Results: We identified three main themes: (a) the multifaceted nature of the end of the treatment phase; (b) navigating challenges in providing early survivorship care; and (c) healthcare professionals' views and wishes regarding their role in transition care. The healthcare professionals conveyed uncertainty regarding how and when to talk about survivorship during treatment. Post-treatment, healthcare professionals' challenges included time restrictions, meeting the families' individual information needs and providing tailored psychosocial care. Suggestions for improvements included checklists, defined roles and dedicated transition consultations.

Conclusions: Healthcare professionals were aware of the challenges families face during transition, and felt many were not addressed adequately. Although they had similar concrete suggestions for improvements, system barriers and lack of time and focus on survivorship were seen to hamper implementation. Implementing a standardized transition programme with increased nurse involvement could potentially improve the transition phase for everyone involved.

1. Introduction

Ending successful treatment is a major and often celebrated milestone for an adolescent with cancer, but the transition back to everyday life can be challenging for the whole family (Walker et al., 2018). More

than 80% of children and adolescents survive cancer in high-income countries, and survival rates are still increasing (Ward et al., 2014). Therefore, it is essential to recognize the transition period from active cancer treatment to 'survivorship' as an important stage of the cancer trajectory—albeit one that has received limited attention (Nathan et al.,

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2011).

Throughout treatment, most families will have close contact with a multidisciplinary team of healthcare professionals (HCPs) from the specialist healthcare services, often with an 'open door policy' at their local paediatric ward. These HCPs are in a unique position to share insights on different stages of the adolescent's cancer trajectory, including the transition to survivorship.

In Norway, you are referred to as an adolescent when you are between 13 and 19 years of age. Being diagnosed with cancer as an adolescent often has a dramatic and life-changing impact on young patients and their families (Warner et al., 2016). The treatment and side effects, together with day-to-day living, are typically the family's main concerns during active treatment (Lea et al., 2020a). The treatment is mainly guided by diagnosis-specific protocols which offer the family a concrete plan and a detailed overview on day-to-day medication, hospitalization and assessments during the treatment phase. A majority of the families regard this as the essential backbone of everyday life, making the treatment period more predictable and manageable.

Post treatment there are still scheduled plans for follow-up and evaluations, but the treatment-associated backbone for daily planning and the close contact disappears (Greenzang et al., 2016). On one hand, the adolescents and their families can look forward to spending less time in the hospital and resume a more normal life (Björk et al., 2011). On the other hand, they need to readapt to reduced medical surveillance, master their fear of recurrence, and adjust to having the healthcare team less-available than before (Wilkins et al., 2014). Post-treatment, the adolescent routinely attends scheduled outpatient consultations with a paediatric oncologist. The Norwegian specialist healthcare service is publicly funded and provides these controls regularly for five to ten years post-treatment, or until the adolescent reaches 18 years of age. Then, they are transferred to adult specialist healthcare services or to their GP, after which plans for follow-up become not always within a predictable organizational framework.

In the first years following treatment, the main medical follow-up concerns are recurrence surveillance and management of or screening for adverse effects from treatment. Furthermore, as adolescents are near the time when they will transition to non-paediatric follow-up, it is relevant for HCPs to provide childhood cancer survivors (CCSs) with sufficient information about their cancer, treatment and future follow-up recommendations. It is also essential for HCPs to support adolescent CCSs in building autonomy and making informed health choices, as the adult healthcare system often expects them to participate independently, without parental involvement (Oth et al., 2020).

Moreover, research points to the transition off treatment as a particularly demanding period, marked by stress and unmet needs for the adolescents and their families (Nathan et al., 2011; Psihogios et al., 2019). A recent systematic review on families' experiences with end-of-cancer treatment indicates that the transition arrives abruptly, without adequate preparation. Additionally, the families express a necessity for education and support, and continued relationship with the oncology team (Keller et al., 2020). These findings are supported by other studies, which report that families feel abandoned, unsafe, unsupported and unprepared for this transition (Pedersen et al., 2018; Pini et al., 2017; Walker et al., 2016).

Research is limited on how HCPs perceive this transition phase (Keller et al., 2020; Walker et al., 2016), despite the fact that they can help identify strengths and limitations within the current system and provide recommendations to improve follow-up care (Berg et al., 2016; Mouw et al., 2017; Ålykkja et al., 2020). Further research is therefore needed on HCPs' present practices, in order to address the persistent need to develop models around preparation, education and follow-up for adolescents entering cancer survivorship.

Consequently, the present study aims to explore (a) HCPs' experiences caring for adolescents with cancer and their families in the transition from active cancer treatment to follow-up care; (b) what HCPs do to prepare adolescents and their families for this transition; and (c) their

ideas to improve current practice.

2. Methods

The present study was conducted in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines (Tong et al., 2007).

2.1. Study design

In this descriptive qualitative study, we conducted eight focus group interviews (Krueger and Casey, 2009) with 56 HCPs, representing 13 of the 20 paediatric departments within the Norwegian specialist healthcare services. Six of the interviews were comprised of multidisciplinary personnel, arranged at the three largest paediatric cancer units in Norway, and conducted in a suitable hospital room. The last two focus groups included nurses involved in paediatric oncology care and were arranged during a national educational seminar. Purposive sampling was used (Patton and Patton, 2007). The participants were recruited through key personnel in the paediatric oncology units and included a broad selection of participants regarding age, professional background, and experience. The inclusion criteria were more than one year of experience working with adolescents with cancer, adequate language skills (Norwegian), and signed consent after verbal and written study information was provided. Two persons declined to participate due to time limitations. The eight focus group interviews had a mean duration of 76 min (62–89).

2.2. Data collection

A semi-structured interview guide was developed based on the literature and on the clinical knowledge of the research team. Two user representatives (one 19-year-old survivor and her mother) gave feedback and ensured the relevance of the guide. Then, the guide was discussed with three key representatives of HCPs within child and adolescent cancer care, before finalisation. (Available in Supplementary information for this article, Table 1).

The focus groups were facilitated by female researchers (HCL, AKW and MHL), all experienced in conducting focus group interviews and familiar with childhood cancer care. Another female researcher was present during the interviews and took notes and observed (EHL and LJH). Data collection was continued until data saturation had been achieved, with no new information obtained from the participants. The interviews were audio-recorded and transcribed verbatim by the first author.

2.3. Data analysis

Thematic analysis were used, following the six phases by Braun and Clarke (2006). The research team was experienced and inter-disciplinary, with backgrounds in psychology, medicine and nursing. This interaction gave breadth and depth to the analytic process. The phases of the analysis are described in Table 1. NVivo qualitative data analysis software (Version 12, 2018) was used to code and organize the data set (Bazeley and Jackson, 2013). (Examples of codes, subthemes and main themes identified from the analysis are available in the Supplementary for this article, Table 2).

2.4. Ethical approval

Ethical approval was obtained from the Norwegian Centre for Research Data (NSD, ref.876825) and the Personal Data Protection Officers at the three participating hospitals. The study was conducted in accordance with the Helsinki Declaration (World Medical Association, 2013). All participants signed informed written consent forms before participation, and were given the right to withdraw from the study at

Table 1
The six phases of thematic analyses inspired by Braun and Clarke.

| STEP | Description of tasks: |
|---|---|
| Phase 1. Familiarization with the data | <ul style="list-style-type: none"> The analysis process started with an inductive approach, where all the authors read the same interview, making notes of items of potential interest and preliminary codes |
| Phase 2. Generating initial codes | <ul style="list-style-type: none"> With the initial codes from phase 1 in mind the research group met to compare notes and discuss the topics of interest. These were then compiled in a list of initial codes, which became the first draft of the codebook. Two researchers (AÅ and EHL) then separately coded two more interviews, discussing recurring patterns across the data sets, and then reviewing the initial codebook. Next, two new interviews were coded using the revised codebook (AVM and EHL). The codebook was then discussed by the research team and finalized after consensus was reached regarding what codes to include. Lastly, the first author coded the remaining three interviews. No new codes were included. |
| Phase 3. Searching for themes | <ul style="list-style-type: none"> In the third phase of the analytical process, codes were collated and sorted into potential themes, gathering all data relevant for each potential theme |
| Phase 4. Reviewing the themes | <ul style="list-style-type: none"> A thematic map was generated, to assess whether the themes worked in relation to the coded extracts and the whole data set. Three overarching themes were identified. |
| Phase 5. Defining and naming themes | <ul style="list-style-type: none"> The themes were discussed, and the theme names were defined by the research group. To ensure that the analysis had captured each theme's primary content. |
| Phase 6. Producing the report | <ul style="list-style-type: none"> The findings related to the study aim and research questions were reported on, using supporting quotes. |

any time.

3. Results

The 56 multidisciplinary participants in the focus groups ranged from 23 to 66 years of age, with a mean of 43 years, and 51 were female. [Table 2](#) Participants' characteristics.

3.1. Results from the thematic analysis

The thematic analysis resulted in the identification of three main themes, with eight subthemes ([Fig. 1](#)): (a) The multifaceted nature of the end of treatment phase; (b) Navigating challenges in providing early survivorship care; and (c) HCPs views and suggestions regarding their role in transition care. See [Table 3](#) for supporting quotes.

3.2. The multifaceted nature of the end of the treatment phase

This first main theme consists of two subcategories, and comprises HCPs experiences caring for adolescents with cancer in the period leading up to treatment completion. The HCPs described this as a phase of change, involving numerous aspects of care needs for the families. They expressed ambivalence regarding (a) how, when and what information to provide, and (b) how best to balance support between the present 'in-treatment' situation and preparing the family for survivorship.

3.2.1. Focusing on surviving, not survivorship

Throughout the focus groups, the HCPs discussed how cancer severity made survival and remission their all-consuming focus during treatment. Some HCPs explained that they believed families to be so affected by the uncertainty of the cancer and its treatment that their

Table 2
Characteristics of focus group participants.

| | Nurses (n = 13) | Specialist nurses (n = 24) | Physicians (n = 8) | Allied Health Care Personnel ^a (n = 11) | Total (%) (n = 56) |
|---|--------------------|----------------------------------|-----------------------|---|--------------------------|
| Female (%) | 12 (23.5) | 24 (47.1) | 5 (9.8) | 10 (19.6) | 51 (91%) |
| Male (%) | 1 (20) | 0 | 3 (60) | 1 (20) | 5 (9%) |
| Age at interview Median (min–max) | 46.0 (23–60) | 48.5 (39–66) | 46.5 (38–65) | 44.5 (35–66) | 47.0 (23–66) |
| Years of experience Median (min–max) | 17 (2–36) | 23.5 (15–41) | 16.5 (10–30) | 17 (6–40) | 21 (2–41) |
| Years of experience paediatric oncology Median (min–max) | 10 (1–34) | 22 (5–37) | 12 (3–20) | 8.5 (1–37) | 17 (1–37) |
| Type of hospital | 10 (23.3) | 17 (39.5) | 7 (16.3) | 9 (4.2) | 43 (76.8) |
| University hospital | 3 (23.1) | 7 (53.8) | 1 (7.7) | 2 (15.4) | 13 (23.2) |
| Local hospital | | | | | |

^a Physiotherapists, dentist, nutritionist, social workers, psychologists, school counsellor, music -therapist.

focus was on the here-and-now—not the future ([Table 3](#), Q1). This, combined with the unpredictability of how each cancer trajectory unfolds, made it challenging to discuss survivorship until end-of-treatment.

Several HCPs explained that a key persistent barrier to focusing on survivorship was that their time and attention was largely spent on the inpatients who were seriously ill. They reported a 'natural' progression, from close and intense contact with newly diagnosed adolescents, to significantly reduced interaction towards the end-of-treatment. The HCPs felt that they 'lost track' of both how their patients were doing and their treatment protocol, describing this gradual loss of contact as a kind of 'fading away' ([Table 3](#), Q2). Consequently, when families approach the end-of-treatment and wants a shift of focus onto survivorship, the HCPs familiar with their history have limited opportunity to support them ([Table 3](#), Q3). The HCPs found this frustrating, explaining that although they are aware of how important the milestone of ending treatment is for the whole family, they are not always able to follow through or prepare for the 'big occasion' ([Table 3](#), Q4).

3.2.2. Balancing celebrations with concerns for the future

The HCPs described the period leading up to treatment completion as marked by mixed emotions for families: elation that their ordeal is almost over, alongside worries about managing on their own and fear of relapse ([Table 3](#), Q5). In response, the HCPs wanted to provide patients and their families with a break from the strain of being in treatment and to celebrate its completion with them. Thus, they reported that it was never a good time to discuss the potential challenges ahead, including adjusting to a 'new normal' and risks of late effects ([Table 3](#), Q6). This often resulted in ambivalent feelings of 'cheering the adolescent across the finish line' without preparing them sufficiently for life after treatment ([Table 3](#), Q7).

Some nurses reported that less-experienced colleagues often care for patients towards the end-of-treatment as their situation becomes less medically complex; these colleagues were described as more hesitant to answer survivorship questions, due to lack of knowledge. Moreover, many nurses noted that, when a patient is diagnosed with cancer, they conduct multidisciplinary team meetings and have routine assessments of the family's psychosocial needs; they also have well-established

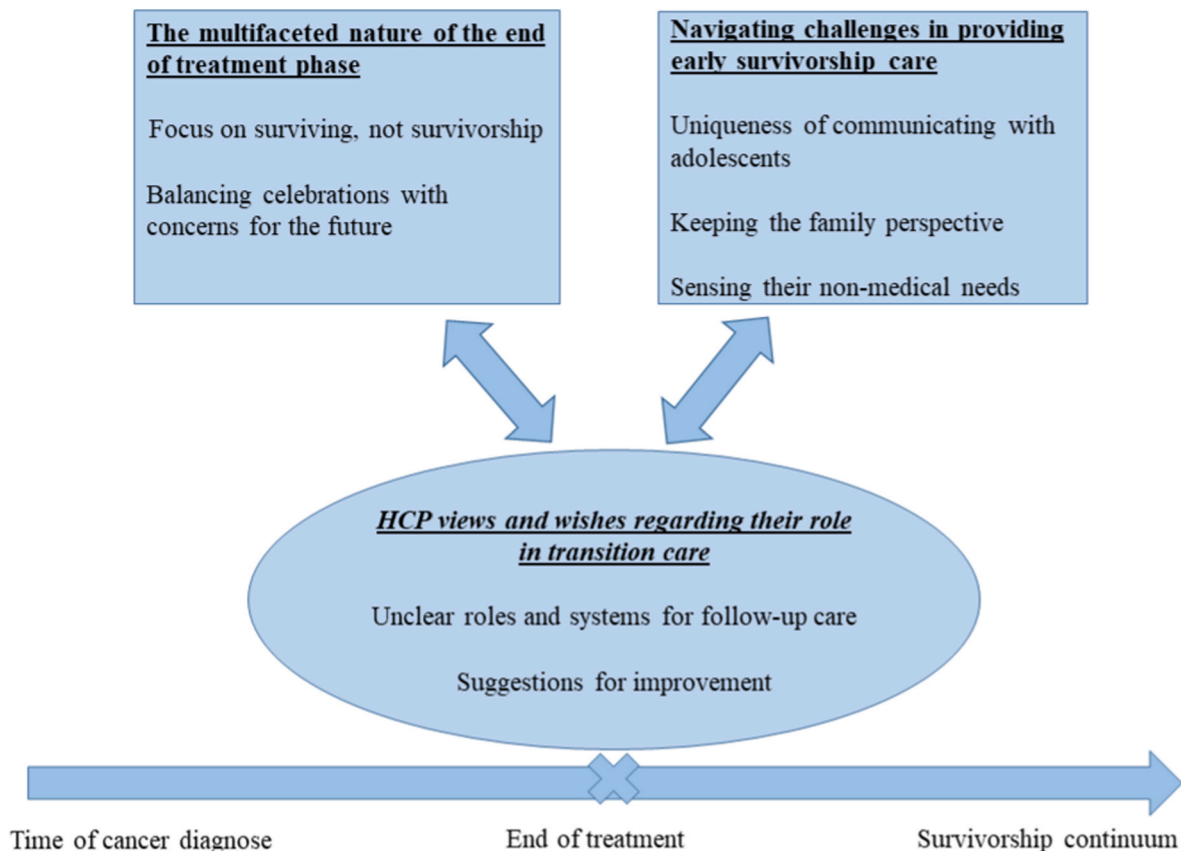


Fig. 1. Note. The arrows between the main themes represent the reciprocal influence these themes have on each other; the timeline arrow shows that this transition is happening during a specific time period.

routines for providing thorough information to teachers, school nurses, and classmates. In contrast, when transitioning off treatment, they rarely hold meetings or provide updated information to the adolescents' school or to local HCPs (Table 3, Q8).

HCPs highlighted that only the physicians follow patients throughout the whole cancer trajectory. With the exception of the nurses involved in follow-up care, the other participants described limited knowledge about "lives beyond end-of-treatment" and as such had little information to share about what to expect (Table 3, Q9). Moreover, some HCPs felt that the great individual variation among the patients and their families, with respect to risks of long-term effects, resources, coping and resilience, made it challenging to balance providing sufficient information with avoiding causing unnecessary concern (Table 3, Q10).

3.3. Navigating challenges in providing early survivorship care

The second main theme captures the HCPs' descriptions of different aspects of providing follow-up care for adolescents newly off treatment. The outpatient clinic staff pointed to the challenge of communicating and interacting with adolescents and parents in a way that meets everyone's individual expectations and care needs, in only a half-hour consultation. They expressed the awareness that while medical surveillance is the main focus of these consultations, it is nevertheless important to provide psychosocial support.

3.3.1. Uniqueness of communicating with adolescents

Many HCPs spoke about how they found it challenging to communicate well with adolescents because they felt more comfortable caring for younger children (Table 3, Q11). Some physicians also noted that talking with adolescents at the outpatient clinic was even more challenging as their parents usually accompanied them and were the more

proactive communicators during consultations.

Relatedly, several HCPs mentioned that talking alone with survivors facilitated their participation and a more 'open' conversation (Table 3, Q12). The outpatient nurses highlighted some 'golden opportunities' in which to have this one-to-one conversation, such as when measuring height and weight. However, these moments often ended in superficial talks, only giving hints as to the adolescent's survivorship challenges, due to frequent interruptions and limited time (Table 3, Q13). While the HCPs expressed an impression that many adolescents were psychosocially well-adjusted post-treatment, they acknowledged the many challenges survivors face while adjusting back to 'normality': for example, how the cancer experience can influence the adolescent CCS' maturity compared to peers, and their dependence on their parents (Table 3, Q14).

Several HCPs expressed that the approaching transition to adult follow-up made a stepwise transferral of health knowledge and responsibilities essential, and would support the adolescents' self-management within a future adult healthcare setting (Table 3, Q15). Paradoxically, however, HCPs also described a tendency among both parents and themselves to 'wrap the adolescent in bubble wrap', wanting to shield them from health-related responsibilities (Table 3, Q16). Some HCPs mentioned that they seldom asked adolescent CCS' whether they wanted more responsibility, or were content with parents as the main holders of information.

3.3.2. Keeping the family perspective

The HCPs expressed a shared understanding that the cancer trajectory was challenging for the entire family. They identified the importance of meeting different family members' individual needs, in addition to caring for the family as a unit (Table 3, Q17). Many of the allied members of the multidisciplinary team (physiotherapists, dentist,

Table 3
Illustrative quotes.

| | Focus on surviving, not survivorship |
|--------------------|---|
| Quotations in text | Illustrative quotes (words in italics indicate speaker emphasis) |
| Q1 | Nurse34: We talk very little about what happens post-treatment, or about late effects, for that matter. We seldom mention it, because there is so much other stuff all the time—so it's never a good time to address it. The families have to prepare for the next chemo [session] and then it's a holiday and after that it is the antibiotic treatment ... how much can they process? We experience that it's difficult for them to think as far ahead as post-treatment. The hope and the focus are for their child to get well—that's all they can think about. How their post-treatment life will be is too difficult for many to grasp. The result is that we don't talk about post-treatment or late effects. |
| Q2 | Nurse10: It just 'fades away', so it's like, all of a sudden, they're just not there anymore, without you really having discovered it. |
| Q3 | Allied*19: My experience is that we focus our efforts primarily on those who are very ill and in the phase where everything is difficult. When things are going better, we don't follow through. And it's a bit problematic, at least when you <i>know</i> that there are many who struggle with stuff later on—and you don't really have the opportunity to do very much about it, but you see that there's something missing. |
| Q4 | Nurse10: We had a party for one boy, because the family told us that it was the last chemo the next day. I just—'Oh, yes that's right! <i>Shit!</i> ' And he'd been really looking forward to it, so we had a party—and it was so <i>nice!</i> They were like, 'We've finally reached the finish line'. For <i>me</i> , it was just another chemo infusion—a short one! For <i>them</i> , a milestone, right! |
| | Balancing celebrations with concerns for the future |
| Quotations in text | Illustrative quotes (words in italics indicate speaker emphasis) |
| Q5 | Physician22: Parents and sometimes patients say ... it's like driving a car for the first time without a driving instructor. When finishing medication, some become a little more nervous and worried. They think it's scary not to be on any anti-cancer medication. Many people experience this phase as frightening because they've been kept under strict surveillance—and been hospitalized regularly and always received answers to everything they're wondering about. Then—at least as parents, they often experience that they feel a little ... <i>lost!</i> Where shall we go now? Whom can we call? How can we get in touch? |
| Q6 | Nurse25: I wonder when they're approachable. My experience is that they're a little unresponsive when treatment finishes and life starts again. I think that we must start talking about [survivorship] during active treatment, because they're a little 'Teflon' right when they're going out to regain 'normality' again. |
| Q7 | Nurse42: I have the impression that, when it comes to the end of treatment—that we nurses might paint, paint it a little too rosy: 'Just think that you're finished now, it's so good that you're done with it all'. Adolescents actually tell a different story. There's quite a lot that still can go wrong—and they're not prepared for a downturn. There are a lot who experience a challenging period. |
| Q8 | Nurse1: We're very eager when they're newly diagnosed to bombard them with information. We have lists and brochures and ... but when they are finished with treatment, they get like, 'Well, all the best and good luck!' |
| Q9 | Allied*9: I would've liked to know a little more about those who I've established a relationship with in such a critical phase of their young life. I would like to have the mandate, the time and the capacity to check in on them. For my sake and not least for their part, of course—how's it really going? Because I feel that I know so little about how they're doing out there. There's no such system. |
| Q10 | Nurse17: It's a very vulnerable period—what happens now? It's very different levels of coping, as some go out and deal with their life, while others ... they probably have kind of a mental breakdown—thinking that they'll be able to go back to the football team and be the goalie the way they were before the treatment and then they feel very depressed, as they are not on the team anymore, and they wish to be where they were before! |
| | Uniqueness of communicating with adolescents |
| Quotations in text | Illustrative quotes (words in italics indicate speaker emphasis) |
| Q11 | Physician5: We're not good enough with those adolescents, especially those who are about to become adults ... I know a lot about 4-, 5- and 6-years-olds, but I'm not always as good at talking to someone at 17. |
| Q12 | Nurse2: This applies to all of us, because we mostly see the young ones. |
| Q13 | Allied*37: There's at least one thing that is absolutely certain—we have some adolescents at our outpatient clinic, and they talk much less when mom or dad accompanies them. |
| Q14 | Nurse8: Follow-up consultations at the outpatient clinic are scheduled for half an hour. The adolescents come a quarter of an hour in advance to take measurements and blood samples, for instance—so there's limited time. So you ask, like this: 'How are you?' And then you have 1 min to listen—and they pick up on our time deficits—it's really a question like, 'Yes' and 'No' and 'Nothing!' |
| Q15 | Nurse12: The challenge for some of these adolescents, when they get sick in the phase where they really are supposed to break away from their parents—they're going <i>out</i> into the world, they're going to explore, they're supposed to ... do things they're not really allowed to do—all these things that everyone else is doing ... Well, then regression happens—they become much more childish again, at the same time as they're having an experience that makes them, in some areas of life, much more mature when returning to their friends. So it's that mixture of ... having some experiences that the others don't understand anything about, that makes them more mature—but they also regress and become more dependent on their parents. |
| Q16 | Physician41: Yes, I think at least in the transition—when they're about to grow up and have to start taking more personal responsibility, and ... build on that, [and] they're turning 15 and 16 and 17 and 18—when we talk to them. There, we have a very important role ... to influence or to educate them to take good care of themselves. |
| Q17 | Nurse2: But I think it's important to start earlier than what we do now, at transition. Maybe we have to start when they're 16 and send those parents out. Then they have to take a little more responsibility for their own disease. Those parents wrap them in bubble wrap—and we don't do anything about it either, we just let it happen. |
| | Keeping the family perspective |
| Quotations in text | Illustrative quotes (words in italics indicate speaker emphasis) |
| Q17 | Nurse6: I think we are so good at seeing the family as a unit and as a whole, that we have some trouble letting that go and spot them as individuals. |
| Q18 | Nurse12: But then you have the parents—parents who have lived a bit 'on edge' for quite a long time ... Parents who are unable to find their way back to everyday life—so we have to see the whole family and not just the teenagers. |
| Q19 | Physician21: Sometimes, I've been through the whole list, and I'm so happy with myself. [I] have 10 min left, you know, for stuff—then the parents say, 'I have some questions'. Then it takes another half an hour. I think I've been through everything and 'passed', but no ... it turns out that we haven't touched their problems at all! #00:16:19-8# |
| | Sensing their non-medical needs |
| Quotations in text | Illustrative quotes (words in italics indicate speaker emphasis) |
| Q20 | Nurse25: The outpatient follow-up consultation becomes in a way ' <i>the check</i> '—right! It's like, the bloodwork was fine, and they heard what they wanted to hear, and then they leave—satisfied! |
| Q21 | Physician21: I think that continuity in the follow-up is important in this context, so that you know what you've said, and know the patients and don't have a new doctor like that every time. Of course, sometimes it may be ... if there is new input or the doctor has gotten stuck in a track, that can be unfortunate—but mostly I think it is to know the patient and know what challenges they have, and stuff like that is then an absolute advantage at the outpatient check-ups. |

(continued on next page)

Table 3 (continued)

| | Focus on surviving, not survivorship |
|-----------------------------|--|
| Quotations in text | Illustrative quotes (words in italics indicate speaker emphasis) |
| Q22 | Nurse26: You meet the whole family, get to know them so well, and can read their body language. You see from consultation to consultation—Yes, today was a good day, but the next day he's down, and with both his parents present. So we know from experience that they're not feeling okay. So then, we spend a little extra time. Unclear roles and systems for follow-up care |
| Quotations in text | Illustrative quotes (words in italics indicate speaker emphasis) |
| Q23 | Nurse46: [The physicians] may have a little more like a transition conversation, but there is no system, there is no checklist, so I feel there's a <i>lot</i> that's missing. We see them at the ward, and then it's like someone else takes over when they're finished with treatment—then they're out of our system. So, I feel that a <i>lot</i> should've been done differently. |
| Q24 | Nurse6: I believe that people feel it's very important during the last treatment, <i>not</i> to meet an unknown doctor then! Well, this last time when they actually have quite a lot of questions ... Once again, here comes someone that has to read up on their medical history. I think, just in that last treatment, it's important to talk to someone ... who knows your story. Who has seen you, throughout the trajectory! |
| Q25 | Physician21: It's perhaps a bit expected, that when they're finished, we'll talk about the way ahead. However, I think a lot of them have some expectations for that transition, so in a way they really should've been better prepared, so they didn't have such high expectations for that conversation. I'm thinking, 'Hey, why are they so curious <i>now</i> —now they're just finishing'. So we might have prepared them too poorly for it, when we see how very interested they are in gaining more knowledge. |
| Q26 | Nurse28: I'm sitting here with a slightly embarrassed feeling inside, because I feel that I've learned so much lately about survivorship—I didn't have knowledge about it, even though I've been working for many years. They're healthy, and that's so enjoyable and all that. But I feel like I've failed them a little. |
| Suggestions for improvement | |
| Quotations in text | Illustrative quotes (words in italics indicate speaker emphasis) |
| Q27 | Nurse6: I think that last treatment is so special, so once during that stay there should be something called 'a conversation'. It shouldn't just be during the regular visit or when we're either in there talking randomly, seriously or shooting the shit. There's something about the fact that there will actually be a dedicated 'conversation' before discharge. I think it would've helped that <i>now</i> we sit down and talk about <i>this</i> . |
| Q28 | Nurse30: If we had a checklist, then we could talk through important post-treatment issues. What <i>they</i> have to take care of and what <i>we</i> are supposed to take care of—not only give them an overview of their follow-up appointments, but also what they might expect about ailments. I know that some of the doctors would arrest me now and say that we should not say anything about fatigue—because then they <i>will</i> certainly get it, in a way—but there is something about preparing them for the life that comes after cancer. With teens, we could talk about sexuality afterwards and things like that, because I don't think even a word of that is mentioned. |
| Q29 | Physician21: I think such a meeting should really be scheduled well in advance and follow a standard format. It might need to be a PowerPoint presentation on the disease and the treatment—sort of, where are we now, what is the way forward, what is special about that patient group and then about <i>this</i> patient. |
| Q30 | Nurse8: Having time to actually talk to them and ask how they are, how they are doing—I think it could mean a lot. If you could schedule half an hour extra with a nurse, for example, or ... something that would've given them a little more time then, I think it would've been ... Pick up a little more on how life works, how it's going at school, in their leisure time, what they can manage and [so on]. |

^a Allied HCPs (Physiotherapists, dentist, nutritionist, social workers, psychologists, school counsellor, music –therapist).

nutritionist, social workers, psychologist, school counsellor and music therapist) were especially concerned about the parents, and the extent to which they received adequate psychosocial support to adjust to life post-treatment (Table 3, Q18). The physicians reported experiencing that the parents had a substantial need for information, and that answering their questions was often time-consuming. Some also described feeling that their agenda for the follow-up consultation did not always reflect that of the parents (Table 3, Q19).

Furthermore, HCPs acknowledged that siblings also needed attention after treatment, but labelled this as outside their responsibility: they delegated the follow-up care of siblings to the families and other stakeholders as their schools or cancer organizations. While some psychologists, physicians and nurses reported having conducted a few consultations with siblings at the outpatient clinic, these were only upon parental request.

3.3.3. Sensing their non-medical needs

The physicians spoke about providing a thorough medical follow-up for the adolescents, with a focus on screening for adverse treatment effects and recurrence surveillance. They also noted that, without the treatment to keep the cancer in remission, families often worried—labelling the adolescence as still 'cancer-free' were thereby the message the families desired and made other issues less important (Table 3, Q20).

Physicians felt that seeing the same patient repeatedly made it easier to follow up on psychosocial challenges. In contrast, the non-physician HCPs described limited opportunities to do so, but were confident in the physicians' ability to handle this (Table 3, Q21). Only adolescents with significant problems were offered consultations with allied HCPs at the outpatient clinic. HCPs working at the university hospitals explained that they expected the local hospital to address the family's psychosocial

concerns—they also noted that this delegation of responsibility was rarely discussed or agreed upon with the local hospitals. However, nurses at small outpatient units explained that they knew the families well, and had more flexibility around providing informal support when needed; as such, they felt that this system seemed to work (Table 3, Q22).

3.5. HCPs views and wishes regarding their role in transition care

This third (and final) main theme spans the end-of-treatment and the early survivorship phases. The HCPs voiced a growing awareness of survivorship, due to increased research among colleagues, late effect seminars, and more media exposure. The two subthemes captured by this theme include HCPs' views on themselves and colleagues performing transition care, and on their suggestions for improving current practice.

3.5.1. Unclear roles and systems for follow-up care

When the participants described challenges in their current practice, certain phrases related to systemic barriers were repeated across the focus groups: these included a lack of clearly defined roles and responsibilities, work overload, time constraints, and a lack of continuity of care. In addition, the HCPs reported that their need for more time and resources to care for CCSs was unsupported by leaders and co-workers involved with other patient groups. They also emphasized that transition care suffered from a lack of guidelines around facilitating the transition; this contributed to the HCPs' expressed concerns regarding these adolescents' unmet needs (Table 3, Q23). Only the physicians described having conversations dedicated to transition during the last course of treatment. However, they stated that these conversations were often part of the regular daily rounds on the ward, and sometimes took

place with a clinician who did not know the family well (Table 3, Q24).

Furthermore, some HCPs were surprised by the high expectations and numerous questions at the end of treatment, especially from parents (Table 3, Q25). HCPs described that, with their existing system, information provision around the transition was random, and dependent on the individual HCP's capacity and priorities; they noted that this potentially resulted in adolescent CCS' and families being provided insufficient information. Indeed, many HCPs used the focus group to ask other participants about their transition routines, believing that other professionals or hospital wards had better systems in place. Some described that they felt embarrassed talking about their lack of a system, given what they knew about the families' perceived challenges and struggles (Table 3, Q26).

3.6. Suggestions for improvement

Several HCPs suggested establishing more meetings with the families at end-of-treatment. The physicians and the ward nurses expressed a wish for a joint transition consultation with the family during the final admission (Table 3, Q27). Similarly, the allied HCPs wanted to establish end-of-treatment consultations; they explained that this would give them the opportunity to have closure with the families, answer questions and evaluate the need for referrals to local healthcare services.

To ensure that consistent and equal information is provided to the adolescents, the HCPs suggested creating a 'transition checklist' with key information topics. Using the list as a communication tool would facilitate discussions of topics known to be important for adolescent CCSs, but that many found challenging to initiate, such as sexuality, smoking and alcohol use (Table 3, Q28).

Another suggestion was to arrange standardized digital network meetings between the specialist healthcare services, the family and HCPs in the municipality, such as the school nurse and the general practitioner; this, they felt, would ensure that the local support providers are informed about the family's current follow-up needs. The participants reflected on the fact that HCPs in communities might have limited knowledge of adverse long-term or late effects, and that direct information would facilitate more tailored local support (Table 3, Q29).

At the outpatient clinic, the HCPs suggested establishing separate nurse consultations with families to allow more time for psychosocial support and information provision. They explained that nurses with a focus on everyday living and self-management issues could complement the medical follow-up and contribute to more holistic care (Table 3, Q30). Another topic discussed throughout the groups was that many adolescents would benefit from rehabilitation post treatment. Several HCPs saw rehabilitation clinics as an important but underutilized healthcare service, and expressed a need for more widespread knowledge of their services and closer collaboration with the treating hospitals to ease the transferral of relevant patients.

Lastly, there was general agreement among the HCPs that transition off treatment was an important, but somewhat overlooked phase. Regardless of which hospital they worked at, there was consensus on which measures they would implement, with the aim of improving the transition for adolescent CCSs and their families.

4. Discussion

Our aims were to describe the experiences of multidisciplinary HCPs caring for adolescents transitioning off cancer treatment in Norway. Furthermore, we aimed to explore how HCPs prepared the adolescents and their families for this transition, and their ideas for improvements of current practice.

The first main theme, *the multifaceted nature of the end of the treatment phase*, conveys HCPs' feeling of uncertainty around the timing of survivorship preparations. Their clinical experience of families not being ready to 'see beyond treatment' contrasts the extensive literature on survivors' and parents' perspectives which recommends beginning

survivorship preparations before, and continuing through and beyond, transition off treatment (Keller et al., 2020; Nathan et al., 2011; Walker et al., 2016). HCPs also described patients as 'fading away' towards the end of treatment, due to the limited number of contact points. They used the word 'lost' to describe families struggling with unanswered questions and practicalities in early survivorship. This parallels recent findings that young adult CCSs wanted their transition to include time to recapitulate, get advice, and plan for survivorship and rehabilitation (Aase et al., 2022). Addressing information needs early on in survivorship is important, as unmet information needs appear to be common and have been associated with lower quality of life among young survivors (Derouen et al., 2015).

The second theme, *navigating challenges in providing early survivorship care*, concerned providing care to families after treatment and the perceived abrupt end of close contact between the HCPs and the families. While they had confidence in the existing medical follow-up, they were concerned that the psychosocial and academic struggles of some of their patients were not adequately addressed. Indeed, previous research has shown that a history of cancer can create emotional vulnerability and disrupt social functioning (Walsh et al., 2019; Collins et al., 2019; Eilertsen et al., 2011; Gurney et al., 2009). Further, young adult CCSs rate psychosocial support as important, especially at the time of treatment completion (Sender et al., 2020).

The HCPs valued good communication, and described how talking with their patients without parents helped them to speak more freely. The HCPs did, however, find it challenging to do so, due to busy schedules at the outpatient clinics. This is supported by other studies reporting on similar system barriers, including the need for more space, time and human resources in the follow-up of CCSs (Berg et al., 2016; Howard et al., 2018; Nathan et al., 2011).

Similarly, the HCPs were often unsure how to facilitate the CCSs' involvement and elicit their preferences with regards to decision making around their follow-up. HCPs admitted that they often turned to the parents for their opinions, even if the patients were 16 years or older and thus legal adults in the context of healthcare in Norway (Norwegian Ministry of Health and Care Services, 2015). The importance of changing this practice was discussed, and is supported by two systematic reviews emphasizing that adolescents want more involvement and decisional authority in their cancer care (Lin et al., 2020; Smith et al., 2020). The young age of the patients, cancer severity and strict treatment protocols are often seen as contributing to the lack of tradition around involving children and adolescents with cancer in shared-decision-making (SDM) (Coyné et al., 2014). There is, however, limited knowledge on how to best promote SDM in paediatric cancer care (Coyné et al., 2016), which is problematic as engaging young patients in SDM could help prepare them for taking responsibility for their own health care later on in life.

However, on a positive note, a recent systematic review has made recommendations on how HCPs can communicate effectively and facilitate SDM with adolescents and young adults post-cancer (Smith et al., 2020). They recommend e.g. a communication approach where HCPs take interest in the adolescent's life, spend alone time with them and try to bridge information gaps based on the survivor's current knowledge and their preferences for information giving. Indeed, these recommendations are concrete, seem easy to implement in clinical practice and should be advocated for in post-cancer follow up.

The HCPs also described it as challenging to be attentive to the whole family and balance their time between the different needs of the adolescent and the parents. This is in line with research showing that communicating is more complex when more people than just the patient are present (Laidsaar-Powell et al., 2013) and that parents often prefer more information about the future, while adolescents prefer information about the here-and-now (Belpame et al., 2016). Moreover, the adolescents and their family's information needs may change over time and across the stressful transition period, thus making information provisioning a challenging task (Wakefield et al., 2011). Lastly, the HCPs'

perceived lack of psychosocial support for siblings post-treatment is in line with previous studies (Cheung et al., 2020; Long et al., 2018), and emphasizes the need for a whole-family approach when providing transition care.

The final theme, *HCPs roles and responsibilities in transition care*, concerns the participants' views on their own roles and responsibilities during the transition, and their ideas for improving current practice. Most of the participants showed a strong passion for childhood oncology and a high level of job satisfaction. Some, however, also described job-related stressors, including providing inadequate care, a heavy workload and interpersonal conflicts, which have been described elsewhere (Mukherjee et al., 2009).

A main suggestion from the Norwegian HCPs was to establish more meetings with the families at end-of-treatment to better provide information and support. This corresponds with another study where HCPs and young survivors together identified "earlier provision and preparation around impact of cancer and cancer treatment" and "standardized and continued follow-up on emotional well-being" as the two main priorities to better meet the needs of adolescents and young adults at end of treatment (Lea et al., 2020b, p10).

We have also interviewed adolescents and their parents on their experiences at the end of treatment and will in an upcoming article discuss their preferences for information and support and explore to what degree they match the perception of the HCPs.

In line with previous research (Gulati et al., 2014), the HCPs valued having access to the extensive knowledge and expertise of their multi-disciplinary colleagues. However, this support was mainly dedicated to the newly admitted patients, making transition and early survivorship care the responsibility of the nurses and physicians at the outpatient clinic. Systematically involving allied HCPs who knew the families towards the end of treatment could be an opportunity for a more holistic evaluation on the adolescents' survivorship needs. Such concerns for unmet rehabilitation needs post-treatment have also been reported elsewhere (Lie et al., 2019; Thorsen et al., 2022).

The HCPs' suggestion to expand the role of the outpatient clinic nurses to deliver nurse-led consultations could potentially bridge the gap between biomedical follow-up and family's psychosocial supportive needs, in addition to reduce the physician's workload. Nurses play an important role for the adolescents during treatment, and are seen as more easily approachable by the families (Bashore and Hobbie, 2021). During consultations, nurses can serve as counsellors, educators and supporters, and address non-medical survivorship topics. Nurse-led consultations have been established in adult cancer populations with encouraging results (Lewis et al., 2009; Van Der Meulen et al., 2014); moreover, they are evaluated as delivering high-quality care, applicable to other cancer populations (De Leeuw and Larsson, 2013). In addition, facilitating online meetings with the families and local stakeholders, including local HCPs, may have the potential to improve collaboration, coordination and knowledge transfer between the healthcare sectors.

The transition off active treatment is of particular interest to clinical practice because it serves as a 'teachable moment', where patients are more open to making beneficial lifestyle changes and learning helpful self-management strategies (Frazelle and Friend, 2016). However, perceived lack of HCP support can negatively influence cancer survivors' motivation to engage in such adaptive changes (Corbett et al., 2018). Developing and implementing individualized transition programmes for adolescents would therefore have immediate value, both financially and resource-wise. Moreover, the potential long-term savings from empowering adolescents to better manage the medical, physical and psychosocial aspects of cancer survivorship, promote a healthy lifestyle and adhere to follow-up care would likely be substantial.

4.1. Methodological strengths and limitations

This study's main strength was the diversity of the sample, in terms of geographic location, age, gender, professions and experience: this resulted in rich and nuanced data, which enabled the investigation of complex relationships, with both complementary and contradictory perspectives. We found that most participants took an active part in the discussions, willingly shared their reflections, were self-critical and voiced both beliefs and uncertainties within the group. This also corresponds to the use of focus groups as a methodology: as group processes that can help participants clarify and explore views and values that are less accessible via other methods (Carey and Asbury, 2016). The methodological rigour of this study was enhanced by involving several experienced researchers in the data analysis.

This study also has some limitations. The study was conducted within the Norwegian publicly funded, specialist healthcare system. We do, however, believe that the findings have relevance for similar healthcare settings internationally, and that the suggested improvements may be applicable to other transition programmes as well. The paediatric oncology specialist health community in Norway is relatively small, so it was unavoidable that some of the participants were acquainted with the researchers. As the topics were connected to their work experiences, and everyone contributed by choice with no direct individual questions, we considered this acceptable.

5. Conclusion

The HCPs provided a rich perspective on factors contributing to families' needs and the existing challenges associated with delivering transition care. Our work offers concrete suggestions for improvements of current clinical practice. Moreover, prime targets for transition interventions have been identified. While the HCPs were well aware of the many challenges faced by families during the transition off treatment, they experienced having limited opportunities to address them within the constraints of the current system. They called for a more formalized and systematic transition care model, with increased nurse involvement, to mitigate some of the challenges adolescents and their families experience in this vulnerable phase.

CRedit authorship contribution statement

Elna Hamilton Larsen: Conceptualization, Methodology, Validation, Formal analysis, Writing – original draft, Writing – review & editing. **Anneli Viktoria Mellblom:** Conceptualization, Methodology, Validation, Formal analysis, Writing – review & editing, Supervision. **Ellen Ruud:** Conceptualization, Methodology, Validation, Formal analysis, Writing – review & editing, Supervision. **Astrid Klopstad Wahl:** Methodology, Validation, Formal analysis, Writing – review & editing, Supervision. **Hanne Cathrine Lie:** Conceptualization, Methodology, Validation, Formal analysis, Writing – original draft, Writing – review & editing, Supervision, Project administration.

Declaration of competing interest

The authors have no conflict of interest to disclose.

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Appendix A. Supplementary data

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