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# Oncology healthcare professionals' knowledge, attitudes, and practices regarding young carers

Short running title: Oncology professionals' knowledge of YCs

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Pauline Justin LPPS, Université de Paris 71 avenue Édouard Vaillant, 92100 - Boulogne-Billancourt, France. Email: pauline.justin@u-paris.fr **ONCOLOGY PROFESSIONNALS' KNOWLEDGE OF YCS** 

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Abstract

**Objective:** Increasing numbers of youths are facing a relative's cancer. In this context, some

are required to provide significant support and are called young carers (YCs). However, little

is known about how these youth are viewed and supported by health professionals. The aim

of this study was to investigate the knowledge, attitudes, and practices of oncology

healthcare professionals regarding YCs.

Methods: Thirty-one oncology professionals working in France (adult and pediatric

departments and homecare services) participated in semi-structured interviews.

Results: The results indicated that almost all professionals had already met a YC and could

identify several situations in their professional context. Their knowledge of YCs appeared to

influence their attitudes and practices. They perceived this situation in a rather superficial

way when their discourse and ideas were explored in-depth. They mentioned some ideas for

improving support for YCs, but also many barriers.

Conclusion: The results highlight a moderate level of awareness. Thus, it is necessary to

enhance providers' awareness and knowledge of YCs.

Practice Implications: Awareness campaigns and training programs need to be developed

for oncology healthcare professionals to help them better identify, understand, and support

YCs and their families. This type of action would positively impact patient care.

**Keywords:** cancer, healthcare, oncology, professionals' awareness, support, young carers

#### 1. Introduction

Cancer is one of the most common diseases globally. In 2018, approximately 400,000 new cases in adults and more than 2,200 new cases in pediatrics were diagnosed in France [1]. Considering that 63.9% of French families have at least 2 dependent children [2], the likelihood of an underage child facing a relative's cancer (parent, sibling, or grandparent) seems relatively high, although it has not been statistically determined.

Illness, particularly cancer, upsets the family homeostasis and dynamic [3]. Studies have shown that youth facing a relative with cancer, primarily a parent or sibling, assume more family responsibilities [4]. They take on tasks to the detriment of their personal interests and activities, which can impact their physical and mental health [5,6].

Several studies have been carried out on young people caring for an ill or disabled relative. These have led to the emergence of the term *young carers* (YCs). YCs are defined as children or adolescents, aged 18 or under, who provide significant and regular help to one or more of their family members or close relatives [7]. YCs can support their relative in housework and emotional support as well as intimate and medical care [8–14]. Studies in several countries have estimated that 2% to 8% of youth are carers [15–18]. No study specifies the prevalence of young people having a relative with cancer, although a large majority of studies assessing the consequences of cancer for youth address the topic of caregiving [4].

In addition to the consequences of facing a relative's cancer diagnosis, providing a supportive role also has negative effects on physical and psychological health. YCs report stress and worry, particularly a fear that something will happen to their relative [19]. YCs often describe feeling tired and almost two-thirds are overwhelmed by the tasks required, develop psychiatric or somatic symptoms, and fall ill in turn [19,20].

Despite these consequences, YCs remain underserved by social and health systems [21]. Indeed, YCs are "invisible" and are therefore difficult for professionals to identify. YCs are currently not recognized as carers, but rather as children facing a relative's illness [12,22]. Thus, YCs are not often asked about the nature and consequences of their caring activities [21].

However, YCs report the need for support, recognition, and the opportunity to communicate about their situation, although they don't know whom they can approach with their problems [23,24]. They also point out the lack of resources available to help them in their caring roles and ask for more information, support, and advice to better support their ill relative and cope with uncertainty [19,23,25]. Some YCs report the need to receive support from health professionals, particularly to allow them to maintain their personal activities, have time for themselves, and rest. Unfortunately, there is a lack of awareness of how to obtain this support [21,23]. In a study by Leu et al. [16], YCs addressed that it was difficult to communicate with health professionals in hospitals regarding their situation.

While the needs of YCs have been explored in the literature, few studies have focused on healthcare professionals' awareness of them. Only Leu et al. [26] showed that many healthcare professionals encounter YCs very frequently in their practice. However, they don't identify them as such and are not aware of their role at home. Indeed, professionals may focus solely on patient care and not necessarily on the family and, therefore, the youth [16]. Thus, it is essential that health professionals become aware of this issue and know what to do when they encounter a YC. This is particularly important in France, where the level of awareness of YCs is very low [27]. The purpose of this study was to explore oncology healthcare professionals' knowledge, attitudes, and practices in oncology departments and

homecare services. As YCs can provide care to adult or pediatric patients, we investigated this purpose among professionals working in both adult and pediatric departments.

#### 2. Methods

#### Sample

The inclusion criteria were professionals who worked in a healthcare institution; cared for patients with cancer; were physicians, health executives, nurses, nursing assistants, psychologists, or social workers; had over 1 year of professional experience; and gave written informed consent. In addition, a large geographical area, a diversity of professions, populations cared for, and care structures was respected.

#### Design

This study was approved by the Ethical Committee of the University (No. IRB: 00012019-63) and was compliant with the regulations of the French National Commission for Informatics and Freedoms (No. Ref-20191206\_Health\_Care\_LPPS). Professionals were solicited within the researchers' peer networks and the snowballing technique was used to identify other professionals across France. The research was presented as a study on health professionals' practices regarding their patients and patients' families to avoid bias based on participants' knowledge of YCs. Professionals who agreed to participate in the study were asked to send their informed consent by email, after which an appointment to conduct the interview was scheduled. Face-to-face or phone interviews lasted approximately 37 min (16 to 59 min). They were audio-recorded and subsequently transcribed verbatim, preserving participant anonymity.

#### Interview

A guide for the participant interviews was designed by the authors, aimed at exploring the professionals' knowledge of YCs, their professional interactions with YCs (practice), and the role they could have with YCs given their profession (attitude). As recommended in knowledge, attitude, and practice (KAP) survey methodology<sup>1</sup>, to gather as much information as possible on this subject, the interview guide was semi-structured and deliberately contained specific questions to direct and encourage the discourse [28]. Questions also encompassed sociodemographic information and personal experience with caregiving. The interview guide is presented in Table 1.

#### 1) Knowledge and perception of caregiving and young carers

Do you know what a young carer (YC) is?

YC definition given to the participants after they gave their definition: "Specialists define a YC as a child or adolescent who provides regular and unpaid care to an ill or disabled relative, family member, or member of the household."

- Which relatives can YCs care for?
- What type of care can YCs provide to their relatives?
- What consequences do you think this situation can have on young people?
- What impact do you think this situation can have on patients?

<u>Information provided to the participant</u>: "The people most commonly helped are parents, siblings, and grandparents. The care provided includes household support (e.g., housework, shopping), emotional support, and personal care support (e.g., toileting, taking treatment)."

<sup>&</sup>lt;sup>1</sup> The KAP survey is meant to be a representative survey of a target population. It aims to elicit what is known (knowledge), believed (attitude), and done (practiced) in a specific context.

#### 2) Experience with YCs in professional context

- Have you ever met a YC? (context of the discovery, reactions, and actions)
- How often do you meet YCs?
- Do you find it difficult to identify these youth? Why?

#### 3) Resources and barriers to support YCs

- With your institution's resources, what do you have in place for YCs?
- What would you or your institution like to put in place for these youth?
- What could be the barriers to these actions?
- What help can experts on YCs provide to you and more broadly to healthcare professionals?

**Table 1.** Interview guide

#### **Data analysis**

The interviews were conducted until data saturation and a satisfactory interprofessional distribution was achieved. A mixed analysis of the interviews was then conducted. First, quantitative analysis was carried out to obtain descriptive data on knowledge and practices and determine the frequency of professionals who knew of, met, and supported YCs. Because it was a semi-structured interview with "rekindle" to encourage clarification, some thoughts regarding YCs emerged among the participants. A thematic analysis was conducted on all interviews to highlight unexpected elements of the discourse, most notably relating to attitudes. This thematic analysis was conducted following a general inductive approach [29], which allows the researchers to extract prominent themes from the participant's discourse to understand their perception of the studied subject. To achieve this, after reading all of the interviews, the primary researcher (PJ) gathered themes and subthemes and developed a code system. The code system was then reviewed and refined

after several discussions with the research team. A theme was defined as a topic that was sufficiently distinctive for the researcher to recognize it and provided important meaning regarding the research question. The transcripts were then entered into the QDA Miner software (Provalis Research). An independent blind-coding session was conducted on half of the transcripts by a second researcher (VB) to test and refine the code system. After discussions and a modification of the code system, the final analysis resulted in a free-marginal score of 0.883, which indicated good intercoder agreement.

#### 3. Results

#### 3.1 Participant characteristics

Between February and April 2020, 45 professionals were contacted and 31 consented to participation in the study. They had a mean age of 37 years and 93.5% were females. They worked predominantly in the adult oncology department (n = 16), pediatric department (n = 10), and home care service for adults with cancer (n = 5). Eight were psychologists, 6 were nurses, 5 were oncologists, 4 were nursing assistants, 4 were social workers, 3 were coordinating nurses, and 1 was a health executive. They had worked in healthcare for an average of 12 years and in their current department for an average of approximately 6 years. Almost all participants reported having a sick relative during their life and 19.4% thought they had been a YC. Participant characteristics are presented in Table 2.

Sociodemographic characteristics	
Age (yrs) Mean (SD)	37 (9.3)
Female N (%)	29 (93.5%)

#### **Professional characteristics**

Work experience	
Professional experience (yrs) Mean (SD)	12 (10.2)
Seniority in the current workplace (yrs) Mean (SD)	6 (4.7)
Workplace	
Oncology adult department N (%)	16 (51.6)
Oncology pediatric department N (%)	10 (32.3)
Home care service N (%)	5 (16.1)
Profession	
- Healthcare N (%)	15 (48.4)
Oncologist N (%)	5 (16.1)
Nurse N (%)	6 (19.4)
Nursing assistant N (%)	4 (12.9)
- Psychological and social care N (%)	12 (38.7)
Psychologist N (%)	8 (25.8)
Social worker N (%)	4 (12.9)
- Management N (%)	4 (12.9)
Coordinating nurse N (%)	3 (9.7)
Health executive N (%)	1 (3.2)
Personal experience with caring	
Past or current ill/disabled relative N (%)	26 (83.9)
Past or current adult carer N (%)	14 (45.2)
Past YC N (%)	6 (19.4)

 Table 2. Participant characteristics

#### 3.2 Quantitative results

#### 3.2.1 Definition and knowledge of YCs

When asked about the definition of a YC, 29% of the healthcare professionals gave a correct definition, and 64.5% of the participants have a partially correct one. They also had correct perceptions of YCs. According to the participants, YCs and adult caregivers are quite similar; a YC is a youth who supports someone with an illness or a disability. Participants perceived a YC as a child, adolescent, or young adult. According to a large majority, the person receiving support could be a parent, sibling, or grandparent. YCs could provide support in daily life duties, particularly with meals and household chores; they could ensure their relative's physical and psychological wellness, particularly through physical presence, psychological support, or encouragement of enjoyable activities; and they could provide support with caregiving tasks, especially dressing and grooming, providing intimate care, and aiding in medical treatment. Participants reported many consequences for YCs, both negative (e.g., emotional and developmental impact, social isolation, difficulties at school) and positive (e.g., maturity, empowerment, sense of utility and pride; Table 3).

#### 3.2.2 Practices relating to YCs

Once provided the definition of a YC, 87% of the participants reported that they had already encountered a YC in their professional activity, and 51% estimated the encounters as occurring frequently. The YCs they discussed were primarily adolescents or young adults supporting a parent or a sibling. Becoming aware that a youth was a YC could happen in multiple ways. Healthcare professionals learned about the situation either by being directly informed by their patient (most of the time the parent) or by their colleagues from the hospital, the patient care coordinator or the patient's home care service. They could also

observe interactions that indicated that a youth was in a YC role (e.g., a parent directly asking their child for help "because we've been to the home, we've seen things"). The participants' perceptions of the support provided by YCs were primarily related to (a) emotional support for the relative through presence, hospital visits, or psychological support; (b) performance of daily tasks; or (c) care assistance, in particular helping with treatment or being involved in care, without giving further details (Table 3).

#### 3.2.3 Support ideas for YCs

The psychologist was identified as the primary resource for YC assistance by 77% of the professionals. Half of the participants also mentioned the social worker. A large majority suggested that psychological support or creating a group therapy program could benefit YCs. They also suggested communicating more with the youth involved, being available to them when needed, paying more attention to patients' family situations, and assessing the impact the caregiving role might have on the youth. Finally, as more active solutions, the professionals suggested taking over some of the care or administrative tasks, setting up home support to relieve the YC, or referring the YC to associations or other resources that can provide support (Table 3).

#### 3.2.4 Barriers and needs for healthcare professionals

Despite many suggestions for improving support of YCs, the professionals expressed many barriers restricting their actions. First, lack of time and work overload were identified as barriers to implementing actions to support YCs (25.8%). Insufficient awareness of this situation also appeared to have an impact on the identification of YCs and, thus, on their ability to support them (42%). One-third of participants admitted that if they did not

perceive the situation to be a problem, they did not take action to support the child. For 16.1%, these situations were not sufficiently common to systematize support in their departments. Others explained that they did not act due to the termination of care (e.g., due to the death of the patient or when they no longer had access to the family because of a decrease in hospitalizations or relocation). Some professionals indicated that they did not see the YCs because they were absent during consultations (51.6%), and thus could not do anything for these children. Finally, they did not act because the family or the YC refused help from healthcare professionals (58.1%; Table 3).

Nevertheless, participants expressed some needs, including the need for assistance in identifying, supporting, and guiding YCs. Indeed, 71% of them asked to know more about this population and to establish indicators to identify them. Fifty-eight percent of professionals wanted help in supporting YCs, while others wished to know how to approach and communicate with them (22.6%). Finally, 22.6% of professionals sought to know where and to whom to refer YCs (Table 3).

Definition and general knowledge of YCs	
Definition	
Correct definition N (%)	9 (29)
Partial definition N (%)	20 (64.5)
Wrong definition N (%)	2 (6.5)
Age of YCs	
Child N (%)	9 (29)
Adolescent N (%)	7 (22.6)
Young adult N (%)	8 (25.8)

Relative being supported	
Parent N (%)	27 (87)
Sibling N (%)	21 (67.7)
Grandparent N (%)	18 (58)
Another relative N (%)	15 (48.4)
YC caring tasks	
Household duties N (%)	17 (54.8)
Psychological support N (%)	20 (64.5)
Caregiving tasks N (%)	13 (41.9)
Consequences of being a YC	
Negative N (%)	31 (100)
Positive N (%)	22 (71)
Practices with YCs	
Practices with YCs  Experience with YCs	
	27 (87)
Experience with YCs	27 (87) 16 (51)
Experience with YCs  Already met a YC N (%)	
Experience with YCs  Already met a YC N (%)  Already frequently met a YC N (%)	16 (51)
Experience with YCs  Already met a YC N (%)  Already frequently met a YC N (%)  Never met a YC N (%)	16 (51)
Experience with YCs  Already met a YC N (%)  Already frequently met a YC N (%)  Never met a YC N (%)  Discovery of the situation	16 (51) 4 (12.9)
Experience with YCs  Already met a YC N (%)  Already frequently met a YC N (%)  Never met a YC N (%)  Discovery of the situation  Informed by the patient N (%)	16 (51) 4 (12.9) 15 (48.4)
Experience with YCs  Already met a YC N (%)  Already frequently met a YC N (%)  Never met a YC N (%)  Discovery of the situation  Informed by the patient N (%)  Informed by colleagues or other professionals N (%)	16 (51) 4 (12.9) 15 (48.4) 8 (25.8)
Experience with YCs  Already met a YC N (%)  Already frequently met a YC N (%)  Never met a YC N (%)  Discovery of the situation  Informed by the patient N (%)  Informed by colleagues or other professionals N (%)  Identified themselves through an event N (%)	16 (51) 4 (12.9) 15 (48.4) 8 (25.8)
Experience with YCs  Already met a YC N (%)  Already frequently met a YC N (%)  Never met a YC N (%)  Discovery of the situation  Informed by the patient N (%)  Informed by colleagues or other professionals N (%)  Identified themselves through an event N (%)  Support provided by the YC	16 (51) 4 (12.9) 15 (48.4) 8 (25.8) 15 (48.4)

### **Ideas for supporting YCs**

Type of professionals	
Psychologist N (%)	24 (77)
Social worker N (%)	15 (48.4)
Type of support	
Psychological support N (%)	23 (74.2)
Communication with the youth, being available to help N (%)	20 (64.5)
Increased attention to YC N (%)	12 (38.7)
Assessment of the impact for YC N (%)	10 (32.3)
Relief of YC care duties	
Professional taking over care duties provided by the YC N (%)	17 (54.8)
Setting up home support N (%)	16 (51.6)
Referring the YC to associations or other resources N (%)	14 (45.2)
Barriers	
Barriers due to professionals	
Lack of time and overload of work N (%)	87 (25.8)
Insufficient awareness N (%)	13 (42)
Lack of consideration of YCs as a problem N (%)	10 (32.3)
Uncommon situation N (%)	5 (16.1)
Barriers due to YC and family	
End-of-care situation N (%)	8 (25.8)
Absence of YC N (%)	16 (51.5)
Assistance refused N (%)	18 (58.1)
Needs for healthcare professionals	
Information N (%)	22 (71)

Ideas of support N (%)	18 (58)
Communication techniques N (%)	7 (22.6)
Associations or resources to refer YC N (%)	7 (22.6)

Table 3. Quantitative results

#### 3.3 Additional qualitative results

The thematic analysis brought to light 3 major themes and their sub-themes (Table 4).

Appendix A presents a thematic tree with additional verbatims comments.

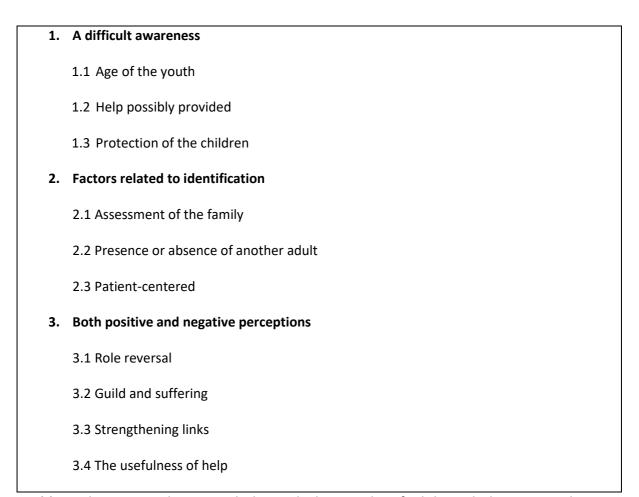


Table 4. The 3 major themes with their sub-themes identified through thematic analysis

#### 3.3.1 A difficult awareness

For many professionals, the support provided to an ill relative depended on the age of the children. It seemed to be more difficult for them to imagine a young child in the role of a carer than it was to imagine an adolescent in this role. Furthermore, there was a perception that many tasks, particularly those related to medical and intimate care, could not be carried out by youth, who, according to professionals, provided only simple and nonintimate assistance. Finally, for many professionals, children were generally kept out of the care.

Children who are able to do this [intimate care], are teenagers, because children... it's a bit complicated... (Oncologist, pediatric oncology department)

Complex care is mainly [provided by] a nurse. But material support at home, such as carrying a chair to help [the relative] get up... It's very practical things that children do (Psychologist, adult oncology department)

#### 3.3.2 Factors related to identification

According to the participants, identification of YCs could be achieved through an informal assessment of the family system during appointments with patients and their relatives. They could quickly assess who is present in the household and each member's role. Paying attention to the patient's relative might allow them to identify a YC.

When patients begin a homecare service, we systematically ask how things will happen at home, who is doing what, how we can help them, and if they need home support to be put in place (Oncologist, adult oncology department).

In pediatric department, because we are interested in the child and the people around him/her, we always ask who the resource persons are and how they are a resource (Nurse, pediatric oncology department).

According to the professionals, many family situations increase the likelihood of a YC in the household. Indeed, the number of adults in the family and the presence or absence of other relatives seemed to play an important role. Participants reported that youth living in a single-parent family were more likely than others to become carers. Similarly, the absence of additional relatives (other family members, friends, neighbors, etc.) would increase the burden on the youth in the household. However, if another adult was present and acted as the primary caregiver, a YC would not be needed. However, most of time, professionals only focused on their patient and not the relatives.

In general, the main caregiver is the spouse, and the existence of YC is particularly in single-parent families, when the mother or father is ill. So... children are even more likely to be... to become carers. (Oncologist, oncology adult department).

#### 3.3.3 Both positive and negative perceptions

Being supported by one's child or sibling could have both positive and adverse effects on the patient. This possible role reversal was mentioned by several participants. It could create a feeling of incapacity and infantilization, especially for the parent (ill or healthy). It could also be associated with guilt and suffering. Nevertheless, this support was also considered very helpful and positive for the relatives and could strengthen the bonds between YCs and their families. Making a definitive decision as to whether YCs should be

encouraged or restricted seemed to be challenging for the healthcare professionals. On the one hand, when the support was for a parent, the professionals' views appeared to be more negative. On the other hand, when it was for a sibling, it was viewed as particularly helpful and very positive for the ill child, the YC, and the family. We can wonder if the perceptions toward the latter situation really pertained to YCs.

I thought it was very violent... I thought it wasn't responsible for parents to ask this to their child. (Nursing assistant, home care service).

It was very positive... the mother brought his friends [to the hospital], it was necessary for him [the patient]. (Oncologist, pediatric oncology department).

#### 4. Discussion and Conclusion

#### 4.1 Discussion

The aim of this study was to investigate the knowledge, attitudes, and practices of oncology healthcare professionals regarding YCs. To our knowledge, only two studies have explored the awareness of YCs among Swiss professionals [16,26]. However, our study was the first to specifically focus on oncology professionals' knowledge, attitudes, and practices and the first to be conducted in France. This study revealed that most professionals had met a YC, had general but not precise perceptions of them, and could identify several situations in their practice. Professionals also highlighted ideas of actions to be taken to support YCs, though many barriers were expressed. Finally, the professionals' knowledge of YCs influenced their attitudes and practices. These results indicate a moderate level of awareness as well as some misconceptions, and a need to improve awareness to optimize

support of YCs. At first glance, the results of this study may appear contradictory. Indeed, the dual approach, using both quantitative and qualitative data analysis, allowed us to identify several inconsistencies in the participants' discourse. The quantitative analysis showed that the professionals had general knowledge which seemed to be correct, but the thematic analysis allowed for in-depth discussion that illuminated some areas of ambivalence toward YCs.

When asked, participants could describe one or more situations in which they had encountered YCs. These results are consistent with the study by Leu et al. [16], which found that health professionals frequently encountered YCs in their practice. In our study, the professionals were able to identify the type of support provided to the patient by the YC and the potential consequences of this situation. These perceptions are consistent with the literature on YCs [11,19]. However, the professionals seemed to minimize the presence and frequency of YCs. According to them, these situations did not seem to be common, although half of them reported meeting YCs frequently. Furthermore, the support provided by youth was perceived as minimal and undemanding, while the literature shows that YCs can have many and important responsibilities [11,30]. Therefore, the professionals appeared to have misconceptions and misunderstandings of the caregiving situation among youth. These misconceptions influenced the identification of, and actions taken to support YCs [28,31]. Indeed, single-parent families and the age of the YC are factors influencing the level and intensity of support [32–34]. Nevertheless, other family situations should not be overlooked. Moreover, although professionals do not mention it, literature shows that girls are more often young carer than boys, including in France [8,35]. This gender ratio imbalance is also observed among adult caregivers [36]. Thus, it seems essential to draw the attention of professionals to this inequality in the role of caregiver, to be more aware of the care burden

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of YC, even more when it is a girl, and not to conform to gender stereotypes, sometimes suggesting that it is more natural for a woman to help. However, even if attention must be given to these population, it is important to recognize that this caregiving situation may exist in all families, regardless of the age, gender of the youth or family structure [37]. While supporting a relative can be a positive experience for YCs and their families [38], these beneficial effects can only occur when the YC receives sufficient social support [39]. Therefore, it is essential to recognize YCs' role and let them know that support can be provided if they need it.

These misconceptions could be due to insufficient awareness of the issue [16], though may also be due to a defensive process causing a certain, and likely subconscious, inability to perceive these youth [40]. Indeed, devoting attention to patients' relatives would be an additional task in an already overloaded professional daily life. This may explain the ambivalent view that professionals may have of YCs. This highlights, however, the extent to which carers are indispensable to our current health system, and it would be challenging to properly care for patients without the assistance of their carers [41]. Furthermore, the lack of consideration for YCs reinforces the idea that care is still too patient-centered, even though more and more studies are encouraging comprehensive care that includes the patient's relatives [41,42]. Moreover, Cass et al. [43] emphasized that improved care for the patient's relatives directly impacts the patient. It is possible that some YCs and their families are reluctant to ask for help or even refuse it. Indeed, many families report shame or fear of social placement [44,45]. Some families and YCs may also not be aware of the care situation [13,46]. Therefore, it is important to raise awareness of this issue among youth and their families as well as health professionals.

Regarding the support that could be provided to YCs, professionals mentioned several ideas. The first action proposed was to refer YC to a colleague, in particular a psychologist or social worker. Indeed, psychological, social, and financial support are recommended and often requested by YCs and their families [44]. However, these services often play a secondary role in supporting families and relatives. This also requires that professionals (e.g., physicians, nurses) first identify YCs. Improved identification and greater vigilance were suggested as ways of increasing support. In addition, relieving the YC of some caregiving tasks seemed to be a positive solution that met the needs expressed by YCs and their families [44]. However, it should be remembered that these were only ideas for support and that few of the professionals currently implemented these actions.

Despite these ideas, many barriers were identified. Lack of time and work overload were reported by a large majority of professionals, both of which can predict burnout and may be important in oncology [47–49]. Burnout can directly impact the physician–patient relationship and quality of care, causing a provider to pay little attention to a patient's relatives [49]. Indeed, Guveli et al. [51] reported that denial and disengagement were positively correlated with burnout.

This study had three limitations that warrant mentioning. First, there was a possibility of selection bias during participant enrollment; due to a snowball sampling, it is possible that the professionals included were those who were the most concerned by the topic of patients, families, and caregiving. Another limitation is that our sample of professionals is predominantly female. Even if it is representative of the gender repartition in health care [52], women also participate more often in studies [53]. Moreover, if in a 93.5% female sample, participants are slightly aware of YC's needs and issues, the awareness of YCs in a more gender-balanced sample may be completed underestimated. Finally, we chose to

quantify some data, though this information did not allow us to make definitive distinctions, particularly between professionals in pediatric and adult departments. These results should be confirmed with a larger sample.

#### 4.2 Conclusion

Our study found that oncology healthcare professionals have some knowledge regarding YCs, but awareness needs to be further developed. It is essential for professionals to be able to identify youth who provide support to a relative with cancer. This disease, now considered chronic, involves long-term and intensive treatment, and has significant physical and psychological consequences for patients, who require daily support. Unfortunately, current healthcare systems tend to focus on outpatient care and provide limited home support that does not sufficiently address the patient's needs. This gap involves relatives, and possibly youth, in patient care. Therefore, professionals must become aware of this issue. To achieve this, gathering more information on this subject is important, as well as the specificities of each professional on the issue. Indeed, it would also be relevant to explore whether there are differences among professionals, particularly according to their occupation (e.g., health executive, psychologist), whether they intervene in patient's home life or only in hospitals, and whether they had a personal experience with caring, particularly during childhood. A nationwide survey could help in obtaining a more precise overview of the subject. It could also aid in the determination of department-specific guidelines and help in the development of targeted interventions.

#### 4.3 Practical Implications

According to Nap et al., [54], the identification of YCs is a crucial first step in supporting them. Thus, professionals need to be aware of this issue, question themselves systematically

when they detect risk factors (e.g., single-parent families, the presence of children) and not be afraid to talk about this issue with families and youth. Awareness campaigns and training programs need to be developed for oncology healthcare professionals to help them better identify, understand, and support YCs and their families. Comprehensive care for the family can also improve the patient's prognosis, optimize quality of life, and reduce the adverse impacts of cancer on the family.

#### **Conflict of interest**

The authors declare that there is no conflict of interest.

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