

REVIEW

Are there young carers in oncology? A systematic review

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Abstract

Objective: This systematic review aims to investigate the support children provide in the case of a relative's cancer.

Methods: Searches were performed on four electronic databases (Embase, PsycINFO, PubMed and ScienceDirect) to identify studies that report on the support provided by children to a relative diagnosed with cancer. Two researchers independently evaluated the eligibility of the studies and cross-checked them for accuracy. The Crowe Critical Appraisal Tool (CCAT) was used to assess the quality of the studies included. **Results:** Out of the 10948 articles screened, 30 were included in this review. Results highlighted that cancer provokes changes in families, such as shifts in roles and increased responsibilities for the youth. Children often provided significant support to their sick relative and family members, including practical, emotional, and medical support such as household duties, medical assistance, companionship, and distraction. However, they were designated as young carers in only one study. The support provided was associated with negative effects such as stress and fatigue, and with positive effects such as increased empathy and independence. Children wished to support their family but also named several needs, such as time for themselves and the opportunity to enjoy their childhood.

Conclusion: The results of this systematic review highlight the importance of taking into account the support provided by young people facing the cancer of a relative and designating them as young carers. Much remains to be accomplished to officially recognize their role and to support them properly.

KEYWORDS

adolescents, cancer, children, family, parent, Psycho-Oncology, sibling, support, systematic review, young carer

1 | BACKGROUND

Cancer is one of the most common diseases in the world, with more than 17 million new cases among adults and more than 272,000 new cases among youth in 2018.¹ Nearly 25% of all new cases of cancer occur in individuals aged between 20 and 54, in prime childbearing and child-rearing years.^{1,2} Worldwide, women have an average of 2.4

children,³ therefore an important number of children are likely to have to deal with the cancer of a family member, whether that of a parent, a sibling, or a grandparent.

Chronic diseases, and cancer in particular, are known to affect the whole family system.⁴⁻⁶ Rolland's model explains the whole family have to readjust when one of the family members has a chronic illness such as cancer.⁷ Subsequently, disruptions in family

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life appear and the family dynamic changes, in terms of family relationships, interactions, daily routines, or recreational habits.⁶ Many studies have examined the impact of cancer on the family, especially on the patients' children. Studies on psychosocial adjustment to a relative's cancer have shown that family functioning is an important variable for determining the way the child functions.^{8,9} Indeed, having a family member with cancer can cause psychosocial, cognitive, and emotional difficulties among children (under 12 years old) or adolescents (13 to 18 years old)^{10,11} such as sadness, anxiety, and worrying,¹² as well as stress and concern about the illness.¹³ However, adolescents tend to develop more emotional problems, depression, and distress than children.^{2,11}

In spite of this, the experience of cancer in the family can foster psychological and social growth among children, aspects including positive self-esteem, enhanced social competence, greater compassion, and increased empathy and sensitivity. Children who have had to deal with this issue also seem to be more mature, independent, and responsible.¹⁴ Cancer can increase cohesion and closeness between family members¹⁴ and foster increased depth of relationships.¹⁵ Visser et al.¹¹ found that families with adolescents having to face a relative's cancer were more expressive, cohesive, organized, and experienced less family conflicts and role strain than families with younger children in the same situation.

Because of cancer, families must reorganize their day-to-day roles, responsibilities, and patterns of functioning to accommodate the demands of the illness.¹⁶ Family routines change, and children and other family members make collaborative and constant efforts to deal with the situation and adjust the family organization.^{6,7} Therefore, adolescents and even young children¹⁷ must take on more responsibilities at home,¹⁴ as is often done by adults who become caregivers.¹⁸ The Family Ecology Framework Model¹⁹ shows that the presence of any family member with a serious illness is associated with an intensification of youth caregiving experiences, particularly when the parent is ill. Children report increased requests to support their healthy parent either by taking care of the sick relative, running errands, or doing household chores, among other tasks.² Several literature reviews have named the support provided by young people^{2,4,6,11,14} which resonates with the concept of "Young Carers".

Young carers (YC) are children and adolescents who provide significant support to a family member with a disease or a disability.²⁰ This support can include housekeeping, emotional support, assistance in the education of siblings, intimate care, and administering medical treatment.²¹⁻²⁷ Studies in several countries (Australia, Austria, Italy, United Kingdom, United States of America, etc.), report that 2 to 8% of young people may be a YC.²⁸ Being a YC has negative effects on children's lives and mental health.²⁹ They are more isolated and less likely to see their friends or to engage in extracurricular activities.^{30,31} They have more difficulties at school, nonattendance is higher, and they are more at risk of school dropout.³² YC also suffer more from physical issues such as headaches, back pain, fatigue, and sleeping and eating problems³³ compared to their peers. They also report high levels of psychosocial distress, including anxiety, depression, stress, suicidal thoughts, and more behavioural problems.

YC have low self-esteem and a low quality of life.^{29,30,32,34-36} These consequences are similar to those experienced by young people confronted with a family member with cancer.

Thus, being a YC has many consequences on a child's life. However, it is difficult to clearly identify the status of these youth in the context of cancer. To develop targeted interventions for the prevention of adverse consequences, one must clarify the type of help children provide in the case of a relative's cancer. To date, no systematic review has been conducted to identify the roles of children in oncology and they seem to be unfamiliar to healthcare professionals. The literature reviews mentioned previously^{2,4,6,11,14} which report on the support provided by children, aimed to examine the impact of cancer and the psychosocial adjustment to it. This systematic review aims describe the type of support children dealing with a relative's cancer may provide, the context of care, and its consequences.

2 | METHODS

This review followed the guidelines described by the Preferred Reporting Items for Systematic Reviews and Meta-Analysis Statement (PRISMA)³⁷ It was registered on PROSPERO (No. CRD42020186090).

2.1 | Search strategy

Four electronic databases (Embase, PsycINFO, PubMed, and ScienceDirect) were used for this systematic review on December 18th, 2019, and then updated on May 14th, 2020. The search was restricted to scientific articles written in English, French, or Spanish. The databases were explored with a combination of keywords relating to the sick family member, the YC and the support provided, and the impact of the illness. The search terms used are presented in Box 1. To complete our search and find other relevant publications, an additional search was performed on Google Scholar and Google Web Search. Additionally, the reference lists of the articles included, and their authors' other studies were checked.

2.2 | Selection criteria

These were the criteria for study inclusion: (a) the study had to investigate the experience of siblings/families dealing with a relative's cancer (adult or children) and the support provided by children to the patient or the family; (b) for qualitative studies, the support had to be reported in the results section, and not just in the verbatims; (c) the family member had to be a parent, a brother or sister, a grandparent, an uncle, an aunt, or a cousin; (d) the study population had to be children under the age of 21. We chose 21 years old as the maximum age because in several countries it is the age of legal majority.

Box 1. Database search terms

("parental cancer" or "parents with cancer" or "mom with cancer" or "mother with cancer" or "dad with cancer" or "father with cancer" or "cancer patient" or "parent has cancer" or "parent cancer diagnosis" or "adult with cancer" or "adults with cancer" or "pediatric cancer" or "siblings with cancer" or "child with cancer" or "children with cancer" or "grandparent with cancer" or "grandmother with cancer" or "grandfather with cancer" or "uncle with cancer" or "aunt with cancer" or "cousins with cancer" or "cousin with cancer")

AND

("child*" or "sibling*" or "brother*" or "sister*" or "teen*" or "twin*" or "young*" or "adolescen*" or "offspring" or "caregiving" or "caregiver" or "young carer" or "carer" or "caring roles" or "peer support" or "guardian" or "nursing role" or "cancer caregivers" or "grandchild*" or "young people" or "youngsters")

AND

("help*" or "support*" or "care" or "caring" or "impact")

Only qualitative, quantitative, and mixed studies were included. Case-reports, literature reviews, and systematic or meta-analyses were not eligible for this study.

2.3 | Study selection and data extraction

All search results were saved on Zotero reference manager. After removing all the duplicates, studies were screened independently by two researchers (PJ and KL) on the basis of titles and abstracts. Once full articles were screened, a complete review of the potentially eligible studies was carried out to verify the inclusion criteria and to establish a final list of eligible studies. To avoid the omission of any eligible studies, articles on overall cancer experience or family adjustment to cancer were included for full-text reading. In case of disagreement between researchers, a consensus was reached with the study coordinator (AU).

The following data was extracted from the studies included: country, research design and methods, study purpose, participants' characteristics (sample size, age, sex), patients' characteristics (relationship with the child [parent, sibling, etc.], cancer localization), measures, children's roles and support provided, and key findings.

2.4 | Quality assessment

The Crowe Critical Appraisal Tool (CCAT)³⁸ is a reliable and valid tool^{38,39} and was used to assess the quality of the included studies.

This 22-items checklist is divided into eight categories assessing: preliminaries, introduction, design, sampling, data collection, ethical matters, results, and discussion. Each category includes several items which were assessed as present, absent, or not applicable. Each category received a score between 0 and 6. These scores were then added together to reach a total score out of 40 and transformed into a percentage.

Two researchers (PJ and KL) independently assessed the methodological quality of each study. In case of disagreement, the evaluation was discussed to reach consensus.

3 | RESULTS

3.1 | Study selection

Out of the 10948 results from databases and the four articles from a manual search, 91 studies were identified as potentially eligible for the review. Then, 61 of them were excluded according to the selection criteria, with very high inter-judge agreement (91.7%). In the end, 30 studies were included in this systematic review. Appendix A presents a flow diagram of the research article selection process.

3.1.1 | Quality assessment of the included studies

The mean quality score of the studies included was 66%. Half of the articles included were of high quality,⁴⁰⁻⁵⁴ 13 of moderate

TABLE 1 Characteristics of the studies included

	N studies	References
Country of publication		
North America		
United States	14	44,45,48,49,55,57–60,63–65,67,68
Canada	2	47,54
Europe		
United Kingdom	3	42,53,56
Belgium	1	46
Denmark	1	52
France	1	61
Germany	1	51
Norway	1	62
Sweden	1	41
Middle east		
Turkey	2	40,69
Asia		
Taiwan	1	43
Oceania		
New Zealand	1	50
South America		
Brazil	1	66
Study design		
Qualitative	22	40–52,54,58–60,62–64,66,68
Quantitative	2	65,69
Mixed	6	53,55–57,61,67
Participants		
Children with a sibling with cancer	15	40,42,45–47,50,51,54,55,57,59–61,63,68
Children with a parent with cancer	10	41,44,49,52,53,56,62,64,66,69
Children's parents	6	43,57,60,62,63,65
Parent with cancer	5	44,52,58,62,67
Children with cancer	1	60
Grandparent with cancer	1	44
Nurses	1	48
Person with cancer		
Children	17	40,42,43,45–48,50,51,54,55,57,59–61,63,68
Parents	13	41,44,49,52,53,56,58,62,64–67,69
Grandparents	1	44
Cancer localization		
Several cancers	20	40–43,45–47,49,51–53,55–

(Continues)

TABLE 1 (Continued)

	N studies	References
		58,60,61,64–66
Specific cancer	2	44,67
Not specified	8	48,50,54,59,62,63,68,69
Main objective related to YC	1	64
Children support is identified as ...		
A main outcome	19	40,41,43–52,54,56,58,59,61,64,69
A secondary outcome	11	42,53–55,57,60,62,63,65,66,68

Note: YC = young carers.

quality,^{55–67} and two of low quality.^{68,69} Quality was considered moderate or low when there were issues regarding sampling and or ethics. Indeed, few studies justified their sample size, which were quite important, especially in qualitative designs. Moreover, many articles were published approximately 20 years ago, and concern for ethical issues was not as strong as it is today. The details of the studies' quality assessment are summarized in Appendix B in Supporting Information.

3.1.2 | Study characteristics

All characteristics of the studies are presented in Table 1 and in Appendix C in Supporting Information. The included studies were published between 1985 and 2020. A majority of them were published after 2011 ($n = 14$)^{40–42,44–51,53,66,69} and conducted in North America ($n = 16$).^{44,45,47–49,54,55,57–60,63–65,67,68} The 30 studies included were qualitative studies ($n = 22$), quantitative studies ($n = 2$), and mixed studies ($n = 6$). Out of the 30 studies, only one studied YC as its main objective.¹⁰

In 17 studies, the family member with cancer was a sibling,^{40,42,43,45–48,50,51,54,55,57,59–61,63,68} it was the parent in 13 studies,^{41,44,49,52,53,56,58,62,64–67,69} and in one study, it was the grandmother.⁴⁴ In 20 of the studies, patients had different types of cancer,^{40–43,45–47,49,51–53,55–58,60,61,64–66} and in two studies, patients had breast cancer.^{44,67} Most articles interviewed the healthy individual: about their sibling with cancer in 15 studies^{40,42,45–47,50,51,54,55,57,59–61,63,68} and about their parent with cancer in 10 studies.^{41,44,49,52,53,56,62,64,66,69}

Ten studies interviewed parents,^{43,44,52,57,58,60,62,63,65,67} one study interviewed a grandparent,⁴⁴ one study interviewed the sibling with cancer,⁶⁰ and one the nurses taking care of the relative with cancer.⁴⁸

In 19 studies, the support provided by children was identified as a main outcome^{40,41,43–52,54,56,58,59,61,64,69} whereas it was a secondary outcome for the 11 others.^{42,53,55,57,60,62,63,65–68} To be considered as a main outcome, the support provided had to be a major theme, a sub-theme, or used to define a theme/sub-theme in the studies' results.

A thematic analysis of the studies included revealed 4 major themes: 1: Role changes,² Responsibilities,³ Consequences on the family and the child facing the relative's cancer, and⁴ Ambivalence in support.

Theme 1 role changes

Twenty studies explored role changes between family members.^{41,43,45,46,48-50,52,53,57,59,60,62-69} We identified 3 sub-themes: the role in the family, the age of the child, and the reasons for children to provide support.

3.1.3 | The role in the family

Eleven studies discussed the disruptions provoked by cancer on family life.^{41,45,53,57,59,62,63,66-69} Four studies talked about changes at home, in daily life, since the diagnosis, and the changing priorities of family members.^{41,53,62,63} Several studies detailed how the roles in the family could shift between the family members.^{57,59,69} These changes also affected children, who sometimes took the role of the parent, most often the mothering role (6 studies)^{45,59,66-69} to provide support to the sick parent or sibling.^{59,68} These changes affected parenthood.^{57,67,68} Indeed, parents had to reassert their role towards their children,⁶⁷ while children sometimes became a parental figure to their siblings.⁶⁸

Studies considered this situation in different manners. Role changes in the family could be negative for children and generate a feeling of loss of normality.⁵⁷ However, three studies reported that for some children the support they provided felt natural and did not have a negative impact on them.^{57,66}

3.1.4 | The importance of children's age

In families with many children, all the siblings may take part in support.^{43,64} One study showed that tasks could be divided between the members.⁴³ Another study⁶⁴ showed that siblings shared the responsibilities according to their number and their physical ability. In general, it's the primary adult caregiver who delegated tasks within the family.⁶⁰ However, the support provided by children was adapted to their age,^{53,59} and age seemed an important predictor of their ability to support.^{59,65} Seven studies^{48-50,52,58-60} reported that the support was often provided by the older child or adolescent in the family, especially when there were several siblings at home. One study showed that young children, especially those under the age of 10, provided little support, in comparison to older children or adult children living in the household.⁶⁵ Chesler et al.⁵⁹ reported that younger children felt that they had no way of helping their sick brother or sister and consequently, that they had no meaningful role to play in this context. However, O'Shea et al.⁴⁸ underlined that children could provide support as soon as they reached school age.

3.1.5 | Reasons for children to provide support

Six studies gave reasons to explain why a child provided support to their relatives.^{41,43,46,62-64} Some of these reasons were related to the cancer and especially to its consequences and treatment.^{41,62,63} Fatigue,^{41,62} physical ability,⁶⁴ chemotherapies,⁶² and hospital stays⁴⁶ explained parents' incapacity and their need to be supported.⁵²

Another reason was related to the fact that the child was the only person who could help at home.^{43,63,64} This appeared in two cases: (i) when parents were separated/divorced or in single-parent families, the child lived with the sick parent and there was no other adult who could be a support;^{43,63,64} (ii) when the only adult in the family felt burdened, and could not manage both the home and the sickness of their other child.⁴³ Finally, some studies also described the parents' absence⁴⁶ as a reason, notably because of their work,^{46,63,64} meaning they could not manage everything.

Theme 2 Responsibilities

Almost every study included ($n = 27$) described an increase in the number of tasks the children did at home due to their relative's cancer.^{40-42,44-64,67-69}

Studies reported that children had more responsibilities than before the cancer diagnosis. Ten of them did not give any further details.^{40-42,45,47,49,52,62-64}

Practical support such as household chores was the most frequently reported support. Twenty studies found that various tasks were carried out at home,^{40,44-47,50-57,59-62,64,69} as well as cooking,^{40,41,44,51,53,64} cleaning,^{41,44,51,53,64} ironing,^{44,51,64} and running errands.^{44,62,64}

Caregiving help, both for the parent and the siblings, was reported in 20 studies.^{40,44,45,47,49-52,54-60,62-64,67,68} This support could be medical assistance^{57,63} such as taking a parent's temperature, positioning bandages,⁵⁸ or giving pain medication.⁶⁴ Caregiving help also included feeding the relative^{59,64} and the physical assistance given to help the relative with their personal appearance.⁴⁴

Twelve studies reported emotional support as another type of support provided by children.^{41,44,46,49,52,54,57-59,61,63,64} They comforted parents and siblings,^{52,59,64} supported their relatives, helped them to cope with the cancer,^{44,46} participated in their well-being, and protected them.^{41,54,61} They were kind and affectionate,^{41,46,58,61} and gave kisses or hugs to their relatives.^{46,58} Finally, one study reported praying for one's relative as a type of emotional support.⁴⁴

Physical presence was reported in eight studies,^{44,46,47,51,54,55,59,64} such as spending more time at home, or companionship.⁴⁷ This type of support sometimes aimed to distract the relative.^{46,47,51,61,64} Children talked,^{46,64} listened,⁶⁴ read,⁵¹ and played games^{61,64} with their parents or siblings. Children were also asked to care for healthy siblings, to look after them when the parents could not^{45,62,64,69} and for this purpose, they were sometimes asked to stay home.

Youth also provided help with organization. They could coordinate medical visits, professionals, and medical information,⁵⁰ and accompany their relative to the medical visits.^{44,58,64} They also visited him/her at the hospital.⁵⁸

Finally, in some studies they played a role in managing the family's income, by generating income,⁶⁹ collecting financial assistance,⁵⁰ or paying bills.⁶⁴

Theme 3 Consequences for the family and for the youth

Providing support to a relative had both positive and negative impacts, as found in 16 studies.^{40-42,45,47,49,52,54-59,64,68,69}

3.1.6 | Negative effects

Three studies reported the negative impact of role changes in the family.^{47,55,64} Indeed, responsibilities that arose from the cancer increased strain, anger, and conflicts between family members^{47,55,64} and decreased time for leisure activities.⁵⁵

Twelve studies addressed the problems faced by the child as a result of the support provided.^{40,42,45,49,52,55-57,59,64,68,69} Barbarin et al.⁵⁷ highlighted the fact that role shifts had adverse consequences on children, but the authors didn't specify what they were. However, negative impact was found in several studies. First, caregiving caused restrictions^{40,49,52,55,64} and interfered with normal child activities.⁶⁴ Youth had to put aside their own needs and interests,⁵² which meant staying at home,⁴⁹ and restricting their social life and activities^{40,55} such as playing with friends, inviting them to stay at home,⁶⁴ but also spending time alone⁴⁰ and with their relatives.⁵⁵ The care provided could also have an impact at school.^{45,49,64,68} Some children had difficulties doing their homework,^{49,64} frequently missed school, performed poorly in school, or dropped out of school.⁶⁸

Furthermore, they can develop psychological issues such as stress, fear, or depression.^{55,64,69} Children were also at risk of fatigue, burden, and somatization.^{64,68,69}

Finally, supporting or caring for a family member could place the child in a parental or adult role, disrupting the development of the child's identity and leading to a "loss of childhood" because of having to grow up quickly.^{40,42,59} This could cause difficulties adjusting to the situation.⁵⁶

3.1.7 | Positive effects

For the family, this situation could also have a positive impact.^{52,54} Supporting a relative can provide family stability,⁵² strengthen family bonds, and bring family members closer together.⁵⁴

Being a caregiver of a relative with cancer can have positive consequences for children, as shown in five studies.^{41,42,57-59} First, it

reassured children about the cancer.^{41,58,59} The support provided normalized the situation and reduced children's fear of medical technology,⁵⁸ comforted them,⁴¹ and alleviated their worries about the cancer.⁵⁹ It could also strengthen children's sense of control over the situation.⁵⁹

The situation could also increase children's empathy, compassion, and solidarity.^{42,57,59} Some studies reported the children becoming more independent, self-reliant,⁵⁷ mature,^{42,57} and patient.⁵⁷ Finally, higher self-esteem, a sense of accomplishment,⁵⁹ and increased self-confidence⁴² have been reported due to the caregiving situation.

Theme 4 Ambivalence in support

Children were ambivalent about caregiving. They wanted to support but also wanted to enjoy their childhood. This underlines the needs of children, separate from the illness. Ten studies reported results on this theme.^{45,47,48,50-52,54,64-66}

3.1.8 | Willing to support

Four studies found that it was important for the children to support their relative.^{50,54,65,66} For some of them, it was a real desire to support their parent or sibling.^{48,59} Several reasons explained this phenomenon.^{45,52,54,64-66} Children found meaning in supporting their relative: they found a sense of normalcy⁴⁵ or a sense of connectedness and belonging. Indeed, providing support allowed some participants to feel closer to their family, since the illness can cause distance between individuals or cause the child to feel left out of cancer issues.^{45,54} It could also represent a challenge for them,^{45,64} an opportunity to learn,⁶⁴ a source of personal growth,⁴⁵ a reason to be proud of themselves,⁶⁶ or a sign of affection.⁶⁵ They had the feeling that they contributed to their siblings' recovery and felt important.^{45,50} Indeed, O'Shea et al.⁴⁸ showed that it might be important for children to find a role in the family during the illness; otherwise, they could feel guilty, helpless, or frustrated if they felt they had not done enough.^{45,52,54}

3.1.9 | Children's needs

Two studies reported ambivalence about the desire to support.^{47,52} Indeed, children expressed the desire to support their relative, but also the desire to be with friends⁵² and care for themselves.⁴⁷ One study discussed the needs of children, notably having time for themselves, for friends, and for childhood activities.⁶⁴

Studies also explored children's needs regarding their role in the family. It could be difficult for them to know how to provide appropriate support.⁵¹ They also needed an available parent to spend more time with them and the family.⁶⁴

4 | DISCUSSION

The current review is the first one to explore the support provided by children to a relative with cancer. Our results show that many studies investigating the impact of cancer on family members mention the support provided by children. However, among the 30 studies included, only one explored this support as its main object of investigation. Results show that the support provided is mostly related to daily tasks, care, and emotional support. Furthermore, children seem to become carers to compensate for the incapacity of the sick parent or the absence of another adult in the family, but also to restore family homeostasis. Providing support can have both positive and negative consequences.

4.1 | The support provided by youth

The oldest study included in our review was published in 1985.⁶³ However, researchers had already identified that youth have been supporting or caring for their parent with cancer more than 40 years ago. In 1979, Wellisch⁷⁰ published case studies underlying the increased responsibilities and help an adolescent may provide to a parent with cancer (this publication was not included in our systematic review due to the study's participant selection bias).

Many studies in this review explored the emotional experience of living with a parent or a sibling with cancer,^{8,9} including its impact on the family or on the children's lives. Cancer, like other illnesses, causes family upheaval and reorganization.⁷¹ Indeed, one third of the included studies reported changes in the family, role shifts, and increased responsibilities for the children because of the cancer. The support provided was mostly related to daily tasks, care, and emotional support. As highlighted, providing support can have both positive and negative consequences. Negative consequences identified were similar to those reported in the wider literature (specific to cancer or not): impact on children's physical and mental health,³⁵ social life,³⁰ and school experience.^{32,72} Positive consequences such as increased maturity, independence, empathy, or solidarity have also been reported previously.⁷³ However, several positive aspects previously reported were absent from our results, notably increased resilience and better coping skills which have been associated with less fear about the cancer and its treatment.⁷⁴

Furthermore, results showed that children are willing to support their relative. New roles might provide secondary benefits and have a positive impact on them or on the family. When helping is handled properly, and when children are sufficiently supported and recognized in the support they provide, consequences tend to be more positive than negative.⁷⁵ In these cases, children *wish* to support, which restores a certain family homeostasis. However, most children (and their families) are rarely aware of their role and the responsibilities they undertake.^{22,76} Becoming more conscious about their increased responsibilities and its impact could help them

identify their needs for support. In addition, children facing a relative's cancer want to be included in the care of their relative, but also wish to pursue their extracurricular activities, see their friends, and spend time with their family.⁷⁷ In light of this, parents need to be careful not to assign too many tasks to children since negative consequences can arise depending on the nature, the frequency, and the amount of time spent each week helping.⁷³ Children also express the need for information about the illness and its treatments, in order to better cope with the situation.⁷⁴ However, health professionals are often reluctant to talk to children about illness.⁷⁸ Thus, it would be important to help parents and oncology healthcare professionals' become more aware of children's needs. Regarding healthcare, information and support might be improved, particularly by including the entire family in the care and not just focusing on the patient.⁷ In addition, this could also enable youth to develop effective coping strategies and to become aware of their place within their family and the impact of the cancer's advent on their lives.⁷⁸

Finally, we notice studies included more adolescents and older children. When studies mentioned support, it was always provided by adolescents. It seems that children's significant support (under the age of 12) to a family member is not possible or conceivable. Yet the literature indicates that children can provide support to a relative as early as the age of 6, and maybe even earlier.⁷⁷ However, there is no information about children under the age of six in the studies included, which is also the case in studies on YC in general.

4.2 | Can we talk about young carers in oncology?

The support cited in the included studies resembles the type of support reported in studies on YC, that is domestic tasks, household management, personal care, emotional care, sibling care, and financial/practical care.²¹⁻²⁷ Other studies give insight into intimate, medical, and personal care.^{18,78} However, the studies included mainly explored household duties, emotional support, and caregiving help, especially medical assistance. Studies also insisted on children being present at home to support the relative. Regarding adult caregivers, a study¹⁸ showed that the main care provided in cancer was intimate care (getting dressed, getting to and from the toilet, feeding the relative...) in comparison to the care provided in other disabilities (dementia, diabetes, and frail elderly) described in the same study. Intimate care was not found in our systematic review as a significant support provided by youth. This may be because the majority of the studies included had a qualitative design in which the type of support was not precisely explored or evaluated. Thus, it would be interesting to use validated measures such as the *Multidimensional Assessment of Caring Activities (MACA-YC)*⁷⁹ or the *Young Carer of Parents Inventory* to determine the support provided by youth in future research. Another explanation can be the fact that children might be protected from this kind of help, often provided by an adult.⁶⁵ However, children living in single-parent households are often the only caregiver and therefore at risk of having to provide this intimate care. Additional caregiving tasks are mentioned in the

literature on YC, such as providing help in the education of siblings and managing communication with health professionals. Thus, it is important to explore the type of support provided by youth confronted with a relative's cancer more precisely, to gain a better idea of their responsibilities and relieve them of some tasks.

In view of the tasks described in our included studies and the link with the literature on YC in other diseases, we can confirm that there really are young carers in oncology. However, children who provide significant support at home in the context of cancer are still being considered "only" as children facing the disease of their relative, and not as YC. Only one of our included studies⁶⁴ considered these children as YC.

Literature shows that children want to be recognized in their caregiving role, to be supported.²⁸ Thus, being able to consider and name them as such could help to better identify and support them. Indeed, more and more countries are undertaking research about YC and recognizing their existence. Leu and Becker⁸⁰ published a cross-national comparison of countries' awareness of and policy responses to YC. Indeed, recognizing YC helps them gain rights and dedicated services (i.e., guidelines for professionals, dedicated interventions and services⁸⁰⁻⁸²). In comparison, the term « caregiver » is used more frequently in the scientific literature and in the media to designate adults. In the past few years however, more and more measures have been implemented to support them and they are now better identified by health professionals.^{77,80}

Henceforth, it is important to ask why YC are not identified and named as such in the context of cancer? First, it is important to underline that YC are almost always studied as a whole, without considering specificities according to diseases, even though the need for help can vary greatly depending on the type of illness/disability. For example, it has been shown that gradual diseases have greater negative impact on YC.⁸³ Second, it may be due to a certain resistance to recognize these children as carers in oncology, or because some children do not identify themselves as such.⁸⁴ Moreover, it may be because the term is not well known.⁸⁵ Currently, the term « young carers » is not frequently used except in social sciences. This may explain why the articles included in our review do not talk about YC, except one.⁶⁴ Thus, there is still a lot of work to be done to recognize YC in oncology. Developing research should be a first step.

4.3 | Study limitations

Several limitations have to be discussed. First the majority of the studies included were of qualitative design. Thus, few standardized measurements to evaluate the support provided were carried out. Moreover, even if there is an increasing number of studies worldwide exploring the support provided by youth in the context of cancer, most included studies were undertaken in the United States of America. Therefore, our results cannot be generalized. Secondly, only one study focused on YC with the primary aim of exploring the support provided by children.⁶⁴ Most results were thus extracted in articles exploring the impact and adjustment of children with a sibling

or a parent with cancer. Hence, we may have omitted some studies when caregiving was a minor result. However, based on PRISMA's criteria our methodology was robust.³⁷ Finally, it was important to identify YC in oncology, and this systematic review allows to confirm the existence of YCs in this context. Our results show that the support provided by children in cancer is quite similar to the one provided in other diseases and can be linked to research on YC in general. Therefore, holding on newer literature on YC would also be relevant for the oncology context.

4.4 | Clinical and research implications

This systematic review fosters a better understanding of children's role, consequences of this situation, and the needs of children in a cancer-specific context. Indeed, cancer is currently one of the most common diseases in the world and, given the chronic nature of the illness, the number of YC is likely to increase over the next few years.¹ In this way, as it is done for adult caregivers, it is essential to recognize the role of the children who provide a significant support to a family member with cancer. This will particularly help to better identify and support them. Indeed, following the recognition of their role, many countries (mostly Anglo-Saxon) offer interventions specifically aimed at YC.⁸⁰⁻⁸² However, these interventions could be improved by better understanding the specific experience and needs of YC in oncology. Nevertheless, according to our results, it seems important to focus actions on the recognition and identification of YC, specifically in oncology. Healthcare professionals can play an important role in supporting YC and their families. They can actively participate in the identification of YC by systematically assessing the family organization, exploring the place that children may have in the household and referring YCs to dedicated organizations and associations.

In future research, it would be interesting to investigate the evolution of the needs and support provided on the long term (longitudinal design), according to sociodemographic, clinical, and medical factors (e.g. cancer localization, treatments, side-effects). Many aspects of the family system could be investigated, such as difference according to the care recipient (ill parent, ill sibling or healthy parent); the age of the YCs and their experience with caregiving; and the quality of relationships between family members. A dyadic approach could also be used to explore whether the psychological impact associated with cancer (for the patient) has an effect on the one associated with caregiving. Further research would help target ways to support YC facing a relative's cancer and should aim to evaluate the need for developing dedicated interventions.

5 | CONCLUSION

To our knowledge, no studies specifically investigate young carers in oncology, compared to an important number of studies investigating adult carers. This systematic review therefore gives a broad idea of the support youth are providing. It is important to undertake more

targeted research on this subject. In order to offer adapted support, there is a need for more in-depth studies on YC in oncology as it is a significant health issue. First and foremost, it is essential to identify the children who provide significant support to a family member with cancer and to recognize their role. Then, it is crucial to raise awareness among healthcare professionals, patients and the population in general about the existence of YC and the support that can be provided to them.

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CONFLICT OF INTEREST STATEMENT

The authors have no conflict of interest to declare.

AUTHORSHIP

All authors contributed to and approved the final manuscript.

ETHICAL APPROVAL

Ethical approval was not required for this study because it is a literature review and as such, no human participants were interviewed by the authors.

DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

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APPENDIX A

Flow diagram of study selection according to PRISMA.

