

# Prevalence and characteristics of adolescent young carers in France: The challenge of identification

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## Abstract

**Aims:** The aim of this study was to explore the prevalence and characteristics of adolescent young carers in France, with an identification method based on the extent of caring activities including emotional support.

**Design:** Cross-sectional.

**Methods:** Between May 2018 and February 2021, 4037 adolescents (grades 10–12, mainly aged 15–17, 60.2% female) answered a self-reported questionnaire at school. The questionnaire assessed sociodemographic characteristics, illness/disability in the family, support provided by the adolescent (Multidimensional Assessment of Caring Activities, MACA-YC18, and a specific scale for emotional support), and quality of life (KIDSCREEN-10).

**Results:** Results showed that 42.5% of adolescents faced the illness/disability of a relative and 14.3% provided a high level of support and could be considered adolescent young carers. They were most commonly females caring for a parent. Adolescent young carers reported a lower quality of life than non carers. Results also highlighted differences in care and quality of life between adolescent young carers who shared the same household as their ill/disabled relative and those who did not, according to gender as well as type and perception of support provided.

**Conclusion:** Identifying adolescent young carers is a challenge. Identification methods based on the extent of caring activities seem appropriate but not entirely satisfactory. Self-identification criteria also seems important. An international consensus on the best identification methods and tools should be proposed. In France, the prevalence of adolescent young carers is high. These results highlight the crucial need to enhance awareness about adolescent young carers in France in order to identify and support them through appropriate health services policy.

**What problem did the study address?:** Little is known about young carers in France and there is no prevalence study. However, it is difficult to know which methods and identification criteria to apply to assess the prevalence, because they differ between studies and have an impact on the prevalence observed in each country.

**What were the main findings?:** The prevalence of adolescent young carers in France is high with a rate of 14.3%. Among them, 74.9% were female, 74.2% lived in the same

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household as their ill/disabled relative and 70.2% were aware that they provided support. Female young carers or those sharing a household with their ill/disabled relative provided higher levels of caring activities and had a lower quality of life. Adolescent young carers who were aware they provided support were less likely to have a relative with a serious/chronic physical illness but were more likely to have a relative with a mental illness, be a carer for a sibling or a grandparent and share the same household. **Where and on whom will the research have impact?:** These results should enhance awareness about young carers in France. Health care and education professionals have a major role to play to identify and support young carers, but public policy has to sustain it. Thus, the high prevalence rates highlight the importance of this phenomenon and the need to be attentive to this hidden population. Results also suggest an international consensus should be proposed to identify young carers.

## 1 | INTRODUCTION

Over the past 30 years, a growing body of research has been undertaken on children, and adolescents who have a family member with a chronic physical or mental health issue or disability. Among these youth, it has been shown that some provide care regularly. These are called 'young carers' (YC). According to Becker (2000) YC are 'children and young persons under 18 who provide or intend to provide care, assistance or support to another family member. They carry out significant or substantial caring tasks, often on a regular basis, and assume a level of responsibility which would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent or other relative who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision'. (p. 378). There is a wide range of activities in which YC might help: household tasks, emotional care, general and nursing-type care, intimate personal care, sibling care and administrative and financial support (Dearden & Becker, 2004). YC can also provide significant support to the primary adult caregiver (Thomas et al., 2003). It is crucial to identify and support these youth, as it has been shown that, compared with young people who do not provide care to a close relative, YC experience higher levels of psychological distress, higher emotional exhaustion, lower self-confidence and increased isolation (Jarrige et al., 2020). Academic difficulties have also been observed, including problems concentrating in class, failure to complete homework, absenteeism and school dropout (Dearden & Becker, 2004). Caring for a relative also appears to affect youths' long-term life plans (Aldridge & Becker, 1993).

It has been shown that caregiving can begin as soon as the age of 5, though it becomes more important in youth aged 10–15 years old (Dearden & Becker, 2004; Moore & McArthur, 2007). Thus, caring activities evolve according to stage of development and become more important during adolescence (Joseph et al., 2019). Indeed, many changes occur during adolescence, including the development of autonomy and advances in social and cognitive abilities (Blakemore, 2008; Steinberg, 2014). Moreover, helping is often seen as a normal activity for adolescents (Smyth et al., 2011). This may impact

the type and level of assistance adolescents can provide to an ill/disabled relative. In line with this variability, some studies have focused specifically on adolescent YC (AYC). For example, the European MEWE project studies AYC during middle adolescence (i.e. 15–17 years old) (Casu et al., 2021; Leu et al., 2021). This developmental stage demands specific attention as it is recognized as a critical period of transition into adulthood and is associated with a higher risk of various mental health problems (Blakemore, 2019; Ogden & Hagen, 2018).

A classification index was developed by Leu and Becker (2017) to compare countries' awareness and policy responses to YC. Out of seven levels, one being the best, France was classified as level 6, indicating it is 'awakening' to issues related to caregiving in youth, while the United Kingdom was the most advanced country at level 2. Indeed, in France, YC were identified by the government as a specific target group only in 2019, through a National Strategy for Carers' Mobilization and Support (Ministère des Solidarités et de la Santé, 2019). It highlighted the need to increase awareness of education professionals to identify and support YC, and to propose specific arrangements for young adult carers following university courses. Before 2019, only one non-governmental association (Association nationale Jeunes AiDants Ensemble, JADE) worked to increase awareness and offer some respite to YC. Thus, YC were only perceived as children or adolescents facing the illness of a parent or a sibling, without considering the support they provided (Jarrige et al., 2020). Since 2020, awareness has risen slightly and some services are provided by other organizations, though mainly on a local level. In terms of research, to date, no scientific research has been published on YC in France, except one study on school professionals' awareness of YC (Justin et al., 2021). This study showed a low level of awareness, although healthcare professionals and school counselors seemed more aware of YC than teachers and were more likely to offer support. Estimating the prevalence of YC is therefore a crucial first step to support awareness of the existence of YC and the development of services and public policies. As caregiving becomes more important during adolescence, the present study examined the prevalence and characteristics of AYC in a sample of French pupils, mainly in middle adolescence. However, identifying YC or AYC is a

challenge because the identification methods used in the literature differ from one study to another and age ranges are not consistent across all studies. This affects the accuracy of the estimated prevalence. Therefore, we analysed the different criteria used in the literature to try to determine the most suitable.

## 1.1 | Background

### 1.1.1 | Prevalence of young carers and adolescent young carers

The prevalence of YC reported in the literature is quite varied and ranges from 3.2% to 22% (see [Appendix A](#)). All studies include AYC, whether in early (10–13) and middle (14–17) adolescence or in middle adolescence and young adulthood. Most studies are either based on census data, like those published in Australia, Italy and New Zealand, or on data collected among youth in schools, like those published in Austria, Germany, Switzerland and the United Kingdom. The lowest rate (3.2%) was observed in the United States in a study in which 2000 households were surveyed about children aged 8–18 (Hunt et al., 2005). The highest rates were observed in the United Kingdom, with studies reporting prevalence values of 12% in Northern Ireland among pupils aged 10–11 (Lloyd, 2013), 12% in Scotland among pupils aged 11–18 (Robison et al., 2020) and 22% in England among pupils aged 11–15 (Joseph et al., 2019). Some prevalence studies have focused specifically on adolescent YC. In Australia, results showed a prevalence of 5.1% in adolescents aged 15–19 (Australian Bureau of Statistics, 2016). In New Zealand, a prevalence of 7.7% was observed in adolescents aged 15–18 (McDonald et al., 2009).

The differences in prevalence rates are largely due to differences in the studied populations about age range, recruitment method (Newman, 2002) and identification criteria; cultural differences (i.e. structuring of health systems) also cannot be excluded.

### 1.1.2 | Identifying young carers: assessing the support provided

In most studies, YC were identified based on their subjective perception of providing support for a relative (Australian Bureau of Statistics, 2016, 2018; Cass et al., 2009; Joseph et al., 2019; Landi et al., 2020; Leu et al., 2019; Lloyd, 2013; Robison et al., 2020; Warren & Ruskin, 2008). For example, in the Swiss study by Leu et al. (2019), participants were asked if they supported someone on a regular basis and, if so, why the relative needed support. To be classified as an AYC, the child's responses had to show clear evidence of a caring role related to a health issue (physical, mental or both) or disability. In this study, 7.7% of the sample (mostly aged 10–15) was identified as YC. The Multidimensional Assessment of Caring Activities (MACA-YC18) was used to measure the level of caring activity undertaken by the children (Joseph, Becker, & Becker, 2009; Joseph, Becker, Becker, & Regel, 2009), and the results revealed that 61.9% of the AYC group

provided a low or moderate level of caring, 21.5% provided a high level and 16.6% provided a very high level. In a study conducted in England (Joseph et al., 2019), a different method was used to identify AYC (11–15 years old); participants were first asked if they were living with someone with an illness or disability and then if they were helping to look after this person. Using this method, 22% of the participants were classified as AYC. Among them, 59% performed a low or moderate level, 32% a high level and 9% a very high level of caring based on the MACA-YC18. Those providing a high or very high level of caring corresponded to approximately 7% of the total sample. In these two studies, in which the identification of YC/AYC was based on the youth's perception of support, the results indicated that over half of the identified YC/AYC provided a low or moderate level of support, though we can question what level of support is considered significant, as stated in the definition of YC/AYC.

An additional challenge highlighted by Becker (2007) is that YC do not always identify that they are providing support. Some youths consider it to be normal and natural to support their families (Mauseth & Hjälmlult, 2016; McDonald et al., 2009; Nagl-Cupal et al., 2014). Thus, some YC may not be identified by methods relying on their perception of support, which would underestimate the observed prevalence (Becker, 2007). Moreover, questions relating directly to the support provided to the ill or disabled relative exclude young people who largely support the primary caregiver (Thomas et al., 2003).

In other studies, the identification of YC/AYC was based on the type and/or extent of the caregiving tasks (Australian Bureau of Statistics, 2018; Hunt et al., 2005; Metzting et al., 2020; Nagl-Cupal et al., 2014). Through specific questions or scales, youths had to report a high level of support or significant performance of a particular activity (e.g. household tasks, emotional care, general care) to be considered a YC/AYC. For example, in the study by Nagl-Cupal et al. (2014) in Austria, the extent of support provided by youth was measured for household activities, general care and emotional support (ES). In the study by Metzting et al. (2020) in Germany, youth was considered YC/AYC if they took part in household chores or medication and nursing activities, while ES was not measured. Both studies ultimately demonstrated similar rates of YC/AYC (5% in Austria and 6.1% in Germany), even though they studied samples of different ages (5–18 years old in Austria and 10–22 years old in Germany) and different caring activities.

According to Nagl-Cupal et al. (2014), there is no existing appropriate questionnaire to identify YC in a general population, and specific attention should be given to the provision of ES as one of the functions of YC. Indeed, some YC/AYC may provide important levels of ES but little or no physical assistance, as may be the case for youths having a relative with a mental illness.

### 1.1.3 | Young carers and household arrangement

An important factor to consider is the living arrangement of YC/AYC and their relatives. Some studies have focused on YC/AYC living in the same household as their relative (Joseph et al., 2019; Lloyd, 2013; Metzting et al., 2020; Robison et al., 2020; Warren

& Ruskin, 2008), while others do not (Australian Bureau of Statistics, 2016, 2018; Hunt et al., 2005; Landi et al., 2020; Leu et al., 2019; McDonald et al., 2009; Nagl-Cupal et al., 2014) and thereby consider that YC/AYC may care for a family member who is not in the same household. Indeed, YC/AYC may provide significant support for a grandparent living nearby. They may also provide support by taking over the responsibilities of a parent at home while the parent assists the grandparent living outside the home. This difference between studies might be related to the fact that most definitions of YC do not specify household arrangement (Thomas et al., 2003), which consequently impacts prevalence rates.

Although most studies have shown that YC/AYC primarily face the illness or disability of a parent or sibling (Chikhradze et al., 2017; Joseph et al., 2019; Leu et al., 2019), there are substantial proportions of YC/AYC caring for other relatives. For example, in the study by Leu et al. (2019), 18% reported caring for a family friend and 13% for another relative (without specifying who the relative was). However, when studies have included YC supporting a relative outside their household, the proportions of relatives supported at home and outside the home are rarely reported. Yet, this appears to be an important consideration, as highlighted in a study in New Zealand on a sample of adolescents aged 15–18, in which the proportion of AYC sharing their relatives' home was 4.2% while those not sharing the same household was 3.5% (McDonald et al., 2009).

To our opinion, youths providing significant support to a relative outside their household should be considered YC/AYC, particularly if the relative is a parent, sibling or grandparent. Moreover, the proportion and characteristics of these YC/AYC should be explored, as they are largely unknown.

## 2 | THE STUDY

### 2.1 | Aims

The aim of this study was to estimate the prevalence of AYC in a French sample of pupils and to explore their characteristics (sociodemographic and related to the relative's illness/disability) and quality of life. We chose to focus on high school pupils (grades 10–12, mostly aged 15–17), corresponding to middle adolescence.

Based on the different identification methods reported in the literature, we retained the following criteria to identify AYC: (a) having a relative with an illness or disability and living in the same household or having a parent, sibling or grandparent with an illness or disability not living in the same household; (b) providing a high level of support measured by the MACA-YC18 and a specific scale of ES.

### 2.2 | Design

This research was designed as a cross-sectional, descriptive study.

### 2.3 | Sample/participants

The sample was comprised of adolescents attending 15 public senior high schools (general and vocational) in three regions of France, with most recruited in Paris Region. All schools were located in dense to semi-dense urban areas. Participants were included if they were between the grades of 10 and 12, gave oral consent to participate in the study, and had the written consent of a legal guardian. A total of 4058 adolescents took part in the study (participation rate: 65%); however, 21 questionnaires had inconsistent or missing responses and were excluded. Thus, the total sample included in this study was 4037 adolescents. Participants' mean age was 16.1 years ( $SD = 1.1$ ; 3.3% were 13–14, 87.1% were 15–17 and 9.1% were 18–21, with missing data for 0.3%), and 60.2% were female. The majority of participants were in grade 10 (44.6%), 23.1% were in grade 11 and 31.6% were in grade 12. Most participants lived with both parents (66.3%) and had siblings (92.8%). About parents' professional status, most were employed (81.1% of mothers and 84.3% of fathers). Participants' characteristics are available in Table 1.

### 2.4 | Data collection

Data were collected from May 2018 to February 2021. After the agreement of the headmaster was obtained, the school's professionals were informed of the study. The study was presented to adolescents during class and the following week consent to participate was collected from the adolescents and their parents or legal guardians. The participants then completed a self-reported and anonymous questionnaire during class under the supervision of a researcher and a teacher. The questionnaire was available in paper- and computer-based versions. It was composed of eight scales, part of which will be presented in this article. The questionnaire took approximately 30 min to complete.

#### 2.4.1 | Sociodemographic characteristics

Several questions assessed gender, age, family and household structure, school grade level and parents' professional status.

#### 2.4.2 | Illness or disability of a relative

Adolescents were asked if they lived at home with a person having at least one of the following health issues: a serious or chronic physical illness (e.g. cancer, diabetes, multiple sclerosis), a mental illness (e.g. depression, schizophrenia), an alcohol or drug problem, a disability or any other health issue. They had to indicate who had this issue (e.g. father, mother, sibling, grandparent). For adolescents living in two separate households (e.g. in the case of separated parents and alternating custody), the questions were asked for both households. The same questions were then asked for relatives living outside the home.

TABLE 1 Characteristics of the entire sample and the subgroups of adolescent young carers and non-adolescent young carers

	Total sample (N = 4037)	AYC group (n = 577)	Non-AYC group (n = 3460)	T, Welch, or $\chi^2$	p
Age, M (SD)	16.1 (1.1)	16.23 (1.07)	16.06 (1.10)	3.37	<.001
Gender: females, n (%), ASR)	2390 (60.2%)	427 (74.9%, <b>7.8</b> )	1963 (57.7%, <b>-7.8</b> )	60.22	<.001
School grade, n (%), ASR)				18.88	<.001
Grade 10	1794 (44.6%)	217 (37.6%, <b>-3.6</b> )	1577 (45.7%, <b>3.6</b> )		
Grade 11	931 (23.1%)	159 (27.6%, <b>2.7</b> )	772 (22.4%, <b>-2.7</b> )		
Grade 12	1273 (31.6%)	193 (33.4%, <b>1.0</b> )	1080 (31.3%, <b>-1.0</b> )		
Two-year vocational training	27 (0.7%)	8 (1.4%, <b>2.3</b> )	19 (0.6%, <b>-2.3</b> )		
Family living conditions, n (%), ASR)				4.79	.188
With both parents	2669 (66.3%)	374 (64.8%, <b>-0.8</b> )	2295 (66.6%, <b>0.8</b> )		
With parents separately	832 (20.7%)	114 (19.8%, <b>-0.6</b> )	718 (20.8%, <b>0.6</b> )		
With one parent	397 (9.9%)	64 (11.1%, <b>1.1</b> )	333 (9.7%, <b>1.1</b> )		
Other	125 (3.1%)	25 (4.3%, <b>1.8</b> )	100 (2.9%, <b>1.8</b> )		
Sibling, n (%)	3739 (92.8%)	559 (96.9%, <b>4.1</b> )	3180 (92.3%, <b>-4.1</b> )	16.49	<.001
Mother's professional status, n (%), ASR)				74.67	<.001
Employed	3249 (81.1%)	400 (69.4%, <b>-7.7</b> )	2849 (83.1%, <b>7.7</b> )		
Unemployed	121 (3.0%)	23 (4.0%, <b>1.5</b> )	98 (2.9%, <b>-1.5</b> )		
Stay-at-home mother	418 (10.4%)	98 (17.0%, <b>5.6</b> )	320 (9.3%, <b>-5.6</b> )		
Leave of absence for health reasons	91 (2.3%)	32 (5.6%, <b>5.7</b> )	59 (1.7%, <b>-5.7</b> )		
Other	127 (3.2%)	23 (4.0%, <b>1.2</b> )	104 (3.0%, <b>-1.2</b> )		
Father's professional status, n (%), ASR)				44.94	<.001
Employed	3358 (84.3%)	445 (77.4%, <b>-4.9</b> )	2913 (85.5%, <b>4.9</b> )		
Unemployed	156 (3.9%)	41 (7.1%, <b>4.3</b> )	115 (3.4%, <b>-4.3</b> )		
Leave of absence for health reasons	70 (1.8%)	24 (4.2%, <b>4.8</b> )	46 (1.3%, <b>-4.8</b> )		
Other (including stay-at-home father)	400 (10.1%)	65 (11.3%, <b>1.1</b> )	335 (9.8%, <b>-1.1</b> )		
Caring activities (MACA-YC18), M (SD)					
Total MACA-YC18 score	11.5 (5.84)	18.32 (4.66)	10.27 (5.15)	35.06	<.001
Domestic tasks	3.6 (1.31)	4.47 (1.18)	3.45 (1.27)	359.25	<.001
Household management	2.65 (1.4)	3.54 (1.36)	2.50 (1.35)	17.21	<.001
Financial/practical help	0.69 (1.15)	1.37 (1.48)	0.57 (1.04)	155.73	<.001
Personal care	0.59 (1.35)	1.59 (1.92)	0.42 (1.15)	203.81	<.001
Emotional care	2.08 (1.89)	3.79 (1.65)	1.78 (1.76)	717.34	<.001
Sibling care	1.88 (2.03)	3.55 (2.04)	1.60 (1.89)	461.29	<.001
Emotional support (ES), M (SD)	14.35 (4.63)	16.34 (4.02)	13.36 (4.59)	165.69	<.001
Quality of life (KIDSCREEN-10), M (SD)	44.26 (10.19)	41.70 (10.62)	44.70 (10.05)	-6.47	<.001

Abbreviations: ASR, adjusted standardized residuals: bolded values indicate overrepresentation or underrepresentation; M, mean; SD, standard deviation; YC, young carer.

### 2.4.3 | Perception of the support provided

The About Me and My Family questionnaire created by Joseph, Becker, and Becker, (2009) and adapted to French by Leu et al. (2019), assesses whether youths think they provide regular support for a

relative (e.g. 'Some children and adolescents do have a family member or friend who needs support on a regular basis, for example, because he/she is ill. Do you support someone on a regular basis?'). An affirmative answer is followed-up with questions about who the relative(s) is(are) and the reasons they provide support. This questionnaire was

used in this study, with an additional question asking participants for the name of the illness or disability, if they knew it.

#### 2.4.4 | Caregiving activities

The revised version of the MACA-YC18 from Joseph et al. (2019) was used to measure caring activities. The MACA-YC18 was initially developed to assess already identified YC/AYC (Joseph, Becker, & Becker, 2009; Joseph, Becker, Becker, & Regel, 2009). The revised version was developed to be used with youth regardless of their caring role. It is a self-reported instrument of 18 items that yields an index of the total amount of caring activities undertaken by youth (range 0–36) as well as caring activities in specific dimensions (range 0–6), including domestic tasks, household management, financial/practical help, personal care, emotional care and sibling care. Higher scores indicate greater caring activities. The following score categories have been proposed by Joseph, Becker, and Becker (2009): 1–9 indicates a low amount of caring activities, 10–13 indicates a moderate amount, 14–17 indicates a high amount and above 17 indicates a very high amount. The French adaptation has good psychometric properties (Chevrier et al., under revision), with a confirmed six-factor solution and internal consistencies in line with those reported by Joseph, Becker, Becker, and Regel (2009).

The emotional care items from the MACA-YC18 focus on companionship ('Keep someone in the house company, for example sitting with them, reading to them, and talking to them'), vigilance ('Keep an eye on someone in the house to make sure they are alright') and accompaniment ('Take someone in the house out for a walk or to see friends or relatives'). To achieve a more complete measure of this type of support, we included an additional measure of ES provided to the ill/disabled relative. The items were constructed based on the description of emotional and esteem support provided by House (1981, as cited in Tardy, 1985) and Cohen and Wills (1985). The ES scale was only presented to adolescents stating they had an ill/disabled relative. It consisted of four items with a 5-point Likert scale (1 = *Never*, 5 = *Always*), which assessed the extent to which the participants provided ES to their ill/disabled relative through (a) showing empathy by listening or understanding, (b) providing esteem support by encouraging or supporting, (c) showing confidence by giving assurance or comfort and (d) providing signs of love by showing affection (see Appendix B). An ES score was calculated by summing the four items (range 4–20).

#### 2.4.5 | Quality of life

The KIDSCREEN-10 index was used to measure adolescents' general health-related quality of life (Ravens-Sieberer & The Kidscreen Group Europe, 2006). It is an abbreviated version of the initial KIDSCREEN-52 questionnaire and consists of 10 items covering physical, psychological and social facets of quality of life. It provides an overall score of health-related quality of life (range 0–100,

calculated with a Rasch model transforming raw scores into *T* values), with a higher score indicating greater quality of life.

### 2.5 | Ethical considerations

This study was approved by the Ethical Committee of the University (No. IRB: 2018-06) and was compliant with the regulations of the French National Commission for Informatics and Freedoms (No. TDCP-GEST-17). As recommended by the Ethical Committee, we obtained written informed consent from parents or legal guardians of each adolescent who took part in the study as well as oral consent from each adolescent.

### 2.6 | Data analysis

Descriptive analyses were performed and presented as frequency, range, mean and standard deviation.

To identify the group of AYC, all participants from the sample who reported facing the illness/disability of a relative ( $n = 1715$ ) were identified. Among these, the distributions of the MACA-YC18 and ES scale scores were analysed to determine the adolescents providing a high level of support. The median MACA-YC18 score was 11 and the 75th percentile was 15. Thus, a score between 11 and 14 was considered to indicate a moderate level of caring activities, and a score equal to or above 15 was considered a high level of caring activities. The 75th percentile for the ES score was 18; a score equal to or above 18 was considered a high level of ES.

Participants were considered AYC if they (1) faced the illness/disability of a relative (any relative in the household or a parent, sibling or grandparent outside the household) and (2) provided a high level of support, defined as (a) a high level of caring activities without a high level of ES, (b) a high level of both caring activities and ES, or (c) a moderate level of caring activities and a high level of ES.

About the perception of support provided for a relative, the method reported by Leu et al. (2019) was used to process responses to the About Me and My Family questionnaire. When adolescents perceived themselves as providing regular support for a relative (by responding 'yes' to 'Do you support someone on a regular basis?'), the explanations they reported for why they provided support were analysed, as well as the name of the illness or disability if they knew it. Two researchers worked independently to determine if the responses showed clear evidence of a caring role related to a health issue. The calculated interrater agreement was acceptable ( $\kappa = 0.997, p < .001$ ). Differences in ratings were discussed to find a consensus and determine the group of adolescents who perceived that they provided support because of a caring role.

Group comparisons between the AYC group and the non-AYC group, and in the group of AYC were made with Welch's *t* test, student's *t* test and chi-square test of independence. IBM SPSS Statistics (version 24.0; SPSS Inc.) software was used to perform data analyses.

## 2.7 | Validity and reliability/rigour

For the MACA-YC18, internal consistency in our sample was satisfactory for total score ( $\alpha = .82$ ), personal care ( $\alpha = .88$ ), emotional care ( $\alpha = .78$ ) and sibling care ( $\alpha = .84$ ), but weak for domestic tasks ( $\alpha = .47$ ), household management ( $\alpha = .43$ ) and financial/practical help ( $\alpha = .53$ ). These results were comparable to those reported in the validation study by Joseph, Becker, Becker, and Regel (2009), except for personal care, which had higher internal consistency in our study, and domestic tasks, which had weaker internal consistency. For the ES scale, exploratory factor analysis of the four items showed a unifactorial structure explaining 72.73% of the variance and satisfactory saturations ( $>0.64$ ). Internal consistency was satisfactory ( $\alpha = .87$ ), and the score was significantly but weakly correlated to the MACA-YC18 total score ( $r = .25$ ;  $p < .001$ ) and the Emotional Care subscore of the MACA-YC18 ( $r = .30$ ;  $p < .001$ ), highlighting the value of using these two measures. For the KIDSCREEN-10, internal consistency in our sample was 0.83, which is consistent with the consistency reported by Ravens-Sieberer & The Kidscreen Group Europe (2006;  $\alpha = .82$ ).

The questionnaire was pretested among a sample of eight adolescents, four being AYC. Some wordings were improved to get a final and acceptable version of the questionnaire.

The method used to identify AYC was established by discussing the methods used in the literature and applying them to the data of this study. All the authors took part to these discussions as well as one researcher specialized in methodology, a health professional working with YC/AYC and a director of a non-governmental organization for YC/AYC.

## 3 | RESULTS

### 3.1 | Identification of the group of adolescent young carers

Among the 4037 participants, 42.5% reported facing the illness/disability of one or several relatives. Of the total sample, 26.8% had at least one ill/disabled relative in their household and 10.6% provided a high level of support. Adolescents who had an ill/disabled relative outside their household comprised 15.7% of the sample, and 2.9% provided a high level of support to a parent, sibling or grandparent outside their household.

Some adolescents did not indicate in the first portion of the questionnaire related to the illness or disability of a relative that they had a relative with a health issue. However, in the scale measuring perception of support provided, 2.5% reported that they provided support because of a relative's health issue (e.g. 'she is physically ill', 'because of alcohol', 'because my brother has sickle cell anemia', 'disability since birth (mental retardation)', 'she has suicidal ideations and mutilates herself', 'because he has a rare respiratory illness'). Thirty-two participants reported providing a high level of support.

When combining the subgroups of adolescents facing the illness or disability of a relative and providing a high level of support, an AYC prevalence of 14.3% was obtained (Figure 1).

AYC can be divided into three groups: 7.6% provided a high level of caring activities without a high level of ES, 4.2% provided a high level of caring activities and a high level of ES and 2.5% provided a moderate level of caring activities and a high level of ES.

### 3.2 | Adolescent young carers characteristics compared with non-adolescent young carers

AYC were slightly older than non-AYC, and the AYC group contained significantly more females than the non-AYC group. There was a higher proportion of AYC in grade 11 (usually 16 years old) and 2-year vocational training.

AYC had significantly more siblings than non-AYC and their parents were significantly more often unemployed and taking a leave of absence for health reasons. The mothers of AYC were also more often stay-at-home mothers.

About caring activities, AYC had significantly higher scores than non-AYC on the total MACA-YC18, its subscales, and the ES scale. Their quality of life was also significantly poorer. These results are presented in Table 1.

### 3.3 | Characteristics of the adolescent young carers' ill/disabled relatives

Among the group of AYC, the ill/disabled relatives were mostly parents, then grandparents, and less were siblings or another close relative (9.5% aunts or uncles, 5.5% cousins, 3.3% friends). More than a third (38.7%) of participants had several relatives with an illness or disability. About their relatives' health issues, most had a serious or chronic physical illness (70.5%). Most AYC lived with the ill/disabled relative (74.2%). Among the identified AYC, 29.8% did not report they perceived providing support regularly for a relative. These results are presented in Table 2.

Some characteristics emerged when AYC were compared according to the type and level of support provided (Table 2). In the AYC group providing a high level of caring activities without a high level of ES, there was a higher proportion of AYC facing the illness/disability of a mother or grandparent, having a relative with a serious or chronic physical illness, and perceiving providing support. In the AYC group providing high levels of both caring activities and ES, there was a higher proportion of AYC facing the illness of a mother, having more than one ill/disabled relative, having a relative with a serious or chronic physical illness or disability, living in the same household as their relative, and perceiving providing support. In the AYC group providing a moderate level of caring activities and a high level of ES, there was a higher proportion of YC facing the illness of a grandparent and a lower proportion of YC living in the same household as their relative.

Group comparisons showed a significant difference in quality of life. AYC providing a high level of caring activities without a high level of ES had a lower quality of life than AYC with a moderate level of caring activities and a high level of ES.

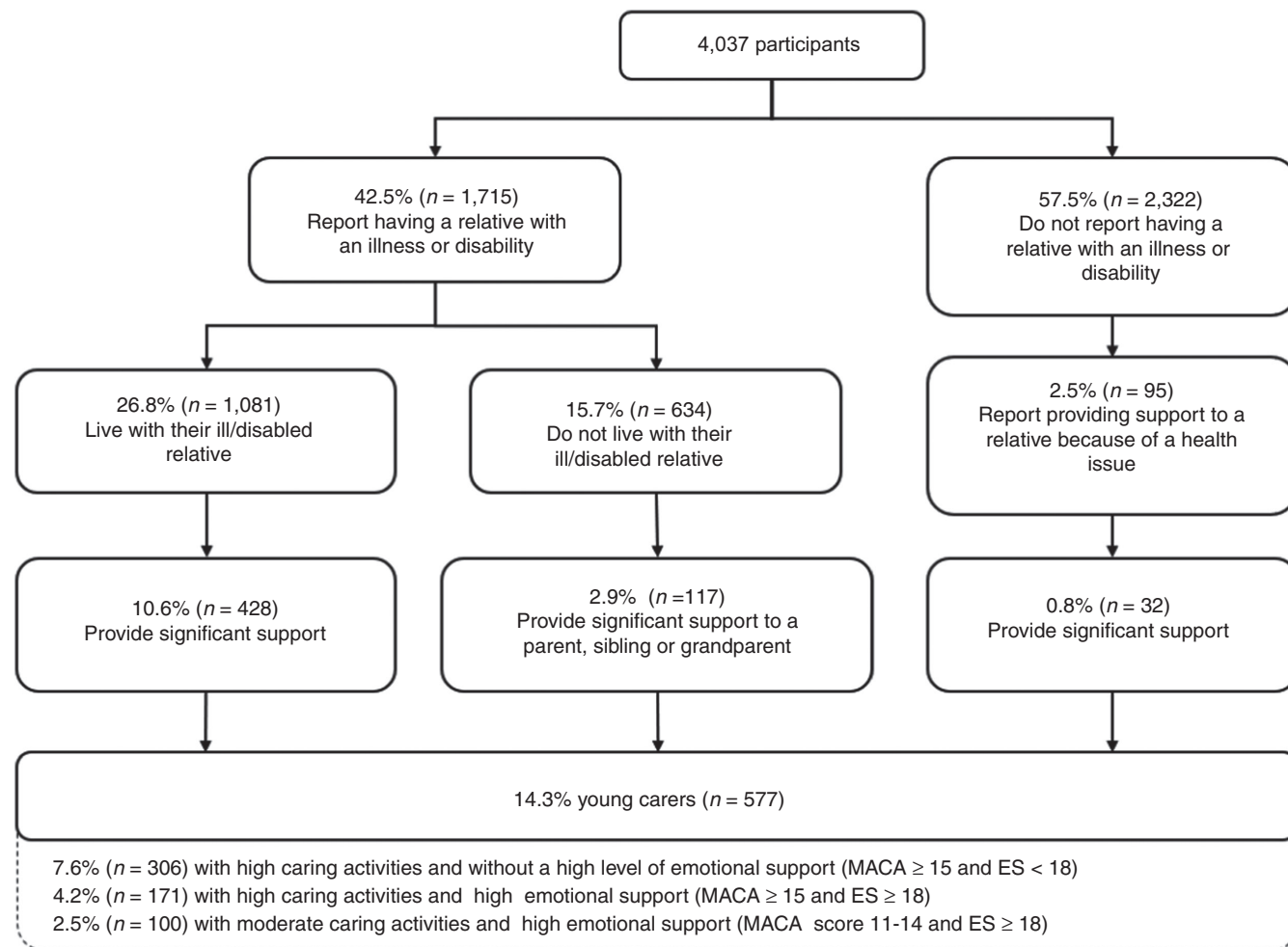


FIGURE 1 Identification of the young carer group

### 3.4 | Adolescent young carers and gender

Gender comparisons showed a higher proportion of females facing an ill/disabled mother and grandparent, as well as a relative with serious or chronic physical illness. About the level of provided support, female participants had significantly higher scores for caring activities related to domestic tasks, personal care and total MACA-YC18 score, while males had significantly higher scores for household management. Female AYC reported a significantly poorer quality of life than male AYC. These results are presented in Table 3.

### 3.5 | Adolescent young carers and household arrangement

There was a higher proportion of AYC with an ill/disabled relative in their household facing the illness/disability of their mother, sibling or another relative as well as having a relative with a mental illness or disability. For AYC with a relative living outside the household, there was a higher proportion of AYC facing the illness of a grandparent.

AYC sharing their household with an ill/disabled relative reported significantly more overall caring activities (total MACA-YC18

score) and financial/practical help. They also had poorer quality of life. These results are presented in Table 3.

### 3.6 | Adolescent young carers and perception of providing support

There was a higher proportion of AYC perceiving that they provided support when they were facing the illness of a sibling or grandparent, when they had a relative with a serious or chronic physical illness or mental illness, and when they lived in the same household as the relative. AYC perceiving that they provided support also had higher scores than AYC who did not perceive that they provided support for three caring activities, household management, financial/practical help and emotional care, as well as higher scores on the ES scale. These results are presented in Table 4.

## 4 | DISCUSSION

This study is the first to provide a prevalence of AYC in France. Our results show a higher prevalence than the values that have



TABLE 2 Characteristics of the ill/disabled relatives according to young carers caring activities

	AYC with high caring activities (MACA ≥ 15) and low emotional support (ES < 18) (n = 306)		AYC with high caring activities (MACA ≥ 15) and high emotional support (ES ≥ 18) (n = 171)		AYC with moderate caring activities (MACA 11–14) and high emotional support (ES ≥ 18) (n = 100)		χ <sup>2</sup>	p
	n (%)	n (%), ASR)	n (%)	n (%), ASR)	n (%)	n (%), ASR)		
<b>Ill or disabled relative</b>								
Mother	175 (30.3%)	83 (27.1%, -1.8)	66 (38.6%, 2.8)	26 (26%, -1)	7.91	.019		
Father	178 (30.8%)	105 (34.3%, 1.9)	45 (26.3%, -1.5)	28 (28%, -0.7)	3.75	.153		
Sibling	100 (17.3%)	45 (14.7%, -1.8)	34 (19.9%, 1.1)	21 (21%, 1.1)	3.19	.073		
Grandparent	192 (33.3%)	82 (26.8%, -3.5)	64 (37.4%, 1.4)	46 (46%, 3.0)	14.40	<.001		
Other relative	103 (17.9%)	54 (17.6%, 0.1)	34 (19.9%, 0.8)	15 (15%, -0.8)	1.04	.593		
More than one ill or disabled relative	202 (38.7%)	90 (34.4%, -2.0)	77 (47.2%, 2.7)	35 (36.1%, -0.6)	7.38	.025		
<b>Type of health issue</b>								
Serious or chronic physical illness	407 (70.5%)	197 (64.4%, -3.4)	133 (77.8%, 2.5)	77 (77.0%, 1.6)	11.91	.003		
Mental illness or addiction	117 (20.3%)	69 (22.5%, 1.4)	29 (17.0%, -1.3)	19 (19.0%, -0.3)	2.24	.326		
Disability	97 (16.8%)	44 (14.4%, -1.7)	40 (23.4%, 2.7)	13 (13.0%, -1.1)	7.63	.022		
YC lives in the same household as the relative	428 (74.2%)	219 (71.6%, -1.5)	144 (84.2%, 3.6)	65 (65%, -2.3)	14.47	<.001		
Perception of providing support	405 (70.2%)	203 (66.3%, -2.1)	134 (78.4%, 2.8)	68 (68%, -0.5)	7.86	.020		

Abbreviations: ASR, adjusted standardized residuals; bold values indicate an overrepresentation or underrepresentation; YC, young carer.

TABLE 3 Characteristics of adolescent young carers according to gender and household arrangement

	Gender				Relative's household			
	AYC females (n = 427)	AYC males (n = 143)	T, Welch, $\chi^2$	p	Same as AYC (n = 428)	Different (n = 149)	T, Welch or $\chi^2$	p
Age, M (SD)	16.19 (1.02)	16.32 (1.21)	1.28	.259	16.26 (1.07)	16.15 (1.06)	1.07	.283
Ill or disabled relative, n (%)								
Mother	139 (32.6%)	34 (23.8%)	3.90	.048	170 (39.7%)	5 (3.4%)	69.16	<.001
Father	132 (30.9%)	42 (29.4%)	0.12	.729	174 (40.7%)	4 (2.7%)	74.69 <sup>o</sup>	<.001
Sibling	76 (17.8%)	24 (16.8%)	0.08	.782	94 (22%)	6 (4%)	24.82	<.001
Grandparent	152 (35.6%)	38 (26.6%)	3.93	.048	88 (20.6%)	104 (69.8%)	120.68	<.001
Other relative	84 (19.7%)	18 (12.6%)	3.66	.056	86 (20.1%)	17 (11.4%)	5.68	.017
More than one ill or disabled relative, n (%)	162 (40.9%)	39 (32.8%)	2.55	.111	165 (40.7%)	37 (31.6%)	3.18	.075
Type of health issue n (%)								
Serious or chronic physical illness	311 (72.8%)	90 (62.9%)	5.03	.025	304 (71.0%)	103 (69.1%)	0.19	.661
Mental illness or addiction	86 (20.1%)	29 (20.3%)	0.001	.971	103 (21.1%)	14 (9.4%)	14.71	<.001
Disability	67 (15.7%)	28 (19.6%)	1.17	.280	90 (21.0%)	7 (4.7%)	21.08	<.001
Caring activities (MACA-YC18), M (SD)								
Total MACA-YC18 score	18.53 (4.81)	17.55 (3.99)	5.85	.016	18.57 (4.67)	17.58 (4.58)	2.24	.025
Domestic tasks	4.49 (1.13)	4.08 (1.26)	4.60	<.001	4.45 (1.23)	4.53 (1.03)	0.62	.430
Household management	3.38 (1.36)	4.01 (1.23)	26.14	<.001	3.60 (1.37)	3.39 (1.33)	1.60	.110
Financial/practical help	1.34 (1.49)	1.45 (1.48)	-0.75	.452	1.55 (1.54)	0.85 (1.16)	33.78	<.001
Personal care	1.81 (2.02)	0.92 (1.40)	33.87	<.001	1.66 (1.96)	1.40 (1.82)	1.46	.144
Emotional care	3.85 (1.66)	3.60 (1.62)	1.58	.116	3.79 (1.62)	3.79 (1.73)	0.06	.954
Sibling care	3.55 (2.05)	3.49 (1.99)	0.31	.757	3.52 (2.08)	3.63 (1.92)	-0.58	.563
Emotional support (ES), M (SD)	16.49 (3.96)	15.90 (4.22)	1.39	.167	16.23 (4.12)	16.79 (3.62)	-1.27	.206
Quality of life (KIDSCREEN-10), M (SD)	40.50 (9.85)	45.44 (11.99)	-4.85	<.001	40.98 (10.87)	43.18 (9.40)	-2.699	.007

Abbreviations: M, mean; SD, standard deviation;  $\chi^2$  should be taken with caution as theoretical frequency is less than 5.

been reported in other countries, with an AYC prevalence of 14.3% among adolescents in high schools. The characteristics of our sample of AYC are in line with those reported in the literature: a high proportion of females, primarily facing the illness or disability of one of their parents, most often supporting a relative with a severe or chronic physical illness, and reporting lower quality of life than non-AYC. Our results also highlight the differences in care and quality of life between AYC who share the same household as their ill/disabled relative and those who do not. The strength of this study is that it was based on a rigorous identification method based on the extent of caring activities and included ES and a large sample. It also provides insight into the challenges of identifying AYC.

To our knowledge, this is the first study to observe such a high prevalence of AYC through identification based on level of support.

Previous studies reporting AYC prevalence in a comparable age range have identified lower prevalence rates: 7.7% in New Zealand (McDonald et al., 2009) and 5.1% in Australia (Australian Bureau of Statistics, 2016). One could wonder if these differences are related to the organization of the health care systems, which may require young people to undertake fewer caring responsibilities than in France. It should be noted that these two countries are much more advanced in the recognition and support of carers and YC, particularly Australia, in which support for young people and their families is provided through a 'whole-family approach' (Leu & Becker, 2017). Moreover, the prevalence rates in Australia and New Zealand were obtained through census data and by surveying households. Studies identifying YC/AYC by data collected directly among youth in schools systematically report higher rates. Nevertheless, our prevalence is

**TABLE 4** Characteristics of adolescent young carers according to their perception of providing support

	Perception of providing support		T, Welch, $\chi^2$	p
	Yes (n = 405)	No (n = 172)		
Age, M (SD)	16.26 (1.07)	16.16 (1.06)	1.05	.294
Gender: females, n (%)	302 (75.3%)	125 (74.0%)	0.12	.735
	Ill or disabled relative, n (%)			
Mother	131 (32.3%)	44 (25.6%)	2.61	.106
Father	120 (29.6%)	58 (33.7%)	0.95	.330
Sibling	81 (20.0%)	19 (11.0%)	6.76	.009
Grandparent	123 (30.4%)	69 (40.1%)	5.17	.023
Other relative	72 (17.8%)	31 (18.0%)	0.005	.944
More than one ill or disabled relative, n (%)	148 (41.5%)	54 (32.7%)	3.63	.057
	Type of health issue, n (%)			
Serious or chronic physical illness	268 (66.2%)	139 (80.8%)	12.45	<.001
Mental illness or addiction	92 (22.7%)	25 (14.5%)	5.00	.025
Disability	70 (17.3%)	27 (15.7%)	0.22	.641
YC lives in the same household as the relative, n (%)	310 (76.5%)	118 (68.6%)	3.97	.046
	Caring activities (MACA-YC18), M (SD)			
Total MACA-YC18 score	18.56 (4.76)	17.75 (4.38)	1.92	.056
Domestic tasks	4.42 (1.22)	4.59 (1.09)	-1.64	.103
Household management	3.62 (1.33)	3.36 (1.41)	2.10	.036
Financial/practical help	1.48 (1.54)	1.11 (1.31)	8.79	.003
Personal care	1.59 (1.89)	1.60 (2.02)	-0.08	.934
Emotional care	3.92 (1.62)	3.48 (1.67)	2.96	.003
Sibling care	3.53 (2.08)	3.60 (1.95)	-0.39	.695
Emotional support (ES), M (SD)	16.75 (3.68)	15.34 (4.61)	10.72	.001
Quality of life (KIDSCREEN-10), M (SD)	41.88 (10.91)	41.31 (9.95)	0.58	.564

Abbreviations: M, mean; SD, standard deviation.

higher than in most studies and we can wonder if French adolescents overestimate or more easily report the support they provide compared with adolescents in other countries. This should be investigated in future studies with international comparisons to better understand this result.

The high prevalence of AYC in this study may also be related to the identification criteria used. Indeed, we chose to include AYC whether they were living with their ill/disabled relative or not. According to our results, 10.6% provided support for a relative in the same household and 2.9% provided support for a relative outside the household. Compared with the study by McDonald et al. (2009), our proportion of AYC is much higher about those sharing the same household and comparable for those not sharing it (4.2% and 3.5%, respectively, in a sample aged 15–18). These results come from data supplied by Statistics New Zealand, in which participants reported looking after someone with an illness or disability, though the amount of support was not explored. Other studies including YC/YAC caring for a relative outside their

household do not specify their proportion. In addition, it was interesting to observe that, in our study, AYC were more likely to share the same household with their relative when they provided a high level of caring activities combined with a high level of ES, while they were more likely to live in a different household when they provided a moderate level of caring activities and a high level of ES. This finding might be related to the fact that AYC caring for relatives outside their household most often care for a grandparent. We can wonder if ES is something that an adolescent is more likely to provide for a grandparent.

The methodology we used also enabled the identification of AYC who did not initially report having a relative with an illness or disability when directly asked, but did report that they provided support because of a relative's health issue in the second portion of the questionnaire. Those were 0.8% providing a high level of support. This result is quite surprising, as some adolescents reported very precise illness or disability diagnoses in the second portion of the questionnaire (e.g. cancer, sickle cell anaemia, mental retardation).

The reasons these adolescents did not report the health condition of their relative in the first part of the questionnaire may be due to two factors. First, some adolescents may have been reluctant to share this kind of information at the beginning of the questionnaire, but when they registered that the study focused on their experience of having a relative with a health issue, they may have allowed themselves to reveal this information. Second, some adolescents may not have known the diagnosis of their relative, either because they had not been informed by their family or the diagnosis had not been obtained yet, though they were able to identify the presence of a health issue and report it when they were asked about the motive for the support they provide. This result shows that including questions about adolescents' perception of the support they provide is an important component of AYC identification, even if it appears insufficient to identify all AYC.

Among the AYC identified in this study, 29.8% did not report that they perceived providing support for a relative regularly, which can be explained by a deficiency in AYC self-identification, particularly because YC/AYC and their families may hide their situation or consider it normal (Becker, 2007; Cassidy et al., 2014; Mauseth & Hjälmhult, 2016; McDonald et al., 2009; Rose & Cohen, 2010). As stated above, providing help is often considered a normal activity during adolescence (Smyth et al., 2011; Steinberg, 2014). In addition, French awareness of YC/AYC is low (Leu & Becker, 2017) and probably does not support self-identification. These AYC would not have been identified if our identification method had been based solely on their perception, as was the identification methods of Joseph et al. (2019) and Leu et al. (2019). This highlights the importance of using a method of identification not solely based on self-perception. As underlined by other authors, the use of a questionnaire to measure the amount of care is an important component of AYC identification (Metzing et al., 2020; Nagl-Cupal et al., 2014a), making the MACA-YC18 an interesting tool. However, in our study, three dimensions had a low internal consistency, and while these were comparable to the results reported by Joseph, Becker, Becker, and Regel (2009), the scale might be improved. Furthermore, the addition of the ES scale garnered interesting results, as AYC providing a high level of caring activities and a high level of ES were more likely to perceive providing support, while those not providing a high level of ES were less likely. This also allowed us to observe that AYC whose relative was outside the household were more likely to provide a high level of ES.

It is difficult to compare estimated prevalence between studies due to differences in identification methods. Therefore, international and comparative studies using homogeneous methodology are essential and should help to provide a consensus on the best identification methods and tools, even if cultural characteristics should be considered in the way studies are undertaken and how the youth are interviewed.

The characteristics of the AYC found in this study are comparable to those reported in the literature. AYC were mostly female (74.9%). This considerable difference in gender has been frequently reported, with observed rates between 60% and 70% (Joseph

et al., 2019; Metzing et al., 2020; Nagl-Cupal et al., 2014). In our study, female AYC provided significantly more support for domestic tasks and personal care, while male AYC provided more household management support. Differences in care type have also been observed in other studies, but the findings are inconsistent except for domestic tasks, which appears to be consistently higher for females (Joseph et al., 2019; Leu et al., 2019). The AYC group had a lower quality of life than the non-AYC group, and among AYC, females had a lower quality of life than males.

The ill/disabled relative was most often a parent, followed by a grandparent, sibling and another relative. These results are in line with those observed in other studies, particularly studies including YC/AYC caring for a relative both in and outside their household (Leu et al., 2019; Nagl-Cupal et al., 2014). However, our findings had the unique characteristic of having almost equal proportions of mothers and fathers. We can wonder if this is a French characteristic, as in the literature, results have shown that AYC more often care for mothers than fathers (Joseph et al., 2019; Leu et al., 2019; Nagl-Cupal et al., 2014). Our results also showed that more than a third of AYC had more than one ill/disabled relative, similar to results observed in the United Kingdom (Joseph et al., 2019). These characteristics were associated with the features of the provided support, as AYC facing the illness/disability of a mother and those having more than one ill/disabled relative were more likely to provide high levels of both caring activities and ES, while those facing the illness/disability of a grandparent were more likely to provide a moderate level of caring activities and a high level of ES.

Most AYC in our study had a relative with a severe or chronic physical illness, while less had a relative with a mental illness or addiction or disability. These results are consistent with those reported in the literature (Joseph et al., 2019; Metzing et al., 2020; Nagl-Cupal et al., 2014). In addition, our results showed that YC with a relative with a serious or chronic physical illness or disability were more likely to provide high levels of both caring activities and ES.

## 4.1 | Limitations

This study had several limitations that warrant mentioning. Although the study was carried out in 15 high schools in three regions of France, most adolescents were recruited in the greater region of Paris. Rural areas were poorly represented, as well as high schools with vocational education programs. In France, about 28.5% of high school students receive vocational education (Ministère de l'Éducation Nationale de la Jeunesse et des Sports, 2020). This might have affected the results as the proportion of AYC might be higher among these students, with vocational education being offered to youth having difficulties in secondary school. A second limitation is linked to the sample being exclusively comprised of adolescents in high school, as some youth drop out from secondary schools (grades 8 and 9, usually aged 13–14). Academic difficulties (absence, poor academic achievement) have been observed among AYC aged 11–15 years old (Dearden & Becker, 2004), which is before high school

in France. Thus, the AYC in our sample might be particularly resilient academically. In France, approximately 11.9% of young adults drop out of school without a diploma (Le Rhun & Dubois, 2013); further studies will thus need to include those not attending high school. A third limitation is related to the identification criteria. When adolescents had a relative with an illness/disability outside their household, we chose to limit the eligible relative to a parent, sibling or grandparent. This choice does not take into account the emotional proximity between the adolescent and other relatives and excludes other family members with whom the youth may feel close. In future studies, it would be interesting to explore more completely the adolescents' relation to their relative when they do not share the same household. Finally, the choice of cut-off scores for the levels of caring and support were determined by the data distribution in our sample, rather than the established cut-off points for the tools used as they do not exist for the French version. However, the cut-off points are very close to those reported by Joseph, Becker, and Becker (2009) for the MACA-YC-18.

## 4.2 | Implications for practice

This study has several implications. About the important prevalence of AYC and the 'awakening' level of France according to the classification by Leu and Becker (2017), a first step will be to enhance awareness among professionals.

For school professionals, increasing awareness of AYC is crucial, not only for health professionals such as school nurses, school physicians or psychologists, but also for school counsellors and teachers. Each professional may play a role in the identification of AYC, which will consequently enhance their ability to support them. Currently, thanks to the national strategy for carers (Ministère des Solidarités et de la Santé, 2019), the first program to enhance awareness is being tested in four regions of France. It will need to be extended across the country and deeper reflection will need to be undertaken to support AYC throughout their education.

Enhance awareness among health professionals working in hospitals and more broadly, across organizations taking care of the ill/disabled relative will also be required. Currently in France, care is centred on the ill/disabled relative and AYC often remain invisible. As stated by Nagl-Cupal et al. (2014), health care providers should develop a holistic view to assess families' and children's needs and prevent children from taking on an inappropriate caregiving roles.

Professionals working in organizations specializing in physical and mental care for adolescents may also have a major role to play. In France, several structures exist on a local level. Here, too, enhancing awareness of AYC and their specific needs will be a first step.

Overall, increasing awareness among health, social and educational professionals is crucial to facilitate the identification of YC/AYC and to provide them with appropriate support. Although it is only a first step, it will facilitate the perception professionals have of their ability to support YC/AYC and the relevance to their work (Leu et al., 2020). Awareness of the high prevalence of YC/AYC could

empower professionals to initiating support, which is not always the case (Leu et al., 2018).

## 4.3 | Research perspectives

The identification of AYC is challenging. In this study, we proposed an identification method based on the attributes and limitations of the different methods employed in the literature. We used as a principal criterion the amount of support provided by the youth and considered ill/disabled relatives sharing and not sharing the youth's household. In our opinion, as also stated by Becker (2000), it is important to place the level of care provided by the young person at the heart of the investigation. However, the youth's self-perception of care is also important to consider to achieve a complete measure of the situation.

In terms of research perspectives, using a method that considers the level of care provided by the youth allows researchers to distinguish AYC from young people facing the illness/disability of a relative without providing significant support. The boundary between being a AYC and not being one is difficult to determine, particularly as care changes over time in relation to the young person's age, the relative's disease, the family's situation, etc. Hence, there is a need for longitudinal studies exploring the evolution of care and the transition from facing the illness or disability of a relative to becoming an AYC.

## 5 | CONCLUSION

In France, this study is the first to provide a prevalence of AYC. According to the Ministry of National Education of Youth and Sports, there are 2,266,100 high school students in France (Ministère de l'Éducation Nationale de la Jeunesse et des Sports, 2020). Based on our estimate of 14.3% of adolescents being AYC, we suggest that around 294,600 high school students in France may be AYC. It is now crucial to enhance the identification and support of this population as well as explore the prevalence and characteristics of YC/AYC among younger adolescents and children in France. Public policies should work to reduce the phenomenon of YC/AYC but also improve their well-being, particularly by offering formal care for the whole family (Moore & McArthur, 2007; Purcal et al., 2012) and promoting respite and resources for YC/AYC (Purcal et al., 2012; Stamatopoulos, 2016). The French national strategy for carers (Ministère des Solidarités et de la Santé, 2019), which includes for the very first time a specific portion devoted to YC/AYC, is an important step, but much more needs to be done.

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## CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

## AUTHOR CONTRIBUTIONS

AU and GD were scientific coordinators of the study and designed it with EJ. AU, GD, EJ, and CV supervised the data collection, and EJ and CV collected a portion of the data. EJ cleaned and coded the data, computed part of the analyses, and drafted a preliminary version of the paper. AU computed the analyses and wrote the original draft of the paper. GD, EJ, and CV reviewed and edited the paper. All authors have approved the final version of the manuscript for submission.

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## PEER REVIEW

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## DATA AVAILABILITY STATEMENT

The datasets used and analyzed during the current study are available from the corresponding author on reasonable request.

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