



Children and Adolescents Acting as Carers for Family Members - Results of the School Health Promotion Study 2019

MAIN FINDINGS

- Of the respondents of the School Health Promotion (SHP) study 2019, roughly 6 percent of young people acted as carers every week or daily, and 10 percent acted as carers a few times in the year or every month.
- Young people with a care responsibility had, in some respects, fewer hobbies and were less satisfied with their life than other young people.
- Working while studying and a poor financial situation in the family were also more common among those with a care responsibility.
- School burnout, symptoms of depression, anxiety and loneliness were more common in young people with a care responsibility than in others.

According to international studies, 2–8% of all children and adolescents under the age of 18 in Western countries care for or are concerned about a family member due to their physical or mental illness, substance abuse problem or other health-related challenge. The caring role has been shown to have an impact on the education, health, wellbeing, social opportunities and employment prospects of young carers (Joseph et al. 2020).

The first studies concerning the help and care provided by children and adolescents under the age of 18 to ill or disabled family members typically in a home environment were conducted in Britain in the late 1980s (e.g. Page 1988, Elliot 1992, Aldridge and Becker 1993). In Sweden, the number of child carers (“barn som anhöriga”) and the impact of this care have been studied using e.g. patient and cause of death registers and other statistical data and questionnaires. In the survey conducted in Sweden by Nordenfors et al. in 2014, 7% of 9th graders in comprehensive school reported a significant care responsibility towards a parent or sibling. Of the respondents, 3% stated that they are absent from school at least once a week due to care. The prevalence of young carers in Switzerland in the 10–15 age group is 7.9%, i.e. around 38 400 children and adolescents (Leu et al. 2019).

In the School Health Promotion (SHP) study 2017, roughly one in five respondents reported that a family member had fallen seriously ill or had died during the school year (School Health Promotion study 2017), but there is no previous data in Finland as to the prevalence of help and care provided by children and adolescents to their family members. A question about the help and care provided for a family member by a child or adolescent was added to the SHP study in 2019. Based on the results, we can now identify the group of young carers for the first time in Finland and describe their circumstances and experienced wellbeing.

The purpose of this publication is to examine the various aspects of the circumstances of young carers and make professionals working with young people and their families aware of young carers' needs for support. The publication is based on the answers provided by 8th and 9th graders in comprehensive school and 1st and 2nd year students in upper secondary and vocational school. The circumstances of young people with a care responsibility are examined using several indicators. There may also be underlying factors in the life of the young person which not only affect their life and health directly, but may also be connected to the care responsibility situation in the family. Due to this, indicators were divided into underlying factors in the family, the elements of wellbeing and the challenges to wellbeing, and the combined effects of the various factors are considered at the end.

Around 15 percent of respondents are young people with a caring role

The majority of the young people who answered the SHP study 2019 lived in urban municipalities (71%). In addition, 17 percent lived in semi-urban municipalities and 12 percent in rural municipalities. Of the respondents, 51 percent were girls and 49 percent were boys.

The level of care responsibility among young people was examined using a three-tier indicator: “no need for care in the family”, “care a few times in the year or every month” and “care every week or daily”. About one in ten young people stated that they provide care a few times in the year or every month. Around 6 percent of the respondents reported providing care every week or daily. Having a care responsibility was slightly more common among girls than boys. In terms of the 8th and 9th graders, 7 percent of girls and 6 percent of boys had a weekly or daily care responsibility. Of the girls in upper secondary school, 5

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Care responsibility indicator:

Care responsibility was examined by asking “Are you helping or caring for a family member or some other person close to you who has, for example, a serious illness or an injury or who is very old?”

The possible answers were:

- This situation or need for help does not concern my family
- A few times in the year
- Every month
- Every week
- Daily or almost daily

The indicator was divided into three categories. The first category is “this situation or need for help does not concern my family”. The second consists of both “care a few times in the year” and “care every month”. The third consists of both “care every week” and “care daily or almost daily”.

percent reported a weekly or daily care responsibility, while 4 percent of boys reported the same. In vocational schools, 7 percent of girls and 6 percent of boys had a weekly or daily care responsibility. In terms of municipal groups, care responsibility was distributed fairly evenly and not concentrated in certain types of areas. The percentages of young people per gender and municipal group, broken down by type of educational establishment and level of care responsibility, are shown in Table 1.

Table 1. Percentages of young people per gender and municipal group, broken down by type of educational establishment and level of care responsibility, %

8th–9th grade		n	No need for care in the family	Care a few times in the year or every month	Care every week or daily
Gender	Girls	42 909	83	10	7
	Boys	39 728	85	9	6
Municipal group	Urban	55 963	84	10	6
	Semi-urban	14 982	82	11	7
	Rural	11 844	81	11	8
Upper secondary school		n	No need for care in the family	Care a few times in the year or every month	Care every week or daily
Gender	Girls	26 008	86	9	5
	Boys	17 778	88	8	4
Municipal group	Urban	32 730	87	9	4
	Semi-urban	6 366	87	8	5
	Rural	4 735	85	10	5
Vocational school		n	No need for care in the family	Care a few times in the year or every month	Care every week or daily
Gender	Girls	9 106	82	11	7
	Boys	12 943	85	9	6
Municipal group	Urban	17 353	84	10	6
	Semi-urban	3 488	82	10	8
	Rural	1 238	82	11	7

Young people with a care responsibility perceive their family's financial situation more negatively than others

The financial situation of the family was perceived more negatively in families with young people caring regularly for a family member than in other families. Of the girls in upper secondary school who care for a family member every week or daily, 45 percent rated their family's financial situation as moderate or poor. Among those who provide care a few times in the year or every month, 41 percent gave a similar rating, whereas among the other girls in upper secondary school, 32 percent gave a similar rating. For boys, the corresponding figures were 35, 31 and 25 percent. A similar difference between the financial situations of families with extensive care provided by a young person versus no care at all could also be seen among students in vocational school and 8th and 9th graders in comprehensive school.

In terms of 8th and 9th graders in comprehensive school and students in upper secondary or vocational school, about one in five respondents lived with one of their parents. There was no difference in the level of care responsibility between young people living with one parent and other young people.

Of the 8th and 9th grade girls who provided care every week or daily, 9 percent did not have plans after comprehensive school, and 8 percent of girls who provided care more seldom

How the research was conducted:

The results presented in this publication are based on data from the School Health Promotion (SHP) study 2019, conducted by the Finnish Institute for Health and Welfare (THL). The SHP study is a nationwide population study that gathers extensive data about the wellbeing, health and services of young people. The study is conducted every second year. The questionnaire is voluntary and answered anonymously during class.

Participants and response rate:

Data was received from 73 percent of 8th and 9th graders and roughly 70 percent of 1st and 2nd year students in upper secondary school. A response rate for vocational schools is unavailable, because the size of the target population (under 21-year-olds studying for a vocational upper secondary qualification for young people) is unknown.

In 2019, the SHP study was answered by 87 283 comprehensive school pupils in 8th and 9th grade, 44 597 1st and 2nd year students in upper secondary school and 23 419 1st and 2nd year students in vocational school. The respondents were aged between 12 and 21 years.

The results of the SHP study are available (in Finnish) at: thl.fi/kouluterveyskysely/tulokset.

had no plans. In terms of other girls, the figure was 6 percent. A lack of plans after comprehensive school was slightly more common among boys than girls: of the boys who cared for a family member every week or daily, 14 percent had no plans, and of the boys who provided care more seldom, 11 percent had no plans. For other boys, the figure was 8 percent.

Working in paid employment was more common for those with a care responsibility. Of the girls in upper secondary school who provided care every week or daily, 31 percent were working while studying. This figure was 28 percent for those who provided care more seldom, and 24 percent for others. One fifth of the boys in upper secondary school who provided care every week or daily or more seldom also worked while studying, whereas 15 percent of other boys worked while studying. In terms of vocational school students, working while studying was likewise most common among those who provided the most care. For these students, 30 percent of girls who provided care every week or daily, 27 percent of girls who provided care a few times in the year or every month and 25 percent of other girls were working while studying. For boys, the corresponding figures were 25, 23 and 17 percent. Young people with a care responsibility reported harm caused by a parent's alcohol consumption slightly more often than non-carers, but the differences were small. Girls reported harm caused by a parent's alcohol consumption more often than boys. The underlying factors describing the families of young people, broken down by level of care responsibility and type of educational establishment, are shown in Table 2.

Table 2. Underlying factors of the families of young people, broken down by type of educational establishment and level of care responsibility, %*

8th–9th grade		n	No need for care in the family	Care a few times in the year or every month	Care every week or daily
Financial situation of the family perceived as moderate or poorer	Girls	2234	27	37	40
	Boys	8539	20	29	31
Lives mainly or only with one parent	Girls	9416	22	24	25
	Boys	7040	18	21	18
No plans after comprehensive school	Girls	2687	6	8	9
	Boys	3461	8	11	14
Parent's alcohol consumption has caused harm	Girls	3099	7	10	12
	Boys	1110	2	6	6

Upper secondary school		n	No need for care in the family	Care a few times in the year or every month	Care every week or daily
Financial situation of the family perceived as moderate or poorer	Girls	8738	32	41	45
	Boys	4516	25	31	35
Lives mainly or only with one parent	Girls	5103	20	22	21
	Boys	2748	16	17	15
Working while studying	Girls	6369	24	28	31
	Boys	2618	15	20	20
Parent's alcohol consumption has caused harm	Girls	2126	8	12	11
	Boys	551	3	5	5

High-quality health examinations are provided to young people

The quality of the health examinations provided by school health care was measured using the question “How were the following things at your latest health examination?”

- Issues that are important to me were addressed
- My views were listened to
- Things about my home were discussed
- I was able to talk about my situation honestly”

The possible answers were: fully agree/agree/neither agree nor disagree/disagree/fully disagree. Respondents who selected answer 1 or 2 in all parts of the question were examined. The percentage was calculated from the respondents who had had a health examination provided by a school health nurse or a school physician during the school year.

Vocational school		n	No need for care in the family	Care a few times in the year or every month	Care every week or daily
Financial situation of the family perceived as moderate or poorer	Girls	3852	40	52	53
	Boys	4153	31	40	40
Lives mainly or only with one parent	Girls	1816	20	22	20
	Boys	2463	20	22	18
Working while studying	Girls	2207	25	27	30
	Boys	2153	17	23	25
Parent's alcohol consumption has caused harm	Girls	1000	10	15	14
	Boys	406	3	6	5

* Differences are statistically significant (Pearson 2-sided Chi-2-test, $p < 0.05$) in all other variables except for living with one parent in terms of boys studying in vocational school and in upper secondary school

Care responsibility is linked to life satisfaction and, in part, to hobbies and school satisfaction

Care responsibility was linked to the life satisfaction of young people: 59 percent of 8th and 9th grade girls in comprehensive school who provide daily or weekly care were satisfied with their life at the time of taking the questionnaire, whereas 69 percent of girls with no care responsibility reported the same. The difference was equally large in all levels of education and boys as well. Care provided regularly a few times in the year or every month similarly affected the life satisfaction of young people. Boys with a care responsibility studying in upper secondary school or vocational school engaged in hobbies less than others. Of the 8th and 9th grade boys in comprehensive school without a need for care in the family, 96 percent had a weekly hobby, whereas the corresponding figure for boys providing weekly or daily care for a family member was 89 percent. In terms of boys studying in vocational school, 86 percent of those providing care for a family member every week or daily had a weekly hobby, whereas the corresponding figure for non-caring boys was 92 percent. There were no differences among girls.

Care responsibility was linked to how much 8th and 9th graders like school. The smaller the care responsibility, the more common it was to like school, both for girls and boys. In this age group, liking school was less common overall than in the groups of older students, but at least half of the respondents still liked school. The same trend can also be seen in the 8th and 9th graders' answers as to whether they feel they are important members of the classroom community. Of the 8th and 9th grade girls who provide care for a family member every week or daily, 46 percent felt like an important member of the classroom community, whereas the figure was 48 percent for those who provide care a few times in the year or every month, and 51 percent for others. For boys, the corresponding figures were 60, 61 and 65 percent. For students in upper secondary school and vocational school, feeling like an important member of the classroom community was more common and was not linked to their care responsibility. Providing a high-quality health examination to young people was not associated with the care responsibility of young people. The elements of wellbeing, broken down by level of care responsibility and type of educational establishment, are shown in Table 3.

Table 3. Elements of wellbeing, broken down by level of care responsibility, type of educational establishment and gender, %*

8th–9th grade		n	No need for care in the family	Care a few times in the year or every month	Care every week or daily
Satisfied with life at the moment	Girls	28517	69	60	59
	Boys	32714	86	77	76
Engages in a hobby at least every week	Girls	40991	97	96	95
	Boys	37047	96	93	89
Likes school	Girls	23730	62	58	57
	Boys	20720	61	55	53
Feels like an important member of the classroom community	Girls	21300	51	48	46
	Boys	25188	65	61	60
High-quality health examination is provided	Girls	18559	59	52	55
	Boys	19643	73	67	72
Upper secondary school		n	No need for care in the family	Care a few times in the year or every month	Care every week or daily
Satisfied with life at the moment	Girls	18160	71	65	63
	Boys	14299	82	77	80
Engages in a hobby at least every week	Girls	25204	97	97	98
	Boys	17376	99	98	98
Likes school	Girls	17757	71	72	69
	Boys	12105	72	70	71
Feels like an important member of the classroom community	Girls	13213	51	52	48
	Boys	11461	65	64	63
High-quality health examination is provided	Girls	9848	64	58	62
	Boys	7132	76	71	71
Vocational school		n	No need for care in the family	Care a few times in the year or every month	Care every week or daily
Satisfied with life at the moment	Girls	6117	69	62	62
	Boys	10424	83	76	76
Engages in a hobby at least every week	Girls	8230	91	91	93
	Boys	11653	92	91	86
Likes school	Girls	6312	80	76	78
	Boys	8971	84	82	82
Feels like an important member of the classroom community	Girls	5072	56	54	56
	Boys	9080	71	70	71
High-quality health examination is provided	Girls	3404	65	56	66
	Boys	4885	77	72	73

* Differences are statistically significant (Pearson 2-sided Chi-2-test, p<0.05) in all other variables except hobbies (upper secondary and vocational school girls), liking school (upper secondary, vocational school boys) and feeling like a member of the classroom community (upper secondary and vocational school)

Young people with a care responsibility face challenges relating to mental health and school

Young people with a care responsibility faced various challenges in their everyday life more commonly than other young people. Young people with a care responsibility perceived their health as somewhat worse than others. Roughly 35 percent of 8th and 9th grade girls providing care for a family member rated their health as average or bad. In terms of other young people, one in four provided a similar answer. The boys with a care responsibility also perceived their health as worse. Care responsibility also played a role in the self-perceived health of girls in upper secondary school and students in vocational school.

A third of all 8th and 9th grade girls who provided care daily or every week had experienced symptoms of depression lasting at least two weeks. In terms of those in the same age group with no care responsibility, slightly more than one in five had had symptoms of depression. Of the boys without a care responsibility, 9 percent had had symptoms of depression, compared to 19 percent in boys providing care daily or every week. Of the girls in upper secondary school who provided care for a family member every week or daily, 30 percent had experienced symptoms of depression, whereas the figure was 26 percent for those who provided care a few times in the year or every month, and 21 percent for others. For students in vocational school, symptoms of depression lasting at least two weeks were equally common among young people providing care a few times in the year or every month and those providing care every week or daily: around 30 percent for girls and around 14 percent for boys.

Similarly, the greater the care responsibility of a young person, the more common anxiety and school burnout were. This was seen among both girls and boys in all types of educational establishment. Young people with a care responsibility also reported feeling lonely more often than other young people, as well as being bullied at school at least once a week. Being bullied at school at least once a week was more common among 8th and 9th graders in comprehensive school and students in vocational school than students in upper secondary school. A care responsibility also seemed to be associated with being absent from school without permission at least every week. In addition, young people with a care responsibility more often felt that they had not received help and support from the school health nurse during the school year despite needing it. Depression, burnout, anxiety, loneliness and the experience of not receiving help from the school health nurse were more common among girls than boys in all groups. The challenges to wellbeing, broken down by the level of care responsibility and type of educational establishment, are shown in Table 4.

Table 4. Challenges to wellbeing, broken down by level of care responsibility, type of educational establishment and gender, %*

8th–9th grade		n	No need for care in the family	Care a few times in the year or every month	Care every week or daily
Self-perceived health is average or bad	Girls	11272	25	34	36
	Boys	5628	13	21	20
Symptoms of depression lasting at least two weeks	Girls	10222	23	31	34
	Boys	4132	9	17	19
Moderate or severe anxiety	Girls	8232	18	26	29
	Boys	2068	4	10	13
School burnout	Girls	8336	19	24	28
	Boys	4078	9	15	19
Feels lonely	Girls	6441	14	19	19
	Boys	2298	5	9	12
Bullied at least once a week	Girls	1856	4	7	8
	Boys	2334	5	11	14
Absent without permission at least every week	Girls	1419	3	4	6
	Boys	1452	3	6	9
Has not received support and help for their wellbeing from the school health nurse during the school year, despite needing it	Girls	1978	12	16	15
	Boys	900	8	10	14

Upper secondary school		n	No need for care in the family	Care a few times in the year or every month	Care every week or daily
Self-perceived health is average or bad	Girls	6524	24	30	33
	Boys	2653	15	20	16
Symptoms of depression lasting at least two weeks	Girls	5743	21	26	30
	Boys	2137	12	16	16
Moderate or severe anxiety	Girls	5036	19	24	29
	Boys	943	5	9	9
School burnout	Girls	5218	19	24	27
	Boys	1505	8	10	13
Feels lonely	Girls	3893	14	18	20
	Boys	1188	6	9	9
Bullied at least once a week	Girls	208	1	1	2
	Boys	244	1	3	4
Absent without permission at least every week	Girls	1140	4	4	7
	Boys	869	5	6	7
Has not received support and help for their wellbeing from the school health nurse during the school year, despite needing it	Girls	992	9	11	13
	Boys	306	8	10	11

Symptoms of depression lasting at least two weeks

Symptoms of depression were assessed using the PHQ-2 indicator (Patient Health Questionnaire 2). The score ranges from 0–2. Respondents with a score of at least one are included in the results.

Moderate or severe anxiety

Symptoms of anxiety were examined using the Generalized Anxiety Disorder-7 indicator. The results include the young people who scored at least 10, which is the cut-off point for moderate anxiety.

School burnout

School burnout was measured using an indicator based on the School Burnout Inventory (SBI-10) questionnaire. The question was: “Have you had any of the following feelings relating to your studies?”

- I feel overwhelmed by school work
- It feels like my studies have no meaning
- I feel inadequate at my studies”

The possible answers were: hardly ever/a few times a month/a few days a week/almost daily. The reclassified scores of the sections are added up. The respondents who scored 3–6 are included in the results. The calculation only includes those who answered all the three parts of the question.

Vocational school		n	No need for care in the family	Care a few times in the year or every month	Care every week or daily
Self-perceived health is average or bad	Girls	2924	31	41	40
	Boys	2127	16	21	23
Symptoms of depression lasting at least two weeks	Girls	2156	23	28	30
	Boys	1221	9	14	13
Moderate or severe anxiety	Girls	1778	19	25	28
	Boys	631	4	8	11
School burnout	Girls	1002	10	13	18
	Boys	658	5	7	10
Feels lonely	Girls	1596	17	22	22
	Boys	803	6	8	11
Bullied at least once a week	Girls	264	2	4	7
	Boys	442	3	6	8
Absent without permission at least every week	Girls	760	8	11	11
	Boys	1300	10	12	13
Has not received support and help for their wellbeing from the school health nurse during the school year, despite needing it	Girls	391	9	15	12
	Boys	299	8	12	14

* Differences are statistically significant (Pearson 2-sided Chi-2-test, $p < 0.05$) in all other variables except receiving support from a school health nurse for boys in upper secondary school

The relationship between the care situation and school burnout and anxiety symptoms was also examined using multivariate analysis. When the financial situation of the family and the educational level of the mother were controlled, care also provided a direct explanation for school burnout and anxiety. The odds ratio in terms of burnout and anxiety was greater for those providing care at least every week than those providing care a few times in the year.

Summary and discussion

In light of the results, care responsibilities have various associations with the wellbeing of young people. Providing care was associated with challenges relating to mental health and school, loneliness and being bullied, self-perceived health, life satisfaction and engaging in hobbies, and the financial challenges of the family. In addition, young carers felt more often than others that they had not received help from a school health nurse. The challenges faced by young people with a care responsibility may also be interlinked. For instance, the financial challenges of a family may increase the need for a young person to work and reduce their opportunities to engage in hobbies. On the other hand, the poor financial situation of the family may be linked to the care situation in the family, because a parent may be unable to work due to a personal illness or the illness of a family member.

In some of the indicators, the challenges that carers face were most obvious among the group of 8th and 9th graders. One explanation for this may be that 8th and 9th graders are still more dependent on their parents due to their age, so the family situation has a stronger impact on them. On the other hand, the proportion of 8th and 9th graders was also higher in the data.

Many challenges were more common among girls than boys. Symptoms of depression, burnout, anxiety, loneliness and the experience of not receiving help from a school health nurse were more common among girls than boys in all groups. Girl carers therefore stand out as a group where supporting resources should in particular be directed. More research is still needed concerning the mechanisms behind the stress of care responsibility. Data is also needed on whether various challenges to wellbeing are accumulated in young carers

as well as on possible protective factors. Although it appeared that a school health examination was provided equally successfully to young people with a care responsibility and others, those with a care responsibility reported slightly more often that they had not received help from a school health nurse despite needing it.

Identifying young carers and supporting them in school and via student welfare services should therefore be given particular attention to prevent the burnout of these young people and the negative effects of this on school work. The family situation should be considered as a whole also when planning services for a family member who needs care. Any help and care provided by children and adolescents to their family members should be addressed in the extensive school health examinations. This could be important in terms of the early recognition of the need for support, because it is often extremely difficult to bring up these issues oneself and problems may not become visible until they become aggravated or result in a crisis. It may be challenging for children and adolescents themselves to identify stress factors associated with their family situation and their impact on their life and wellbeing.

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