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ORIGINAL RESEARCH

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

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Background: Adolescents and young adults (AYAs, aged 18-39 years) with advanced cancer have an increased life expectancy due to improvements and refinements in cancer therapies, resulting in a growing group of AYAs living with an uncertain and/or poor cancer prognosis (UPCP). To date, no studies have examined the difficulties of health care professionals (HCPs) providing care to AYAs with a UPCP. This study aimed to understand the challenges in daily clinical practice experienced by HCPs from different disciplines who provide palliative as well as general care to AYAs with a UPCP.

Methods: HCPs from a variety of backgrounds (e.g. clinical nurse specialists, medical oncologists, neurologists psychologists) were invited for a semi-structured interview. The interviews were transcribed verbatim and analysed using reflexive thematic analysis. Two AYA patients were actively involved as research partners to increase the relevance of the study design and to optimise interpretation of results.

Results: Forty-nine HCPs were interviewed. Overall, we found that the threat of premature death within this young patient group increased emotional impact on HCPs and evoked a feeling of unfairness, which was an extra motivation for HCPs to provide the most optimal care possible. We generated four key themes: (i) emotional confrontation (e.g. feeling helplessness and experiencing a greater sense of empathy), (ii) questioning own professional attitude and skills, (iii) navigating uncertainty (e.g. discussing prognosis and end of life) and (iv) obstacles in the health care organisation (e.g. lack of knowledge and clarity about responsibilities).

Conclusions: HCPs experienced unique emotional and practical challenges when providing care to AYAs with a UPCP. The results from this study highlight the need to develop an education module for HCPs treating AYAs with UPCP to increase their own well-being and optimise the delivery of person- and age-adjusted care.

Key words: adolescents and young adults, poor or uncertain cancer prognosis, palliative care, health care professionals, qualitative research

INTRODUCTION

Adolescent and young adult (AYA) cancer patients, defined as those aged 15 to 39 years at first cancer diagnosis, are recognised as a distinct population within the oncology community due to the unique challenges they face throughout their disease trajectory: related to diagnosis, treatment, advanced care planning and survivorship.[1-3] Over 80% of AYA cancer patients are expected to survive beyond 5 years; however, cancer remains one of the top five leading causes of death in AYAs.[4,5]

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Following the introduction of immune checkpoint inhibitors, molecular targeted treatments and further advances in systemic and local therapies, including those applied in AYAs with advanced cancers, survival has increased significantly.[6,7] Patients living long-term with metastatic disease are also referred to as 'metavivors' or people living with cancer as a chronic and terminal illness.[7] This term, however, does not adequately reflect the diversity of the growing group of AYAs living with an uncertain and/or poor cancer prognosis (UPCP).[8] AYAs with a UPCP are those with advanced or metastatic cancer for whom there is no reasonable hope of cure, indicating that patients will die prematurely from cancer, but without immediate threat of death.[9] Patients with a UPCP are either those (i) treated with standard established treatments (e.g. chemotherapy; traditional survivors with a life expectancy of 1-5 years), (ii) undergoing novel treatment(s) (e.g. immunotherapy; new survivors with uncertain prognosis) or (iii) with a low-grade glioma (LGG) who are living with the knowledge that tumour recurrence and progression inevitably occur and most of them will consequently die of their disease.[9] We introduced the term UPCP to cover this broad spectrum of diseases and to include associated age-specific challenges.[9]

AYAs with a UPCP represent a particularly vulnerable and to date insufficiently recognised group. A cancer diagnosis at the AYA age disrupts normal life trajectories and achievement of developmental milestones, such as establishing autonomy, social relationships, education or career goals and starting a family.[10] These issues are even more profound in AYAs with a UPCP since the prospect of a 'normal' life may vanish and the future becomes uncertain.[9] These AYAs may experience a loss of control of their life and fundamental questions emerge about the meaning of life and their limited remaining time.[11,12] There is growing attention that person-centred care initiatives must be developed to meet the unique medical, psychosocial and supportive care needs of these patients to give them a meaningful remainder of their lives.[9]

Health care professionals (HCPs) are key figures to provide person-centred care. To date, studies focused primarily on HCPs treating AYAs with advanced (life expectation undefined or <1 year) or terminal cancer. These studies show that providing care to this young patient group is emotionally challenging for HCPs.[13-17] For example, Avery and colleagues found a sense of tragedy and emotional proximity to AYAs with advanced cancer among HCPs due to countertransference.[13] This phenomenon describes how reactions of HCPs to their AYA patients may have been a projection of their own experiences as young adults or parents of young adults.[13,14] Other studies revealed that HCPs experience caring for AYAs with terminal cancer as more challenging than caring for older patients due to the unknowns and uncertainties, the struggle with the injustice of dying young and a lack of age-specific knowledge.[14-16] To date, no studies have examined the difficulties HCPs experience in providing care to AYAs with a UPCP, who are confronted with permanent disease, often being on treatment, with an ongoing thread of disease progressions. The aim of this study was to understand the challenges in daily clinical practice experienced by HCPs from different disciplines who provide palliative as well as general care to AYAs with a UPCP.

METHODS

Study design

This study employed a qualitative descriptive design, utilising semi-structured interviews to explore the challenges (e.g. emotional, practical and social) of HCPs in providing care to AYAs with a UPCP. Reflexive thematic analysis with a critical realistic theoretical framework was used with an inductive orientation and focus on semantic meaning.[18,19] This critical realistic framework implies that there is a reality independent of us but we all have another representation of this reality dependent on the persons' experiences and perceptions.[20,21] This framework acknowledges that experiences occur within a social world. By choosing for the reflexive thematic analysis with a critical realistic framework, we aimed to identify deeper levels of understanding by finding the challenges and multidimensional factors which impact the challenges HCPs experienced, and to understand which factors must be addressed in each unique context to ensure implications for clinical practice.[21,22]

Participants

Participants were HCPs from a variety of disciplines delivering palliative as well as general care to one of the three distinct subgroups of AYAs with a UPCP as described in the introduction.[9] A purposive sampling strategy was applied to ensure a heterogenic predefined (minimum) sample of 48 HCPs [16 HCPs treating AYAs with LGG and 32 (2 × 16) HCPs treating AYAs with established and/or novel treatment(s)]. This minimum sample size was a starting point for the recruitment phase to cover the full heterogenic spectrum of professionals working with the diverse group of AYAs with a UPCP. Data collection stopped when saturation was reached in addition to the minimum sample size and the researcher therefore had a clear overview of the challenges HCPs experienced in delivering care to AYAs with a UPCP. Given the fact that HCPs often treat patients with established as well as novel treatments, no distinction was made between those two groups. Participants included clinical nurse specialists, medical oncologists, neurologists, psychologists, social workers, other medical specialists and paramedics. Since all these different HCP disciplines are to some degree involved in the care of the diverse group of AYAs living with a UPCP, challenges might be different. HCPs were recruited from 12 different hospitals in the Netherlands and were invited by e-mail. Ethics approval was obtained by the Institutional Review Board of The Netherlands Cancer Institute (IRBd20-205).

Data collection

Interviews were conducted between September 2020 and August 2021, during the coronavirus disease (COVID-2019) pandemic. A trained female psychologist and qualitative investigator (VB) conducted the semi-structured interviews via video calls, after informed consent. An interview guide with open questions and probes was created to examine the challenges of HCPs providing care to AYAs with a UPCP. This interview guide was drafted based on literature and in collaboration with experienced researchers (WG, OH) and AYA patients who were actively involved as AYA research partners in this study (NH, CTH). The interview guide was adapted twice during the data collection in which two unclear questions were removed and more prompts were added (Table 1). The AYA research partners were also present during three interviews (one at the time), where they asked additional in-depth questions fuelled by their own patient experience. Interviews were audio-recorded and lasted on average 46 min (Range: 20-100 min). Notes were taken to provide context for analysis. In addition to these interviews, demographic information from each participant was collected just before the interview, including: age, gender, specialisation, years of professional experience with AYA care and number of unique AYA patients per year.

Table 1. Semi-structured interview guide

Questions	Probes
1. Could you please tell what difficulties you ran into when delivering care to AYAs with a UPCP?	Could you please take me through a specific case which describes this experience in the best way? How do you currently cope with this challenge?
2. Do you experience any difficulties when discussing some topics with AYAs with a UPCP?	Could you please elaborate? Could you please give me an example that showcases this well? What are you afraid of?
3. What do you perceive as challenging patient groups within this AYA population?	Can you give an example that visualises the challenges you come across when dealing with this patient group(s)? How do you currently cope with this patient groups?

AYA, adults and young adults; HCPs, health care professionals; UPCP, uncertain and/or poor cancer prognosis.

Data analysis

Interviews were transcribed verbatim and the transcripts were analysed using reflexive thematic analysis.[18,19] VB read all interviews after transcription, made notes and coded important features. The codes of all the data were organised using NVivo (QSR International, Doncaster, Australia).[23] The first eight interviews were double coded by a second coder (MR) to see different perspectives on the same data, which helped with reflecting on the initial codes and with generation of initial themes.[18,19,24] When the two coders were not able to find a compromise for the discrepancies, these remaining codes were discussed with the AYA research patients (NH, CTH) and the research team (WG, OH, AGW, ASD). This research team was carefully composed by the executive researcher (VB, psychologist), to cover the full spectrum of disciplines: epidemiologist (OH), medical oncologist (WG), psychologist (ASD) and social worker (AGW). In the meetings with the AYA research patients and research team, everyone was equal in the decision-making process given the different background perspectives. The researcher used the initial codes to identify relationships between these codes and sort the codes into potential themes and sub-themes. This iterative process of generating, reviewing, defining and naming of the themes was done by VB with the help of the members of the research team and the AYA research partners to discuss the multiple perspectives and to check interpretations during the online meetings. The goal was always to find a compromise, which regularly resulted in recoding or refining themes. Additionally, all members of the research team and the AYA research patients have reviewed this paper. The analysis process was fluid rather than linear since coding, theming and developing thematic maps were activities that overlapped and sometimes led us back to an earlier analysis phase.

To ensure rigour in our research, the ‘Consolidation Criteria for Reporting Qualitative Studies’ (COREQ) guidelines were followed[25] (presented in Supplementary Material 1, available at https://doi.org/10.1016/j.esmoop.2022.100476). In order to optimise the transparent reporting of the active involvement of patients as research partners in this study, the GRIPP2-SF reporting checklist was used[26] (presented in Supplementary Material 2, available at https://doi.org/10.1016/j.esmoop.2022.100476).

RESULTS

Demographics

In total, 63 HCPs were approached of which 11 were non-responders and 4 did not consider themselves as suitable for the interview because they did not provide care to AYAs with a UPCP. The final sample included 49 HCPs; the majority were clinical nurse specialists, followed by medical oncologists, neurologists, psychologists and social workers (Table 2).

Findings

Overall, all HCPs experienced some extra challenges caring for AYAs with a UPCP in comparison to older and/or curative patients. Four main themes were identified: (i) emotional confrontation, (ii) questioning professional attitude and skills, (iii) navigating uncertainty and (iv) obstacles in the health care organisation to provide age- and disease-appropriate care. Each main theme is explained according to the different sub-themes (Figure 1). These themes are interrelated constructs that together capture the challenges of delivering care to AYAs with UPCP experienced by HCPs. The numbers in the sentences refer to matching quotes of the interviewed HCPs to give a vivid illustration (Table 3).

THEME 1. EMOTIONAL CONFRONTATION

1.1 I can put myself in your shoes

HCPs experienced more emotional proximity associated with caring for AYAs in comparison to older patients. HCPs in or around the AYA age attributed this to the fact that they are in the same life phase and sometimes even can identify with the AYA and their family (Table 3 - 1.1.1). Older HCPs could still relate to AYAs as they have gone through adolescence and young adulthood themselves and sometimes could draw similarities between their own

Table 2. Characteristics of HCPs

Characteristics	*N* (%)
Age (years)	
Range	31-64
Mean (SD)	46.6 (9.5)
Gender	
Female	42 (85.7)
Male	7 (14.3)
Specialisation	
Clinical nurse specialist	10 (20.4)
Medical oncologist	9 (18.4)
Neurologist	7 (14.3)
Psychologist	5 (10.2)
Social worker	5 (10.2)
Gynaecologist	3 (6.1)
Surgeons	2 (4.1)
Clinical occupational doctor	1 (2.0)
Occupational therapist	1 (2.0)
Psychiatrist	1 (2.0)
Pulmonary physician	1 (2.0)
Radiotherapist	1 (2.0)
Rehabilitation physician	1 (2.0)
Support consultant	1 (2.0)
Urologist	1 (2.0)
Years of experience with caring for AYAs	
Range	2-40
Mean (SD)	13.1 (8.8)
Number of unique AYA patients per year	
0-9	13 (31.0)
10-19	9 (21.4)
20-29	8 (19.0)
30-39	2 (04.8)
40-49	2 (04.8)
>50	8 (19.0)
Unknown	7 (14.3)

AYA, adults and young adults; HCPs, health care professionals; SD, standard deviation.

children and the AYA with cancer (Table 3 - 1.1.2). Some HCPs projected the situation of an AYA with cancer to their own life and experienced intense sadness. HCPs reported that they are able to put themselves into the shoes of the AYA, which is experienced as confronting on an emotional level and caused them to dwell more on their emotions in comparison with older patients.

1.2 Enduring the sense of helplessness

Many HCPs expressed they felt helpless because they were not able to provide a curative treatment for the AYA (Table 3 - 1.2.1). This feeling was intensified, and sometimes goes along with a sense of failure when an AYA rejected any form of treatment or was hoping for curative treatment. Some HCPs mentioned that especially AYAs have the expectation that there is a solution for everything, including a curation for their cancer. Psychosocial HCPs mentioned that the anxieties and emotions felt by AYAs with a UPCP are realistic and appropriate to their situation. In practice, these HCPs support the AYA to cope with these feelings instead of changing these feelings. This implies that psychosocial HCPs themselves also have to endure the often negative and severe feelings during a consultation with an AYA.

1.3 Greater sense of empathy

An overall sense of sadness was experienced when HCPs provided care to AYAs with a UPCP (Table 3 - 1.3.1). Most of the HCPs cannot express this sense of sadness in words but they all experienced some extra empathy towards AYAs with a UPCP in comparison to older patients. HCPs are confronted with the fact that a young person is facing premature death, which evokes a feeling of unfairness, since dying at a young age is perceived as injustice of not achieving an acceptable length of life (Table 3 - 1.3.2). Providing care to AYAs who are facing premature death can feel like a tragedy and increases the emotional burden on HCPs.

THEME 2. QUESTIONING PROFESSIONAL ATTITUDE AND SKILLS

2.1 Caring versus meddling

HCPs wanted to respect and support the wish for autonomy of AYAs but are afraid patients do not ask for help when needed. HCPs are struggling to find the right balance between supporting the AYA and not ignoring their wish to be autonomous, which can be seen as a sort of paternalism (Table 3 - 2.1.1). Related to this, some HCPs were afraid to be seen as a 'mother' figure for AYA patients when discussing certain topics (e.g. financial matters) or due to their older age.

2.2 Uncertainty in providing optimal psychosocial care

HCPs reported that many challenges and issues of AYAs with a UPCP were not always visible for them. Some HCPs believed they did not know enough about their patients and felt like they could have been more proactive when it comes to asking about the issues AYAs experienced. HCPs were also doubting whether they asked the right (critical) questions and were wondering if there are non-discussable topics for AYAs (Table 3 - 2.2.1). HCPs are especially struggling how to provide optimal care to AYAs with a different kind of coping strategy, like who did not want or could not talk about their cancer or AYAs without any feeling of responsibility (Table 3 - 2.2.2). HCPs are questioning the kind of language or method they have to be able to successfully approach these patients. The emotional impact AYAs with a UPCP have on HCPs makes HCPs want to provide excellent care, which also can make them feel more uncertain as they often do not know how or if the AYA is not responding to the provided help. It is remarkable that specifically HCPs working with AYAs with LGGs experienced this uncertainty. This uncertainty is triggered when HCPs were contacted by a spouse about issue(s) related to cognitive decline experienced by an AYA, while these issues were not discussed in the consultation room earlier.

2.3 Consultation room composition

The triangle consisting of AYA (and partner), parent(s) and HCP was experienced as an extra challenge by some HCPs when making and/or maintaining contact with the AYA. Especially when there was a disagreement between the AYA and their parent(s), or when parents were imposing their own

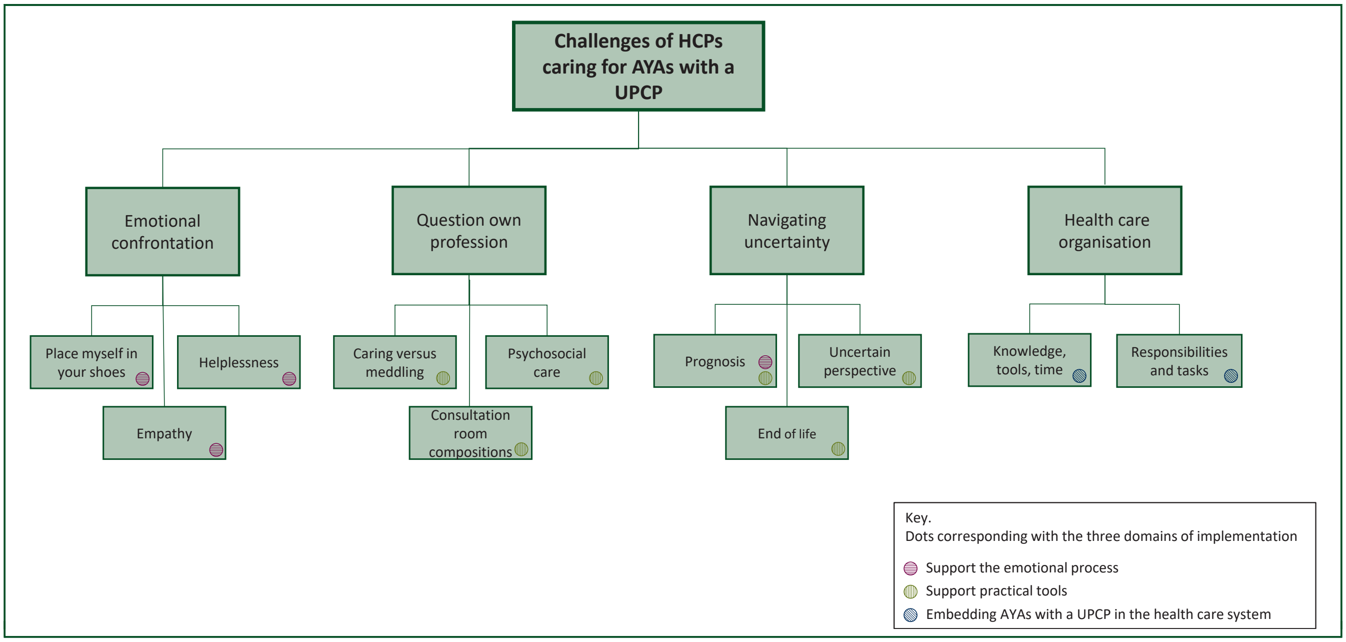

Figure 1. Representation of themes and sub-themes of the challenges of HCPs delivering care to AYAs with a UPCP.
AYA, adults and young adults; HCPs, health care professionals; UPCP, uncertain and/or poor cancer prognosis.

viewpoints on to their child. With the presence of a parent, HCPs noticed a kind of guarding effect, in which an AYA was not telling everything to protect their parent(s) from sadness (Table 3 - 2.3.1). Besides, HCPs felt that it is not appropriate to discuss sensitive topics like death, intimacy and sex when a parent is present in the consultation room. The family dynamic was reported as an extra challenge in religious families. Normally, children assist their parents during health care appointments, while this is reversed in AYA patients. In religious families, in which dealing with diseases and death can differ, it is not always clear if the AYA has the same cultural norms and wishes as their parents (Table 3 - 2.3.2). Therefore, HCPs are struggling to find a balance that meets the needs of the patient and family members, while respecting their cultural norms and in which the HCPs can provide the necessary information to provide the best care for each patient.

THEME 3. NAVIGATING UNCERTAINTY

3.1 Communication about prognosis

Some HCPs expressed that uncertainty about the course of the disease can result in the failure to provide a clear future perspective for the AYA. Many HCPs would like to give AYAs some certainty and guidance for the future and not being able to do that is emotionally hard (Table 3 - 3.1.1). Answering questions of an AYA about their future, like 'can I become a parent' or 'can I start a study' is perceived as being difficult since HCPs do not want to give the AYA any false hope or take away any hope. According to the HCPs the wish to become a parent is ethically difficult in AYAs without any hope of cure. HCPs are struggling as to what extent they have to interfere with this decision.

Besides, HCPs mentioned some struggles with providing prognostic information, since this is at times unique for specific patients and can change over time.

3.2. Communication about end of life

Because of the whimsical nature of the disease and the sometimes durable survival, explicit moments to start talking about end of life are not always very well defined, can pop up unexpectedly or are sometimes even planned too late (Table 3 - 3.2.1). Therefore, many HCPs struggle with finding the right moment to start a conversation about end-of-life issues. For HCPs it is more difficult to start talking about end-of-life issues when death is not in the nearby future, since they are afraid to take away patients' hope as well as their own hope. HCPs struggle with balancing between not going along with the patients' denial or avoidance regarding death and discussing end-of-life issues without scaring the AYA (Table 3 - 3.2.2).

3.3 Whimsical patterns and uncertain perspective as an extra challenge in treatment

Psychosocial care, which is especially important for AYA patients because of their developmental milestones, has to be adjusted to the unpredictable pattern of the cancer characterised by alternating periods of stabilisation and progression. This required flexibility of HCPs (Table 3 - 3.3.1).

THEME 4. OBSTACLES IN THE HEALTH CARE ORGANISATION TO PROVIDE AGE- AND DISEASE-APPROPRIATE CARE

4.1 Lack of knowledge, tools and time

AYAs can experience multiple issues due to their age, life stage and life-limiting situation. Physicians reported a lack of sufficient time to map the biopsychosocial situation of the AYA. Some HCPs felt inadequate to provide psychosocial age-appropriate care to AYAs, and especially knowledge

Table 3. Quotes of HCPs

1.1.1	"What I find difficult are the people of my own age [..]. I really think the people with which you mirror yourself, is sometimes very confronting. That is sometimes very difficult." (Neurologist)
1.1.2	"I am not 25 anymore, but I have experienced that age. So that too makes me, at a certain level [...], empathise more easily with this young age group compared to people who are 50 or 60. Because I don't live in that phase or have that age yet. And therefore I don't have the same life experience yet." (Neuropsychologist)
1.2.1	"I feel more hopeless, more in the sense that you cannot offer the help you would like to offer. Because you wish someone can stay alive. So, that hopeless feeling is more present when working with AYAs." (Clinical nurse specialist)
1.3.1	"The sadness of young people, yes that is something that really hits you. [...] But yes, really young people who, totally unexpected, are torn from life, that is very dramatic every time right?" (Medical oncologist)
1.3.2	"First of all, it is more unreasonable, if you are young, that you are diagnosed with such a disease. That also makes the impact harder. If someone is 72 then everyone would believe he has had the majority of his life. If someone is 28, that's just unreasonable." (Neurologist)
2.1.1	"These are people who are simply in a phase of their lives in which they work very autonomously and independently. You have to encourage them on the one hand, but on the other hand you don't want people to sit at home, struggling immensely, but find it difficult to ask for help. That's why you really want some simple form of communication. So I find that difficult. A sort of search between when it will be a form of meddling and when it is a rightly timed concern for the AYA. That you want them to know they can count on you." (Social worker)
2.2.1	"That you also think, maybe they don't want me deeply involved into it. I also don't want to make the impression that I'm making a happening out of it, that you dig deeply into what it is they are doing. So that's what you're afraid of. Being afraid is a big word, but it is difficult. You don't want to push people to tell things that are not there or what they don't want to tell in the first place." (Neurologist)
2.2.2	"Young boys, who are very busy with: 'I don't want to make you sad, I don't want my girlfriend and mother to worry'. These boys are saying: 'yes, it's all fine', while you see the enormous effort in all of their muscles to avoid crying. One puncture and the balloon will burst. And I sometimes wonder: do I have to burst that balloon or not… do I let this be?" (Neuropsychologist)
2.3.1	"Sometimes you deliberately make an appointment with the patient alone. Or you ensure that you speak with the patient in privacy, because sometimes other topics are discussed if the parents are present. Young people also want to protect their parents against sadness. So then they are comforting their parents and not telling the real story because they want to stay strong in front of their parents. And when you speak to them in private, they say 'I know I will die, but I don't want to tell my mother since she will be so sad'." (Medical oncologist)
2.3.2	"You do not discuss a topic like death. Death happens when Allah decides that you are ready. It is not for me to decide. Of course that is not the case, and I don't do that at all. But yes, the interaction with death is just very different culturally which makes it harder because there is no room for conversation." (Medical oncologist)
3.1.1	"Within the AYA group, which can already be a complex group, this is also a group with a high level of uncertainty. That is a difficult group. In which we think, and I hope, we do our best to provide optimal care, but where you cannot always provide something. But where you cannot always give some kind of certainty. And then it is also a matter of endurance for the healthcare provider." (Support consultant)
3.2.1	"Look, it is determined by the chance that a patient still has available to be stable on treatment for a long time. In low-grade glioma patients it is not that clear. And in low-grade glioma patients it is also difficult because if it doesn't go well it can be a matter of a year/half year before it goes really wrong. So, it's difficult to point out the moment to start talking about end of life." (Neurologist)
3.2.2	" [...] What I find difficult in caring for AYAs is that I am continuously searching if I will go along in the moment with the risk of downplaying the situation or is it my responsibility to shine the light on other present issues without unbalancing, scaring or losing the AYA." (Social worker)
3.3.1	"It can be a challenge since we work little with protocols and the disease, symptoms, progression and treatments requires a flexible approach in our therapy. We have to work around the new treatments or symptoms, stop our therapy or focus more on how to cope with the progression or new treatment." (Neuropsychologist)
4.1.1	"We have a few girls from an age of 21 who started their study and then got sick, so questions are also very often about contact with school and postponement of student grants and that is not entirely our expertise." (Rehabilitation doctor)
4.2.1	"Do I have to look whether the best support should be social work or a psychologist? Sometimes you just get those responsibilities back. The question then is, am I able to define what the exact needs are or is it better if someone else takes this responsibility. I am not so sure myself either." (Clinical nurse specialist neuro-oncology)

AYA, adults and young adults; HCPs, health care professionals.

about their preferences in guidance, treatment goals (prolong life, better quality of life) and tools to assist them with school and work issues were lacking (Table 3 - 4.1.1).

4.2 Lack of clarity about responsibilities and tasks within the hospital

Even though AYAs with a UPCP face multiple challenges, it is unclear for some HCPs as to what extent the treatment of psychosocial issues is the responsibility of the hospital and whether patients should be referred to psychosocial services outside the hospital. Since roles and responsibilities within the hospitals were not always clearly defined, some HCPs were not able to find the right psychosocial support for the patient at all times (Table 3 - 4.2.1). Some psychosocial HCPs observed difficulties among physicians to distinguish normal emotional reactions versus psychosocial problematic behaviour. This sometimes resulted in unnecessary referrals to psychosocial teams. Some physicians were uncertain about their own expertise and responsibilities (am I capable of helping this patient?).

Although it was not the main aim of this study, overall there was little variation in experiences across HCPs based on their demographics, medical specialty and professional experiences.

DISCUSSION

This qualitative study is among the first to examine the challenges of HCPs in delivering care to AYAs with a UPCP. HCPs described challenges with: emotional confrontation, questioning professional attitude and skills when providing care to AYAs with UPCP, navigating uncertainty, and obstacles in the health care organisation to provide age- and disease-appropriate care.

Based on the challenges HCPs expressed during the interviews, we recommend practical implications on three different domains: (i) supporting emotional process, (ii) providing practical tools and (iii) embedding AYAs with a UPCP in the health care system (Figure 1).

Supporting emotional process

In line with previous research focusing on advanced and terminal AYA patients, this study revealed that HCPs experienced some extra empathy for AYAs with a UPCP in comparison to older adults.[13-15] Empathy is being able to resonate with others' emotional states and to be sensitive to their inner experiences.[27-29] This greater sense of empathy is created by feelings of unfairness of dying young. This is related to the fair innings argument, which reflects the idea that everyone is entitled to some 'normal' span of life years.[14] Another factor contributing to the sense of empathy was being able to put yourself into the shoes of the AYAs and their families and for some even self-identification. In previous research, identification with the AYA was interpreted as a countertransference reaction.[13,14] The feelings of emotional proximity and unfairness of HCPs drive HCPs to go above and beyond for these AYA patients. However, since they are not able to provide a curative solution or clear guidance for the future, feelings of helplessness and a sense of failure can be experienced by HCPs. This is a dynamic emotional process in which emotions and hope of the HCPs and the AYA (and their significant other) interacted. Being too empathic, experiences of failure and exposure to suffering and death puts HCPs at risk for developing compassion fatigue, a phenomenon well documented among oncology HCPs.[27,30,31] Compassion fatigue, in other words 'empathic fatigue', is a state of tension which HCPs can develop when stress accumulates due to the constant need to relieve others' suffering and is related to burnout and secondary traumatic stress.[30,32] To take care of the well-being of HCPs and to be able to provide the best care possible for AYAs with a UPCP, it is important to train HCPs to be (more) reflexive regarding their own emotions in formal intervision.[14,31] HCPs in our study were unaware of this impact, but became more conscious about the impact of delivering care to AYAs with a UPCP during the interview. Therefore, the actual behaviour of HCPs towards AYAs with a UPCP deserves attention in future research. Furthermore, it is essential for HCPs to transcend their emotional empathy by being compassionate. Compassion is the willingness to act when you have concerns for another persons' suffering. It is considered as the next step beyond empathy, in which you take some emotional distance to empower yourself to help others while setting boundaries for yourself, which will potentially positively impact patient and HCP.[29,33] Therefore, we recommend compassion training and regular planned deliberation on situations in the clinical setting based on AYAs with a UPCP, which can further help to bring compassion as well as expertise into clinical practise.

Providing practical tools and embedding AYAs with a UPCP in the health care system

The emotional internal process of HCPs and the age-specific challenges of the AYA age group creates some self-doubt about own knowledge and skills 'in supporting AYAs with UPCP on a psychosocial level, resulting in challenges in their daily clinical' practice. It is remarkable that specifically neurologists and clinical nurse specialists in neuro-oncology seemed to experience this kind of self-doubt. Some explanation could be a lack of data in order to make essential decisions about the timing and type of treatment within this LGG patient group. This decision could be more complicated within the AYA population since anti-tumour treatment is usually associated with side-effects which negatively impact quality of life, and therefore important milestones can be at risk within this age group. HCPs in this study experienced a lack of knowledge and skills about how to best support and communicate with AYAs with a UPCP. Especially, initiating topics like 'end of life' and the 'wish to become a parent' are experienced as difficult because of the uncertainty. Most of the time there is no clear answer and HCPs are afraid to harm patients by taking away their hope, causing hopelessness and demoralisation. Furthermore, HCPs are searching how to provide optimal care for AYAs who did not want or could talk about their cancer and are struggling with some complex family dynamics. It is important to educate HCPs from diverse disciplines and help them to build skills and confidence to provide AYA disease-specific care.[16] Recently, worldwide, guidance documents and education modules relating to AYA care management have emerged.[16,31,34-36] For example, Sansom-Daly and colleagues published best practice recommendations to guide clinicians in end-of-life conversations with AYAs.[35] However, this document does not adequately address AYAs with a UPCP. In the Netherlands, the AYA Care Network provides education for (clinical) nurse(s) (specialists) and medical students.[36] The results of our study suggest that this educational module should be complemented with new material relevant for HCPs working with AYAs with a UPCP. This new education module could include information (e.g. AYA guidance preferences, how and when to talk about 'end of life'), concrete dos and do nots (e.g. be proactive to discuss AYA-specific topics and give the AYA emotional space) and the possibility to learn from others in different settings.[31] This module should be accessible for medical as well as paramedical HCPs working directly with this patient group, taking into account medical as well as non-medical issues.

Limitations

Although a qualitative study design provides valuable in-depth insights, this design does not allow formal comparison between subgroups and also hinders the determination of causal relationships. Something we have to take into account is having only one HCP from certain professions (clinical occupation doctor, occupational therapist, psychiatrist, pulmonary physician, radiotherapist, rehabilitation physician, support consultant, urologist) may make it hard to generalise the perspective of that specific discipline. Furthermore, our results cannot be generalised to other countries as health care system factors and cultures might also play a role into the challenges HCPs experience when treating AYA with a UPCP. Since we were not able to analyse HCPs of every patient subgroup, specific items requiring attention with respect to treatment and life expectancy could therefore not be extracted and warrants further research. The fact that similar themes were mentioned across health care disciplines and no notable differences were found across different subgroups of HCPs shows the commonalities in the experience. An in-depth analysis will be done on the challenges of HCPs delivering care to AYAs with an LGG, as they described some topics more often (e.g. uncertainty in providing optimal psychosocial care) than HCPs taking care of those patients undergoing established or new treatments.

Conclusion

This study revealed that delivering care to AYAs with a UPCP is experienced as emotionally and practically challenging by HCPs. Age-specific care for this young patient group is not yet embedded in the health care system, neither in the medical training, resulting in a lack of tools and support for HCPs. To provide person-centred care to AYAs with a UPCP, and to protect the well-being of HCPs, educational tools and bespoke support for HCPs need to be developed.

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