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How do healthcare providers adapt to AYA–parent dynamics when supporting adolescents and young adults (AYA) with cancer? A qualitative study

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ABSTRACT

Purpose: This paper aims to better understand the challenges faced by oncology teams in dedicated adolescent and young adult (AYA) units as they strive to involve both patients and their parents, seeking a balance between patient-centered and family-centered care. Specifically, it examines the dynamics between AYAs, their parents, and healthcare providers (HCPs) during prolonged hospitalizations.
Methods: Conducted between 2018 and 2021 in a dedicated AYA hematology unit in Paris, the study included 10 in-depth individual interviews, research observations, and focus groups. Data were analyzed inductively according to Grounded Theory principles.
Results: Rather than combining patient-centered and family-centered care, HCPs tend to adopt an "AYA-parent dyad-centric" model of care. These results highlight the importance of understanding and assessing the unique dyadic dynamics between AYAs and their parents to effectively support AYA's psychosocial needs, particularly in fostering their autonomy process.
Conclusion: Our findings suggest that a dyad-centered model of care, one that allows the involvement of AYAs and their parents as a dyad, enables a better understanding of and adaptation to the family dynamics at play, leading to more tailored and effective healthcare management.

1. Introduction

Over the past two decades, adolescents and young adults (AYAs) with cancer, primarily diagnosed between the ages of 15–29, (Balliot et al., 2019; Boissel & Baruchel, 2018) have become a distinct oncology group (D'Agostino et al., 2011), challenging traditional pediatric and adult oncology models of care (Ferrari et al., 2021). While earlier studies have highlighted the inadequacy of pediatric and adult oncology models in meeting AYA patients' unique needs – both medical (Reaman et al., 1993; Boissel, 2003) and psychosocial (Reynolds et al., 2005; Fernandez et al., 2011; Docherty et al., 2015) – more recent evidence confirms the persistent gap in addressing AYAs' psychosocial and developmental needs (Beerbower et al., 2018; Bradford, 2020; Braun, 2023; Ferrari, 2021; Ferrari and Barr, 2017; Janssen, 2021; Peeters, 2018).

Pediatric and adult oncology models differ notably in patient-healthcare team (HcT) interactions and involvement of patients'

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caregivers. In pediatric teams, parents serve as the primary liaison with pediatric oncology teams, given children's legal dependency on their parents until patients reach official adulthood, typically at the age of 18 or 21 years (Bongrain, 2005). This is particularly obvious in the delivery of medical information and the decision-making process (Brand et al., 2016; Magni, 2016). Conversely, in adult oncology, the HcT engage directly with their patients, whose autonomy is fully recognized in the therapeutic relationship, particularly regarding their ability to process medical information, navigate the healthcare system, and make autonomous decisions. Close family members are often excluded from HcT discussions with their patients. Moreover, the inclusion of family members requires patient consent (Osborn, 2019).

Thus, traditional pediatric and adult oncology models of care clearly designate the respective main addressees of medical information and care. However, for AYAs, the extent to which each patient is willing to assume the primary role in interactions with the HcT remains uncertain (Sawyer and Aroni, 2005; Zebrack and Isaacson, 2012).

AYA patients face unique challenges as they confront cancer during critical developmental stages (Fernandez et al., 2011; Sisk et al., 2020; Braun, 2023), necessitating increased distancing from their parents (Ricadat, 2019; Janssen et al., 2021) while at the same time requiring reliance on parental support (Juth et al., 2015; Kirakosyan et al., 2022; McNeil, 2019; Morgan and Soanes, 2016). Indeed, whereas recent studies tend to highlight the significance of parental support throughout the AYA's cancer journey (McNeil et al., 2019; McInally et al., 2021), other authors caution against an overly parent-centric pediatric approach, as this might hinder the AYA's autonomy process (Butow, 2010), thus contributing to emotional distress (Kim et al., 2016). Moreover, there is some evidence that an “overprotective” or “controlling” parental styles could lead to AYA-parent conflicts (Michaud et al., 2004; Psihogios, 2019; Sawyer and Aroni, 2005) and eventually affect treatment adherence (Barakat, 2014; Butow, 2010; Cooke et al., 2011; Kondryn, 2011; Robertson, 2015).

Conversely, while AYAs typically desire more autonomy, they may not be fully prepared to manage their care independently while also dealing with the challenges of cancer (Zebrack and Isaacson, 2012). Indeed, AYA patients may feel overwhelmed by medical information, particularly regarding long-term effects (Belpame et al., 2016). Furthermore, a gap may exist between AYAs understanding of the information and their ability to incorporate it into decision-making (Vandermorris et al., 2020). This aligns with neurodevelopmental theories that suggest ongoing maturation of the prefrontal cortex into the mid-twenties (Kondryn, 2011; Schriber and Guyer, 2016). AYAs' cognitive and emotional immaturity poses risks for treatment adherence, especially during maintenance phases (Boissel and Ducassou, 2017; Butow, 2010; Wu, 2017). As such, parental support and family cohesion are considered as key elements of AYA cancer care as they may positively influence both treatment adherence (Butow, 2010; Kondryn et al., 2011; Psihogios, 2019) and psychological well-being (Docherty, 2015; Michaud et al., 2004; Sawyer and Aroni, 2005) .

Recognizing AYA developmental requirement for autonomy despite cancer, AYA oncology models have been built on a "patient-centered" approach (Ferrari, 2021; Magni, 2016; Sawyer and Aroni, 2005). In this model, medical information and decision-making are preferably explained directly to the AYA (Cheung and Zebrack, 2017). AYA cancer care settings should involve an AYA-friendly multidisciplinary team (Bradford, 2020; Cheung and Zebrack, 2017; Ricadat, 2019) aware of AYA special needs and developmental issues, and able to adapt communication (D'Agostino et al., 2011) to provide adequate informational (McCarthy et al., 2018) and emotional support (Ricadat, 2019). However, given the huge heterogeneity inherent to this age group (Osborn, 2019) and their need for navigation and support through cancer care and treatments, the importance of including parents in AYA cancer care models through a "family-centered" approach has emerged as an alternative model (Magni et al., 2016; Ferrari et al., 2021).

This has led many to advocate for an integrated “patient-centered” and “family-centered” approach of care to AYAs (Ferrari et al., 2021). However, this has not translated into recommendations yet, as regards how healthcare providers (HCPs) may concretely implement care for AYA cancer patients while complying with this “dual-reference” care basis. This paper aims to better understand the challenges faced by AYA healthcare teams as they seek to integrate patient-centered and family-centered care models, while addressing young patients and also involving parents.

2. Methods

2.1. Study background

The present study took place from September 2018 to December 2021 in a French AYA hematology dedicated unit. This unit was created in 2010 in response to the French National cancer Institute's recommendation to better meet AYA medical and psychosocial needs. This AYA in-patient hematology unit comprises 16 beds for patients aged 15 to 25, commonly treated for acute lymphoblastic leukemia or high-grade lymphoma.

2.2. Study design

This qualitative study adopted a participatory approach, involving the first author and the HcT in a collaborative research process (Vinatier and et Morrissette, 2015) conducted across two phases of data collection and analysis. The first phase included 10 in-depth individual interviews (April–June 2019) and research observations during psychosocial staff meetings (January 2019 to December 2021), which led to the development of initial research hypotheses through triangulated data analysis. This initial phase was subsequently complemented by four deliberative feedback sessions (October 2020), which allowed for the confrontation of emerging hypotheses with field practice. The second phase consisted of six focus groups (March 2021), designed to further explore and refine the hypotheses developed in phase one (see Diagram 1).

2.3. Ethical considerations

This study did not fall under the scope of the French Jardé law on interventional research. Consequently, approval from a Comité de Protection des Personnes (CPP) was not required. However, all participants were informed of the study objectives and procedures, and provided written informed consent prior to participation. Anonymity and confidentiality were strictly ensured during data collection, transcription, and analysis.

2.4. Phase 1: sampling, data collection, data analysis

To achieve our research goals of understanding the dynamics of the AYA-parents-healthcare provider relationship and its impact on daily practice, we implemented an exploratory research design that combined individual interviews with HcT members as well as psychosocial staff observations.

2.4.1. Research information meetings (enrollment)

The first author organized two meetings in April 2019 to inform the healthcare providers and invite them to participate in individual interviews. These meetings were scheduled to accommodate both day and night shifts to ensure the inclusion of all members of the team. The research topic was presented through an open-ended question: "How do AYA healthcare providers perceive their role when interacting with AYA patients and their parents?" At the conclusion of the meetings, all team members were encouraged to volunteer for individual interviews to delve deeper into this topic. An interview schedule was posted in the staff room to allow the staff members to register for an individual

interview.

2.4.2. Participants

10 out of 40 HCPs agreed to participate (Table 1). Participants were mainly staff members preparing to leave the AYA unit (9 out of 10), either because they had finished their internship or because they were experiencing life changes. Most of them were at the beginning of their professional lives and had not worked very long in the unit (from 6 months to 3 years) when we met them. Only one participant, a night-shift nurse, had more than three years of experience and was not planning to leave the unit soon.

2.4.3. Interviews

In-depth individual interviews were conducted with HcT members from April to June 2019 at their workplace and during working hours, including night-shifts. The interviews, led by the first author, a clinical psychologist and PhD student at the time, utilized open-ended questions to prompt participants to reflect on their beliefs and experiences. Participants were asked a first question: "Can you tell me about how you establish relationships with AYA patients and their parents?" The interviews were then allowed to proceed as a natural discussion, with the researcher building prompts into the participants' narrative. The duration of the interviews ranged from 44 to 110 min (average 69 min) and were audio-recorded with the participants' consent before being transcribed verbatim.

2.4.4. Psychosocial staff' (PS) observations

In addition to the interviews, the first author conducted non-participant observations during the weekly 1-h psychosocial staff (PS) meetings from January 2019 to December 2021, with occasional interruptions during SARS-COV quarantines. Initially, PS observations were not part of the research setting. The researcher had been invited to attend PS as an external, collaborative team member among others. Gradually, however, PS revealed their relevance to both the research topic and sample. Indeed, this additional data source was of particular value as it ensured that the sample was not limited to professionals who were about to leave the unit, as was the case for the individual interview participants. While psychosocial staff observations did not include night-shift teams, they nevertheless provided access to a broader range of professionals, bringing together physicians, nurses, supportive care providers including one clinical psychologist, one youth worker, one school teacher, one physiotherapist, one dietician, and nurse aides—who were not represented in the interview sample. Moreover, PS focus almost exclusively on the psychosocial aspects of hospitalization and treatment. The HcT typically selects a few inpatients to discuss as a group—often those about whom they are particularly concerned or find challenging to care for. Discussions frequently revolve around treatment elements that may distress patients (repeated medical tests, pain, uncertainty, end-of-treatment transitions), and how these emotional burdens affect AYAs' interactions with staff. Questions such as "When are parents present in the unit? According to what rules?" and "How, and to what extent, should they be involved in daily care?" are also widely debated during these sessions and often spark disagreements among team members. As such, PS emerged as a valuable data source, offering a collective perspective to triangulate with data from individual interviews. With consent from staff members, notes were taken during these meetings and anonymized after each session.

Table 1
Individual interviews sampling characteristics.

		N	%
Age			
	20–30	4	40
	30–40	3	30
	40–50	3	30
Sex			
	Female	7	70
	Male	3	30
Profession			
	Resident doctor	3	30
	Day-shift nurse	1	10
	Night-shift nurse	3	30
	Social worker	1	10
	Dietician	1	10
	Physiotherapist	1	10

2.4.5. Data analysis

Data analysis followed an inductive and iterative approach, triangulating data from both individual interviews and PS observations. The first author coded transcripts from both sources using NVIVO software. Initial descriptive coding from both data sources generated preliminary codes, which were then compared through a process of constant comparison (Charmaz, 2006) to develop themes and, subsequently, two transversal categories, following the principles of Grounded Theory (Strauss and Corbin, 1997).

For instance, comparing initial codes such as "the presence of parents in care" and "taking the parent into consideration while preserving the HCP–AYA relationship" led to the theme "a three-part relationship functioning." Further comparison between this and other themes, such as "a different way of communicating with the AYA patient" and "ambiguity in the categorization of AYA patients," resulted in the broader category: "the uniqueness of the AYA–parent–HCP healthcare relationship setting". Similarly, descriptive codes like "infusing treatments with project" and "to keep growing and building oneself" formed the theme "the AYA patient is an adolescent before being a sick patient," which contributed to the second emerging category: "care practices in relation to the AYA's autonomy process." Throughout the analysis, analytic memos and the definition of code properties helped refine codes into categories, distinguishing those that remained descriptive from those evolving into more analytical insights.

A preliminary hypothesis was issued in relation to the first category, specifically that healthcare teams need to expand the healthcare relationship setting to include the AYA-parent relationship when caring for AYAs. The second category, which emerged more subtly in individual interviews but was emphasized in situations discussed during PS, led to the hypothesis that: daily care practices may support the continuity of the AYAs' developmental journey, particularly through supporting the autonomy process.

2.4.6. Deliberative feedback sessions (DFS)

In line with the collaborative research process undertaken with HcT members, and to enhance the grounded validity of the initial findings, we sought to confront emerging hypotheses with feedback drawn from field practice.

To this end, four 1-h deliberative feedback sessions were integrated into the study design, supporting a co-constructive approach to data analysis and ultimately promoting the transferability (Ricadat et al., 2018; Proulx, 2019; Ricadat, 2024) of findings to clinical settings. The DFS (October 2020) were organized to accommodate both day and night-shift teams, and were led by the first author with supervision from the third and last authors. The DFS were designed as multiprofessional discussions, with no intent to include only people from the same professional field. They involved a variety of professionals (nurses, nurse-aides, the unit's clinical psychologist, available supportive care providers, resident doctors, physicians), so that findings stem from triangulated analysis of both individual interviews and PS would be re-examined and contextualized collectively.

The two hypotheses generated during the first phase were discussed and refined, based on the feedback from the participants. The researcher adjusted hypotheses according to HCPs' requests for clarity or precision, supplementing hypotheses with examples from daily practice, as revealed during both the psychosocial staffs or the interviews.

Additional examples were reported by the participants during meetings. Two issues in particular sparked debates among participants, which the researcher rephrased as such: 1) "the importance of personal experience as a parent in caring for AYAs" and 2) "setting limits when providing care to AYAs." As concerns the first aspect, some professionals underscored how their own experience as parents would guide their interactions with AYAs and their parents. For the second aspect, HCPs discussed the demanding nature of adjusting care to the AYA patient's needs, which participants described as often challenging team cohesion and raising questions about authority and boundaries in the healthcare relationship setting.

The recurrence of these two issues across the four sessions, along with their ability to generate debates within the team, confirmed the relevance of these issues to the research topic. Similarly, the capacity of these research hypotheses to stimulate debates among participants and potentially reveal new perspectives not previously identified in data analysis would be considered a consistent criterion for validating these hypotheses. Following these discussions, staff members were invited to further explore emerging hypotheses in focus group settings.

2.5. Phase 2: sampling, data collection, data analysis

A second phase consisting of six focus groups was designed to further explore and refine the two research hypotheses that had emerged during phase 1 and were deemed sufficiently robust after being tested against feedback from field practice during the deliberative feedback sessions.

2.5.1. Focus groups

The focus groups aimed to deepen reflections about emerging hypotheses which had arisen from the primary data analysis and had been further explored during DFS. To do this, four issues were proposed to participants. Two of them were directly rephrased from the preliminary hypotheses established in phase 1, while the other two were rephrased from the two main issues brought by staff members during DFS. By combining issues derived from primary analysis with those arising from DFS, researchers aimed again to facilitate a co-constructive process in research analysis and enhance the transferability of results to practical settings. The points presented were as follows: 1) The AYA patient, his/her parents: the healthcare provider's place 2) The role of personal experience in caring for AYAs: as a parent, as a care provider 3) Limits in taking care of AYAs 4) AYA patient care and autonomy process.

2.5.2. Participants

Six focus groups were established, involving a total of 24 participants, comprising nurse-aides and nurses, including those on night-shifts (see Table 2). It was decided to maintain separate groups based on different roles, primarily due to the hierarchical structure typical of healthcare institutions, which we believed could potentially affect the ability of all involved to express themselves freely. For example, while nurse aides' participation was typically limited during psychosocial staff meetings, their active involvement during the DFS was considered beneficial and led the research team to decide to provide them with more opportunities to express themselves within the focus group design. While it was challenging to gather supportive care providers from other units, doctors were generally not included, with one exception, as the chief physician (7th author) unexpectedly participated in a night-shift nurse group (see Table 3). Only one night-shift nurse took part in both individual interviews and focus groups.

Table 2
Participants characteristics (phase 2).

		N	%
		24	100
Sex			
	Female	20	83
	Male	4	17
Profession			
	Day-shift nurses	8	34
	Night-shift nurses	7	29
	Nurse-aids	7	29
	Chief doctor	1	4
	Secretary	1	4
Participation to phase 1		1	4

Table 3
Focus groups sampling characteristics.

Focus Group 1		N	%
		4	
Sex			
	Female	3	75
	Male	1	15
Profession			
	Day-shift nurses	4	100
Participation to phase 1		0	0

Focus group 2		N	%
		4	
Sex	Female	2	50
	Male	2	50
Profession			
	Day-shift nurses	4	100
Participation to phase 1		0	0

Focus group 3		N	%
		4	
Sex			
	Female	3	75
	Male	1	15
Profession			
	Night-shift nurses	3	75
	Chief doctor	1	15
Participation to phase 1		0	

Focus group 4		N	%
		4	
Sex			
	Female	4	100
	Male	0	0
Profession			
	Night-shift nurses	4	100
Participation to phase 1		1	15

Focus group 5		N	%
		5	
Sex			
	Female	5	100
	Male	0	0
Profession			
	Secretary (former nurse-aid)	1	20
	Nurse-aids	4	80
Participation to phase 1		0	

Focus group 6		N	%
		3	
Sex			
	Female	3	100
	Male	0	0
Profession			
	Nurse-aids	3	100
Participation to phase 1		0	0

The focus groups were conducted in March 2021 at the HcT workplace during working hours, led by the researcher and alternately supervised by the third or last authors. With all participants' consent, focus groups were audio-recorded and transcribed verbatim by the 1st author). Recordings lasted from 57 min to 62 min (average 60 min).

2.5.3. Data analysis

The Focus group transcripts were coded by the first author using NVIVO software, following constant comparison principles, and were added to the analysis of previously collected data. Codes from the first phase of analysis were systematically compared with the codes generated during the focus group analysis. Categories were discussed extensively with supervisors (3rd and 8th authors) and fellow PhD students (4th and 5th authors) during research seminars, and refined to ensure consistency.

Ultimately, "Dealing with AYAs and their parents as a dynamic dyad instead of as separate individuals" emerged as a core category explaining how HCPs would address the needs of the AYAs and their parents in practice, particularly regarding the autonomy process. This core category emerged from the iterative refinement and deepening of the two initial transversal categories: 'the uniqueness of the AYA–parent–HCP healthcare relationship setting' and 'care practices in relation to the autonomy process.' While it builds on these categories, it also transcends them by revealing the dynamic interplay between them, highlighting connections that were not fully visible in the initial categories alone.

Two supporting subcategories were further developed: 1) the AYA-parent relationship as the primary reference for HCPs, and 2) the HCPs' need to adapt to a delicate AYA-parent dyad compounded by the challenge of cancer.

2.5.4. Reflexivity and critical assumptions

The research team included the chief doctor, the unit's clinical psychologist, and researchers familiar with the AYA hematology unit. This contextual knowledge facilitated access to the field and enriched data interpretation but may also have introduced potential biases. To address this, the team engaged in regular reflexive discussions during the development of research questions, participant recruitment, and data analysis. Coding was discussed collaboratively, and divergent interpretations were debated until consensus was reached. Reflexive notes were kept throughout the process to ensure transparency regarding the researchers' assumptions and their potential influence on data collection and interpretation. In addition, the main researcher actively participated in other qualitative and interdisciplinary research seminars outside her own team. This allowed her to critically reflect on her positioning both towards the participants and within the research team, to confront her assumptions with external perspectives, and to continuously revisit how the research design and its implementation in the field were being shaped. Altogether, these different strategies acted as safeguards, preventing the researcher from relying solely on her own initial interpretations.

3. Results

In response to our research question, which focused on understanding how HCPs approach caring for AYAs with cancer according to a "dual-reference care basis" – patient-centered and family-centered models – our analysis revealed that HCPs tend to adopt an "AYA-parent dyad-centric" model of care rather than operating "in-between" the two models.

4. The AYA-parent relationship as a primary reference for HCPs

In essence, the HCPs in our sample emphasized the importance of recognizing and respecting the unique dynamics within each AYA-parent dyad when caring for AYAs with cancer. HCPs acknowledged the necessity of understanding and relying on the inherent dynamics of each dyad to effectively support AYA psychosocial needs, particularly in fostering the autonomy process. This may be illustrated through 3 types of considerations reported by the participants, highlighting how the AYA-parent dyad serves as the primary reference for HCPs: 1) Deal with AYA-parent relationship as a third interlocutor 2) Detect where each AYA-parent dyad stands regarding autonomy process 3) AYA-parents' relationship interference with the AYA-HCP relationship setting.

4.1. Deal with AYA-parent relationship as a "third interlocutor"

HCPs highlighted the uniqueness of healthcare relationships in AYA settings, particularly when compared to traditional pediatric or adult contexts, where the healthcare relationship setting is typically perceived as dualistic:

"*In adults, it was more like a two-kind of thing with the patient at first, and then with the family*" (Female, resident doctor, interview)

"*In pediatrics, medical information goes rather to the family than directly to the patients*" (Female, resident doctor, interview)

Conversely the dynamics in AYA settings are perceived as more complex, functioning as a three-part relationship functioning regarding HCPs' interactions with AYA patients and their parents:

"There really are two speakers so it's a bit like playing ping-pong. You're like: 'Ok, I'm talking to the mom but she's not the one to be receiving chemo so "bam" I look over there but "bam" (laughs) … it's a bit subliminal but there's still this kind of tricky situation and I still don't know whom I should address first." (Male, resident doctor, interview)

One difficulty reported by participants is that simply using existing laws, to define the legal age at which patients should be addressed as the primary recipients of information, is of no help:

"Even if they are over the age of legal majority, when we inform the patients, to explain their disease to them etc., generally the parents must be present and overall, we can't take any decision without the parents (Female, resident doctor, interview)

Or:

"When they're under 18 (legal age of majority in France), you're legally bound to keep their parents informed; when they are over 18, you're not legally bound, though, they're still the parents … so, it remains … it's difficult." (Male, resident doctor, interview)

Therefore, while HCPs often rely on legal age majority to define the parents' right to accessing medical information and communication regarding the patient health, this approach proves ineffective in daily practice. Furthermore, the absence of an external third-party (i.e external directives or legal age majority) to define the boundaries of the AYA-parents-HCP relationship is likely to hinder HCPs' ability to assume the third-party role they typically adopt in adult or pediatric care settings, thus complicating the differentiation between the AYA-HCP and the patient-parent dynamics:

"Well with adults, what I usually do is first ask the patient if he's okay, in a joking manner – because patients' entourage often ask 'can we stay?' but sometimes, the patient doesn't really want that, so I'd say 'it's up to you' trying to lighten the mood. And sometimes, there's a surprise, some say 'well, no, I'd prefer to talk just the two of us.' So, I ask the patient's children or wife to step out." (Male, resident doctor, individual interview)

This resident doctor mentions no trouble asking adult patients about their preferences regarding the presence of children or family in the room. Similarly, he expresses no hesitation in asking relatives to step out if necessary. However, he admits feeling uneasy about doing so when dealing with AYAs:

"*Here, it's not really an option, especially when … when they're over 18, it gets tricky. I mean, I'm not sure if I'm experienced enough to just say, 'Okay, you're 18, your parents are here, is it cool if they stick around*?" (Male, resident doctor, interview).

So, if HCPs view AYAs and their parents as the two primary participants in a three-part relationship, these findings imply that they also regard them as part of a "parents-child" dyad dynamic. This dynamic may potentially influence the patient-HCP relationship, serving as a "silent third interlocutor" for HCPs.

4.2. Detect where each AYA-parent dyad stands regarding the autonomy process

Participants also expressed difficulty in determining the extent to which each AYA patient is prepared to take on the role of the main communicator with the HCPs. Regardless of their age, some older patients would find it hard to be addressed as the main interlocutor, while others would turn out to be more mature than anticipated on the basis of their age only, as we shall illustrate hereafter with citations regarding two patients of 19 and 16 years respectively:

"*Yeah, (some patients are) harder to engage, as they regress in a way. I remember this one patient, every time I tried to get him to sign the discharge papers, he'd be like 'no, you gotta explain it to my mom.' Yeah, it's like he regressed … It was tough because he was 19, so … "* (Female, resident doctor, interview)

"We must tend to a happy medium and not only rely on the age on the file (in this case 16). The "psychological age" too … what they've experienced up until now, also plays a huge role." (Female dietician, interview)

Despite HCPs attempt to refer to legal age limits to delineate the roles in the healthcare relationship and prioritize communication with either the AYAs or their parents regarding either group's concerns, this approach proves ineffective in practice. Additionally, patients sometimes spontaneously defer to their parents on different matters of concern. Consequently, rather than relying solely on the AYA patient's actual age to adjust the healthcare relationship and communication, HCPs emphasize the importance of assessing each AYA-parent dyad dynamics, specifically considering the AYA's "psychological age." This refers directly to the autonomy process and each AYA patient's ability to take care of themselves.

4.3. AYA-parents' relationship interference with the AYA-HCP relationship setting

HCPs often report having to deal with the AYA as "a different person" according to whether the parents are present or not:

"In reality, some patients stay silent when their parents are around, so we end up just talking to the parents. It's like, 'well, since my parents are here, I'll just go back to being their kid and not say anything.' But once the parents leave at night, we start talking and they ask questions we've already answered like 10 or 15 times. But now that they're the ones asking, it's like they were really listening to the answers." (Female, night-shift nurse, interview)

Dealing with the identity lability of AYAs – oscillating between being the child of their parents and transitioning into young adulthood, concerned about their own well-being – poses significant challenges for HCPs working with AYAs. Consequently, the HCP occasionally struggles to discern whether AYAs' negative emotions or reluctance stems from healthcare-related issues or conflicts with their parents at that particular moment:

"*Yeah, I was actually thinking about this one patient. Her relationship with her parents is pretty rough, you know, typical teenage rebellion stuff (…) when she complains: is it because of the side effects of the treatment? Or because of the legitimate pain from cancer? Or is it just because things aren't going well with her parents? We try to figure that out, to find the right balance."* (Male, day-shift nurse, FG)

Continuing from the previous statement, some HCPs in our sample argued that due to the developmental stage of AYAs, the presence of parents brings back into focus a relational context that they must navigate, as it is likely to influence daily care.

5. Adjust to a delicate AYA-parent dyad compounded by the challenge of cancer

Overall, HCPs recognize that the emotional distress caused by cancer can compromise parents' ability to set boundaries. They also understand patients' need to test limits and express dissatisfaction. In such situations, HCPs view it as part of their role to support AYAs' emotional distress when patients cannot turn to their parents and to bolster parental authority when weakened by cancer-related challenges. Consequently, HCPs must constantly shift between acting as a supportive third party for either the parents or the patient, depending on the evolving dynamics perceived within each dyad, particularly in light of the strains brought about by the cancer journey.

5.1. Embody a "third-party support" role to sustain parental authority weakened by the presence of cancer

HCPs have recognized the importance of incorporating an educational aspect into their healthcare responsibilities. They mentioned scenarios where they might take on the role of "the bad cop" within the AYA-parent dyad, being the one to set boundaries or address behavior that they perceive as crossing the line with the parents:

"*Sometimes, um, parents hesitate. They hesitate to be a little … so, well, I end up being the bad cop. The thing is, parents love that. Like, when I see mommy trying to get him to take the pills, but she can't because she's the mom, so the kid says no. And then I come in, and I might be a bit more 'matter-of-fact', so he ends up taking it. And then the parents are happy because they couldn't do it themselves. So, it's kind of a little game."* (Female night-shift nurse, interview)

The silent collaboration facilitated by the nurse, acting as a "third-party support" and tacitly endorsed by the parents, has a dual effect, bolstering both the treatment process and the quality of functioning within the AYA-parent dyad. HCPs were keenly aware of how parental capacity to establish and reinforce boundaries could be compromised by the emotional distress stemming from the cancer crisis:

So sometimes, when I see parents who are, you know, getting tired because … um, psychologically (…) it's like, it's their kid, whom they love. Um, the kid makes them go through … well, hell. Because he's not doing well, we don't know if he'll pull through, and on top of that, he gives orders, so yeah, parents are sometimes a bit lost. So, I think it's good for the nurse to, you know, sometimes set boundaries for the child or the teenager; especially teenagers". (Female night-shift nurse, interview)

The previous statement implies that by assuming this educational role, HCPs recognize the extent to which AYA-parent dyads may be challenged by cancer, despite being a "system" typically expected to support and withstand the expressions of AYA developmental processes. Consequently, HCPs have observed that AYAs might potentially exploit cancer as a pretext to resist hospital ward rules or treatment procedures, with parents sometimes condoning their actions, even if it risks compromising the treatment process:

"*Somehow, they take advantage of the parents. … well, the parents don't dare to say anything because the kid is sick. (…)"* (Female nurse-aid, FG)

Or:

"*There's this patient (…) you can tell her parents are super worried because, well, she's their only daughter (…) And … they're struggling to set boundaries with their sick kid. I get it, you know, it's tough. Like, imagine being 16 and dealing with all this. It's not fair. But that doesn't mean the kid gets a pass to be rude or disrespectful. They still gotta be polite, behave well, and follow the rules, just like at home."* (Female nurse-aid, FG)

Later during this interview, nurse-aides refined their thoughts about the rules and the function they may have regarding the following of the developmental course:

"Because if this kid gets through this at the end, and everything's ok, well she might have forgotten all the rules, the essence of what is respect of others; every time, it will be a pretext to say "yeah, but I went through cancer". (Female nurse-aid, FG)

These findings indicate that HCPs recognize the importance of supporting the AYA developmental journey with cancer by assisting parents in fulfilling their parental role. Specifically, this involves enabling parents to maintain themselves in a parental role with their child, who, despite facing cancer, remains an adolescent or a young adult.

Embody a "third-party support" role to sustain the AYAs' needs to still be adolescents, not just patients with cancer.

Conversely, some HCPs mentioned that they extend themselves as third-party support for AYAs who are hesitant to communicate things that matter to them, because they are concerned that this might cause distress to their parents:

"I also like to tell the kids, you know, when aunties, uncles, and everyone would come over, and the kid was just … exhausted, you know, from seeing them. But out of respect for his family, he wouldn't dare say, "You guys are annoying me, seriously." So, I tell him, 'Tell us' like, 'Use us' by saying, 'Damn, they're (family members) coming this afternoon, but I really don't feel like seeing them today'." (Female nurse-aid, FG)

Aligning with previous statement, the following excerpt illustrates how patients may rely on the support of HCPs as a third-party ally to adopt a different stance towards their parents or assert their needs as adolescents and young adults, rather than solely as cancer patients:

"*Afterwards, I'm not sure if the patient agrees with everything his father imposes because, for example, when his father insists that he goes to bed at 8 p.m., well, just last week, when his father told him 'Come on, turn it off, you need to go to bed,' he responded with 'No, no, chief physician said I need to have a teenage life' (laughs)*. (Female, night-shift nurse, FG)

5.2. HCPs' difficulty to embody the role of third-party support for AYA-parent dyads

Eventually, HCPs recognize that parents, when overwhelmed, and patients, when seeking solitude, may not always feel comfortable expressing their needs or seeking assistance. Consequently, HCPs must remain attentive to the interactions and dynamics within each AYA-parent dyad to discern unspoken needs and adapt care approach accordingly. The following excerpt exemplifies potential misunderstandings in the relationship dynamic, as HCPs continually strive to navigate the distinct needs of both AYAs and their parents in order to foster the optimal functioning of the AYA-parent dyad throughout the cancer journey:

"There's a kid who absolutely wanted his dad to stay even though … dad is not supposed to stay (because of 18 y.o. limit). There were no dramatic things that required the dad to stay. But, he called the mother, in tears, he cried so much on the phone that we heard it at the other end of the ward (…) He made a whole scene, and we didn't have the information that we shouldn't play along with him. So, the nurse gave in, saying 'yes, of course, if daddy wants to stay, ok,' and the dad just fell apart, like, 'Aaagh'. In fact, no, he didn't want to stay, and he was waiting for us to assert authority by saying, "No, you're an adult, your dad isn't supposed to stay." (Night-shift nurse, interview)

HCPs also cited instances of failure in the alliance between parents and HCPs when attempting to assist parents who seek aid in reminding their child of ward rules and procedures crucial for delivering quality care. At times, the nascent alliance between parents and HCPs is eventually thwarted by the pre-existing alliance between AYAs and their parents. Furthermore, the breakdown of this new alliance between HCPs and the parents appears to strengthen the original alliance between AYAs and parents, heightening resistance against both HCPs and the constraints of hospitalization:

"*So, here's what happened – I tried to team up with the parents. I told them, 'We're on the same side, so when I say no, you say no too. And when I say yes, you're on board too.' But then, I found out they were sneaking around behind my back, like 'shh, don't let the nurse know, we're going out for pizza, we're going … '*" (Female nurse-aid, FG)

HCPs commonly expressed the difficulty of striking a balance between supporting AYAs and their parents as a dyad affected by cancer without compromising the quality of care and the organization of the HcT. They noted that their ability to act as third-party support could be compromised, particularly when confronted with the dyadic functioning of AYA-parent relationships where HCPs perceive little space for their involvement. For instance, a group of nurse-aides recounted a challenging situation where they struggled to engage with a patient because the parents consistently spoke or responded on behalf of the patient. Even when it came to simple preferences like meal choices, the patient deferred to the father, leaving the nurse-aides feeling disconnected and unsure of how to support the patient effectively. They described feeling "clueless" and "lost" in such scenarios, unable to discern whether the patient's silence stemmed from acquiescence to his/her parents' wishes or a genuine need for HCP intervention. Moreover, they highlighted instances where parents imposed restrictions on their child's access to HCPs, dictating when they could enter the room without consideration for the HcT's schedule, and exerted pressure on the staff during interactions. Consequently, the nurse-aides expressed concern and insecurity regarding the delivery of quality care, as they feel like there is no longer room for their professional analysis in this type of situations.

Overall, these results show that working within a healthcare relationship extended to the AYA-parent dyad requires HCPs to care for the dyad itself, as it is potentially affected by cancer. This means attending not only to patients and parents separately, but also to the fragile balance of their relationship.

6. Discussion

Drawing from a participatory approach fostering collaborative analysis between AYAs HCPs and researchers, this qualitative study sought to provide grounded data for innovating practice concerning how HCPs practically navigate AYA care practices, particularly in balancing AYAs' growing autonomy with parental involvement. While existing research underscores the inadequacy of traditional healthcare models in meeting the unique needs of AYAs with cancer, evidence remains scarce to underpin the development of a dedicated AYA healthcare model (Bradford et al., 2020; Telles, 2021).

In a recent scoping review (Telles, 2021) categorizing studies on AYAs with cancer and survivors, the authors noted that the theme of "AYA healthcare system/treatments" was the most prevalent (46 %), surpassing categories like quality of life (39 %), sexual health (8.7 %), and social issues (6.2 %). However, they also highlighted that the majority of studies aimed at "raising awareness" (73.3 %) about existing gaps for future fulfillment rather than focusing on "action" (11.2 %) or post-action evaluation (13.7 %). Conversely, our findings may contribute to bridge the gap between "awareness" and "actions" in AYA

healthcare practice. Firstly, our primary discovery – the necessity for HCPs to operate within an "AYA-parents'" dyadic framework to adequately address the specific needs of each AYA patient – provides a clearer understanding of the daily challenges faced by HCPs in caring for AYAs. Secondly, it offers data to inform concrete actions regarding "age-appropriate" care delivery, which remains essential (Gorman et al., 2018). Lastly, it suggests that expanding healthcare practices to include an AYA-parent relationship framework may not only support AYA patient psychosocial needs during cancer treatments but also yield positive implications post-treatment.

First, our findings confirm that navigating between two distinct interlocutors in the healthcare relationship setting can be challenging for HCPs. However, even more daunting is the task of managing AYAs and their parents as separate entities while recognizing their interconnectedness. Our study demonstrates that in order to adjust to each AYA patient's autonomy needs while also acknowledging the importance of parental support, HCPs must first assess the dynamics within each AYA-parent dyad. This highlights a concrete example of "age-appropriate" care practice, which aligns with the developmental perspective rather than relying solely on normative age categorization, which may not accurately reflect AYAs' psychological growth or maturity. Interestingly, our findings may diverge from previous studies advocating for an AYA healthcare model focused on "age-appropriate care" delivery (Ferrari and Barr, 2017). In fact, while existing recommendations often pertain to adapting care practices organizationally or environmentally to accommodate AYAs' unique needs, these recommendations overlook the relational aspect of care provided by HCPs on a day-to-day basis. Our study underscores the importance of HCPs making nuanced adjustments to their relational care gestures based on each AYA's autonomy and maturity level. This entails broadening the healthcare relationship setting to include the AYA-parent dyad, which directly addresses the call for comprehensive assessment of patient autonomy and parent-AYA relationship quality to empower AYAs and improve their sense of control (Ricadat, 2019).

At another level, developing communication skills with AYAs is essential to AYA cancer care (Fernandez et al., 2011; Ferrari et al., 2021). Thus, previous studies have underlined the necessity for HCPs to refine their communication strategies to ensure that AYAs grasp medical details and feel empowered in managing their care (D'Agostino et al., 2011; McInally, 2021). It also implies addressing AYAs' informational needs concerning psychosocial issues such as body changes, fertility, and sexuality (Ricadat, 2019). Yet, while prior research has predominantly focused on direct verbal communication of information, our findings suggest that caring for AYAs may also require HCPs to develop meta-communication skills (Bateson, 1955). As developed by Bateson, meta-communication refers to communication about the relationship itself. This involves not just *what* is said, but *how*, and what it signals about the relational dynamic. HCPs routinely use such skills to adapt support to each AYA–parent dyad, whether reinforcing parental roles or enabling AYAs' self-expression. Importantly, neither party explicitly requests this support; HCPs interpret and respond to implicit needs. This dual level of communication—informational and interpretative—can be challenging, requiring active engagement, responsiveness to ambiguous cues, and might be emotionally challenging. Team support is thus crucial to help HCPs navigate relational uncertainty and emotional strain (Ricadat, 2019). These findings underscore the transformative nature of nursing AYAs with cancer, necessitating constant adjustments and rethinking of conventional nursing practices (Morgan and Soanes, 2016).

At a third level, our findings offer new evidence on how HCPs, by adapting to the specific dynamics of each AYA–parent dyad, can help preserve the positive functioning of this system. Such functioning is closely tied to constructive coping strategies and is a strong predictor of post-traumatic growth (Zebrack et al., 2015). Assessing "family functioning" typically involves evaluating cohesion—the degree of support and involvement among family members—and flexibility, or the family's ability to adapt to stress, compromise, and share responsibilities. Cancer-related stressors—diagnosis, treatment, long-term effects—can challenge both, leading to adaptive or maladaptive responses (Gutiérrez-Colina et al., 2017). In this context, our findings shed light on adjustments to relational care that support family functioning while maintaining adaptability during a cancer crisis. Specifically, our findings suggest that when HCPs adopt a "third-party role" to support AYAs or their parents they can foster flexibility within the AYA-parent system. This, in turn, preserves flexibility within the relationship, a crucial element for supporting developmental progress despite cancer. By doing so, HCPs may help maintain the roles of both parents and AYAs within the caregiver-care recipient dynamic, thereby mitigating the risk of either party becoming overly protective and settling into a caregiver-patient relationship focused solely on medical care for cancer. These insights align with studies on post-traumatic growth (Blickle et al., 2024; Yi, 2015; Zebrack, 2015)—defined as "a positive psychological change following highly challenging life experiences" (Tedeschi, 2018)—which highlight the importance of "family functioning" and "interpersonal relationships with peers and family" (Tremolada et al., 2016, Tremolada, 2018) as key predictors of post-traumatic growth. Therefore, if our findings offer insights into AYA healthcare practices during treatment, this recent literature suggests that a healthcare approach based on AYA-parent dyads during acute cancer treatments may also enhance the ability of AYAs and their parents to cope as a unit during post-treatment phases, potentially fostering post-traumatic growth among AYA cancer survivors.

6.1. Strengths and limitations

The strengths of this study lie in its participatory research design, which engaged both researchers and healthcare team members in a co-constructive process, notably through deliberative feedback sessions. The use of multiple data sources—individual interviews, research observations, and focus groups—enabled data triangulation throughout the analysis. This iterative process was reinforced by a flexible research design capable of evolving in response to developments in the field and to participants' reactions to the research team's proposals. Such adaptability represents a further strength, as it fostered genuine co-construction with healthcare professionals and enhanced the ecological validity of the findings. Incorporating deliberative feedback sessions likely enhances the transferability of findings to clinical practice and helps fill gaps in the AYA cancer care literature by providing empirical, field-based data that remains scarce. This design reinforces both the external validity and internal validity of the study.

However, several limitations must be acknowledged. First, the sample was predominantly composed of female healthcare professionals, which is consistent with the gender distribution observed within healthcare professions in France. While this composition may have influenced the perspectives expressed, it also reflects the social and professional context in which the study was conducted. Besides, the research could have been further enriched by including additional observation settings, such as medical staff meetings or direct observations of patient–HCP interactions during care. It is also unfortunate that the perspectives of AYA HCPs could not be triangulated with those of AYAs and their parents. Future research should compare HCP perspectives with those of AYAs and their families to gain a more comprehensive understanding of the care relationship. In particular, it would be valuable to explore whether AYAs and their parents perceived the HCPs' adjustments as beneficial, how these were experienced, and whether they remained meaningful beyond the treatment phase. In this regard, future attention could be given to how cultural and family backgrounds may shape AYAs' and parents' experiences of care and how they may, in turn, influence HCPs' practices. Investigating these aspects could help to better contextualize the AYA–parent dynamic and the ways in which care models resonate with families from diverse cultural backgrounds. Furthermore, while our study focused on the AYA–parent relationship, it did not explore the possible involvement of partners in the care process.

For some AYAs, partners may represent a key source of support (Davies, 2019) alongside or instead of parents. Although this aspect was beyond the scope of our research, future studies could usefully examine how partners' experiences interact with family dynamics and healthcare practices. Finaly, although triangulation and feedback processes enhance rigor, researchers' involvement in a participatory framework may introduce interpretive biases. We sought to mitigate these by implementing safeguards throughout the research process. Such an approach requires the support of a strong research team, capable of fostering collective reflexivity. Regular and structured meetings are essential to sustain the researcher's reflective and deliberative activity, enabling critical discussion and continuous methodological support.

7. Conclusion

This research provides crucial insights into expanding the AYA healthcare relationship setting to the AYA-parent system, acknowledging the AYA-parents-HCPs as a complex, tripartite healthcare relationship. Indeed, our findings reveal that a dyadic-centered model of care, involving AYAs and their parents as dyads, allows for better understanding and adaptation to family dynamics, leading to more tailored and effective healthcare management. This approach is perceived by staff as enhancing AYAs' psychosocial well-being, particularly in fostering the continuity of autonomy process. While direct evidence from AYAs and their parents was not collected, HCPs perspectives suggest that acknowledging and working within the AYA-parent dyad framework may contribute to more tailored and supportive care practices. A model that recognizes the evolving parent–child dynamic and incorporates it into the care framework may be essential in addressing AYAs' comprehensive needs. Further research should explore how these relationships shape care outcomes and how best to support the changing needs of AYAs across the oncology care spectrum—from acute treatment to long-term survivorship.

CRediT authorship contribution statement

Cassandra Patinet: Writing – review & editing, Writing – original draft, Validation, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Isabelle Aujoulat:** Writing – review & editing. **Karl-Léo Schwering:** Writing – review & editing, Validation, Supervision, Methodology, Funding acquisition, Conceptualization. **Manon Fontaine:** Writing – review & editing, Methodology. **Anne-Laure Sébert:** Writing – review & editing, Methodology. **Cécile Perrier:** Writing – review & editing, Conceptualization. **Nicolas Boissel:** Writing – review & editing, Project administration, Methodology, Conceptualization. **Elise Ricadat:** Writing – review & editing, Validation, Supervision, Resources, Methodology, Funding acquisition, Conceptualization.

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Declaration of competing interest

Authors declared no conflict of interest.

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Appendix

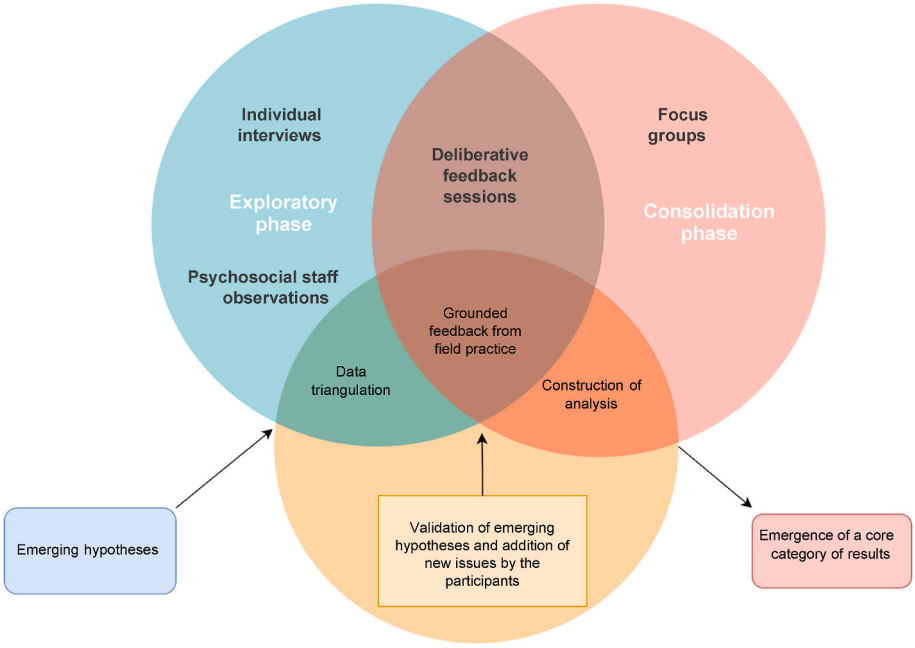

Diagram 1. co-constructive research process

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