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# Profiles of French young carers taking part in an arts and respite care program

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## Abstract

Young carers (YCs) are children and adolescents who provide meaningful, regular support to a relative with a health problem. In France, only one programme exists to support them: the arts and respite care programme of the national association JADE. The aim of this study is to describe the profiles of YCs who had participated in this programme and to evaluate their expectations, opinions, and the evolution of their quality of life over the course of the programme. All YCs enrolled in the programme between 2017 and 2020 were invited to participate in the study. Upon arrival, the youths completed a self-report questionnaire addressing their sociodemographic and family situations, their caregiving activities, their quality of life, and their expectations for the programme. At the end of each week, a questionnaire evaluating their opinion of the programme and their quality of life was completed. A hundred and seventeen children participated (average age: 12; 71.8% girls). Most YCs provided support to a parent or sibling with a chronic somatic disease. The support mainly concerned doing domestic tasks and providing emotional support for the relative and was significantly higher among adolescents. Their expectations were mainly about getting respite and meeting other young people. Their levels of satisfaction were high and aligned with their expectations. Their quality of life increased significantly. French YCs in this programme had characteristics comparable to those observed internationally. The results underline the importance of respite and the benefits such a programme can bring to YCs.

## KEYWORDS

artistic programme, disability, disease, family, quality of life, respite, young carer

## 1 | INTRODUCTION

### 1.1 | Definitions and prevalence

Some children and adolescents who are confronted with the illness or disability of a relative provide them with significant support, both emotionally and practically. These youths who provide significant assistance to a family or household member on a regular basis are referred to as young carers (YCs) when they are under the age of 18 or as young adult carers when they are between the ages of 18 and

25 (Becker & Becker, 2008; Joseph et al., 2020). The care recipient may require assistance due to a physical or mental illness, disability, frailty associated with ageing, or a substance use disorder (American Association of Caregiving Youth, 2012). YCs predominantly care for a parent or sibling (Aldridge, 2006; Dearden et al., 2004). Quantitative studies have identified YCs' responsibilities and tasks in the care they provide. Hunt et al. (2005) found that 58% of YCs help their cared-for relative with at least one daily activity (such as bathing, dressing, getting into bed, toileting, or feeding); almost all YCs provide daily instrumental assistance in the home (shopping,

housework, meal preparation); and 96% of YCs keep their relative company. YCs may also help their relative indirectly by taking on some of their responsibilities, such as caring for younger children (Hunt et al., 2005).

Studies conducted in Europe, Australia, and the United States indicate that 2%–8% of children under the age of 18 are YCs (Banks et al., 2002; Becker, 2007; Kavanaugh et al., 2015; Leu & Becker, 2017; Leu et al., 2019; Metzging et al., 2020; Smyth et al., 2011). With reference to international data, there may be approximately 500,000 YCs aged between 8 and 20 in France (Ellien, 2015). However, results from a French study of high school students suggest that this figure is an underestimation. Indeed, the prevalence in a sample of 4037 high school students (average age: 16.1) was 14.3% (Untas et al., 2022).

## 1.2 | The effects of the caregiving situation on YCs

The caring situation has consequences for the physical and psychological health of YCs, and for their leisure time, social life, and schooling (Hendricks et al., 2021; Jarrige et al., 2020). In a meta-synthesis conducted on 11 qualitative studies, Rose and Cohen (2010) found that: (1) becoming a YC is generally not a choice and leads to ambivalent feelings, both positive and negative, that are difficult to resolve; (2) the YC role comes with responsibilities that are rarely recognized and that come with specificities depending on the illness of the relative; (3) the expectations and involvement of YCs are different according to their gender; (4) Often, YCs keep their situation secret and are reluctant to talk about it with others, especially with teachers, which leads to social isolation.

YCs have been found to be significantly more depressed and more anxious, and to have lower self-esteem and more behavioural problems than other children (Banks et al., 2002; Dearden & Becker, 2002; Hunt et al., 2005). They express a variety of worries (Cree, 2003) and have more physical problems (e.g., headaches, back pain, fatigue; Nagl-Cupal et al., 2014). Common issues reported by YCs include sleep problems (60%), suicidal ideation (34%), eating-related problems (30%), self-harm (24%), and use of psychoactive substances (12%; Cree, 2003). According to McAndrew et al. (2012), up to 60% of YCs have mental health problems. Studies comparing YC to non-YC children and adolescents have shown that being a YC affects leisure and socialisation: YCs have more responsibilities, are more worried about their parents, are more isolated, and limit their leisure activities (Pakenham et al., 2006). In addition, the YC status affects academic achievement, learning, and the possibility of further education (Dearden & Becker, 2002; Siskowski, 2006; Smyth et al., 2011; Stamatopoulos, 2015).

Conversely, several studies have shown that this caregiving situation allows YCs to develop resilience skills and perceive personal benefits such as increased self-awareness and maturity (Nagl-Cupal et al., 2014); a sense of responsibility; support for identity construction (Evans & Becker, 2009); and a sense of being useful, valued, and having strong family ties (Lackey & Gates, 2001). However, studies suggest that positive consequences of this care situation only arise

### What is known about this topic?

- Young carers (YCs) are children and adolescents who provide significant support to a relative with an illness or a disability. The support provided concerns household tasks, emotional support, general care, nursing care, intimate personal care, sibling care, and administrative and financial support. Awareness of and knowledge about YC in France are just emerging.
- Being a YC has consequences for the physical and psychological health of youths; for their leisure, social life, and schooling; and potentially for their long-term life plans.
- As they do for adults, respite care programmes may respond to YCs' specific needs. Although various programmes have been developed for this population, they are rarely evaluated and have been the subject of few publications.

### What does this paper add?

- French YCs participating in this arts and respite care programme have sociodemographic and family characteristics quite similar to those reported in other Western countries, but they show high levels of caregiving activities.
- The arts and respite care programme was adapted to the expectations of YCs and was positively received by the youths, especially concerning respite, relationships built during the programme, and the sharing of their experiences as carers. Some specificities related to age emerged and must be considered to respond to developmental needs.
- The significant increase in quality of life observed among both child and adolescent YCs shows the relevance of the programme. However, the long-term effects of participation in this programme should be evaluated to support further implementations.

when youths feel supported and recognized in this position of care (Cassidy et al., 2014; Pakenham et al., 2007).

## 1.3 | Schemes for YCs

Becker (2007) has explained that YCs must be recognized, identified, and supported as a specific group of children with unique needs. Over the past 30 years, services for YCs have developed internationally, particularly in the United Kingdom, and in parallel with research on this population (Leu & Becker, 2017; Leu et al., 2021). YC services typically provide support and advice for young people as well as leisure activities and respite (Banks et al., 2002; Grant

et al., 2008; Phelps, 2021; Wind & Jorgensen, 2020). These accompaniments vary widely in terms of social activities, individual support, and frequency (Clay et al., 2016) but have so far mainly been developed abroad (e.g., Jarrige et al., 2020).

In France, only the national association JADE, which seeks to promote the recognition of YCs and to develop solutions for their unmet needs, has deployed an initiative specifically aimed at them: the 'cinema-respite' programme.

## 1.4 | The artistic programme run by JADE

Since 2017, the cinema-respite programme has been deployed nationwide. This scheme is designed to be a space of respite and freedom of expression that allows YCs to not only assert themselves as individuals through artistic practice but also meet up and discuss ideas about what they are experiencing (Ellien, 2015). These in-residence programmes, at no cost to the families, take place during the school vacations. They are supervised by cinema professionals and certified animators and are directed by a project leader from the health and social care sector and a cinema professional. A psychologist is also present at dedicated times during the stays. Each age group (a maximum of 12 children between 7 and 12 years old and 12 teenagers between 12 and 18 years old) comes twice for 5 or 6 days in residence. The child and teenager groups are hosted on different weeks. The YCs are referred to the association by various partners from the health, social, and school sectors or by their families. An information meeting with the youths and their families is organised before the first week of the programme. It aims to present the process of the programme, to introduce the facilitators, and to prepare the weeks' workshops. Various activities are offered to the YCs during the workshop weeks: activities involving artistic creation, cinema, and music, as well as games, outings, leisure activities, and time for the youths to share their experiences of their situation. A screening of the films created by the YCs is planned to take place several weeks after the end of the workshops. It takes place in a cinema, in the presence of the YCs who participated in the workshops, their families and, if they wish, other relatives. These opportunities provided by the association JADE allow the YCs to have a place for expression and to temporarily take a step back or get away from their daily lives (Bourgeois, 2020).

International interest in the issue of YCs has contributed to the development of interventions and schemes aimed at accompanying YCs and offering them support, respite, advice, and information. This interest in YCs has also led to the development of awareness-raising activities for various audiences. However, although there are many initiatives for YCs abroad, they are very rarely evaluated. It is therefore impossible to appreciate their advantages and limitations. Therefore, researchers have strongly encouraged services and organisations to evaluate the initiatives developed for YCs (Jarrige et al., 2020), a process that the national association JADE has undertaken in the context of the deployment of its respite and artistic expression programme.

Thus, the objectives of this study were to describe the profile of the young people in this 'cinema-respite' programme

(sociodemographic characteristics, family situation, caring activities provided, and quality of life), and to evaluate their expectations for and opinions on the programme and the evolution of their quality of life. Finally, a developmental perspective was provided by comparing data collected from children and from adolescents.

## 2 | METHODS

### 2.1 | Population and procedure

All children and adolescents enrolled in the cinema-respite programme between 2017 and 2020 were asked to participate in the study, as long as they had sufficient command of the French language to answer self-report questionnaires. They had to give their consent to participate and their legal guardians signed the consent form that was given to them, along with information notes, at the meeting introducing the scheme. Only one child during the period of the study did not participate in the evaluations.

The YCs completed self-report questionnaires on arrival, on the first day of the first week (regarding their sociodemographic information, the relative they cared for and their care activities, their quality of life, and their expectations regarding the workshops), and then before leaving, at the end of the first and second weeks (regarding their quality of life and opinion on the workshops). The young people answered the questionnaires individually but in a group setting in the presence of the psychologist-researcher, to whom they could ask questions should they need assistance. It took about 30 min for the YCs to complete the arrival questionnaire and about 10 min for them to complete the post-workshop questionnaires.

This study received approval from the Research Ethics Committee of the University Paris Descartes (no. 2019-110).

### 2.2 | Measures

The assessments included standardised questionnaires and ad hoc questionnaires created for the specific needs of the study.

#### 2.2.1 | Sociodemographic information

Sociodemographic information (age, gender, language spoken at home, house characteristics, family status) and information regarding schooling (years of schooling, grade repetition) were collected through an ad hoc questionnaire.

#### 2.2.2 | Caregiving status

Caregiving status was assessed with (a) questions about the situation's characteristics (the sick/disabled relative, the type of illness/

disability) through an ad hoc questionnaire and (b) the 'About me and my family' questionnaire (Joseph et al., 2009), assessing the amount of regular support brought to a member of their entourage, the people to whom they regularly provide support, the reasons for the need for support, the relative's type of illness/disability, and what age the helping started. This questionnaire comprises five open and closed questions.

### 2.2.3 | Caregiving activities

The Multidimensional Assessment of Caring Activities (MACA-YC-18; Joseph et al., 2009, 2019) assesses the caring activities undertaken by YCs through 18 items that yield a total score (ranging from 0 to 36) and six subscores: household chores (e.g., 'Washing dishes and filling or emptying the dishwasher'), home management (e.g., 'Helping with heavy lifting and carrying'), financial and practical support (e.g., 'Earning money alongside school to help the family'), personal support (e.g., 'Helping someone wash'), emotional support (e.g., 'Making sure everything is OK for the person you are caring for'), and sibling management support (e.g., 'Watching your siblings while an adult is around'). Questions are rated on a 3-point Likert scale (from 'never' to 'frequently'). The higher the score, the greater the level of help provided. In addition, threshold scores are used to categorise the level of caring activities: a total score between 1 and 9 corresponds to a low level of support, 10–13 corresponds to a moderate level, 14–17 corresponds to high, and >18 corresponds to very high. The French version has good psychometric qualities (Chevrier et al., 2022).

### 2.2.4 | Quality of life

The KIDSCREEN-10 (Ravens-Sieberer & The KIDSCREEN Group Europe, 2006) measures a young person's overall quality of life and level of well-being. It provides a 10-item total quality-of-life score. Each youth responds to items on a 5-point Likert scale (from 'not at all' to 'very'). The items cover physical quality of life, psychological quality of life, leisure and activities, social relationships with family and peers, and schooling. Standardised scores range from 0 to 100. The higher the score, the better the quality of life.

### 2.2.5 | Workshop expectations

YCs answered questions developed for the purpose of the study to assess their expectations for workshop participation. Based on previous evaluations carried out by the association, a list of affirmations with two answer modalities (yes/no) was constructed. The affirmations address the following themes: respite, activities (related to cinema and leisure more generally), meeting with other YCs, and experience-sharing.

### 2.2.6 | Opinion

To collect the perceptions of the YCs over the course of their stays, they were asked to specify: the three elements that were the most positive, the three elements that were the most difficult, and their general opinion on the week. This final element was asked using two questions: their satisfaction on a scale from 0 to 10 and whether they would advise other young people in the same situation to participate in these workshops (yes/no/I do not know). This evaluation was created for the purpose of the study.

## 2.3 | Data processing

Statistical analyses were performed using the SPSS-21 software. For the quantitative data from the self-administered questionnaires, descriptive analyses were performed for the total sample and by subgroup (children vs. adolescents). Chi-square tests for categorical variables and Mann-Whitney tests for quantitative variables were conducted to compare data from children and adolescents. Repeated measures analyses of variance (Friedman ANOVA) were performed to assess changes in the YCs' quality of life over the course of the programme. Data from the open-ended questions (e.g., positives and difficulties) were subjected to thematic content analysis to allow for their grouping into supra-categories.

## 3 | RESULTS

### 3.1 | Participants' sociodemographic characteristics

One hundred and seventeen YCs participated in this study: 54 children and 63 adolescents. The majority were girls (71.8%), the average age was 12 (9.8 years old for the children and 13.9 years old for the adolescents). Regarding schooling, almost all of the young people were in school (with the exception of two adolescents), and 11.1% had repeated at least 1 year. Concerning their family situation, just over half of the participants lived with both parents (54.7%). A large majority had brothers and sisters or step-siblings (91.5%). Regarding sibling status, adolescents were more likely to be the oldest of the siblings (41.3%) and children were more likely to be the youngest (44.4%). Almost a quarter of the participants spoke a language other than French at home (23.9%). These results are presented in Table 1.

### 3.2 | The care recipients and assistance provided

The majority of YCs helped a parent, who was more often their mother (62.4%) than their father (35%). Half of the sample helped a sibling (49.6%). A minority supported a grandparent (8.5%) or another family member (6.8%). Almost half helped more than one relative (46.2%).

**TABLE 1** Sociodemographic characteristics of the YCs and of the care recipients

	Total sample (N = 117)	Child group (n = 54)	Adolescent group (n = 63)	Z/Chi <sup>2</sup>
Age (mean, range)	12 years (7–17)	9.8 years (7–12)	13.9 years (13–17)	–8.825***
Gender (% of girls)	71.8	68.5	74.6	0.457
Schooling (%)				
Currently in school	98.3	100	96.1	1.772
Repeating a year	11.1	1.8	23.0	10.864**
Family situation <sup>a</sup> (%)				0.322
Lives with both parents	54.7	57.4	52.4	
Shared custody between the parents	22.4	18.5	23.8	
Lives with one parent only	23.1	24.1	22.2	
Other	0.9	0.0	1.6	
Siblings (%)	91.5	90.7	92.1	0.065
Position among sibling order <sup>a</sup> (%)				
Oldest	32.5	22.2	41.3	4.811*
Second oldest	21.4	14.8	26.9	2.563
Youngest	30.8	44.4	19.0	8.804**
Twin	6.8	12.9	1.6	5.907*
Language other than French spoken at home (%)	23.9	27.8	20.6	
Care recipient <sup>a</sup> (%)				
Mother	62.4	57.4	66.7	1.062
Father or step-father	35.0	38.9	31.7	0.652
Sibling	49.6	53.7	46.0	0.685
Grandparent	8.5	9.2	7.9	0.065
Other family member	6.8	5.6	7.9	0.259
More than one care recipient (%)	46.2	46.3	46.0	0.001
Type of health problem <sup>a</sup> (%)				
Physical illness	45.3	31.5	57.1	7.727**
Disability	18.8	24.1	14.3	1.825
Mental illness	5.1	3.7	6.3	0.418
Does not know	34.2	40.7	28.6	1.914
Duration of care so far (mean, SD)	4.76 years (2.8)	3.20 years (1.7)	6.10 years (2.6)	–4.965***

<sup>a</sup>This variable was not measured the first year that evaluations were carried out.

\* $p < .05$ ; \*\* $p < .01$ ; \*\*\* $p < .001$ .

Regarding the reasons for the support, the YCs reported different types of illnesses and disabilities among the care recipients. The precision of their wording differed according to the age of the youths and the state of their knowledge about the condition of the care recipient. Some of the family members had several illnesses

and/or disabilities. The categorisation of the responses indicated that: 45.3% were helping a relative with a chronic somatic disease (e.g., cancer, multiple sclerosis, myopathy, epilepsy), 18.8% were helping a family member with a disability (e.g., motor problems, autism, deafness), 5.1% were helping a relative with a mental disorder

(e.g., depression, psychotic disorder), and 34.2% indicated that they did not know the name of their relative's health issue. The average duration of assistance was greater for adolescents (6.1 years) than for children (3.2 years;  $Z = -4.965, p < .001$ ).

The level of caring activities (MACA-YC-18 score) was significantly higher for adolescents than for children (11.3 vs. 14.1;  $Z = -3.059, p < .01$ ). The support, in order of importance, concerned domestic tasks, emotional support for the person being helped, home management, sibling management, personal support for the person being helped, and, finally, financial and practical support. Adolescents helped significantly more than children with household chores, emotional support, and home management. These results are presented in Table 2.

### 3.3 | Youth expectations for the programme

The expectations of YCs at the beginning of their stay concerned, in order of importance: activities (86%), meeting new people (82.6%), resting/getting some air (80.6%), getting away from home for a few days (75.3%), meeting other young people involved in care (74.2%), discussing the care provided (71%), discovering how to make a film (68.8%), seeing if other young people felt the same way (68.8%), and, to a lesser extent, expressing what they want in a film about their lives (47.3%). All of these expectations were comparable across children and adolescents (see Table 3).

### 3.4 | Youth opinions and changes in quality of life

The average level of satisfaction with the workshops was high, with an average score of 8.44 out of 10, and 79.5% of youths indicated

that they would recommend participation to other youths. Notably, 17.9% responded that they did not know whether they would recommend participation or not (Table 4).

Regarding their opinion about the workshop, the main positive points reported by the YCs were related to relationships (e.g., 'I found people who have almost the same problems as me,' 'I met new people who became my friends,' 'being close to the film crew, we had a lot of fun, I really like them'), workshops (e.g., 'being behind the camera, being able to see the world,' 'being able to "be behind the ", to "direct" the filming of a movie,' 'the group song,' 'I am very proud of the beginning of my movie'), and leisure activities (e.g., 'we do a lot of things and have fun,' 'the party,' 'the games, the books'). Items that emerged to a lesser extent were related to material well-being (e.g., 'food') and psychological respite (e.g., 'I was able to clear my head,' 'I was able to enjoy my vacation,' 'I was able to get some air without my parents around'). Leisure-related items were reported more by children, whereas items related to psychological respite were reported more by adolescents.

Concerning points of difficulty, the two main points were related to organisational constraints (e.g., 'phone time too short,' 'not being able to choose your room,' 'bedtime') and relationships ('not seeing my parents,' 'leaving home,' 'formation of "clans"'). Organisational constraints were reported more by adolescents and relationship-related items were reported more by children. Other difficult elements were related to physical and material well-being (e.g., 'the environment,' 'eating the food'), workshops (e.g., 'finding my song,' 'talking about myself in my film was emotionally complicated,' 'editing, after a while I couldn't take it anymore') and emotions ('to have cried,' 'breaking down without anyone [youths] noticing'). Some youths did not report any negative elements.

Regarding the youths' quality of life (KIDSCREEN-10 score), it significantly increased between the beginning of the stay and the

	Total sample (N = 117)	Child group (n = 54)	Adolescent group (n = 63)	Z/Chi <sup>2</sup>
Caring activities score (mean, SD)	13.1 (6.2)	11.3 (5.6)	14.1 (6.2)	-3.059**
Level of help (%)				8.924*
Low	32.4	44.2	23.7	
Moderate	20.6	20.9	20.3	
High	21.6	23.3	20.3	
Very high	25.5	11.6	35.6	
Type of caring activities (mean, SD)				
Domestic chores	3.6 (1.6)	3.2 (1.6)	4.1 (1.5)	-3.097**
Emotional support	3.3 (1.7)	2.7 (1.5)	3.8 (1.6)	-3.414**
Household management	2.3 (1.4)	1.9 (1.2)	2.7 (1.5)	-3.104**
Sibling management	2.2 (2.0)	1.9 (1.8)	2.4 (2.1)	-1.357
Personal support	1.3 (1.8)	1.2 (1.5)	1.4 (2.0)	-0.105
Financial and practical support	0.5 (1.0)	0.5 (1.1)	0.6 (1.0)	-1.391

TABLE 2 Type of care provided (MACA-YC-18)

\* $p < .05$ ; \*\* $p < .01$ .

TABLE 3 YC expectations regarding the program (%)

	Total sample (N = 93)	Child group (n = 41)	Adolescent group (n = 51)	Chi <sup>2</sup>
Do activities (music, games, etc.)	86.0	85.7	86.3	0.090
Meet people	82.8	83.3	82.4	0.002
Rest and get some air	80.6	76.2	84.3	0.592
Leave home for a few days	75.3	71.4	78.4	0.149
Meet other children who care for a relative	74.2	71.4	76.5	0.287
Discuss and share experiences of caregiving	71.0	66.7	74.5	0.672
Discover how to make a movie	68.8	71.4	66.7	0.454
See if other young carers feel similarly to me	68.8	64.3	72.5	0.716
Express what I want through a documentary about my life	47.3	42.9	41.0	0.392

ends of the first and second weeks (41.3 vs. 49.6 vs. 49.1;  $F = 82.09$ ,  $p < .001$ ) (Table 5).

## 4 | DISCUSSION

The population of YCs is still one that is largely unknown and insufficiently studied, particularly in France (Leu & Becker, 2017). The artistic respite programme run by the national association JADE is currently the only one in France to offer dedicated support to YCs. In the present study, the young people who participated in the workshops were mostly girls, and they were mainly helping a parent with a chronic somatic illness. However, the results showed heterogeneity across the situations of the YCs who participated in the programme, particularly in terms of psychological development. The results concerning the YCs' expectations for and opinions on the workshops underlined the importance of respite and the relevance of such a scheme.

The results regarding the gender-ratio imbalance are consistent with the literature on YCs and caregivers in general, which shows consistent reports of higher proportions of women (Joseph et al., 2019; Kallander et al., 2018). This imbalance raises several questions that need to be explored in future studies. Indeed, this gender ratio is also found among adult caregivers, indicating that women are more likely than men to be family caregivers (Maisonasse, 2016). Explanations related to gender role theories have been proposed to account for this finding (Noël-Hureau, 2015). It seems crucial to draw the attention of families and professionals to this gender inequality in the role of caregiver and to work on deconstructing these gender stereotypes that sometimes lead to the assumption that it is more natural for a woman to help.

Nevertheless, considering that both boys and girls can be faced with a relative's illness or disability, it is legitimate to wonder how the impact of internalised stereotypes may lead professionals to recognize girls' YC experiences more than they recognize those of boys. Moreover, this identification bias could be due to the lower propensity of boys, especially adolescents, to share their family experiences, which would make it more difficult for professionals to identify these situations. In any case, boys can also be involved in care and should not be overlooked. This is all the more important because professionals know little about YCs (Justin et al., 2021; Leu et al., 2020).

Another notable sociodemographic characteristic was the low prevalence of YCs living with both parents—a rate lower than the general data reported in France, where 68% of minors live with both parents (Algava et al., 2020). Thus, YCs in this scheme were more likely to live in single-parent homes. This finding is congruent with the YC literature that suggests that living in a single-parent home, often in association with greater economic insecurity, increases the risk of being a YC (Becker, 2007; Pakenham & Cox, 2015; Smyth et al., 2011). In this context, the residential layout and free facilities available during the programme have the advantage of allowing the YCs time away from home without creating a burden for their families.

The majority of the children and adolescents helped one of their parents (most often their mother) or one of their siblings, who most often needed help for a chronic somatic illness. The results regarding the relational status of the relative being supported and the reasons behind the support were comparable to those in the literature (Aldridge, 2017; Joseph et al., 2019). The percentage of YCs supporting multiple relatives was high. This may be explained by poly-pathologies within YC families, but also by the secondary caregiver



TABLE 4 Youth satisfaction at the end of each workshop week and comparisons between children and adolescents

	Total sample		Child group		Adolescent group		Chi <sup>2</sup> /Z	
	End of 1st week	End of 2nd week	End of 1st week	End of 2nd week	End of 1st week	End of 2nd week	End of 1st week	End of 2nd week
N	117	105	54	52	63	53		
Level of satisfaction (mean, range)	8.44 (0–10; 1.81)	8.46 (3–10; 1.59)	8.50 (3–10; 1.83)	8.31 (3–10; 1.71)	8.40 (0–10; 1.81)	8.60 (4–10; 1.47)	–0.820	–0.773
Would recommend the program to others (%)							3.930	1.849
Yes	79.5	76.2	72.2	73.1	85.7	79.2		
I don't know	17.9	18.1	24.1	23.1	12.7	13.2		
No	0.9	2.9	1.9	1.9	0.0	3.8		
Missing answer	1.7	2.9	1.9	1.9	1.6	3.8		
Positive aspects (%)								
Related to relationships (meeting people, friends, ambiance)	61.5	50.5	55.6	53.8	66.7	47.2	1.517	0.468
Related to the workshops (creating and editing a movie)	52.1	46.7	61.1	55.8	44.4	37.7	3.237	3.430
Related to leisure activities (having fun, relaxing, games, outings)	52.1	56.2	68.5	67.3	38.1	45.3	10.785**	5.172*
Related to material wellbeing (meals)	25.6	30.5	27.8	34.6	23.8	26.4	0.240	0.833
Related to psychological respite (sharing, freeing up, psychologist)	25.6	16.2	13.0	9.6	36.5	22.6	8.454**	3.282
Other	33.3	21.9	29.6	21.2	36.5	22.6	0.619	0.034
Difficult aspects (%)								
Organizational limits (rules)	44.4	44.8	27.8	34.6	58.7	54.7	11.282**	4.289*
Related to relationships (separation from family, conflicts)	41.0	26.7	50.0	40.4	33.3	13.2	3.338	9.913**
Related to physical wellbeing (health, meals)	26.5	17.1	24.1	15.4	28.6	18.9	0.302	0.224
Related to workshops (editing)	23.9	15.2	27.8	11.5	20.6	18.9	0.815	1.092
Related to emotions (sadness)	12.0	11.4	5.6	11.5	17.5	11.3	3.912*	0.001
Other	12.8	11.4	7.4	9.6	17.5	13.2	2.629	0.335
No difficulty	10.3	6.7	7.4	5.8	12.7	7.5	0.884	0.133

\**p* < .05; \*\**p* < .01.

TABLE 5 Young carers quality of life (mean, SD)

	N	Start of 1st week	End of 1st week	End of 2nd week	F
Total sample	80	41.3 (6.1)	49.6 (8.2)	49.1 (7.6)	82.09***
Child group	37	43.2(6.7)	50.0 (8.5)	50.7 (7.5)	30.94***
Adolescent group	43	39.6 (5.1)	49.3 (8.1)	47.7 (7.5)	54.56***

\*\*\* $p < .001$ .

phenomenon (i.e., young people supporting the primary caregiver by relieving them of some of their tasks). The analyses carried out in this article do not make it possible to differentiate between these different configurations, but this exploration would be relevant in future studies, in particular to allow for a detailed investigation of the consequences of caregiving on YCs.

Almost half of the sample provided high or very high levels of support. This proportion appears to be higher than it is in the literature. Joseph et al. (2019) reported a prevalence of 32% of this level of support among children aged 11–15. Moreover, a comparison of prevalence with British data suggests that the YCs in our sample were much more likely to present very high levels of support: 25.5% versus 9% in the study by Joseph et al. (2019). Considering average scores, YCs in our sample also provided higher levels of general help (as assessed by the MACA-YC-18 total score) than those reported in the literature on YCs: 13.1 in our sample versus 10.0 in a sample of 246 YCs aged 8–18 (Kallander et al., 2018). This difference can be explained by the higher scores in the dimensions of emotional and personal support provided to the cared-for relative and sibling management. Nevertheless, like in the international literature, the area in which YCs help the most is domestic tasks (Joseph et al., 2009; Kallander et al., 2018). Given the high levels of support provided by YCs, finding indicators to help professionals identify YCs before the development of an excessive level of caregiving would be important to avoid potential harmful consequences for the youths.

Scores reflecting a high level of assistance should also be linked to the person being supported, most often the mother in our sample. Indeed, it has been shown that mothers who are ill or have a disability receive more help from their child than fathers do (Dearden et al., 2004; Ireland & Pakenham, 2010; Nagl-Cupal et al., 2014; Sieh et al., 2013).

The comparison between the responses of children and adolescents revealed age-related specificity about care activities: adolescents provided higher levels of help than children, particularly for domestic tasks, emotional support to the relative, and household management. This age-related difference in help with household tasks has been previously reported in the literature (Joseph et al., 2019) and is consistent with data suggesting that the intensity of help increases with age, and is therefore higher in adolescents (Ireland & Pakenham, 2010).

Expectations related to respite (e.g., to do activities, rest, take a break, get away from home for a few days), to relationships (e.g., to meet other young people who help), and to sharing one's experience (e.g., to discuss ideas about helping) were among those most frequently expressed by both children and adolescents. This lack of age-related differences suggests a uniformity of needs among these

YCs, regardless of their developmental level. These needs were similar to those previously reported in the literature (Phelps, 2021). The post-stay evaluation, however, revealed differences in opinion about the programme: children expressed more positive elements related to leisure activities than adolescents, but fewer positive elements related to psychological respite. This result suggests that whereas the expectations expressed by YCs are similar regardless of age, the effect of the programme on young people differs according to their age. This finding may be related to the greater level of support provided by and responsibility found among adolescents. Their more advanced level of development, particularly in terms of cognition and emotion, may lead them to question their situation more and to have more needs related to the expression and sharing of their experiences, and thus they may benefit more from the scheme in these aspects. However, the fact that psychological respite was mentioned less by the children does not mean that they did not experience it. The way they put it into words may be different because of their age; the pleasure they get from leisure activities may in some way help them to 'breathe,' 'rest,' and 'distance' themselves from their family situation.

Participants also reported certain difficulties during their stays, some relating to the difficulty of 'living in a group' in a place other than their own home (organisational constraints, relational frictions, meals, separation from the family). Other difficulties appeared to be more closely linked to the content of the workshops, such as the 'psychological load' that came about during the creation of the films when there was a lot of sharing of experiences. These elements of difficulty, although expressed less frequently than the positive elements, must be taken into consideration. They may explain why some YCs indicated that they would not recommend participation in the workshops to others in the same situation as them or why some did not express an opinion on this matter.

Beyond the general satisfaction expressed by the YCs, the significant increase in quality-of-life scores between the beginning and the end of each week of the programme, for both children and adolescents, shows the relevance of the programme in improving their well-being. However, it is important to emphasise that the quality of life of the participants was very low, even after their participation in the programme, compared to French standards for children and adolescents (Ravens-Sieberer & The KIDSCREEN Group Europe, 2006).

#### 4.1 | Limitations

This study has several limitations related to the sample and data-collection methodology. Despite the rigorous procedure, it was not

possible to completely standardise the conditions of the tests due to the heterogeneity of the reading and comprehension levels of the participants, which sometimes required the psychologist-researcher to assist some of them individually during the assessments, particularly the children. A further limitation of our study is that we used several questionnaires created for the purpose of the study, but these had not been psychometrically validated. In addition, the decision to include youths in the workshops was made prior to their actual participation, and given the rapid evolutionary potential of some illnesses, some youths were grieving at the time of their participation. The effect of this variable on the youths, the group, and the workshop dynamics was not assessed in this study.

Methodologically, some sociodemographic dimensions such as socioeconomic level and ethnicity, which have been associated with child caregiving in several studies (Hendricks et al., 2021; Nagl-Cupal et al., 2014; Pakenham & Cox, 2015; Smyth et al., 2011), were not considered in this study, which limits the interpretative scope of some of the results. In addition, the scale selected for the assessment of help provided (MACA-YC-18) does not measure all possible help provided (e.g., meal preparation) and does not sufficiently explore emotional support, which some authors have suggested is an important component of YC help (Nagl-Cupal et al., 2014). Finally, the coding of response items to the open-ended questions into 'supra-categories,' allowing for their statistical exploitation, contributed to a reduction in the fineness of the data presented. In future studies, a more in-depth qualitative approach would make it possible to explore the different points of view in greater detail.

## 5 | CONCLUSION

Research on YCs is growing internationally, and some countries, such as the United Kingdom, are particularly advanced on the issue. Conversely, in other countries like France, there is an urgent need to promote research on this vulnerable population (Leu & Becker, 2017). This article provides the first descriptive approach to French YCs who participated in the cinema-respite programme of the national association JADE. This period of respite offered to YCs through this association allows these children to express themselves, share their experiences, and temporarily gain distance from their daily lives. However, questions remain concerning the continuity of psychological follow-up for these YCs and respite solutions outside of their week of workshop participation. This article proposed an initial evaluation of this cinema-respite programme and showed its relevance. Indeed, despite the difficulties reported by the YCs, the results showed the programme's relevance regardless of the youths' age. Exploring its benefits over time more precisely could be explored in future studies. Moreover, the young people who entered the programme and participated in this study were mainly confronted with physical illness, and few provided help to relatives with mental illness. This could lead national association JADE to rethink their methods of communication to raise awareness among collaborators in mental health institutions and to identify this subgroup of

youths. In addition, the use of an assessment tool such as 'the carers' alert thermometer for YCs' could support this identification and the assessment of youth support needs (Kettell et al., 2021). Finally, with a larger sample, it would be useful to carry out typological analyses to identify profiles of youths for whom this system would be more beneficial than for others, with the aim of refining the support proposal for these young people.

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## CONFLICT OF INTEREST

GD, CV, SM and AU declare no conflict of interest. FE is president and AB is project director of the national association JADE.

## AUTHOR CONTRIBUTION

Géraldine Dorard, AU, Amarantha Bourgeois and Françoise Ellien designed the study and coordinated the data collection. Christel Vioulac and Sasha Mathieu carried out data collection and data entry. Géraldine Dorard and Aurélie Untas performed the data analysis and drafted the first version of the manuscript. Christel Vioulac, Sasha Mathieu, Amarantha Bourgeois and Françoise Ellien provided critical revisions. All authors approved the final version of the manuscript for submission.

## DATA AVAILABILITY STATEMENT

Data available on request due to privacy/ethical restrictions.

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