

# Counting Young Carers in Switzerland – A Study of Prevalence

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*An online survey of children in school grades 4–9 (mostly aged 10–15) was conducted in order to determine the prevalence of young carers in Switzerland using a 2-stage stratified sampling approach. 4082 respondents were drawn from 230 schools. A total of 3991 respondents were included in the analysis and of these 307 (7.7%) were identified as young carers. The population estimate of prevalence was 7.9 per cent. This suggests that there are around 38 400 young carers in school grades 4–9 in Switzerland. Extrapolating to the 9–16 age group gives a figure of almost 51 500. © 2018 The Authors. Children & Society published by National Children's Bureau and John Wiley & Sons Ltd.*

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## Introduction

Children and adolescents who provide regular support and care for ill or disabled family members are now becoming increasingly recognised in research and subsequent policy responses (Day, 2015; Hamilton and Cass, 2017; Phelps, 2017). Despite a number of definitions in use, most have the following in common: young carers are young people under 18 years old who provide care, assistance or support to another family member, often on a regular basis. They take on significant or substantial caring tasks and levels of responsibility that would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent or another relative with a disability who has some chronic illness, mental health problem or condition requiring care, support or supervision (Becker, 2000, p. 378). Recent conceptual research from Switzerland highlights the importance of 'having a common definition' of (young) carers in order to facilitate their identification, as well as to have a common basis in research (Frech et al., unpublished data; Wepf and others, 2017).

Some countries, including Norway, Sweden, Germany and Austria are now actively engaged in identifying and supporting these 'young carers'. At present, however, the UK is the only country to have reached an 'advanced level' of awareness and recognition of the issue among professionals, policy-makers and the public (Leu and Becker, 2016).

The circumstances of younger carers, young adult carers and their families have only recently been the subject of research in Switzerland. The first qualitative data are now available on their caring activities and support needs (Leu and others, 2018). This shows that different definitions and terminologies are being used for children with ill parents or siblings, but very seldom are they referred to as 'young carers'. The research highlights the importance of raising awareness among professionals so that appropriate support can be provided.

At present, there is no national dedicated young carers' support framework in Switzerland that could assist these young people.

Research on these young people is challenging because they often do not recognise themselves as caring relatives or identify themselves as such (Cass and others, 2009; Noble-Carr and Woodman, 2016). This lack of self-identification combined with a low level of awareness among professionals from healthcare, education and social services (Leu and others, 2018) is one of the reasons for a lack of sustainable policies and intervention strategies (Leu and Becker, 2016), and such is the case in Switzerland.

Most existing studies of young carers are qualitative by nature, exploring their lived experiences, the amount and extent of care they provide, their needs and the effects that the caring role can have on their lives (Aldridge and Becker, 1993; Bibby and Becker, 2000; Dearden and Becker, 2000; Devine and Lloyd, 2008; Frank, 1995). They also show, for example the time spent caring and differences in the amount of caring between different age groups (Moore and McArthur, 2007; Nagl-Cupal and others, 2012). The first qualitative study on young carers in Switzerland illustrates the broad variety of their caring roles (Leu and others, 2018). Until now, previous Swiss studies have focused primarily on the circumstances of children with parents with a mental illness, but without exploring in depth the caring responsibilities of those children (Albermann and others, 2012; Gurny and others, 2007). This new research provides a deep insight into the lives of young carers and the challenges they face. For policy-makers, stakeholders and researchers, this is useful in helping them to develop support structures and projects. However, in order to develop appropriate and effective support on a national scale it is necessary to know how many young people have caring responsibilities.

At present, there are few large-scale surveys which provide information on the actual numbers of young carers (Lloyd, 2013; Nagl-Cupal and others, 2014; Stamatopoulos, 2015). Those that have been conducted show, that in industrialised states, on average, at least 2–4, sometimes up to 8 or more per cent of all children and adolescents under 18 years have caring roles; and in the age group of 18- to 25-year-olds the figure is higher. One of the first sources of information on prevalence was the UK Census in 2001 which estimated that approximately 2 per cent of children between 5 and 17 years had a caring role (Becker and Becker, 2008).

These findings should be treated with caution since the census required parents to disclose the caring role of their children. For various reasons, they may have been reluctant to do so and the results, therefore, underestimate the number of young carers (Lloyd, 2013). In a subsequent survey conducted by Becker and the BBC in the UK (Howard, 2010), pupils in ten secondary schools were asked to self-disclose their own caring roles. The findings of that survey suggested that 8 per cent of children had a caring role. However, full details of the methodology used were not published.

In Germany, the first prevalence study was conducted in 2016. It was estimated that 5 per cent of children and young people aged between 12 and 17 years were young carers (Lux and Eggert, 2017). In Austria, Nagl-Cupal and others (2014) reported that 4.5 per cent of children had a caring role. In her study of young carers in Northern Ireland, Lloyd (2013) found a prevalence of 12 per cent among children aged 10 and 11. These and other studies underline, that in all researched countries, a substantial number of children provide care on a regular basis (Table 1). The choice of method will affect the accuracy of the estimate of prevalence.

In a large English interview study of 378 participants, the researchers found 9 per cent of children and adolescents who identified themselves as young carers (Warren and Ruskin, 2008). The first prevalence study in Germany, conducted in 2016, estimated that 5 per cent

**Table 1:** Prevalence of young carers in Europe

United Kingdom	Switzerland	Netherlands	Sweden	Italy	Austria	Germany
8%	7.9%	6%	7%	7.2%	4.5%	5%
11–18 years	10–15 years	13–17 years	14–16 years	15–24 years	10–14 years	12–17 years

of children and young people between 12 and 17 years were young carers (Lux and Eggert, 2017); and in Austria in 2012, Nagl-Cupal and his co-authors reported that 4.5 per cent of children had a caring role (Nagl-Cupal and others, 2012, 2014). In her study of young carers in Northern Ireland, Lloyd found a prevalence of 12 per cent among children aged 10 and 11 (Lloyd, 2013). These and other studies underline, that in all researched countries, a substantial number of children provide care on a regular basis. Additionally, research from different countries has shown that young women are over-represented as young carers. For example in their survey of children in Austria, Nagl-Cupal and others (2014) showed that around 70 per cent of young carers were female; and Sempik and Becker (2013) found a similar percentage among young adult carers (aged over 14) who were still at school. So the responsibility for care appears to lay more heavily on young women.

The choice of method will affect the accuracy of the estimate of prevalence. For our first large scale study on young carers in Switzerland, we wanted to use a method that was as precise as possible in order to give policy-makers the most accurate estimate of young carers. We conducted an online survey of pupils in primary and secondary schools using a systematic random sample that allows for statistical inference to the underlying population in order to provide an accurate estimate of the number of young carers in Switzerland.

At present, there is no data on the prevalence of young carers in Switzerland, neither (to our knowledge) has there been any other research (qualitative or quantitative) which has explored the lives of young carers in Switzerland. In their analysis of policy responses of different countries to the issue of young carers, Leu and Becker (2016) make the point that policy responses are heavily influenced by national research. However, they were unable to identify any relevant findings from Switzerland.

In this paper, we present the first estimate of the prevalence of young carers in Switzerland and show whom they care for, their age, gender, extent of caring and the link between caring and well-being.

## Methods

### *Questionnaire*

A short online questionnaire was created. This was hosted by a commercial provider (Survey Monkey). The questionnaire collected demographic information including age, gender, school grade and school, the household composition, whether they had siblings, their place of birth and the languages spoken. Participants were also asked whether they provided regular support for a friend or relative. ‘Some children and adolescents do have a family member or friend who needs support on a regular basis, e.g. because he/she is ill. Do you support someone on a regular basis?’ and the reason(s) for that support as an open question (‘Why do(es) the person (or these persons) need your support?’). Using a pre-defined coding schedule, the responses were coded into two categories: 1 = young carer; 0 = not a young carer. Those whose responses showed clear evidence of a caring role (e.g. providing regular care for a parent with cancer, addiction, or a mental health problem) were coded as 1 (i.e. a young carer), and those with no evidence of a caring

role or whose responses were too ambiguous or vague to provide clear evidence of care (e.g. 'I like to help') were coded as 0 (i.e. not a young carer). The rating was carried out by two researchers working independently. The interrater-agreement of the two initial ratings was acceptable (Kappa = 0.89). The differences between the two ratings (in 27 cases) were then compared and discussed to find a consensus. The final results of the rating were used to determine young carer status.

The questionnaire included a German, French and Italian version of the Multidimensional Assessment of Caring Activities (MACA-YC18, Joseph and others, 2012) which is an 18-item inventory of caring activities undertaken by children and young people. The MACA provides a total sum score (range 0–36) and domain scores (range 0–6) for domestic, emotional, financial, household, personal and sibling aspects of care. Translation of the MACA was discussed with the authors of the original instrument and the versions used in this study were deemed to be acceptable. The internal consistency reliability of the total scales (Cronbach's Alpha = 0.79) was satisfactory and comparable to the one reported in the validation study by Joseph and others (2009).

The KIDSCREEN-10 index was included as a measure of subjective well-being. This is a health-related Quality of Life Questionnaire (HRQoL) for children and young people (The KIDSCREEN Group Europe, 2006) and is available in all three languages (German, French and Italian). The KIDSCREEN-10 instrument has previously been used in a similar school survey aimed at identifying young carers (Schlarmann and others, 2008). The version of the questionnaire used in this study was a shortened form developed from the 27-item scale that provides a total sum score (range 10–50) with a higher score indicating greater well-being. The authors of the KIDSCREEN-10 index report a good internal consistency reliability (Cronbach's Alpha = 0.82) and test–retest reliability/stability ( $r = 0.73$ ; ICC=0.72). The internal consistency reliability of our data was identical to published values (Cronbach's Alpha = 0.82). The raw scores were transformed using the Rasch model estimates as described by the authors of the instrument (The KIDSCREEN Group Europe, 2006) and T-values were calculated.

The questionnaire also collected demographic information including age, gender, school grade and school, the household composition. It was initially piloted with eleven children in different language regions.

During the pilot phase, we paid special attention to the wording of the questions to ensure they were understood correctly. We then edited the questionnaire according to the pilot results, and discussed any changes with native speakers and the translators in order to produce a correct translation. The changes were also discussed and agreed with the developers of the MACA and with the KIDSCREEN Group. The KIDSCREEN Group now offers Swiss language versions of their instruments.

### *Sampling*

A 2-stage, stratified sample design was used in order to reach children in school grades 4–9. In Switzerland, grades 4–6 are for primary education and grades 7–9 for lower secondary education. These grades cover the population of 10- to 15-year-olds but also include a small number of children aged 9 and 16 years. Students in special-needs schools and classes were excluded, as were those in private schools; these make up only around 3–4 per cent of children in those grades.

The first-stage sampling units consisted of individual schools with students in the required grades. These schools were sampled systematically from a list provided by the Swiss Federal Statistical Office (FSO).

The Schools were divided into eight groups (explicit stratification) using information on grades (primary education vs. lower secondary education) and the school's language (German, French or Italian). The following eight groups of schools were created:

- German speaking (excluding Zurich), primary education
- German speaking (excluding Zurich), lower secondary education
- Canton of Zurich, primary education
- Canton of Zurich, lower secondary education
- French speaking, primary education
- French speaking, lower secondary education
- Italian speaking, primary education
- Italian speaking, lower secondary education

The sample was allocated proportionally to these 8 strata, that is a sub-sample of schools was drawn from each group in proportion to its student population in grades 4–9.

The canton of Zurich forms a separate strata because authorities only allowed for drawing a limited number of schools from this region ( $n = 60$ ). But as the limitations of the authorities only concerned the number of schools and not regions or specific schools within the canton, we believe, this did not affect the overall quality of the sample, only its size. The Italian-speaking region was slightly oversampled due to its relatively small size.

The explicit stratification used in the sampling increases the precision of the estimates of prevalence in the event that language region and student age are related to caregiving. Before drawing a sample of schools from each of the eight groups, the list of schools for each group was also sorted (implicit stratification) by canton, school size and school type (in the case of lower secondary education). This implicit stratification further tended to distribute the sample within the explicit strata across cantons and schools having different sizes and requirements. Then, schools were sampled using probabilities proportional to that school's estimated number of study-eligible students (Probabilities proportional to size; Kish, 1965).

Schools identified by the sampling process were contacted and invited to participate in the study. Of these 711 selected schools, 230 agreed to take part. Since the survey was not compulsory the response rate of schools (32%) was not very high.

Assuming an average classroom size of about 17 pupils and sampling one classroom per school, 711 schools were sampled initially to yield a target student sample of approximately 12 000 students. All participating schools were asked to submit classroom lists for grades 4–6 (primary education) or grades 7–9 (lower secondary education). The second-stage sampling consisted of sampling 1 classroom per participating school using simple random sampling (see, e.g. Lehtonen and Pahkinen, 1995). The teachers of the sampled classrooms were contacted and instructed regarding how to participate in the survey. Short video clips in German, French and Italian were provided for teachers and pupils (<http://www.careum.ch/yc/umfrage-videos>). Pupils received assurance of granted anonymity.

In contrast to high non-response rates at school level, within the participating schools, the non-response rates were very low and almost all students attempted the survey. The overall response rate for students within participating schools was 94 per cent when conducting the survey. The survey was not obligatory either for the schools or for the pupils. Schools that decided to take part in the survey were closely monitored by the research team who contacted the teachers regularly by email and phone. A 'hotline' was available for real-time support. The final sample size was  $N = 4082$  students.

Following standard procedures (Lohr, 2010; OECD, 2014), the inverse of selection probabilities, in combination with non-response adjustments at both sampling stages, were used to

calculate sampling weights. Survey weights ensured that each sampled student represented the appropriate number of students in the population and, hence, allowed for the calculation of accurate population estimates (Lohr, 2010).

The weight  $W_{ji}$  for student  $i$  in school  $j$  consisted of 2 base weights, the school base weight and the within-school base weight, and 2 adjustment factors, and it can be expressed as:

$$W_{ji} = w_{1j} \cdot w_{2ji} \cdot f_{1j} \cdot f_{2ji}$$

where  $w_{1j}$ , the *school base weight*, is the reciprocal of the probability of including school  $j$  in the sample;  $w_{2ji}$ , the *within-school base weight*, is the reciprocal of the probability of including student  $i$  from within the selected school  $j$  in the sample;  $f_{1j}$  is an *adjustment factor* to compensate for *non-participation of schools using other schools* that are in the same explicit strata;  $f_{2ji}$  is an *adjustment factor* to compensate for *non-participation of students using other students* that are within the same classroom.

### *Statistical analysis*

Responses to the survey were downloaded as a Microsoft Excel spreadsheet and then prepared for analysis. IBM SPSS Statistics (ver. 24.0, Armonk, NY: IBM Corp.) was used to provide descriptive statistics, including frequency, mean and standard deviation. The following inferential tests were used on the sample: Student's  $t$ -test; chi-squared ( $\chi^2$ ); and bivariate correlation (Pearson's coefficient) as appropriate. The complex sample analysis functions of SPSS were used with the sample weights described above for population estimates of frequencies and means and measures of their dispersion. The level of statistical significance was set at  $P \leq 0.05$ .

### *Ethical approval*

Ethical approval for the study was obtained from the Zurich canton ethics committee (No. 85-2015). Information about the study was provided to schools, students and parents before conducting the survey. Parents were asked whether they had any objections.

### *Informed consent*

Prior to conducting the survey, we provided written information about the study to schools, pupils, as well as to parents. Parents were able to refuse their children's participation in the study. Additionally, pupils were informed by their teachers using an introductory video suitable for the age group that participation in the study was voluntary and that they could abandon the questionnaire at any time without facing any negative consequences. Before the survey was conducted, pupils again received information about the study and the handling of the data, that is anonymisation and confidentiality.

## **Results**

### *Participants*

A total of 4082 respondents attempted the questionnaire. Twenty-seven participants with incomplete questionnaires (i.e. too little data for inclusion in any analysis), and 19 participants with 'frivolous' answers (e.g. including jocular responses or incomprehensible character strings in open-response questions) were excluded because these answers were not considered reliable. In addition, 45 participants were excluded because they were outside the defined age range for the study (9–16 years). The final sample for analysis consisted of 3991 respondents.

The gender distribution of the sample was approximately equal with 1926 (48.3%) males and 2025 females (50.7%); 40 respondents (1%) did not give their gender. The mean age was 12.9 (SD = 1.7). Of those completing the survey, 3313 (83%) completed in German; 473 (12%) in French and 205 (5%) in Italian. Analysis by language was not carried out because of the disparity in group sizes and small size of the Italian-speaking group. Ethnicity of the respondents was not collected.

### Prevalence of young carers

Using the method described above, 307 respondents were classed as 'young carers' and comprised 7.7 per cent of the sample. When extrapolated to the general population using complex sample analysis (i.e. incorporating the sample weighting as described above) the prevalence was 7.9 per cent. Sample results and population estimates are shown in Table 2, and the process is summarised in Figure 1.

Therefore, a prevalence of 7.9 per cent was estimated for the population of children in school grades 4–9 in Switzerland. These grades largely represent the 10–15 age group but also include some outside this range. Sample participants ranged in age from 9 to 16; with 1.5 per cent aged 9 and 4.9 per cent aged 16.

Our estimates suggest that there are around 38 400 young carers in school grades 4–9. If we apply the same prevalence to the population of children aged 9–16 (approx. 651 459) (Federal Statistical Office, 2017) in Switzerland, we estimate that there are around 51 500 young carers in this age group. Some caution is necessary here since the prevalence of young carers does vary with age. However, when we excluded 9- and 16-year-old respondents from our analysis, we obtained a sample prevalence of 7.7 per cent (no change) and a population estimate of 8.0 per cent (an increase of 0.1 percentage points). Hence, within this limited age range, the change in prevalence with age may be small.

### Characteristics of young carers

#### Age

The mean age of those identified as young carers in the sample was 12.6 ( $\pm 1.8$ ) years; for the population, it was estimated at 12.3 years (95% CI = 12.1–12.5). The mean age at which they started their caregiving role was 9.2 ( $\pm 2.9$ ) for the sample and 9.0 (95% CI = 8.6–9.3) for the population.

There was no significant difference in age between male and female young carers in the sample (both had a mean age of 12.6 years;  $t_{301} = 0.156$ ;  $P = 0.876$ ); and in the age they started their caring role ( $9.0 \pm 3.0$  and  $9.3 \pm 2.9$ , respectively, for males and females;  $t_{303} = 1.043$ ;  $P = 0.298$ ).

Table 2: Prevalence of young carers in the sample and population estimate

	Sample		Population estimate (10- to 15-year-olds, Swiss-wide)							
	Frequency	Per cent	Estimate	Standard error	95% confidence interval		Per cent	Standard error	95% Confidence Interval	
					Lower	Upper			Lower	Upper
No caring role	3684	92.3%	410 868	4330	402 335	419 401	92.1%	0.7%	90.7%	93.3%
Young carer	307	7.7%	35 352	2906	29 625	41 079	7.9%	0.7%	6.7%	9.3%
Total	3991	100.0%	446 220	3264	439 787	452 652	100.0%	0.0%	100.0%	100.0%

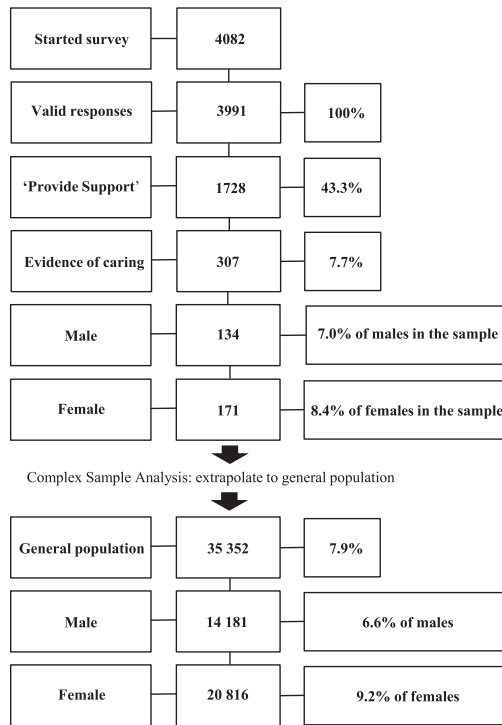


Figure 1. Flow chart of survey results.

Note. The sum of estimates of male and female young carers in the general population are lower than the estimated total since calculation of the total population estimate also included respondents who did not give their gender.

Similarly, for the population estimates, there was no significant difference in mean age between genders (12.4 for males and 12.3 for females;  $t_{146} = 0.671$ ;  $P = 0.503$ ); and in the age at which they started their caring role (8.9 for males and 9.0 for females;  $t_{147} = 0.159$ ;  $P = 0.874$ ).

**Gender**

Although a slightly higher proportion of females in the sample were identified as young carers (8.4% compared with 7%), the difference was not statistically significant ( $\chi^2(1) = 2.859$ ;  $P = 0.091$ ). For the population, the estimate was 9.2 per cent for females, and 6.6 per cent for males. The odds ratio for the likelihood of being a young carer by gender was 1.44, with 95 per cent confidence intervals of 1.10 (lower) and 1.90 (upper). Since, the confidence intervals do not include the value of '1', the difference in prevalence between genders is statistically significant at the 5 per cent alpha level. Hence, the population estimates but not the sample results suggest a difference in prevalence between genders.

**Who they care for**

Fifty four per cent of those identified as young carers provided support for their mother, and 41 per cent for their father; 46 per cent cared for their siblings. Over half of respondents (53%) reported that they cared for a grandparent. 18 per cent reported caring for a family friend; and 13 per cent for another relative. 41 per cent cared for one person; 47 per cent cared for between two and four individuals and 12 per cent cared for more than four people.



### Caring tasks and extent of caring (MACA)

Those identified as young carers in the sample had significantly higher total MACA score compared with those who showed no evidence of providing care ( $12.5 \pm 5.1$  compared with  $10.7 \pm 5.1$ ). The difference was statistically significant ( $t_{3989} = 6.028$ ;  $P < 0.001$ ).

30 per cent of young carers in the sample carried out a low amount of caring (as defined by the MACA score; Joseph and others, 2009; 32 per cent carried out a moderate amount of caring; 22 per cent and 17 per cent carried out a high amount and a very high amount of caring respectively. Population estimates of caring levels were similar to sample findings that is 32 per cent, 31 per cent; 22 per cent and 15 per cent respectively (see Table 3).

MACA domain scores showed that those identified as young carers in the sample had significantly higher scores for emotional ( $P < 0.001$ ), financial ( $P = <0.05$ ) and personal care ( $P < 0.001$ ) compared with those who did not have a caring role. There was no significant difference for domestic or sibling care domains ( $P > 0.05$ ). These are shown in Table 4.

Females in the sample who were identified as young carers had a significantly higher mean total MACA score than the males ( $P = 0.008$ ). They also had significantly higher MACA domain scores for domestic care ( $P < 0.001$ ); emotional care ( $P < 0.001$ ) and personal care ( $P = 0.001$ ). There was no significant difference for financial, household or sibling care domains ( $P > 0.05$ ). These results (including population estimates) are summarised in Table 5.

### Caring and well-being

The mean KIDSCREEN-10 score for the total sample was  $56.3 (\pm 12.7)$ . Those children identified as young carers had a slightly lower, but statistically significant, KIDSCREEN-10 score than those without caring responsibilities ( $54.5 \pm 13.2$  compared with  $56.5 \pm 12.7$ ;  $t_{3984} = 2.605$ ;  $P = 0.009$ ). This suggests that the level of well-being is slightly lower among young carers compared with children who had no caring responsibilities.

The correlation between the mean total MACA score and the mean KIDSCREEN-10 score was very weak for the complete sample (Pearson's  $r_{3991} = -0.035$ ;  $P = 0.028$ ); and there was

Table 3: Extent of caring by young carers

Extent of caring	Sample		Population estimate (10- to 15-year-olds, Swiss-wide)							
	Frequency	Per cent	Estimate	Standard error	95% confidence interval		Per cent	Standard error	95% confidence interval	
					Lower	Upper			Lower	Upper
Low amount of caring	93	30.3%	11 312	1376	8593	14 031	32.0%	3.2%	26.0%	38.7%
Moderate amount of caring	97	31.6%	11 017	1376	8299	13 736	31.2%	3.6%	24.5%	38.8%
High amount of caring	66	21.5%	7721	1101	5544	9898	21.8%	2.6%	17.1%	27.5%
Very high amount of caring	51	16.6%	5302	821	3679	6924	15.0%	2.1%	11.3%	19.7%
Total	307	100.0%	35 352	2221	30 963	39 740	100.0%	0.0%	100.0%	100.0%

**Table 4:** MACA domain scores for young carers and those without caring responsibilities

MACA domain scores	Young carers			No caring responsibilities			Sig
	<i>N</i>	Mean	Std. deviation	<i>N</i>	Mean	Std. deviation	
Domestic	307	3.19	1.26	3684	3.04	1.3	0.054
Emotional	307	3.51	1.68	3683	2.78	1.76	<0.001
Financial	307	0.83	1.1	3684	0.7	1.07	0.046
Household	307	2.6	1.26	3684	2.23	1.26	<0.001
Personal	307	0.93	1.37	3684	0.6	1.14	<0.001
Sibling	271	1.64	1.73	3398	1.45	1.68	0.072
MACA total score	307	12.51	5.11	3684	10.69	5.06	<0.001

**Table 5:** Young carers' MACA domain scores and gender

MACA domain scores	Male			Female			Sig
	<i>N</i>	Mean	Std. deviation	<i>N</i>	Mean	Std. deviation	
Domestic	134	2.88	1.3	171	3.44	1.18	<0.001
Emotional	134	3.14	1.66	171	3.81	1.64	<0.001
Financial	134	0.87	1.2	171	0.78	0.96	0.441
Household	134	2.74	1.29	171	2.5	1.22	0.104
Personal	134	0.63	1.09	171	1.16	1.52	0.001
Sibling	122	1.52	1.66	147	1.75	1.79	0.272
MACA total score	134	11.64	5.17	171	13.20	4.97	0.008

no association between MACA and KIDSCREEN-10 scores for those identified as young carers (Pearson's  $r_{305} = 0.003$ ;  $P = 0.963$ ). Hence, among young carers, increased intensity and broader ranges of caring activities (as shown by the MACA score) did not relate directly to differential well-being.

## Discussion

In this study, we have estimated the prevalence of young carers in the Swiss population of children in grades 4–9, which largely covers the population of 10- to 15-year-olds, to be 7.9 per cent. Within this age group, this is equivalent to around 38 400 Swiss children. Applying this figure to a slightly wider age group of 9- to 16-year-old children, we estimate that there are around 51 500 young carers in Switzerland.

Whilst there is some variation in estimates of prevalence across countries and studies, overall figures suggest that between 2 and 8 per cent of all children in advanced industrialised capitalist societies are carers, depending on the method which is used to identify and count them (Becker and Becker, 2008; Cass and others, 2011; Hill and others, 2009; Howard, 2010; Hunt and others, 2005; Warren, 2007). Our estimate of prevalence is therefore towards the higher end of the estimated range. However, we have only classed respondents as young carers if they showed clear evidence of providing regular support for a person with an illness, addiction, or disability, for an older person, or if they assumed caring responsibilities in the circumstances of a family crisis (e.g. in the event of a family breakup or following the death of a family member). Hence, we believe we have accurately counted those who have caring responsibilities.

In this study, we first identified young carers using an open question and a pre-defined coding schedule, secondly we assessed the extent of their caring activities using the MACA — the Multidimensional Assessment of Caring Activities. Whilst the first question estimated the prevalence of all carers, the MACA showed that of these, whilst a third provided a 'low' level of care, 38 per cent provided a 'high' or 'very high' level of caring. Since these young people provide different levels of care, they will have different levels of need for support. Also, the type of support that they need will depend on the type of caring activities in which they engage. Those whose caring role, for example includes personal care may need specialist support. Additionally, various social and economic factors such as family income, housing quality and household composition may influence the support that needs to be provided and may exacerbate or mitigate the negative effects of having a caring role (De Roos and others, 2017). Therefore, support needs to be tailored to the type and extent of caring and the context in which it occurs.

This study also showed, not surprisingly, that those who were identified as young carers had significantly higher MACA scores than those without caring responsibilities; and that the MACA domain scores of young carers were significantly higher for all domains apart from sibling care. This was higher for young carers but not significantly so. It thus appears that those young people who do provide care for sick or impaired relatives or persons close do so across a wide range of different activities. Interestingly, there were some young people in our study who were not classed as young carers but who did have high MACA scores including for personal care. We do not know the circumstances of these young people and the context in which they provided care but this does raise the possibility of false negatives as identified in our opening question and predefined coding system. Alternatively, these are young people who do provide care but not on the regular basis which was the focus of the present study. It may be helpful for future studies to also ask questions about whether help is ever provided less regularly to provide more nuanced prevalence data.

Although 56 per cent of carers in our sample were female compared to 44 per cent male, there was no statistically significant difference in prevalence between males and females in the sample. However, the population estimate which was weighted to compensate for sampling error did in fact show a significant difference. This is in line with previous research which has shown differences in prevalence between genders. For example in their study of young carers in Austria, Nagl-Cupal and others (2014) showed that 70 per cent were female. The size of the difference (Austria compared with Switzerland) may reflect different national or cultural characteristics or may be due to differences in sampling methodology. Whilst Nagl-Cupal and others (2014) and Sempik and Becker (2013) have shown a greater proportion of females as young carers, more research is needed to show how the activities of male and female young carers differ in their detail, and how the role has developed (and continues to develop) over time. We saw differences in the type of caring activities carried out by male and female young carers. Young women provided more domestic, emotional and personal care (as measured by MACA domain scores). More research is needed to explore the role that gender plays in constructing the caring role. The provision of support for young carers needs to take into account not only the total extent of caring but also the type of activities that are carried out, and this appears to be linked to gender.

Researchers have previously reported poor mental well-being among young carers, for example Nagl-Cupal and others (2014) reported a greater level of worry, sadness and physical pain among young carers compared with those without caring role. In this study, we showed that children with a caring role had a significantly lower KIDSCREEN-10 score than those without caring responsibilities although the absolute difference in well-being was small. In addition, we saw no association between the extent of caring, as measured by the

total MACA score and well-being, as measured by the KIDSCREEN-10 score. Hence, this study has found no obvious direct effect of the amount of caring on well-being. Whilst there may be no simple correlation between the extent of caring and mental well-being, the context of caring may be important. For example those who have a low income, poor housing and little family or social support are likely to be at greatest risk of adverse effects. Caring for a person with a stable disability will be different to caring for someone whose condition fluctuates and who can make random and unpredictable demands on their carer (WHO, 2011). Similarly stress and coping variables could have an impact on the association between caring and well-being. Therefore, further research is needed to address the role of mediator and moderator variables in the context of young carers' well-being, for example using a method such as structural equation modelling.

The KIDSCREEN-10 index is a validated measure that has been found to be useful in the context of young carers (Schlarmann and others, 2008). However, unlike the longer version of the instrument, it only provides an overall score for well-being. It is possible that the caring role affects different aspects of well-being. Therefore, it would be useful in future research to apply the long version in order to explore the impact of a young person's caring role on different dimensions of well-being, including, for example on its emotional, social and personal aspects.

### Limitations and Strengths

Survey participation was not compulsory for schools and only 230 of the schools selected by the sampling process agreed to participate — a response rate of 32 per cent. A non-response bias could be present if the schools which refused to participate had numbers of young carers which were very different to those in participating schools. Hence, some caution may be needed regarding the prevalence estimates reported in this study. Since schools which refused to participate were spread over different regions, were of different sizes and the reasons for refusal were mainly due to overload with other surveys and educational assessments, we believe that non-response bias is small. In addition, among the participating schools nearly all children from the sampled classrooms sampled took part in the survey — the response rate at this level was 94 per cent. Hence, there was no refusal at the level of pupils that could be associated with their caring situation.

In our introduction we mention that the identification of young carers is challenging due to self-identification barriers (Cass and others, 2009; Noble-Carr and Woodman, 2016). In this study, we have used an approach that we believe overcomes this barrier. Firstly, data collection was conducted during regular classes within the classroom setting; the survey was conceptualised so that it could be completed by young people regardless of whether they were young carers or not. Secondly, the questions used to identify young carers were formulated in a way that explored the circumstances of support needs and care provision rather than asking young people to identify themselves as young carers.

### Conclusion

Our survey has estimated that around 38 400 children in grades 4–9 (i.e. aged 10–15) in Switzerland have caring responsibilities. However, young carers are not confined to this age group, research has shown that children as young as five can play a caring role; and that adolescents and young adults aged 14–25 can also be involved in providing care. Hence, many tens of thousands of children, adolescents and young adults are caring for ill and disabled family members in Switzerland, and all will need some support at some time.

As Leu and Becker (2016) reported, one of the key factors that influence policy responses is the presence of a reliable country-specific research base. A robust country-specific

research evidence base provides an important foundation for policy developments and service responses. Policy-makers often prefer to have a national research evidence base to inform their local and national decisions rather than drawing or relying on research from other countries. The data from this study as well as the findings from ongoing projects undertaken by the Swiss research group will underpin the development of a national support framework for young carers. The Swiss Federal Council (2014) launched an Action Plan that consists of different areas of action to improve the situation for all carers. Findings from earlier studies (Leu and others, 2018, under review) have led to amendments in the action plan to include young carers in the national carers strategy.

The challenge now is to develop an appropriate policy response and effective services in order to support all of these young people and their families. The development of such services and policy must include schools and the education sector. Previous research in the UK has shown that caring responsibilities lead to absence from school, lateness and disruption to a substantial number of school days (Sempik and Becker, 2013). Some young people did not inform their teachers that they were carers because they could see 'no point' in it, that is they did not believe that telling anyone would have any effect. Teachers and other school staff are in regular contact with young carers but may often not recognise them as such. However, recent research from Switzerland indicates a lack of awareness and a rather meagre commitment among professionals in education towards young carers (Leu and others, in preparation). Hence, one arm of policy needs to address this issue by raising awareness of young carers among teachers and school staff and developing processes and procedures that will support young carers throughout their education and into their working lives.

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