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RESEARCH

A qualitative study on the healthcare experiences of adolescents and young adults (AYA) with an uncertain or poor cancer prognosis

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Abstract

Purpose Treatment advancements have improved life expectancy for adolescents and young adults (AYAs) with an uncertain and/or poor cancer prognosis (UPCP) and change clinical practice. This improved survival requires a different approach and specific expertise to meet the needs of this group. The aim of this study is to explore the health care experiences of AYAs with a UPCP.

Methods We conducted a multicenter qualitative study using semi-structured interviews and elements of the grounded theory by Corbin and Strauss.

Results Interviews were conducted with 46 AYAs with a UPCP. They were on average 33.4 years old (age range 23–44), and most of them were woman (63%). Additionally, five AYAs with a UPCP participated as AYA research partners in two focus groups. They were on average 31.8 years old and four of them were woman. AYAs with a UPCP reported four pillars for a satisfied healthcare experience: (1) trust, (2) tailored communication, (3) holistic empathic open attitude, and (4) care being offered (pro-)actively. They reported both optimal and suboptimal experiences about distrust based on a delay in diagnostic trajectory, lack of tailored communication and discussion of sensitive topics, preference for a holistic approach, and struggles with finding the way to get additional healthcare support.

Conclusion For AYAs with a UPCP, it is important that both age-specific issues and issues related to the UPCP are understood and addressed; however, this seems not yet optimally implemented in clinical practice. This emphasizes the importance of providing this patient group with tailored care incorporating both aspects. Healthcare professionals need to be supported with training and tools to understand the healthcare needs of AYAs with a UPCP. AYAs can be empowered to take more control over their own healthcare needs

Keywords Adolescents and young adults · Uncertain and/or poor cancer prognosis · Healthcare experiences · Qualitative research

Introduction

Advancements in treatment have led to increased survival rates for cancer survivors overall; consequently, nowadays, a growing number of individuals diagnosed with advanced or metastatic cancer are also living longer with their cancer [1, 2]. People living with advanced or metastatic cancer may receive lifelong treatment to prolong life but without expectation of a cure for their cancer. Next to this group, patients with low-grade gliomas live with the uncertainty of a disease that eventually will evolve to a lethal brain tumour. Living longer with advanced or metastatic cancer often comes with a cost of burdensome physical symptoms; psychosocial issues such as on-going uncertainty, anxiety and stress about running out of treatment options; financial hardship; social challenges and negative impact on one's normal daily life and future perspectives [3–6]. In addition, these patients have complex care needs that include care coordination among multiple care providers [7–9].

A subpopulation within this large group of patients living with advanced or metastatic cancer is the so-called

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adolescents and young adults (AYA) living with an uncertain or poor cancer prognosis (UPCP) [10]. In the Netherlands, AYAs are defined as those diagnosed between the ages of 15 and 39 [11]. Previous studies indicate that AYAs with cancer have different psychosocial and medical needs than their older adult cancer patients, related to their specific developmental life stage and age-related risk factors [12–18]. These unique age-specific needs may be even more complex in AYAs with a UPCP, as they are struggling with a loss of control, a sense of grief about their previous life and about the life that they are not going to live, loneliness and feeling inferior to previous self and others [19]. These challenges are associated with a sense of altered identity, their (new) position in the social network and the future uncertainties of an AYA with a UPCP [19].

Up to now, research on unmet care needs and experiences of AYAs in general showed a lack of clear age-appropriate information and communication by healthcare professionals (HCPs) about disease, treatment and implications for daily life [8, 13, 20]. The way HCPs interacts with the AYA and deal with their care needs is an important contributor to patients' satisfaction with care [13]. However, a recent study showed that HCPs experienced emotional and practical challenges when providing care to AYAs with a UPCP, especially regarding communication about the uncertain life perspective and support on psychosocial level [21]. AYA age-specific knowledge and understanding the psychosocial needs of an AYA cancer patient related to their developmental life phase are important aspects for HCPs to increase trust and confidence of their AYA cancer patients [13]. Multiple studies found unmet needs of AYAs, such as age-appropriate information, life themes (e.g., school, work) and peer support [22–27].

Worldwide, several AYA care programs and interventions are being developed to meet the unique needs of AYA patients [28–31]. For example, the AYA topic list as developed by the Dutch AYA Care Network, which serves as a tool for healthcare professionals for addressing AYA-related topics [32]. However, to date, the care experiences and care needs of AYAS with a UPCP are largely unknown, and there are no specific care initiatives for this new patient group. As treatment advancements ask for changes in clinical guidelines and the need for expert knowledge, there is growing attention that patient-centred care initiatives have to be developed to meet the unique medical, psychosocial and supportive care needs of AYAs with a UPCP. Therefore, this study aimed to explore the care experiences of AYAs with a UPCP, with a focus on areas of improvements. The goal was to provide oncology HCPs with examples and tools to provide the best possible care.

Methods

This paper presents a secondary analysis of the qualitative interview study (conducted April 2021–April 2022) of Burgers et al. [19].The Consolidation Criteria for Reporting Qualitative Studies guideline was followed to guarantee quality and transparency of reporting [33] (Table 3).

Participants

We recruited AYAs with a UPCP from eight University Medical Centers in the Netherlands, the Netherlands Cancer Institute and Haaglanden Medical Center. Eligible patients were those (1) diagnosed with any type of advanced cancer for the first time between 18 and 39 years of age, for which there is no reasonable hope of a cure, indicating that the patient will die prematurely due to cancer, and (2) able to speak and understand Dutch. Terminally ill patients with a life expectancy of less than 3 to 6 months and a poor performance status were excluded. Additionally, we included five eligible AYAs with a UPCP (AD, NH, MH, SF, SF) in a focus group as research partners, which is described in more detail in Burgers and colleagues [19]. This study obtained ethical approval from the Institutional Review Board of The Netherlands Cancer Institute (IRBd20-205).

Procedure

A trained female psychologist and qualitative researcher (VB) conducted the one-on-one semi-structured interviews via Microsoft Teams after informed consent. The interview guide was based on current literature and drafted in collaboration with experienced researchers (WvdG, OH) and AYA patients who were actively involved as research partners in this study (AD, NH, MH, SF, SF) (Table 1). For more details on the active involvement of AYA research partners in this study, see the GRIPP2-SF checklist Table 4 [34] (supplement 3) and study of Burgers et al. [35]. Besides the interviews, we conducted two online focus groups with five AYA research partners to discuss preliminary results of the interviews. The focus group aimed to check for interpretation and correctness of a patients' point of view and gave additional insights into the healthcare experiences of AYAs with a UPCP [19]. Interviews and the focus groups were audio-recorded and lasted on average 84 min (Range: 49–122) and 55 min (range: 40–70) respectively. Furthermore, patients completed a short case record form (CRF) on their sociodemographic and medical status. Additionally, clinical data was asked from the treating clinician after patients gave explicit permission.

Table 1 Interview guide

Questions	Probes
1. Could you please tell me about your experience with the hospital as a young patient with cancer?	Could you please tell me what goes well? Could you please tell me what kind of problems you are running into?
2. Do you or did you have unmet needs regarding information or support?	If so, could you please elaborate? (it was not assessable, you didn't find the right support or didn't know where to find it)
	Could you please give me an example of a situation in which you did not even notice you needed information or support until you received the information or support?
	Who is your contact person within the hospital for specific questions? Could you please elaborate?
3. How would you describe the relationship with your primary healthcare professional? (possible to repeat this questions multiple times for different healthcare professionals)	Could you please give me an example that showcases this well?
	What aspects are you satisfied about? What would you like to see differently?
	What questions should your healthcare professional ask you or what should he/she notice about you to know how you are really doing?
4. With whom of the healthcare professionals do you feel free to discuss whatever you want?	Could you please elaborate? (what topics do you discuss, differences between healthcare professionals)
	Are there any taboo topics you do not want to discuss with your healthcare professional(s)? Could you please elaborate?
5. What do you need from your healthcare professional when talking about end of life?	What are your needs regarding communication about end of life? (when and how)
	Do they communicate clearly about which phase of the disease you are in currently?

Data analysis

Interviews and focus groups were transcribed verbatim, and the transcripts were analysed by VB with the help of NVivo [36]. Analysis was performed according to elements of the grounded theory by Corbin and Strauss, such as open, axial and selective coding in combination with a constructivist philosophical perspective [37–39]. A cyclic process was applied in which we were going back and forth between data collection and data analysis. For the first 15 interviews (five for each subgroup), another independent researcher (MR) repeated this process, in order to identify and discuss different perspectives on the same data. In case of disagreement, the remaining codes were discussed with the research team and the AYA research partners. Axial coding was done with the help of "the paradigm" of Corbin and Strauss [37]. Data collection stopped when conceptual saturation was reached [37].

Results

Demographics

Forty-six of the 64 patients (71%) who were approached completed the interview. Eleven patients declined since they felt too unwell, four patients were too busy or did not want to talk about their disease and three patients did not respond. Five patients participated in the focus groups. The demographics of the 46 patients and focus group are summarised in Table 2.

Healthcare experiences of AYAS with a UPCP

AYAs with a UPCP reported optimal as well as suboptimal healthcare experiences, which can be summarized with the following four themes: (1) trust; (2) tailored communication; (3) holistic, open and empathic relation and (4) care being offered (pro-)actively. The "Results" section focuses on the healthcare wishes and needs of AYAs with a UPCP while the optimal healthcare experiences are mostly presented as examples of helpful behaviour in Table 5.

Theme 1. Trust

For AYAs with a UPCP, trust in the patient-doctor relationship is very important, since the majority experience distrust towards general practitioners and medical doctors based on their previous experiences such as a delay in diagnostic trajectory. They feel that they are not taken seriously due to their young age and that they receive incorrect or incomplete information. For some AYAs, it even caused serious trauma: "They never told me that there was a chance that it would metastasize and certainly not in that place of my body. You lose faith in what they say?" (woman, 28, rhabdomyosarcoma). This attitude of distrust is also projected onto their

Table 2 Demographic and clinical characteristics of the 46 AYA patients and the five focus group participants

Characteristics	Total AYAs[a] *N* (%)	Focus group *N* (%)
Age at initial diagnosis, years		
Range	23–39	20–38
Mean (SD)	29.6 (4.8)	27.6 (6.6)
Current age, years		
Range	23–44	23–38
Mean (SD)	33.4 (6.3)	31.8 (5.5)
Gender		
Woman	29 (63.0)	4 (80.0)
Men	17 (37.0)	1 (20.0)
Religion		
No	38 (82.6)	5 (100)
Yes[b]	8 (17.4)	0 (0.0)
Marital status		
Married or partnered	38 (82.6)	3 (60.0)
Single	8 (17.4)	2 (40.0)
Living situation		
Living alone	7 (15.2)	1 (20.0)
Living with partner and/or children	32 (69.6)	1 (20.0)
Living with children	3 (6.5)	0 (0.0)
Living with parents	2 (4.3)	0 (0.0)
Other[c]	2 (4.3)	1 (20.0)
Children		
Yes	19 (41.3)	2 (40.0)
No	27 (58.7)	3 (60.0)
Highest achieved level of education		
Secondary education or less	4 (8.7)	1 (20.0)
Secondary vocational education	16 (34.8)	1 (20.0)
Applied university	16 (34.8)	1 (20.0)
University	10 (21.7)	2 (40.0)
Employment status[d]		
Student	3 (6.5)	1 (20.0)
Paid work	20 (43.5)	2 (40.0)
Unemployed	1 (2.2)	0 (0.0)
Homemaker	1 (2.2)	0 (0.0)
On sick-leave/ work disabled	23 (50.0)	2 (40.0)
Type of cancer		
(Low-grade) glioma	16 (34.7)	1 (20.0)
Sarcoma	7 (15.2)	1 (20.0)
Breast cancer	6 (13.0)	1 (20.0)
Lung cancer	6 (13.0)	1 (20.0)
Melanoma	3 (6.5)	0 (0.0)
Cervical cancer	2 (4.3)	0 (0.0)
Other[e]	6 (13.0)	1 (20.0)
Stage at diagnosis (interview)		
III	1 (3.3)	0 (0.0)
IV	25 (83.3)	3 (40.0)
N/A or unknown[f]	20 (43.5)	2 (60.0)
Current treatment[g]		
None/Active surveillance	16 (34.8)	2 (40.0)
Chemotherapy	14 (30.4)	1 (20.0)
Targeted therapy	10 (21.7)	1 (20.0)
Experimental therapy	3 (6.5)	0 (0.0)
Hormonal therapy	3 (6.5)	1 (20.0)
Immunotherapy	1 (2.2)	0 (0.0)
Radiotherapy	1 (2.2)	0 (0.0)
Receiving care from		
Medical doctor	47 (100)	5 (100)
Clinical nurse specialist	12 (26.1)	2 (40.0)
AYA clinical nurse specialist	4 (8.7)	1 (20.0)
Other healthcare professionals[h]	20 (43.5)	3 (60.0)

LGG low-grade glioma, *N/A* not applicable

[a]Total *N* = total interviewed AYAs, AYAs participated in focus groups are not included

[b]Yes = Christian, Protestant, Islamic

[c]Other = living with brothers, living with parents and son, living with housemates

[d]Total exceed 100% since some participants were partly disabled and worked part-time for the other part

[e]Other = colon cancer, epithelioid hemangioendothelioma (EHE) neuro-endocrine tumour (NET), ovarian cancer, gastrointestinal stromal tumor (GIST)

[f]N/A includes 16 low-grade gliomas patients, since these are grade 2 tumours according to WHO Classification of Tumours of the Central Nervous System

[g]Not equal to 100% due to the combination of treatments

[h]Psychologist, social worker, physiotherapist, dietician, occupational therapist, oedema therapist, spiritual care provider

treating doctor, even if this doctor had nothing to do with the delay in diagnostic trajectory. AYAs indicate they gain trust towards their medical doctor if they feel that he/she is skilled and has a lot of tumor-specific expertise. AYAs value a HCP who does not make them feel like a number in the healthcare system; they want to be able to reach their medical doctor or another HCP, want a connection, tailored care and want to feel that their medical doctor is fighting for them. "Fighting" is described by AYAs as having the idea that their medical doctor will do everything for them, like deviating from the protocol if necessary and looking for new (experimental) treatments until the end. "To feel like: you are my only patient and I will do everything I can for you, because your life is important" (woman, 41, leiomyosarcoma). Trust in their medical doctor fluctuates over time and can easily be damaged by incidents (e.g. not calling back, no clear information about prognosis). Almost all AYAs with a UPCP call their medical doctor their lifeline; "That man [medical

doctor] decides about my life. He has to make sure that I live longer, I am dependent on him." (woman, 44, lung cancer). According to AYA cancer patients, their dependent position towards their medical doctor results in inequality in their relationship. AYAs want to be a 'good patient' to ensure their medical doctor remains 100% committed, which means that they do not always openly share complaints.

Theme 2. Tailored communication

In the context of an uncertain and/or poor cancer prognosis, the majority of the AYAs are unaware of their prognosis or current disease phase. Besides personal preference not to know, one of the causes is unclear communication by their medical doctor giving ambiguous answers or subjective statements. "My medical doctor has never told me that I am palliative. I would not live to be 80, but what does that mean?" (woman, 33, osteosarcoma).

"My medical doctor is not afraid that I will die soon. What does that mean? A half-year life expectancy? She is more optimistic than me; she thinks my scan looks fine when I see cancer almost everywhere" (woman, 35, breast cancer)

Some AYAs indicate that the information they receive is based on statistics that do not apply to them because of their young age. The content of the medical information is not always matching with the knowledge and understanding of medical jargon of the AYA. Additionally, the way of providing medical information is not always aligned with their information processing speed. Others do experience continuous alignment and find it valuable: "He [medical doctor] asks what you want to know, tells you exactly what is going on and expects you to let him know if you understand. If not (understands), he tries to explain it again" (man, 36, low-grade glioma). AYAs with a UPCP appreciate transparent and honest communication about prognosis, even if there is no clear answer, or if it is bad news. Some AYAs would rather prefer a broad life expectancy range than having no answer at all; others find it helpful to get information on positive outliers. Some AYAs miss the acknowledgement of the emotional impact of the given information and wish to receive some time to process. This is also the case with end-of-life communication, where the right timing is of paramount importance. According to most of the AYAs, the best time is when there is progression, and there are (almost) no treatment options left. However, almost everyone expresses that the expectation is that the medical doctor will initiate this end-of-life conversation. When this conversation is not initiated, the AYA believes it is probably not necessary. As an exception, some AYAs try to initiate the end-of-life conversation but experience that their medical doctor dismisses this topic.

Finally, some young AYAs indicate that they feel not always seen and treated as an adult when communicating with their medical doctor. One AYA explains that her consultations with the medical doctor feel like parental meetings, where she had to learn what to do and what not to do. Another AYA explains: "My neurologist called my father because I was not able to answer the phone. That was frustrating. This is about me, I am an adult woman of 23 and my father is not in charge" (woman, 23, low-grade glioma). On the other hand, one AYA indicates that her young age was not taken into account when she requests to have someone with her during chemotherapy despite the COVID-19 rules.

Theme 3. Holistic, empathic and open approach

Most AYAs describe the relationship with their medical doctor as a professional relationship. Some AYAs report struggling with feeling rushed and the limited time during consultations, which often means that they do not feel the opportunity to ask all questions. Additionally, some AYAs hesitate to ask questions regarding drugs, sexual health and their wish to become a parent because they find it uncomfortable. Others report being afraid of a negative response, a negative impact on their patient-doctor relationship or negative consequences for their treatment when discussing topics like sex without a condom, suicidal thoughts, complementary care and a second opinion. "I have not even told my doctor what kind of supplements I started taking again because at the beginning she was so negative about everything I suggested" (woman, 28, rhabdomyosarcoma). According to AYAs with a nurse specialist or case-manger, this relation is more open, and the threshold to ask questions or initiate topics is less or even not present. However, the majority of the AYAs do feel as if they can discuss everything with their medical doctor since their medical doctor is open-minded and initiate discussions about sensitive topics. The good relationship of AYAs with their medical doctor is defined by the degree of empathy and involvement of their medical doctor. The majority of the AYAs appreciate a doctor who shares some personal information and uses humour during their consultations. Most of all, AYAs with a UPCP find it important that their medical doctor has a holistic approach to treating them as individuals with emphasis on their quality of life. "A doctor who looks beyond his specialty and checks how things are on mental and physical level. Asking specific questions instead of 'how are you' because I often say I am fine so that does not work" (woman, 41, breast cancer). However, in clinical practice critical questions about one's mental health, living situation or family are still not always asked. Some AYAs with a low-grade glioma complain about the lack of attention for brain tumour–related problems like epilepsy.

Theme 4. Care being offered (pro-)actively

According to AYAs, patients have to be assertive if they want additional care in terms of mental or practical support. However, most of them do not know what kind of support they need since they do not know what support is available, and most importantly, they do not know where to get support. AYAs report unmet needs regarding guidance after a bad news conversation, around the start of treatment and during treatment. They prefer someone who can relate to their experience like some experience expert buddy. "The books you get do not describe the emotional impact. It would be nice if you could talk to someone who has been through the same experience, a kind of buddy" (woman, 36, melanoma). Additionally, several AYAs miss support regarding: work, finance, diet, exercise, support for their children and informal caregivers, complementary care, sexual health and fertility, peer support and epilepsy (patients with low-grade glioma). Some AYAs report the lack of a nurse specialist or case-manger in specific: "For me, a nurse specialist would be a solution, someone who I can email for questions. But I do not have a nurse specialist and I am not going to call the doctor" (woman, 35, breast cancer). Several AYAs are in need of an information booklet with all the important aspects they should pay attention to as AYA with an incurable disease, including a list of care initiatives and benefits to which they are entitled to, and existing patient organizations. AYAs without a regular contact person within the hospital often postpone their questions and are in need of a case manager or clinical nurse specialist. While most AYAs with a clinical nurse specialist or case manager reported optimal experiences and see them as gatekeepers for questions and additional care. Some AYAs even believe they are responsible for keeping each HCP of the team up to date. Remarkably, some AYAs had not yet been referred to AYA care and some did not even know they belong to the AYA community.

Discussion

To our knowledge, this study is among the first that shows the healthcare experiences of AYAs with a UPCP. Overall, this group reported optimal as well as suboptimal experiences about the care they receive, reflecting the challenges of AYAs, HCPs as well as healthcare organizations. In this study, we identified four themes that can be seen as pillars for a satisfied healthcare experience according to AYAs with a UPCP: (1) trust, (2) tailored communication, (3) holistic empathic open attitude and (4) care being offered (pro-) actively.

The four themes that were identified in this study show that most of the AYA healthcare experiences are not AYA-specific but are comparable with the healthcare experiences of adult cancer patients [40–42]. For example, trust is generally considered an important component of the patient-doctor relationship (40). Furthermore, previous research showed that adult advanced cancer patients also reported suboptimal experiences when communication was not tailored to their preferences and how important tailored communication is when it comes to prognostic information [41, 42]. Besides their need to know and understand, adult cancer patients also have a need to feel understood [41]. This can be seen as their need for a holistic view and empathy.

However, when zooming in on the four themes, we can conclude that some experiences specifically have to do with combination of a UPCP at AYA age. For example, we found that many AYAs with a UPCP experienced frustration about a delay in the diagnostic trajectory due to their age and tumour characteristics [43]. In most cases, they experienced this frustration before even starting treatment. AYAs with a UPCP feel like they always have to fight for their healthcare because they are often the exception and therefore do not fit within protocols. This makes trust an indispensable foundation for the patient-doctor relationship within this group of AYAs who call their doctor their "lifeline". It has been suggested that a life-threatening disease and the severity of treatment might force patients to trust almost unconditionally [40, 44]. However, this trust and distrust is often not discussed in the consultation room but is reflected in the behaviour of the patient such as searching for available treatments worldwide and assuming a dependent role towards the medical doctor [45]. The concept of distrust is lacking in AYA literature, indicating that it might be specific to the understudied group of AYAs with a UPCP. The amount of distrust in this patient group could be explained by the fact that the medical doctor cannot or is hesitative to give the AYA with a UPCP any certainty. Above, half of the AYA participants in this study were diagnosed with a rare disease (low-grade glioma and sarcoma) with diagnostic difficulties or diseases with less specific symptom features (melanoma), which may play a role in the delay in the diagnostic trajectory [43]. The key elements for trust as reported by the

AYAs in this study, such as a medical doctor with a lot of knowledge and skills, are in line with previous research [13].

Communication about disease status, prognosis and end-of-life care with AYAs with a UPCP is complex for HCPs. Medical doctors are often not able to give a prognosis for AYAs with a UPCP given the low clinical trial participation rates of AYAs, resulting in a lack of reliable data. AYAs experience a lack of clear communication and explanation regarding this uncertain prognosis [46, 47]. Some of them do not even know their disease phase while they want to know, which hinders them from making important treatment decisions and plans for the future. Planning their future is even more important for this young age group since they are in a phase of life where generally important milestones are being achieved. Besides ambiguous information, it is well known that patients' interpretations of their prognosis or disease phase can differ from those of their medical doctors, and some do not want to hear a poor prognosis [48]. Overall, it seems that doctors and patients are still holding each other in a coalition of hope: the doctor does not want to take away patients' hope when initiating the conversation on end-of-life, and the patient believes all is well as long as this topic is not discussed [21]. Although this is a general phenomenon, previous research suggests that it might be more intense in the AYA population since their young age and lack of statistical information are an extra challenge for oncologists when communicating about poor prognosis [21]. As a result, important goals regarding quality of life of the AYA may be missed. Looking at quality of life and the individual behind the disease are essential for trust in the medical doctor and ensure that the AYA does not feel like a number. However, the results of this study suggest that medical doctors do not often ask questions about everyday life and do not always initiate sensitive topics. Nevertheless, AYAs do not dare to ask those questions either. For example questions about complementary care, sex health and suicidal thoughts [49]. These topics are addressed as taboo topics in AYA patients by Perez et al. and are also mentioned in earlier research regarding challenging topics to discuss according to HCPs providing care to AYAs with a UPCP [14, 21]. A future study comparing AYAs and older patients should indicate if these topics are indeed AYA specific.

Furthermore, AYAs with a UPCP wish for a holistic, empathic and open attitude from their medical doctor. This corresponds with literature about generation *x* and *y*, in which this generation is described as empathic and innovative [50, 51]. This can be translated to AYAs' desire for an empathic response on their emotional behaviour and search for more emphasis on health behaviours such as diet, exercise and supplements. A previous study addressed searching for treatment alternatives as a coping strategy to deal with an uncertain prognosis [45]. The request for a holistic approach is also about seeing and understanding the age and developmental life phase in this context of a UPCP. It might be that in this specific AYA group, the UPCP sometimes takes a more central spot than the AYA age [51, 52]. It seems that the combination of a developmental life phase, the expectations and wishes of this age generation, namely generation *Y* (born between 1982-1994) and *Z* (born between 1995 and 2009), according to a patient-doctor relationship and the UPCP making a holistic, empathic and open attitude extra important in AYAs with a UPCP [50]. Finally, AYAs with a UPCP do not always know which support is available and where to get it. Possibly, because most of them are not familiar with the healthcare system and some even do not know what their own needs are.

Although this is the first study to investigate healthcare experiences of AYAs with a UPCP and it pioneers in involving AYA research partners, some limitations need to be taken into account. First, the results of this study should be interpreted with some nuance since we interviewed patients only and did not include experiences from the HCP's perspective. We do know that patients do not process all the information, can be biased and can interpret information differently [48]. Furthermore, this study had a language barrier, and the sample was not ethnically diverse, which limits the generalizability of the results. It is certainly important that future research facilitates access to the study for AYAs with a migration background. Our results cannot be generalized to other countries since healthcare systems are different and might play a role in the experiences of AYAs with a UPCP. Additionally, this study did not succeed to include AYAs with a UPCP between 18 and 22 years of age [53]. It could be possible that these younger AYA patients do have different experiences and needs within the healthcare system because of their developmental life phase and more parental involvement. Because of the qualitative design of this study, we were not able to identify significant interpersonal differences between AYA patients and possible differences between medical specialists including medical oncologists, pulmonary physicians, neurologists and clinical nurse specialists [21]. Therefore, we cannot offer specific

recommendations for subgroups within the population of AYAs with a UPCP or specific healthcare disciplines. Future quantitative research can provide such recommendations, and adding a control group can provide comparisons between curative AYAs and older patients with UPCP. Since clinical nurse specialists play an important role within AYA care, future research should focus on the experiences in relation to clinical nurse specialist specifically.

Clinical implications

In Table 5, we summarized action points for HCPs related to the four themes of satisfied care with among others the optimal experiences as examples for clinical practice to further improve AYAs' healthcare experiences. It is important to keep in mind that the right timing is essential in all of these examples. In the group of AYAs with a UPCP, it is essential to discuss their medical history in relation to trust in medical doctors and the medical system and find out what the key factors are to gain trust. Trust is essential for open and engaging communication [54]. Since the results suggest that AYAs with a UPCP hesitate to initiate sensitive topics, exploration (exploring what AYAs know, want to know and understand what they are aiming for) could be helpful for addressing patients' varying information preferences but also to make communication more helpful in general [41]. Adding specific issues for AYA with a UPCP to the current AYA topic list as developed by the Dutch AYA Care can serve as a tool for healthcare professionals for addressing the important AYA and UPCP-related topics [19, 32]. A question prompt list specifically for AYAs with a UPCP can possibly empower them to address sensitive topics during a medical consultation [55, 56]. Additionally, less than half of the AYA patients in this study do have a clinical nurse specialist, while this is often recommended in AYA care programs, and according to the AYAs with a UPCP, it seems beneficial in terms of being a gatekeeper and a lower threshold to ask questions. Moreover, the results of this study can be integrated into a new education module that is currently under development, focusing on HCPs providing care to AYAs with a UPCP to help them to provide information and support [19, 21, 32].

Another important implication is the context of uncertainty and lack of a clear prognosis. However, an uncertain prognosis still requires clear communication and explanation. There are several suggestions from previous literature to discuss prognosis and end of life in an emotional supportive approach (Table 5) [14, 41, 51, 52, 57]. For example, the 'ask-provide information-respond to emotion-ask' cycle to assess needs or understanding, deliver information compassionately, manage information and explore patients' goals, hopes, worries and values [14]. Additionally, Mori and colleagues studied phrases to communicate prognosis and found that phrases with the median, typical range, best/worst cases and "hope for the best and prepare for the worst" cases were preferred by cancer patients [57]. Since general and tumour-specific information is often spread across websites and patient organizations, it would be beneficial to bundle general information for AYAs with a UPCP [58]. At last, we can learn from existing buddy systems, in which AYAs can reach out for emotional and informational support [59, 60].

In conclusion, age-specific issues and wishes should be addressed while at the same time, the focus is on the UPCP. Moreover, these patients are part of a new generation, which requires different communication, healthcare expectations and needs. Given the challenging combination of a young age and an uncertain prognosis, it is recommended to support HCPs treating this unique patient group and empower AYAs with a UPCP within the healthcare system in order to make sure they receive the best patient-centred care possible.

Appendix 1

Table 3 COREQ checklist

Topic	Item no.	Guide questions/description	Reported on page no.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	3
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	3
Occupation	3	What was their occupation at the time of the study?	3
Gender	4	Was the researcher male or female?	3
Experience and training	5	What experience or training did the researcher have?	3
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	N/A
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	N/A
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. bias, assumptions, reasons and interests in the research topic	N/A
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	2–3
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	3
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	3
Sample size	12	How many participants were in the study?	3–4
Non-participation	13	How many people refused to participate or dropped out? Reasons?	3–4
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	3
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	N/A
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	4
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	3
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	3
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	3
Field notes	20	Were field notes made during and/or after the interview or focus group?	3
Duration	21	What was the duration of the inter views or focus group?	3
Data saturation	22	Was data saturation discussed?	3
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	3
Domain 3: Analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	3
Description of the coding tree	25	Did authors provide a description of the coding tree?	5–7
Derivation of themes	26	Were themes identified in advance or derived from the data?	3
Software	27	What software, if applicable, was used to manage the data?	3
Participant checking	28	Did participants provide feedback on the findings?	3

Table 3 (continued)

Topic	Item no.	Guide questions/description	Reported on page no.
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	5–7
Data and findings consistent	30	Was there consistency between the data presented and the findings?	7–9
Clarity of major themes	31	Were major themes clearly presented in the findings?	5–9
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	7–9

Appendix 2

Table 4 GRIPP-2 checklist

Section and topic	Item	Page no.
1: Aim Report the aim of the study	The aim of this study was to understand the healthcare experiences of AYAs with an uncertain or poor cancer prognosis (UPCP).	p. 2
2: Methods Provide a clear description of the methods used for PPI in the study	Five AYAs with UPCP were actively involved as AYA research partners in this study. One AYA was already involved in the phase of grant application and recruited another AYA, two other AYAs were invited to contribute as research partner after they participated in the AYA interview study, and one AYA was recruited via the researcher. According to each preferences and availability, AYA research partners attending several online meetings to contribute to this study.	p. 3
3: Study results outcomes—report the results of PPI in the study, including both positive and negative outcomes	AYA research partners contributed to the study in several ways, including: - Being a participant in the pilot testing phase - Reviewing and adapting the patient information letter for relevance, word use and level of confrontation - Reviewing and adapting the interview guide for relevance, comprehensiveness, word use and level of confrontation - Discussing about how to provide the best aftercare for participants - Contributing in consensus meetings about the results and checking for correct interpretation - Checking the general framework for misinterpretation or gaps in logic - Editing and being co-author of the paper	p. 3
4: Discussion and conclusions Outcomes—comment on the extent to which PPI influenced the study overall. Describe positive and negative effects	Collaboration with AYA research partners provides more appropriate and relevant research regarding AYAs with a UPCP and contributed to a better translation to suggestions for clinical practice. Adjustment and prioritisation of interview questions, information about appropriate questions and knowledge about the wish for after care, resulted in an improved methodology and more confidence in the researcher. During the discussion of the results, themes were renamed. The experience of the AYA research partners also provides more insight and context to interpret the results of the study. The AYA themselves were proud to contribute, appreciated the feeling of being seen of added value and received support from the contact moments with other AYA research partners.	N/A
5: Reflections/critical perspective Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience	Patient involvement is an investment of time and effort, since you have an extra group of people who have to make decisions about your study. These research partners are included because of their experiential knowledge and not because of their scientific skills, which can result in the need for extra coaching and information. This also requires some extra skills of the researcher. The main challenge but also the most important aspect is regularly evaluating and staying in contact with the AYA research partners. Even when they are not that involved at that moment (e.g. writing manuscript). As conclusion, seeing the impact of performing research with AYA instead of about AYA is worth the investment. Timely preparation and good communication can make it less time consuming.	N/A

Appendix 3

Table 5 Action points and helpful examples for clinical practice

Theme	Action point	Helpful example
Trust	Be aware of the medical history because of possible distrust. Make this a topic for discussion	"What can we do together to ensure that you regain (more) trust?" (focus group)
	Give the AYA the feeling that he/she is not just a number	"You should know that we discuss every patient in a consultation with multiple healthcare professionals. So we know most of you by name." (focus group)
	Show the AYA that you are up to date with regard to new treatment developments: share new studies or treatment options, but also if there are no new developments	"I will keep you updated on new treatments. You should know that I am on top of it, but unfortunately there are no developments for you." (focus group)
	Make sure the AYA can always reach someone to ask for help	"Shall we discuss whom you can best contact with questions?" (focus group)
	Be aware of the possible unequal doctor-patient relationship and its consequences	"I want you to know that you can share everything with me and that nothing of what you share impacts your treatment. If there are topics you would rather discuss with someone else, know that you can contact x." (focus group)
	Say what you do and do what you say (keep agreements)	"I will call you between 5-7 p.m. If I am not able to call you, I will make sure that the nurse specialist calls you and I will call you back later. (focus group)
	Be honest if you do not have an answer to the question and make sure that the AYA still gets the necessary information	"To be honest, I cannot answer your question but I will check it with my colleagues from social work and then I will get back to you" (focus group)
Tailored communication	Tune in: ask about information needs and ask for preferences on how to convey this information	"Want kind of medical information do you like to receive?" "Some people, but not all, want information about their life expectancy. It's different for everyone. What are your needs here?" [41]
	Align medical jargon with AYAs' knowledge	"Your scan shows that the cancer is getting worse. Could we talk about what that means?" [52]
	Check whether the AYA understands (check interpretation)	"To make sure we are on the same page, can you please tell me what you are going to take away from this conversation?" [14] (m, low-grade glioma)
	Be clear about the uncertain prognosis: explain why no prognosis can be given and explore important aspects of quality of life	"We base life expectancy on data from large groups of people. Life expectancy is different for each person, so unfortunately we can't say exactly what it is for you personally. Besides, there are not many people of your age with the same tumour, which makes it even harder to predict your life expectancy. I can imagine that you have some reasons for asking this question. May I ask why?" [41, 57]
	If preferred, provide as much clarity as possible about the prognosis: - Step-by-step assessment of the prognosis	"In your case, It is best if we start treatment and then assess the effect of the first treatment. Then we can take it from there. How long the treatment is effective is different for everyone since it is relatively new and we do not yet have enough data." [41]
	- Discuss the prognosis with help of outliers	"There are always exceptions. People who live shorter, for example…. but also people who live longer than we sometimes think, for example….." [41]

Table 5 (continued)

Theme	Action point	Helpful example
	- Discuss prognosis with help of 'Hope for the best, prepare for the worst'	"Considering the two extremes, it may vary from 1 to 4 years for the average patient. However, this is just an estimate based on the average, so it does not tell us what will happen to you exactly. We will do our best to make sure that you have a better-than-average outcome. On the other hand, if you do progress faster than average, I think it is a good idea to prepare yourself for the unexpected." [57]
	Check if the AYA want to talk about the end of life Make sure you have the right timing for this question	"How much have you been thinking about what might happen if things don't go the way we hope?" [52]" Many patients like you wonder about scary topics like the possibility of dying from their cancer. Is this something you ever think about?" [14]
	Decide together what role the AYAs' parents will take in the communication	"If you are not able to answer your phone, is it an option to call your parents? Or what do you prefer?" (woman, low-grade glioma)
Holistic, empathic and open attitude	Make sure you give the AYA time and space to discuss everything	"Are you worried about […] ? Would it perhaps help to talk about this with the social worker or psychologist?" [41]
	Initiate sensitive topics with the AYA only (without partner or parent(s)). For example sexual health	"Many AYAs worry about how cancer will affect their sexual health. I would like to take some time today to talk about this. Is this okay with you?" [61] "Sometimes young people with cancer feel like they don't get enough information from their doctors/nurses about their sexual health, and I want to make sure I'm giving you all the information you need. What else would you like to know?" [14] "Sometimes teens and young adults with cancer are curious about how their cancer treatment can affect their sexual health but don't feel comfortable asking. Would it help if I share some information about it?" [14]
	React with empathy when discussing complementary care	"I am glad to hear this method is helping you so much. Unfortunately, we do not yet know whether it is effective. As long as it works for you and it does not have a negative effect on your treatment you can continue with it. Can you tell me how it positively impacts you?" (woman, rhabdomyosarcoma)
	Show empathy after sharing scan results	Those were the scan results. I can imagine you may need a moment for it all to sink in." [Depending on the patient's reaction, explore emotions, and ask permission to discuss treatment options]. Can I do something for you?" [41]
	Show the AYA that you are involved	"She run into us in the hallway and immediately congratulated us on our wedding and asked if we had any pictures." (woman, rhabdomyosarcoma) "Even when I was struggling with my fatigue, she called me on her own to check on me and whether she could help me with anything." (focus group)
	Share some personal information	"I have two children myself, so I know how busy it can be at times. How does it go at home?" (woman, low-grade glioma)

Table 5 (continued)

Theme	Action point	Helpful example
	Ask in-depth follow-up questions when asking 'how are you?'	"How are you physically? How are day-to-day activities going, such as groceries? How is it going at home? Are you still working/studying? How are you feeling mentally? (woman, low-grade glioma) (woman, lung cancer) (woman, breast cancer)
	Make sure you use a holistic approach - See the person behind the tumour	"The tumour doesn't seem to be growing, which is good but how are you feeling? Do you have any symptoms?" [41]
	- Ask non-medical questions (AYA anamneses)	"What does it mean for you to know you are not able to study/work anymore?" (woman, epithelioid hemangioendothelioma)
Offering care instead of having to ask for it	Ask regularly if someone needs support (AYA anamnesis)	"Is there anything I can do for you? Don't be afraid to ask what you want. I do not know if I can help you with everything but you can discuss all." (woman, leiomyosarcoma)"A lot has changed in a short time period and you noticed that you are not working anymore. Do you have any questions about government policy and finance when unemployed?" (woman, cervical cancer) (woman, lung cancer)"How are the kids dealing with this situation? Do you feel a need for support?" (woman, lung cancer)
	Include all multidisciplinary healthcare professionals of one patient to ensure it is not the responsibility of the AYA themselves	"I will discuss the arrangements we have made about the anaesthesia for your operation with the anaesthesiologist on duty. Does that feel okay for you?" (focus group)

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Declarations

Competing interests The authors declare no competing interests.

References

1. Tometich DB, Hyland KA, Soliman H, Jim HSL, Oswald L (2020) Living with metastatic cancer: a roadmap for future research. Cancers (Basel) 12(12):3684
2. Larkin J, Chiarion-Sileni V, Gonzalez R, Grob JJ, Rutkowski P, Lao CD et al (2019) Five-year survival with combined nivolumab and ipilimumab in advanced melanoma. N Engl J Med 381(16):1535–1546
3. Langbaum T, Smith TJ (2019) Time to study metastatic-cancer survivorship. N Engl J Med 380(14):1300–1302
4. García-Rueda N, Carvajal Valcárcel A, Saracíbar-Razquin M, Arantzamendi SM (2016) The experience of living with advanced-stage cancer: a thematic synthesis of the literature. Eur J Cancer Care (Engl) 25(4):551–569
5. Kolsteren EEM, Deuning-Smit E, Chu AK, van der Hoeven YCW, Prins JB, van der Graaf WTA et al (2022) Psychosocial aspects of living long term with advanced cancer and ongoing systemic treatment: a scoping review. Cancers (Basel) 14(16)
6. Zwanenburg LC, Suijkerbuijk KPM, van Dongen SI, Koldenhof JJ, van Roozendaal AS, van der Lee ML et al (2022) Living in the twilight zone: a qualitative study on the experiences of patients with advanced cancer obtaining long-term response to immunotherapy or targeted therapy. J Cancer Surviv
7. Koekkoek JAF, van der Meer PB, Pace A, Hertler C, Harrison R, Leeper HE et al (2022) Palliative care and end-of-life care in adults with malignant brain tumors. Neuro-Oncology 25(3):447–456
8. Sella T, Snow C, Freeman H, Poorvu PD, Rosenberg SM, Partridge AH (2021) Young, empowered and strong: a web-based education and supportive care intervention for young women with breast cancer across the care continuum. JCO Clin Cancer Inform 5:933–943
9. Fraterman I, Glaser SLC, Wilgenhof S, Medlock SK, Mallo HA, Cornet R et al (2022) Exploring supportive care and information needs through a proposed eHealth application among melanoma patients undergoing systemic therapy: a qualitative study. Support Care Cancer 30(9):7249–7260
10. Burgers VWG, van der Graaf WTA, van der Meer DJ, McCabe MG, Rijneveld AW, van den Bent MJ et al (2021) Adolescents and young adults living with an uncertain or poor cancer prognosis: the "new" lost tribe. J Natl Compr Canc Netw 19(3):240–246
11. Kaal S. Adolescents and young adults (AYA) with cancer: towards optimising age-specific care: [Sl: sn]; 2018.
12. Marris S, Morgan S, Stark D (2011) 'Listening to patients': what is the value of age-appropriate care to teenagers and young adults with cancer? Eur J Cancer Care (Engl) 20(2):145–151
13. Bibby H, White V, Thompson K, Anazodo A (2016) What are the unmet needs and care experiences of adolescents and young adults with cancer? A Systematic Review. J Adolesc Young Adult Oncol 6(1):6–30
14. Perez GK, Salsman JM, Fladeboe K, Kirchhoff AC, Park ER, Rosenberg AR (2020) Taboo topics in adolescent and young adult oncology: strategies for managing challenging but important conversations central to adolescent and young adult cancer survivorship. Am Soc Clin Oncol Educ Book 40:1–15
15. Patterson P, McDonald FEJ, Zebrack B, Medlow S (2015) Emerging issues among adolescent and young adult cancer survivors. Semin Oncol Nurs 31(1):53–59
16. Meglio AD, Havas J, Soldato D, Presti D, Martin E, Pistilli B et al (2022) Development and validation of a predictive model of severe fatigue after breast cancer diagnosis: toward a personalized framework in survivorship care. J Clin Oncol 40(10):1111–1123
17. Meglio AD, Havas J, Gbenou AS, Martin E, El-Mouhebb M, Pistilli B et al (2022) Dynamics of long-term patient-reported quality of life and health behaviors after adjuvant breast cancer chemotherapy. J Clin Oncol 40(27):3190–3204
18. Devlin SM, Murphy JD, Yeung HN (2019) A retrospective analysis of pain burden in hospitalized young adult cancer patients compared with their older adult counterpart. J Palliat Med 22(3):307–309
19. Burgers VWG, van den Bent MJ, Dirven L, Lalisang RI, Tromp JM, Compter A et al (2022) "Finding my way in a maze while the clock is ticking": the daily life challenges of adolescents and young adults with an uncertain or poor cancer prognosis. Front Oncol 12:994934
20. Smith AW, Keegan T, Hamilton A, Lynch C, Wu XC, Schwartz SM et al (2019) Understanding care and outcomes in adolescents and young adult with cancer: a review of the AYA HOPE study. Pediatr Blood Cancer 66(1):e27486
21. Burgers VWG, van den Bent MJ, Darlington ASE, Gualthérie van Weezel AE, Compter A, Tromp JM et al (2022) A qualitative study on the challenges health care professionals face when caring for adolescents and young adults with an uncertain and/or poor cancer prognosis. ESMO Open 7(3):100476
22. Fern LA, Taylor RM, Whelan J, Pearce S, Grew T, Brooman K et al (2013) The art of age-appropriate care: reflecting on a conceptual model of the cancer experience for teenagers and young adults. Cancer Nurs 36(5):E27–E38
23. Patterson P, Millar B, Desille N, McDonald F (2012) The unmet needs of emerging adults with a cancer diagnosis: a qualitative study. Cancer Nurs 35(3):E32–E40
24. Zebrack B (2009) Information and service needs for young adult cancer survivors. Support Care Cancer 17(4):349–357
25. Zebrack B, Bleyer A, Albritton K, Medearis S, Tang J (2006) Assessing the health care needs of adolescent and young adult cancer patients and survivors. Cancer 107(12):2915–2923
26. Zebrack B, Kent EE, Keegan TH, Kato I, Smith AW (2014) "Cancer sucks," and other ponderings by adolescent and young adult cancer survivors. J Psychosoc Oncol 32(1):1–15
27. Wong AWK, Chang TT, Christopher K, Lau SCL, Beaupin LK, Love B et al (2017) Patterns of unmet needs in adolescent and young adult (AYA) cancer survivors: in their own words. J Cancer Surviv 11(6):751–764
28. Janssen SHM, van der Graaf WTA, van der Meer DJ, Manten-Horst E, Husson O (2021) Adolescent and young adult (AYA) cancer survivorship practices: an overview. Cancers (Basel) 13(19)
29. Ferrari A, Stark D, Peccatori FA, Fern L, Laurence V, Gaspar N et al (2021) Adolescents and young adults (AYA) with cancer: a position paper from the AYA Working Group of the European Society for Medical Oncology (ESMO) and the European Society for Paediatric Oncology (SIOPE). ESMO Open 6(2):100096
30. Mitchell L, Stuart-McEwan T, Panet H, Gupta A (2017) Adolescents and young adults: addressing needs and optimizing care with a clinical nurse specialist. Clin J Oncol Nurs 21(1):123–126

31. Osborn M, Johnson R, Thompson K, Anazodo A, Albritton K, Ferrari A et al (2019) Models of care for adolescent and young adult cancer programs. Pediatr Blood Cancer 66(12):e27991
32. Dutch AYA Care Network 2022 https://ayazorgnetwerk.nl.
33. Tong A, Sainsbury P, Craig J (2007) Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International J Qual Health Care 19(6):349–357
34. Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S et al (2017) GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. bmj:358
35. Burgers VWG, Dickhout A, Harthoorn N, Frissen S, Noordhoek MJ, Franssen SA et al (2023) Involving adolescents and young adults (AYA) with an uncertain or poor cancer prognosis as research partners. Acta Oncol 62(8):961–968
36. QSR International Pty Ltd. NVivo 2020 March 2020, https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home.
37. Corbin J, Strauss A (2014) Basics of qualitative research: techniques and procedures for developing grounded theory. Sage publications
38. Sebastian K (2019) Distinguishing between the types of grounded theory: classical, interpretive and constructivist. Journal for Social Thought 3(1):1–9
39. Rieger KL (2019) Discriminating among grounded theory approaches. Nurs Inq 26(1):e12261
40. Hillen MA, de Haes HC, Smets EM (2011) Cancer patients' trust in their physician-a review. Psychooncology 20(3):227–241
41. Westendorp J, Evers AWM, Stouthard JML, Budding J, van der Wall E, Plum NMF et al (2022) Mind your words: oncologists' communication that potentially harms patients with advanced cancer: A survey on patient perspectives. Cancer 128(5):1133–1140
42. van der Velden NCA, van Laarhoven HWM, Burgers SA, Hendriks LEL, de Vos F, Dingemans AC et al (2022) Characteristics of patients with advanced cancer preferring not to know prognosis: a multicenter survey study. BMC Cancer 22(1):941
43. Herbert A, Lyratzopoulos G, Whelan J, Taylor RM, Barber J, Gibson F et al (2018) Diagnostic timeliness in adolescents and young adults with cancer: a cross-sectional analysis of the BRIGHTLIGHT cohort. The Lancet Child & Adolescent Health 2(3):180–190
44. Corbeil A, Laizner AM, Hunter P, Hutchison N (2009) The experience of uncertainty in young adults with cancer. Cancer Nurs 32(5):E17–E27
45. Burgers VWG, van den Bent MJ, Rietjens JAC, Roos DC, Dickhout A, Franssen SA et al (2022) "Double awareness"—adolescents and young adults coping with an uncertain or poor cancer prognosis: a qualitative study. Front Psychol 13
46. Roth ME, O'Mara AM, Seibel NL, Dickens DS, Langevin A-M, Pollock BH et al (2016) Low enrollment of adolescents and young adults onto cancer trials: insights from the Community Clinical Oncology Program. J Oncol Pract 12(4):e388–ee95
47. Siembida EJ, Loomans-Kropp HA, Tami-Maury I, Freyer DR, Sung L, Crosswell HE et al (2021) Barriers and facilitators to adolescent and young adult cancer trial enrollment: NCORP site perspectives. JNCI Cancer Spectr 5(3)
48. The AM, Hak T, Koëter G, van Der Wal G (2000) Collusion in doctor-patient communication about imminent death: an ethnographic study. Bmj 321(7273):1376–1381
49. Albers LF, Haj Mohammad SF, Husson O, Putter H, Pelger RC, Elzevier HW, Manten-Horst E (2020) Exploring communication about intimacy and sexuality: what are the preferences of adolescents and young adults with cancer and their health care professionals? Journal of Adolescent and Young Adult. Oncology 9(2):222–238
50. Reyes A, Galvan R Jr, Navarro A, Velasquez M, Soriano DR, Cabuso AL et al (2020) Across generations: defining pedagogical characteristics of generation X, Y, and Z Allied Health Teachers Using Q-Methodology. Med Sci Educ 30(4):1541–1549
51. Hagerty RG, Butow PN, Ellis PM, Lobb EA, Pendlebury SC, Leighl N et al (2005) Communicating with realism and hope: incurable cancer patients' views on the disclosure of prognosis. J Clin Oncol 23(6):1278–1288
52. Back AL (2020) Patient-clinician communication issues in palliative care for patients with advanced cancer. J Clin Oncol 38(9):866–876
53. Arnett JJ, Emerging adulthood. (2000) A theory of development from the late teens through the twenties. Am Psychol 55(5):469–480
54. Kim B, White K (2018) How can health professionals enhance interpersonal communication with adolescents and young adults to improve health care outcomes?: systematic literature review. Int J Adolesc Youth 23(2):198–218
55. Terrasson J, Rault A, Dolbeault S, Brédart A (2022) Question prompt lists to improve communication between cancer patients and healthcare professionals. Curr Opin Oncol 34(4):265–269
56. Newman B, Joseph K, McDonald FEJ, Harrison R, Patterson P (2022) Using consumer engagement strategies to improve healthcare safety for young people: an exploration of the relevance and suitability of current approaches. Health Expect 25(6):3215–3224
57. Mori M, Fujimori M, Ishiki H, Nishi T, Hamano J, Otani H et al (2019) Adding a wider range and "Hope for the best, and prepare for the worst" statement: preferences of patients with cancer for prognostic communication. Oncologist 24(9):e943–ee52
58. Olsen PR, Smith S (2018) Nursing adolescents and young adults with cancer: developing knowledge , Competence and Best Practice. Springer
59. Phone Buddy Program GO2 for lungcancer https://go2.org/resources-and-support/emotional-support/phone-buddy/.
60. Collorectal Cancer Alliance. Buddy Program https://www.ccalliance.org/patient-family-support/buddy-program.
61. Frederick NN, Revette A, Michaud A, Bober SL (2019) A qualitative study of sexual and reproductive health communication with adolescent and young adult oncology patients. Pediatr Blood Cancer 66(6):e27673

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