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Adolescents and young adults with cancer: how multidisciplinary healthcare teams adapt their practices to better meet their specific needs

Key words:

cancer, oncology, adolescent, young adult, nursing, dedicated units, qualitative methods.

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ABSTRACT

Objective: Dedicated adolescent and young adult (AYA) cancer units have emerged from the early 90s to address multiple challenges faced by AYA patients with cancer. Specific needs of AYA patients have been considered in an increasing number of studies. However, few describe *how* the healthcare professionals (HCPs) perceive their patients' needs and how they actually adjust their day-to-day practices to meet such needs. The purpose of this study is to identify and describe the practical methods of care and teamwork implemented by HCPs in response to what they perceive as essential to support psychosocial development of AYA patients.

Methods: Qualitative research was conducted between 2012 and 2014 with 31 HCPs from a recently created hematology AYA unit in France. The transcripts of open-ended interviews were subject to inductive analysis using *constant comparison* as recommended by the Grounded Theory methods.

Results: Our results show how HCPs adapt their practices and care relationships to support three major developmental milestones related to identity construction in AYAs: self-determination and individuation from parents; gender and sexual identity; social life and connectedness to peers and adults (other than parents). Our results also show how HCPs adapt their practices and organizational methods to enhance the flexibility required to address their young patients', thus setting consistent and high standards for the whole team. Such adaptation is made possible through collaborative work and collective processes that facilitate self-reflection. **Conclusions**: Our findings shed light on some meaningful young patient-friendly practices of care and advocate for AYA dedicated units.

Background

Adolescence, as a transition from late childhood (12 years) to adulthood (the mid-20s up to 30), is a challenging period due to the intense physical and psychosocial changes that adolescents and young adults (AYAs) need to cope with, in order to build a valued and steady sense of self[1]. Cancer is a complex life-limiting condition which deeply interferes with the transition process inherent to adolescence. Having cancer is likely to hinder or delay the achievement of several important developmental milestones in adolescents: physical and psychological development, sexuality, education and vocation, family and peer relationships[2-5]. As a growing number of AYA patients survive into adulthood[6-8], there is higher awareness of the need to comprehensively address their psychosocial and developmental needs, and to help them cope successfully with the numerous interrelated medical and psychosocial challenges due to their condition. During the last three decades, while medical care to young cancer patients has considerably improved, psychosocial care has become a major issue, with the aim to enhance quality of life in adults who have survived paediatric cancer[9-12].

Several studies have addressed how far the hospitalisation experience may adversely affect the adolescence process in cancer patients, and how HCPs may try to make it the least disruptive possible[13-14]. Arguing that AYA patients are seen as belonging to a "no-man's land" between paediatric and adult models of care[15], the need for dedicated units to bridge this gap has emerged[16-17]. Although AYA units have been created since the early 90s in high-income countries, little is known about their practical organisation and what kind of adaptations are required from HCPs to best respond to their young patients' needs[18-19].

The aim of our study was to investigate how the members of a multidisciplinary team adapt their caring practices and work organisation to meet what they perceive as essential needs for the psychosocial development of AYA patients.

METHODS

Interviews were conducted in an AYA haematology in-patient unit in Paris. This unit was founded in 2010 in line with the second governmental cancer action plan (2009-2013). It admits patients aged 15 to 25. A great majority of them is diagnosed with acute leukemia and high-grade lymphoma, both of which require long lasting treatments, including allogeneic stem cell transplant (HSCT). The unit is composed of 16 single bedrooms, including 4 that are equipped with high-efficiency particulate air filtration mostly used to perform HSCT. The average length of stay is about 11 days, ranging roughly from 3 days – for a short chemotherapy regimen – to 4-6 weeks for the induction phase for acute leukaemia or HSCT.

Procedures

The aim of our study was presented by the head of the AYA unit (4th author) during a regular team meeting. All staff members were invited to participate in an in-depth interview during their working hours, including night shifts. Interviews were led by two external researchers (1st and 3rd author), both clinical psychologists and PhD students at the time of the research. In line with our two research objectives, open-ended questions were used to encourage participants to reflect on their own beliefs and experiences: "*How would you define the AYA patients' psychosocial and developmental needs? How do you see your role and that of the team as a whole in supporting these specific needs?*" Interviews were allowed to evolve as a natural discussion, following the path of every participant. The interviews lasted an average of 60 minutes [30-85], were audio-recorded with the consent of the participants and transcribed *verbatim*.

Participants

Thirty out of the 43 members of the staff agreed to participate (Table 1). All have been working in this unit since its creation 2 years before the study, some of them had a previous paediatric or adult oncology experience, others were at the beginning of their professional life.

Table 1- Sample of the HCPs interviewed at the time of the study

9 day nurses	10 night nurses	1 coordination nurse	2 ward-aides
1 social worker	1 kinesiologist	1 nutritionist	1 community worker
2 doctors	1 junior doctor		
1 senior health manager			

Data analysis

We opted for an inductive and iterative approach for the analysis of the collected data. The initial coding of the transcripts involved the 1st, 2nd, 3rd and 5th authors, who set up a preliminary analysis grid based on an independent coding of the 4 first interviews. Referring to the Grounded Theory approach[19], the rest of the transcripts were coded by the two main researchers (1st & 3rd author) in a process of *constant comparison*. Major emerging categories and sub-categories were discussed and refined until the end of the process to reach a strong consensus. This process involved 2 group discussions around preliminary results with the healthcare team.

Results

Regarding our first research objective, i.e. the AYA patients' psychosocial and developmental needs as perceived by the multidisciplinary health care team, our analysis revealed a core category – namely that of supporting identity construction in AYAs – and 3 subcategories that may be seen as 3 different facets of the process of identity construction: (i) self-determination and individuation from parents, (ii) gender and sexual identity and (iii) social life and connectedness with peers and adults (other than parents). Regarding our second research objective, i.e. to reveal how the HCPs in this unit individually and collectively adapt their practices to meet what they perceive as essential psychosocial needs of their patients, flexibility emerged as a core category, which was made possible by collaborative work and a number of collective processes that facilitate self-reflection and build a solid team cohesion. Our results are presented according to these emerging categories with examples of concrete practices to illustrate the findings.

SUPPORTING IDENTITY CONSTRUCTION

The participants generally attested that AYAs go through an important process of identity construction, which involves major physical and psychological changes to be integrated. They acknowledged that the experience of cancer largely hampers this process and advocated for the provision of in-patient care that includes ways of addressing these specific needs. They argued that an AYA patient does not only have cancer, but is a person who must achieve some important developmental milestones that need to be taken into account in the care relationship: « *They remain adolescents, no matter how ill they are. An AYA patient is not an ordinary patient* » (nurse). To mitigate cancer and treatment effects, they identified 3 major challenges inherent to the identity process of any adolescent that may be particularly threatened by the experience of cancer and therefore require special attention from the healthcare team.

Supporting individuation from parents and self-determination. HCP insisted on the importance of supporting the processes of self-determination and individuation as a way of compensating for the dependence created by in-patient care. Therefore, the team aims to deeply involve patients in decision-making processes during the whole duration of their hospitalisation. Parents are less systematically involved by the HCPs in their children's care, as compared to usual practices in paediatrics: « *What changes, with regards to paediatrics, is that the cancer diagnosis is not given first to the parents but directly disclosed to the teenager* » (doctor). HCPs assumed that the parents' presence has to be constantly discussed to support the separation process, which is even more complex in the context of cancer. According to HCPs, there is no one way of regulating the parents' presence, and individualised decisions need to be made. A concrete example is the management of extra beds for accompanying parents or relatives who ask to stay overnight. In this AYA unit, it is not a rule to have an extra bed in the room, as it is in paediatrics: « *I think that nothing should be imposed but rather proposed at this age. This is more important than for the younger ones.* » (doctor). Another example is how

HCPs engage in trying to prevent parents from reverting to former relationships they would have had with their child at a younger age, induced by the status of being ill: « *A mother washing her small child doesn't shock me. However, when this happens with an AYA, I find it difficult… I try to discuss the matter with the parents and that it's not up to them to help with everyday things.* » (nurse aide). Regulating the distance between parents and AYAs has been acknowledged by the participants as being of significant benefit to AYAs' need for empowerment: « *I am thinking of situations where the parents behave in an exemplary manner whilst being able to maintain the right distance. This has an extraordinarily beneficial effect on both the young patient and the parent.* » (doctor).

Regarding the need to self-determine their goals and actions, the HCPs in our study acknowledged that this is basically undermined because of the cancer treatment, which is not negotiable. As a result of being aware of their young patients' need for self-determination, flexibility is introduced into the manner in which the treatment is administered, to suit the young patients' need to remain active decision makers, thus allowing them to develop a sense of control. Non-compulsory treatments are discussed and sometimes dismissed or postponed: « *I try to respect their preferences. If they don't want to be disturbed too early in the morning for instance, I will accept it once but not a second time. Hence, I am not rushing them but still stand firm.* » (nurse). The participants defined their care relationships and practices as being based on an implicit rule: "allowing for negotiation *within a fixed framework*" (nurse).

In order to allow for negotiations, there are no written internal procedures that would set the rules too rigidly and hinder the necessary flexibility. In agreement with doctors, mask-wearing measures are usually relaxed. External home-prepared or commercial frozen meals, prohibited in other places due to infectious risks, may be permitted under certain conditions.

In their capacity as adults, HCPs saw themselves as playing a key role in supporting their young patients' identity-forging process by tolerating conflicts and differing opinions:

« *After all, we represent the adult world for them, and perhaps it is a good thing that they know they can't do whatever they want to do, even when they are sick* » (nurse). They acknowledged negotiation and conflicts as making sense in the caring relationship: « *Teenagers are looking for conflict. Yes, there are clashes, but these are natural things that happen because we are in facility that deals with adolescence. We need to remember the need for mutual respect all the time* » (nurse).

Supporting gender and sexual identity. HCPs were aware that the challenges around sexuality and body image are crucial in the process of defining one's identity during adolescence. As treatments alter the pubescent body, they perceive the importance of enhancing the patient's emerging gendered identity, much more than when working with younger or older patients: « *when I was working in paediatrics, I didn't ask myself those kinds of questions. But teenagers become conscious about their own bodies so I cannot take over it without asking them. They are a person, already an adult for some and for others still ''in progress'', but at the end of the day, they have their say in things!* » (nurse). Consequently, HCPs are extremely respectful of their young patients' modesty and privacy. In practical terms, the AYA unit is organised with single rooms which are separated by opaque doors, thus precluding from the possibility of being observed from the outside. Moreover, for intimate aspects of care, such as hygiene-related issues or fertility preservation procedures, HCPs single out one member of their team of the same gender as the patient when they perceive that the patient feels too uncomfortable: « *Our male colleagues are involved in matters of care that bother boys, for instance for explaining the semen collection procedure. Talking to a man about this is easier than to confide in a woman, even more so if she is a young caregiver.* » (nurse).

Finally, the staff noticed that when special care was provided to enhance well-being in addition to physical treatment, it eased the suffering stemming from a painful and injured body. Massages are offered to allow for positive experiences and to relieve anxiety and stress. HCPs

were deeply convinced that attending to physical needs other than only those ones exclusively related to the treatment of cancer contributes to a better body image, self-esteem and therefore to positive identity construction.

Encouraging social life and connectedness. HCPs acknowledged that the process of identity construction in AYAs involves developing more intense relationships with peers and maintaining their professional and social projects. They observed the disruptive effects of diagnosis and prolonged in-patient stays on AYAs' social dynamics. Despite the isolation measures mandatory in haematology, the AYA unit has been designed with the aim of opening up the boundaries of the hospital: some open living spaces encourage AYAs' social relationships and informal meetings. Various practical adaptations have been set up to reduce their feelings of isolation despite the usual hospital rules: visiting hours were extended to respect the more nocturnal hours favored by AYAs, hospital discharges are facilitated by a coordination nurse whenever the staff identifies that a patient might be suffering from social isolation, a community worker organises collective activities to encourage links between in-ward patients and coordinates the actions of several out-door organisations. One of these provides a teacher who lectures in the hospital and liaise with schools in order to facilitate the patients' pursuit of their studies. A social worker helps young adult patients already engaged in a professional activity to maintain it by liaising with their employers. This gives an indication of the numerous professions involved in the care to AYAs with cancer in this unit.

These concrete measures show a strong will to approach the AYA patient more holistically and the HCPs' conviction that caring means more than curing cancer: « *After all, I do not look at them as ill people in the first place, but rather as people.* » (nurse). Our participants conveyed that AYAs with cancer need not only efficient and evidence-based medical and technical treatment, but also strong links and genuine human connection, which they acknowledged as the core component of the care relationship: « *If they need to talk, I don't*

leave, I give them time. Interpersonal relationships are very important in this unit. » (ward-aide). Such involvement was recognised as giving sense to their work. On the other hand, they also acknowledged that it might make them more vulnerable: « *In this unit, our caring technique is based on relationships. It is not much more difficult than anything else, but it means that we are much more involved.* » (nurse). Reflecting on their efforts to best address their young patients' needs, HCPs reported that they get personally involved beyond the boundaries of their traditional professional roles, thus exposing themselves to an increase risk of emotional burden. Reflective practices and strategies are used to process the constant adjustments that are required to maintain a collective cohesion and flexibility.

FLEXIBILITY, COLLECTIVE PROCESSES AND SELF-REFLEXION

HCPs were aware that being individually flexible was dependent on collective strategies aimed at protecting their professional roles and ensuring overall coherence of staff decisions: « *I always try to give a consistent message, because otherwise AYA patients fall between the cracks.* » (nutritionist). In practice, they reported that formal and informal teamwork practices had emerged, such as feeling free to ask for help from a colleague whenever they face emotional difficulties with a patient: « *We must have empathy to be a good caregiver, but we also need to attend our own needs". When I feel emotionally fragile with a patient, I hand him/her over to a colleague.* » (nurse). Working in pairs and mutual trust were cited as important team resources in which interpersonal relationships are central. Although such flexibility could be seen as carrying a risk of confusion, HCPs reported that sharing opinions ensures the team's cohesion: « *I cannot work by myself because we all have our small contribution toward building this care project.* » (social worker). Therefore, HCPs acknowledged the importance of the right motivation to work in such a ward: « *We are all very motivated here because facing an adolescent requires a high sense of solidarity* » (night nurse).

The weekly staff meetings aim to favour a multi-focal approach and individualisation of care procedures. Personalised decisions are more appropriate than decisions that would be taken by complying with predefined criteria according to a fixed medical protocol: « *I remember a patient, in aplasia and feverish, who wanted to leave for the weekend. From my typical paediatric perspective, letting her out was out of the question… But after discussing it with the team, I let her go out. This enables us to do work on a case by case* basis » (doctor). Every staff member feels responsible for passing on information while optimising his/her professional role: « *This multidisciplinary exchange is very constructive: it invites us to share different views, thus revealing aspects of a patient's experience, that I would otherwise not necessarily be aware of. This experience enriches me.* » (nutritionist).

Open-mindedness and reflexive practices were described as a strong resource that nurtures in return the HCP's own professional role, and their ability to better meet the demands imposed on them by AYA patients.

DISCUSSION

Identity work was identified by the HCPs as the core challenge that AYAs with cancer must face, along with the interconnected challenges of building one's autonomy and sexual and social identities. Whereas these issues have been well studied from the patients' perspective[21], they have remained understudied with regard to opinions of HCPs'. Yet, HCPs are particularly challenged when it comes to support such needs in the patient-provider relationship. This study does not only report on individual and collective practices meant to support AYA patients' psychosocial needs but also on strategies and skills HCPs should aim to develop in order to meet this challenge.

First, HCPs contribute concretely to individuation and self-determination targets when involving patients in decision-making processes and playing a subtle role in negotiating their parents' presence. Recent research suggests that AYA health communication and collaborative

decision-making is a sensitive issue, because the age of legal responsibility should not determine who (the parents or the young patient) has to be informed[22-23]. Assessing as comprehensively and as early as possible the patient's degree of autonomy and the quality of the parent-AYA relationship should contribute to a better balance of decision-making responsibilities as far as the patient-parent dyad is concerned. This is consistently related to an important coping strategy to develop AYAs' sense of control[24].

Secondly, our results highlight how HCPs pay attention to AYA patients' sexual development by being sensitive and responsive to individual patients' level of sexual maturity and physical development. There is some evidence that treatment-related side effects adversely affect AYAs' early puberty, sexual function and development[25-28]. Recent research suggests that impairments of body image seriously threaten the gendered identity if related to lower self-esteem. Self-esteem plays a key role in the development of the sense of self as a sexual being at that age[29]. Our study shows that HCPs support the body image with the onset of puberty by being highly respectful of modesty and privacy. They promote a better body image as they offer positive sensory experiences and feelings about physical impairments thanks to their careful handling of physical areas affected by illness or treatments by providing massages. As shown in other studies, such attitudes are likely to contribute to a better self-acceptance, thus fostering enhanced relationships with peers and intimate partners[30-31]. We believe that it paves the way for better communication regarding the emotional, romantic and sexual dimensions of their quality of life, all of which are key issues in this population of patients[32-33].

Another major issue for HCPs was about maintaining a bond with peers by favouring outpatient hours, school attendance or the pursuit of work and projects as key elements in building one's identity at that age. They adapt hospital and ward rules to reduce the disruptive effects of hospitalisations. In doing so, they provide personalised adjustments which require that they improve their own tolerance to conflicts. The present study shows how they develop

negotiation skills, patience, with mutual respect as a strategy to promote a genuine and non-authoritative therapeutic bond. There is some evidence that a strong patient-oncologist alliance is associated with psychosocial wellbeing and therapeutic adherence in AYA cancer patients[34].

Lastly, our findings highlight that a genuine personal relationship based on open-mindedness and strong motivation are to be considered subjective abilities HCPs must develop to support such an alliance. The HCPs' skills are strongly linked with the understudied concept of empathy in the patient-caregiver relationship. A recent review concludes that HCPs' empathy is associated with better psychosocial adjustment and less psychological distress in the HCPs[35], although there is a lack of nursing-focused research in this field. Various sections of the transcripts obtained show deep emotional and subjective commitment as core human qualities developed by the HCPs to favour empathy: it can be seen as a main contribution to this topic. However, being empathic exposes HCPs to a "double-edged sword"[36], with a clear benefit for patients potentially counterbalanced by a detrimental effect on professional stress levels, especially when patients are facing life-threatening condition[37-40]. It would deserve further investigation to assess how HCPs' empathy is a source of work exhaustion or distress. Our results suggest that a reflection about what it means to get personally involved in care should be introduced early in the curricula of medical and paramedical studies, and the importance of a trained and balanced workforce within the team (i.e. multidisciplinary and mixed-gendered).

Study limitations

The strength of our study lies in the high participation of a multidisciplinary health care team in an AYA dedicated unit, althought nurses are an over-represented professional category. Moreover, as this was a study conducted in a single centre, the sample of participants was inevitably small, and our results may not be appropriate for extrapolation. In addition, we opted for an iterative process of data collection and analysis. Yet, at this stage of our study, we are

aware that we have not reached saturation of the data. Rather, as is typical in grounded theory, our initial research question has broadened and there are still many issues that need to be explored to improve the AYA's psychosocial care.

Clinical implications

HCPs have delivered useful recommendations to support AYA's psychosocial development such as providing patients personalised adjustments in their caring practices and implementing strategies to that end. As such, these can be transferable to other similar care situations and may initiate a reflection on practical guidelines for young patient-friendly models of care in dedicated units.

Conflict of interest statement

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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